

# NCI DATA BRIEF

ISSUE 1

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## What does NCI tell us about people who self-direct?

The 2008-2009 National Core Indicators Consumer Survey Report (see [www.nationalcoreindicators.org](http://www.nationalcoreindicators.org) for the full 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-states entities. This Data Brief explores characteristics and responses of individuals who use the self-directed supports option and contrasts them with characteristics and responses of individuals who do not. For the purposes of this report all individuals receiving services under the self-directed service option are assumed to be self-directing and those who are not receiving supports under this program option are assumed to not be self-directing. Of the total respondents for whom the information was available (10,722), 4.2% (N=448) were reported to be using the self-directed supports option, while 95.8% (N=10,274) were reported to not be using the option. As a proportion of the total number of individuals responding to the 2008-2009 NCI surveys for whom data were available, the percentage of individuals self-directing varied from 12.5% in Ohio to 0% in Indiana and Oklahoma.

The results reveal interesting and significant differences in some consumer outcomes between individuals who were self-directing and individuals who were not. Additionally, interesting differences were found between the two groups with respect to demographics, and medical/psychological information. Unless noted, all differences reported are significant at the  $p < .05$  level.

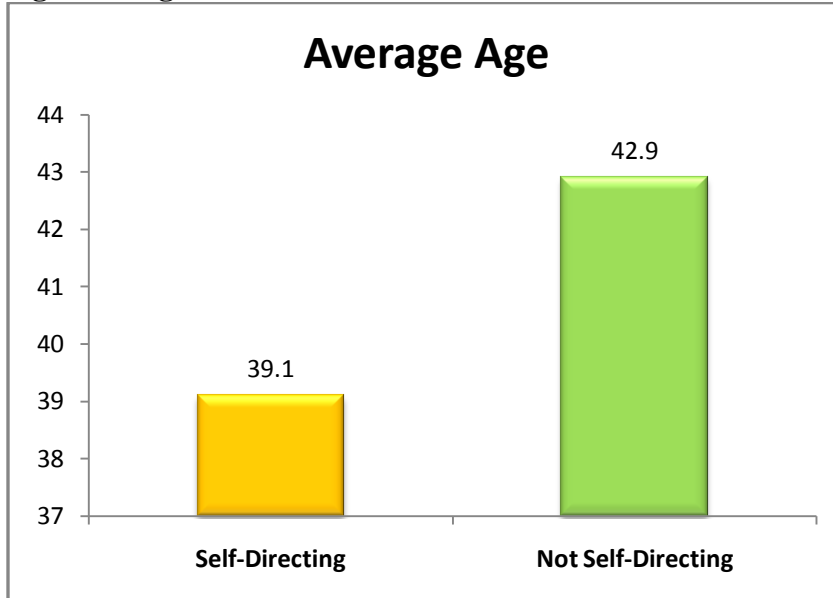
## PROFILE

### Demographics

The demographics of the two groups were very similar (no statistically significant differences) in terms of ethnicity, gender, marital status, type of guardianship, and race (although among people self-directing, marginally fewer were African-Americans). Differences were found to exist, however, in other areas.

Respondents who were self-directing were somewhat younger, with a mean age of 39.1 years vs. 42.9 years for individuals who were not (see Figure 1).

**Figure 1. Age**



As a group, self-directing individuals were more likely to live in their own (24% vs. 13%) or a relative's home (53% vs. 30%), and less likely to live in a group home (12% vs. 29%) or an institution (3% vs. 11%) than people who were not self-directing (see Figure 2).

