

NCI DATA BRIEF

ISSUE 5

December 2011

What Work Means: What does NCI tell us about the quality of life of adults with intellectual and developmental disabilities who are employed in the community?

Employment is a critical need for people with intellectual and developmental disabilities (ID/DD). The recognition of the pivotal role that work can play in the lives of people with ID/DD is driving many state developmental disabilities agencies to adopt “Employment-First” policies that prioritize employment in integrated settings as the preferred day service alternative.¹ The need for this policy shift is clear. While few policymakers, providers, families or advocates fail to recognize the benefits of employment for people with ID/DD, the outcomes have been difficult to achieve. Rates of integrated employment among people with ID/DD receiving services are low and have remained essentially unchanged for the past ten years.² Fortunately, the need to improve employment outcomes among people with disabilities receiving public support is being recognized by state and federal policymakers. Systems change efforts are underway in 25 states to address this issue through participation in the State Employment Leadership Network, a collaborative community of practice assisting state developmental disabilities agencies in changing their systems to improve employment outcomes.

National Core Indicators (NCI) data provide an important window on the lives of people with ID/DD receiving services, the outcomes they achieve and their experiences with the service delivery system. This Data Brief compares quality of life and outcomes of adults with ID/DD who are in community-based employment with quality of life and outcomes of adults with ID/DD who are not receiving those services and supports. It is part of a series of three employment-related data briefs that use NCI data to reveal the experiences of adults with intellectual and developmental disabilities who are employed and receive publicly funded supports.

SAMPLE

The information in this report is drawn from the 2009-10 National Core Indicators (NCI) Adult Consumer Survey of 11,599 adults from 16 states, the District of Columbia, and one sub-state entity³. For the purposes of these analyses we excluded 274 people under the age of 22 who were enrolled in public schools (or for whom this information could not be determined – additional 33 people). 11,292 adults remained in the data.

¹ Moseley C. (June 2009). *Community Services Reporter*. National Association of State Directors of Developmental Disabilities. Alexandria, VA.

² Butterworth, J. et al. (Winter 2011). *State Data: The national report on employment services and outcomes 2010*. Institute on Community Inclusion University of Massachusetts/Boston. Boston MA.

³ The 2009-10 NCI Adult Consumer Survey Report included: Alabama, Arkansas, District of Columbia, Georgia, Illinois, Kentucky, Louisiana, Maine, Missouri, North Carolina, New Jersey, New York, Ohio, Oklahoma, Pennsylvania, California’s Regional Center of Orange County, Texas, and Wyoming.

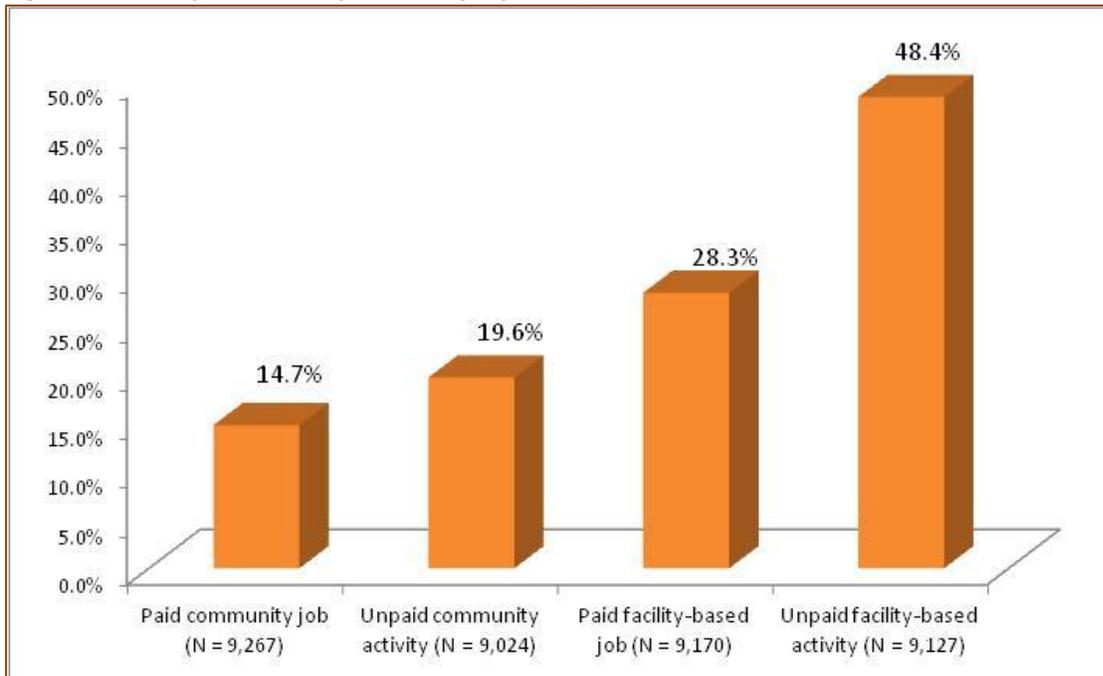
1,366 people in our sample were in a paid community job in the two weeks prior to the interview, and 7,901 people were not. Information was not available for 2,025 people; therefore they are not included in the following analyses.