**Figure 2. Type of Residence**

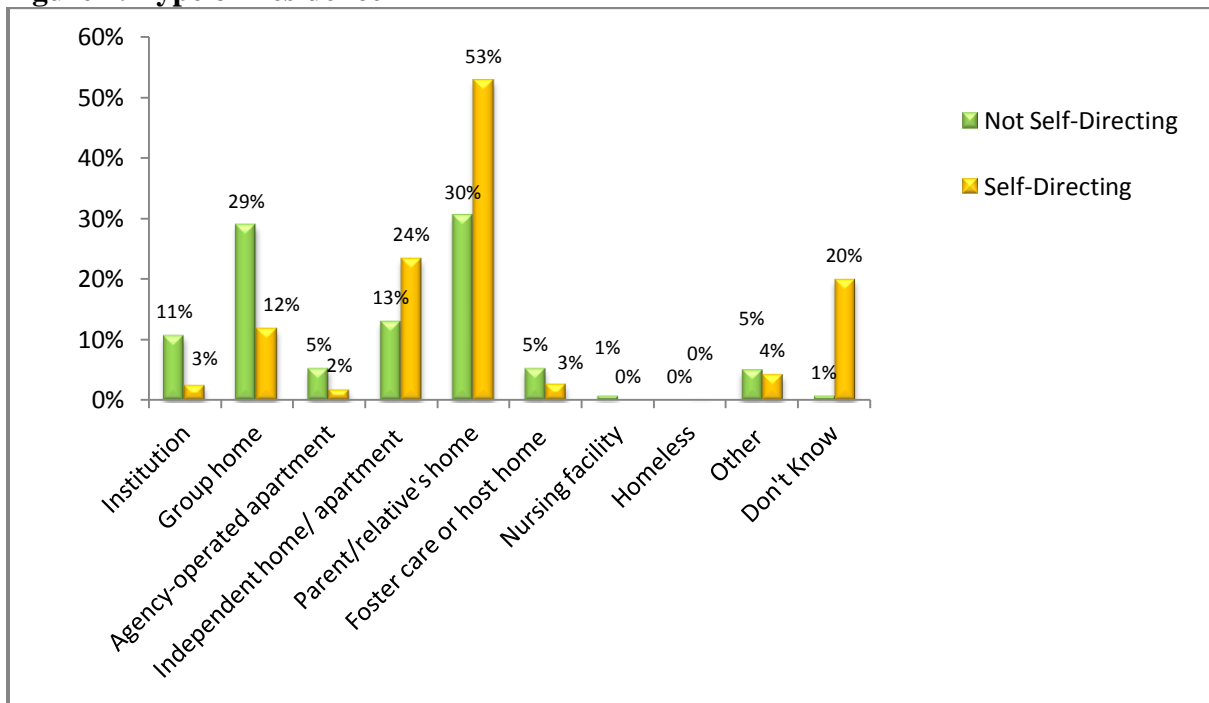
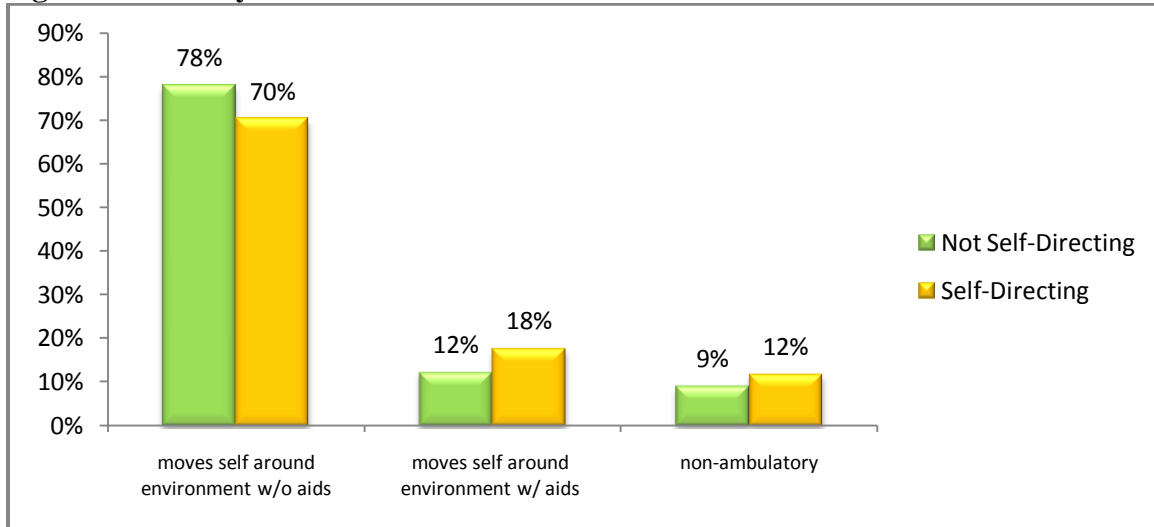


Figure 3 shows that individuals who were self-directing were slightly less likely to be independently mobile (70% vs. 78%).

**Figure 3. Mobility**

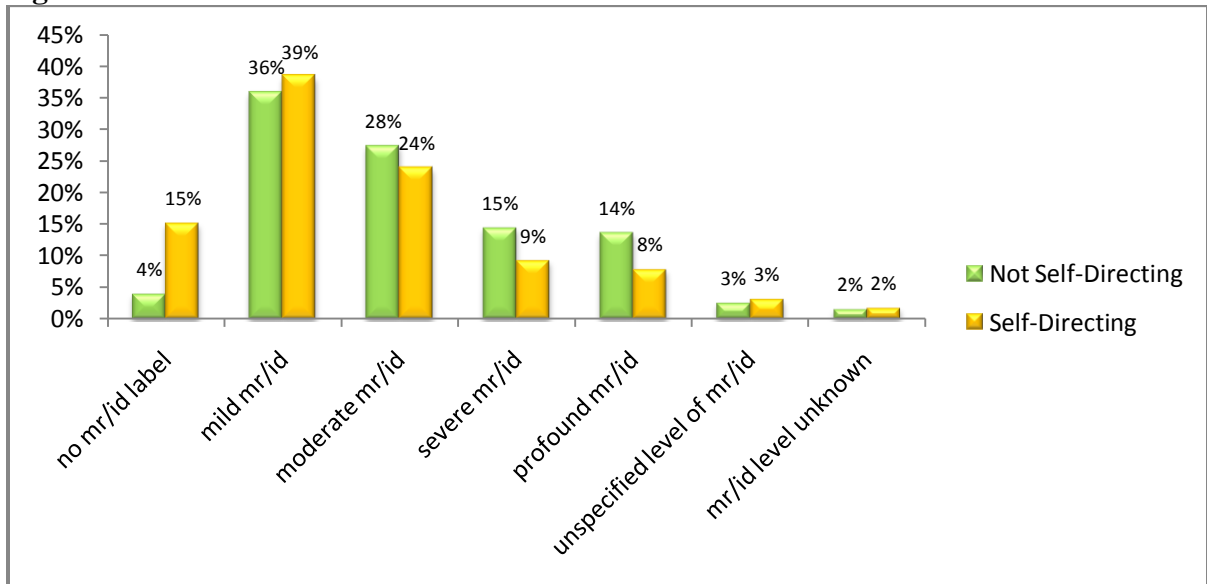


**Diagnostic/Medication Information:**

People who use the self-directed supports option were about as likely as those who are not self-directing to take medications for mood disorders, for anxiety, for behavior problems, and for psychotic disorders (no statistically significant differences were found). Furthermore, they are approximately as likely to take at least one kind of psychotropic medication.

Self-directing individuals were somewhat more likely to not have a label of intellectual disability (15% vs. 4%) than individuals not self-directing, and somewhat less likely to have severe or profound ID (Figure 4).