PROFILE

The Background Section of the NCI Adult Consumer Survey gathers demographic information on all survey participants, with respect to the types of activities they engage in during the day. Day activities are categorized into four groups: a paid job in the community, an unpaid activity in the community, a paid job in a facility-based setting, and an unpaid activity in a facility-based setting.

Some of the data reported in Figure 1 below may overlap because it is possible for an individual to take part in more than one type of job or activity during the same time period. Only about fifteen percent (14.7%) were employed in a community-based job (Figure 1). Twenty eight percent (28.3%) worked in a facility-based job. Almost twenty percent (19.6%) participated in some type of community-based unpaid activity, and almost half of people in the sample (48.4%) took part in a facility-based unpaid activity during the time period.

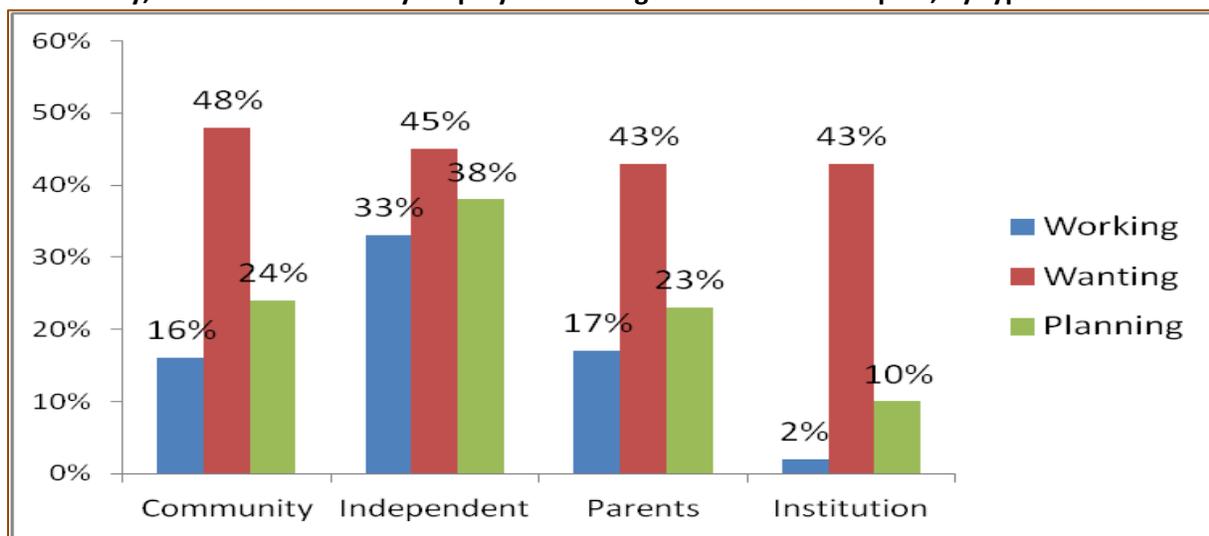
Figure 1. Participation in day-time employment/activities