**Figure 4. Level of ID**

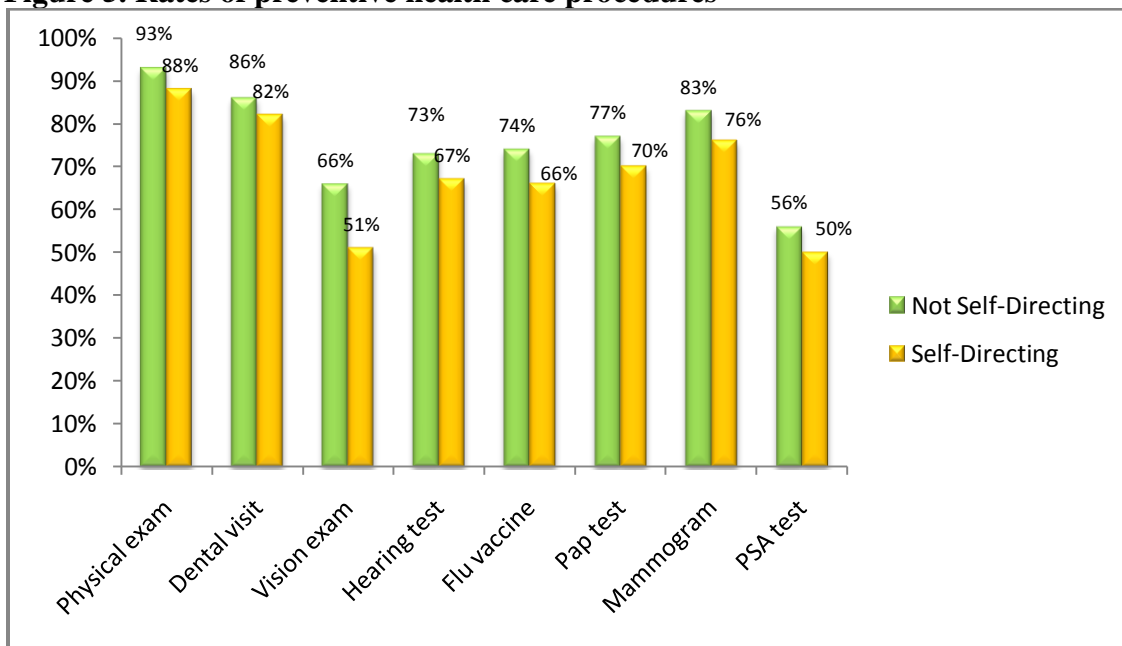


## HEALTHCARE

There are some differences in rates of receiving health care services by people who are self-directing versus people who are not. While some of the differences were not statistically significant, there is a clear trend in the data suggesting that individuals who use a self-directed supports option receive preventive health care procedures at somewhat lower rates than people who do not self-direct.

Self-directing individuals were less likely to have had a physical exam in the past year (88% vs. 93%), a dental visit in the past year (82% vs. 86%, not statistically significant), a vision exam in the past year (51% vs. 66%), a hearing test in the past five years (67% vs. 73%), a flu vaccine in the past year (66% vs. 74%), a pap test in past three years and a mammogram if over 40 in past two years (women only, 70% vs. 77% and 76% vs. 83% respectively, both not statistically significant), and a PSA test in the past year (men over 50 only, 50% vs. 56%, not statistically significant) (see Figure 5). The lack of significance is likely due to small sample size (few people self-directing).

**Figure 5. Rates of preventive health care procedures**



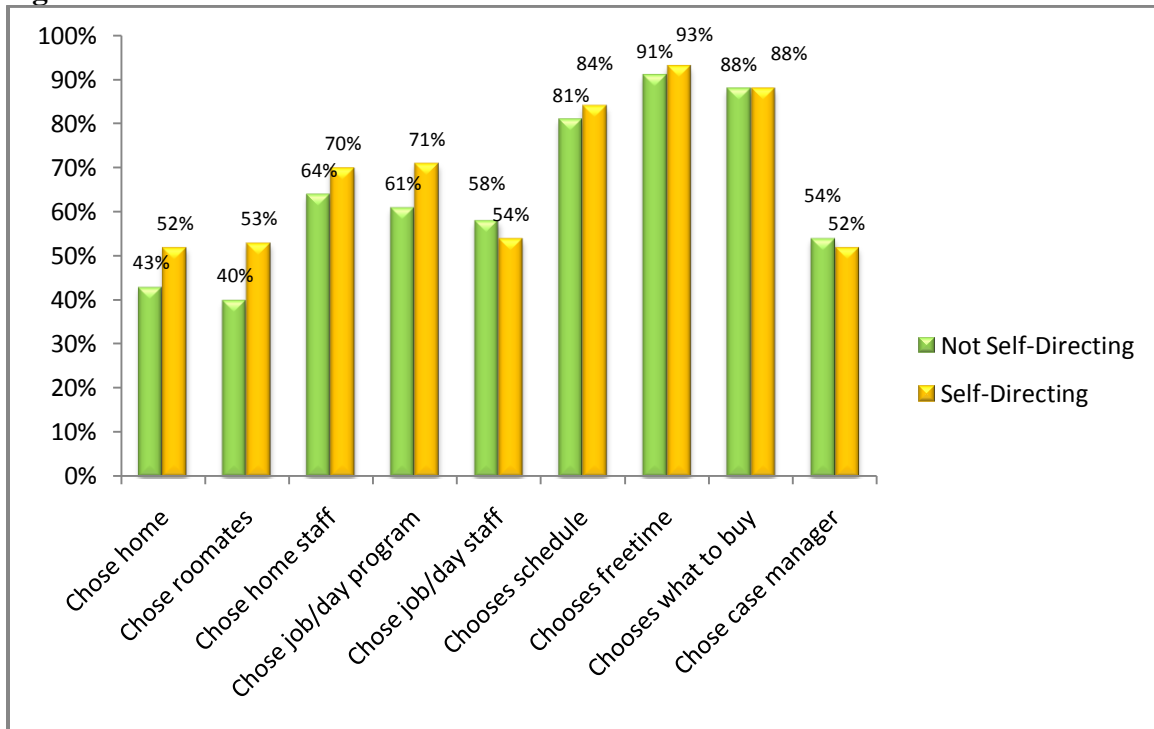
Note: "don't knows" not included in the denominator