These findings are consistent with the national survey data on individual employment outcomes for service recipients reported by the Institute on Community Inclusion at the University of Massachusetts/Boston and underscore the need for significant service reform in this area.⁴

Figure 2 highlights the large disparity between the percentage of people with ID/DD who are working in the community and those who are not working but want to. This was the case regardless of a person’s residential setting, and especially is evident for people who live in an institution (2% working in the community; 43% wanting to work in the community). Significantly, the percentage of individuals who had integrated employment identified in their service plan was substantially less than the percentage of those wanting to work in an integrated setting, regardless of where the person lived (community: 24% to 48%; independent: 38% to 45%; parents: 23% to 43%; institution: 10% to 43%).

Figure 2. Percentages of people who are working in the community, express wanting to work in the community, and have community employment as a goal in their service plan, by type of residence



People with community-based jobs tended to be younger, more likely to be male, more likely to be in better health, and with lower levels of intellectual, physical and communication disabilities. Although they were as likely to have a mental illness or a psychiatric diagnosis as people not working in the community, they were less likely to take at least one psychotropic medication. For other and more detailed demographic and background data on adults with ID/DD in various types of employment/day activities, please refer to the other two Data Briefs in this series (Issues 6 and 7, 2011).

OUTCOMES

Significant differences were found in the outcomes achieved by people with ID/DD who work in community-based jobs as compared to individuals who were not employed. The results described were obtained through t-tests comparing adults employed in the community to adults who are not

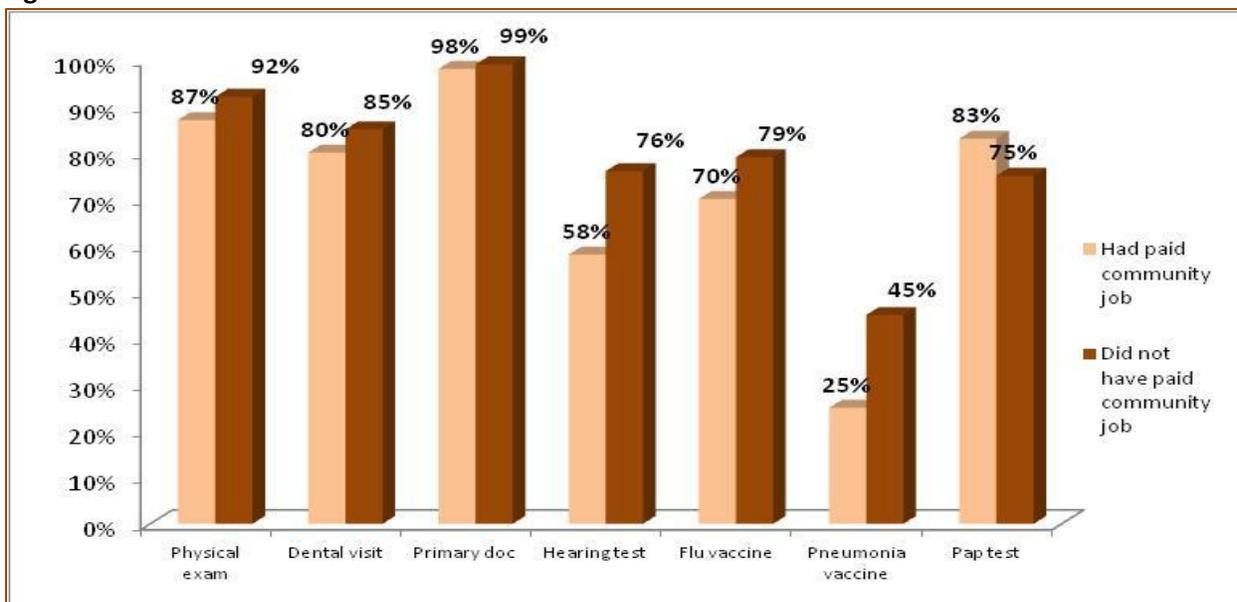
⁴ Butterworth, J., Hall, A.C., Smith, F.A., Migliore, A., & Winsir J. (2011). StateData: The National Report on Employment Services and Outcomes. Boston, MS: Institute on Community Inclusion, University of Massachusetts/Boston.

working in the community. *For the purpose of this Data Brief, only group differences that were significant at the $p < .05$ level are reported.*

Health Care

People with community jobs were *less* likely to get most preventive health care services than people who did not have community jobs. As seen in Figure 3, they were somewhat less likely to have received a physical exam (87% vs. 92%), a dental exam (80% vs. 85%), or a flu vaccine (70% vs. 79%) in the past year. They were slightly less likely to have a primary doctor (98% vs. 99%), and considerably less likely to have had a hearing test in the past 5 years (58% vs. 76%) or a pneumonia vaccination over the course of their lives (25% vs. 45%). On the other hand, women 18 years of age and over who had community jobs were more likely to have had a Pap test within the past 3 years (83% vs. 75%).

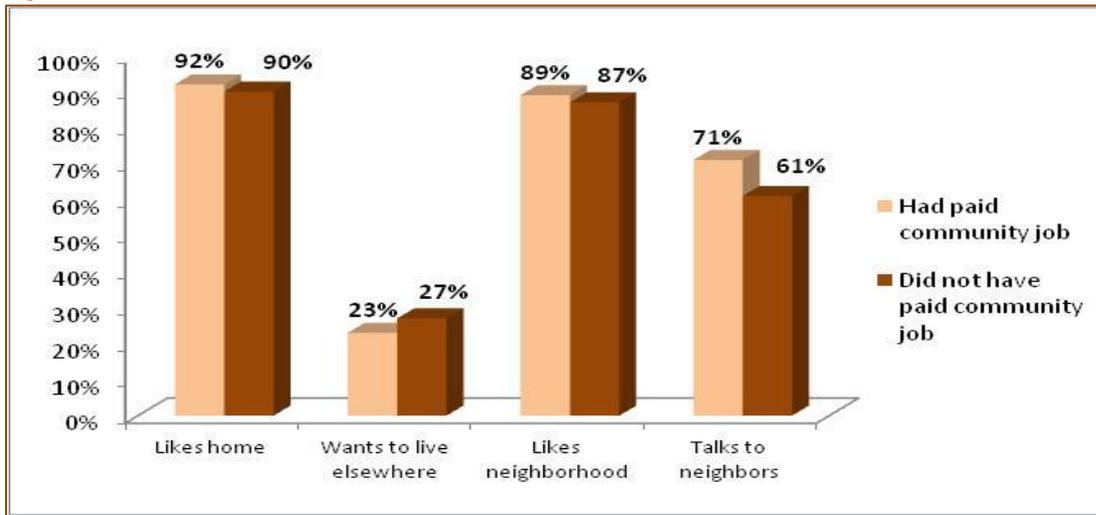
Figure 3. Preventive Health Care



Satisfaction

People with community jobs tended to score higher on the satisfaction domain. They were more likely to like where they live (92% vs. 90% of those without community jobs), less likely to want to live somewhere else (23% vs. 27%), more likely to like their neighborhood (89% v. 87%) and talk to their neighbors (71% vs. 61%) (see Figure 4). While most of these differences were not large, they were statistically significant at 0.05 level.