## OUTCOMES

### Choice outcomes

There were differences in the amount of choice exercised by individuals who were self-directing and individuals who were not, particularly in the areas of major life decisions. Persons who use the self-directed supports option were more likely to choose or have input into choosing where they live (52% vs. 43%), who they live with (53% vs. 40%), their home staff (70% vs. 64%), and their job or day activity (71% vs. 61%). See Figure 6 below.

**Figure 6. Choice**



### Employment

Approximately the same proportion of people who were self-directing reported having a job in the community as people who were not self-directing (19%) and about the same proportion of each group reported wanting a community job (30% and 31% respectively). Similarly, there were no differences between the two groups in the proportion of people reporting that they liked their job (93% vs. 92%) or that they wanted to work somewhere else (31% vs. 32%). Furthermore, similar numbers of individuals who self-direct and those that do not had integrated employment as a support option in their service plans (23% vs. 22%). Similar numbers from each group reported being continuously employed (77% vs. 80%).

However, those using self-directed supports options were considerably more likely to be receiving benefits at their job (47% vs. 27%). Self-directing individuals were less likely to be employed in the building/grounds cleaning and maintenance industry (17% vs. 30%) and retail (9% vs. 16%), and more likely to be employed in the

assembly/manufacturing industry (17% vs. 11%), office and administrative support (9% vs. 4%, not statistically significant) or in “other” category (25% vs. 13%).

Even though the rates of having a job and enjoying it appear to be similar in the two groups, there are significant differences in their earnings. People who were self-directing earned \$225 on average in the two weeks preceding the interview, whereas people who were not earned \$186 on average; the number of hours worked in the same time period was similar (31.5 and 31.9 respectively). As a consequence, their hourly wage in the community job was higher (\$7.89 for those self-directing vs. \$6.18 for those who were not), as were the rates of earning at or above minimum wage (63% of people self-directing vs. 42% of people not self-directing). Furthermore, individuals who were not self-directing were not employed in their current community job as long as people who were (average of 66 months vs. average of 80 months). See Table 1 below.

**Table 1. Employment (community job)**

|                           | Hours worked in two weeks | Amount earned in two weeks | Hourly wage | Proportion earning at or above minimum wage | Length at current job |
|---------------------------|---------------------------|----------------------------|-------------|---|-----------------------|
| <b>Not Self-Directing</b> | 31.9                      | \$186                      | \$6.18      | 42%   | 66 months             |
| <b>Self-Directing</b>     | 31.5                      | \$225                      | \$7.89      | 63%   | 80 months             |

## CONSTRAINTS AND LIMITATIONS

A comparison of findings between adults who were using self-directed supports options and adults who were not revealed some differences among factors such as age, mobility, level of ID, and where the persons lived. Thus, some of the differences noted may be explained by factors other than self-direction. For example, it has been found previously that people living in family homes are less likely to receive preventive health care. Therefore, the fact that people self-directing are receiving preventive health care at somewhat lower rates than people not self-directing may in part be explained by them being more likely to live in a family home.

Furthermore, for the purposes of this data brief we have relied on the reports from interviewers regarding who is self-directing and who is not. It is possible that the interpretation of self direction is not constant and that some people who are reported as self-directing are not. This may be one of the reasons why the percentages of people reported as self-directing are exercising choice in fewer numbers than would be expected.

## SUMMARY OF FINDINGS

The data gathered through the current NCI Consumer Survey raise important issues. First, it is clear that the number of people who self-direct is still extremely small compared to the total sample. Second, the cohort that does self-direct is by no means limited to individuals with mild disabilities but includes people with more serious functional limitations. People who use self-directed supports seem to be at an advantage with respect to making major life decisions. It is important to note, however, that the number of individuals making such life choices is not 100% even though the objective of self-direction is to give people the option of exercising control over their lives.

With respect to employment, individuals who self-direct also appear to have somewhat higher earnings and higher rates of receiving benefits such as paid vacation and sick time. On the other hand, they appear to receive preventive health care services at slightly lower rates than people who do not use self-directed supports.



# NASDDDS