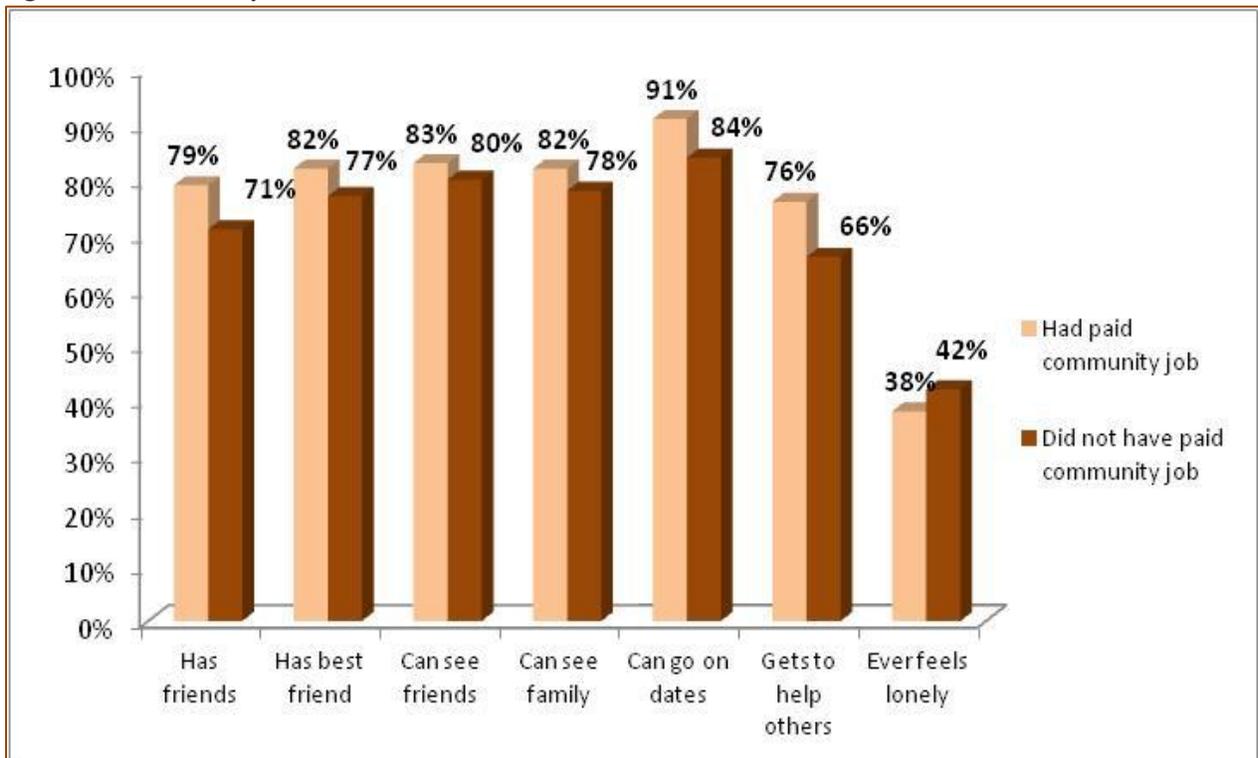
Figure 4. Satisfaction



Relationships

People who had community jobs also reported better results with respect to their personal relationships. Every relationship indicator that the NCI Consumer Survey collects showed a statistically significant difference. Specifically, they were more likely to: have friends (79% vs. 71% of people without community jobs), have someone whom they called a best friend (82% vs. 77%), be able to see their friends when they wanted to (83% vs. 80%) and their family when they wanted to (82% vs. 78%), go on dates if they wished (91% vs. 84%), and be able to help others (76% vs. 66%) (Figure 5).

Figure 5. Relationships

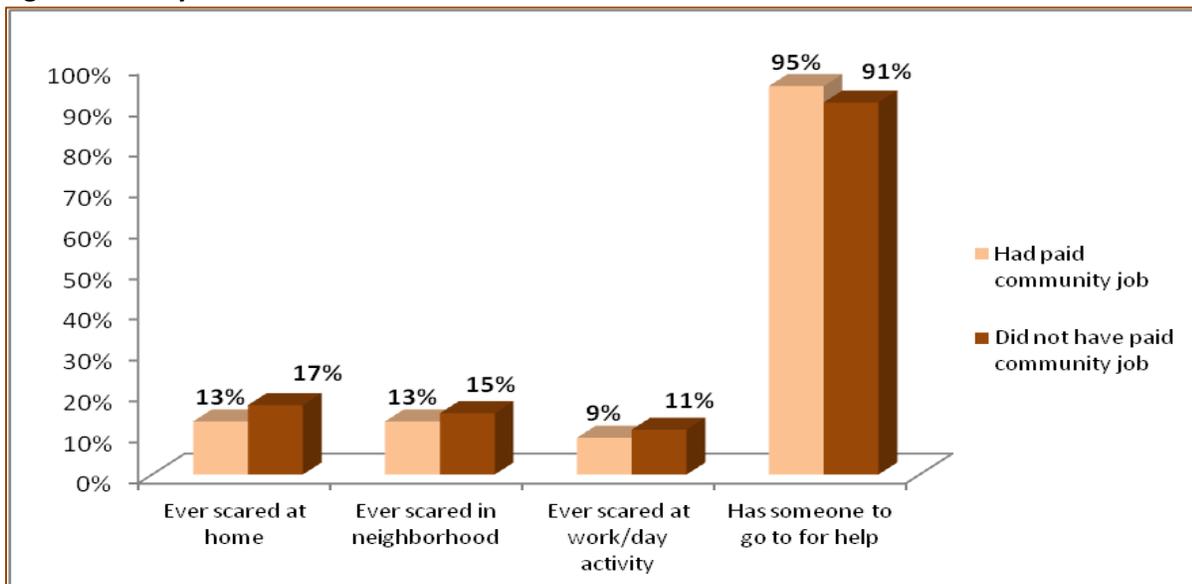


Loneliness is a problem for people with ID/DD who had community jobs; however, their rate of reporting ever feeling lonely was slightly lower (38%) than for those without community jobs (42%).

Safety

People in paid community jobs generally reported feeling safer in their environments. The differences were small, but statistically significant. A lower percentage of people with community work reported ever feeling scared at home (13%), in their neighborhoods (13%) and at their work (9%) than people without community work (Figure 6). Additionally, a higher percentage of people working in the community reported having someone to go to for help if they ever felt scared (95% vs. 91%).

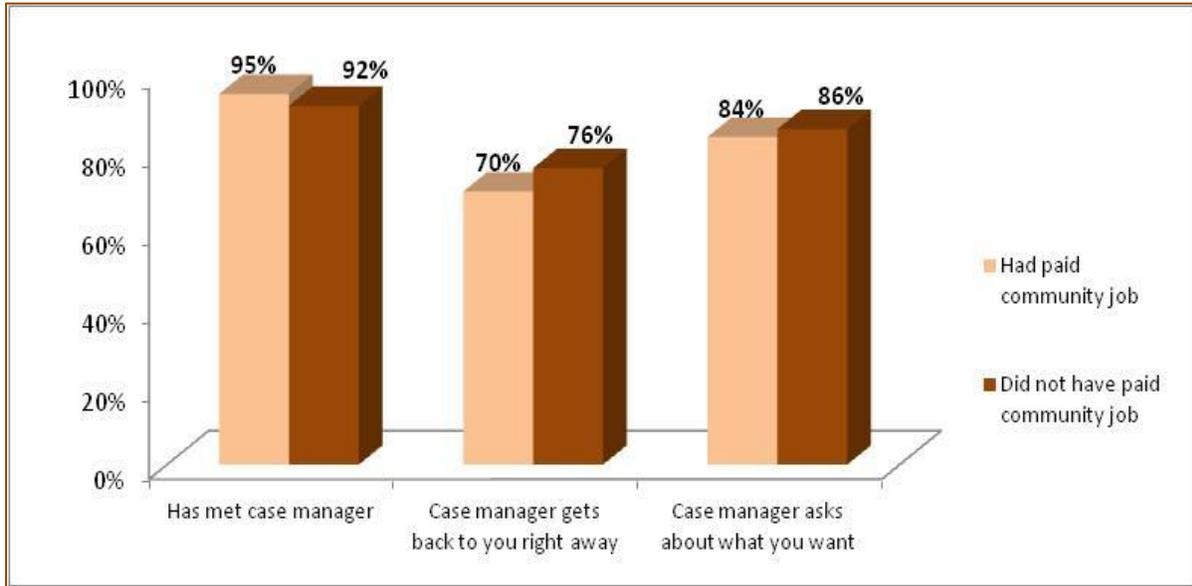
Figure 6. Safety



Service Coordination

Interestingly, people in paid community jobs had a generally less favorable view of the service coordination that they received. Although a slightly higher proportion of people with community jobs reported that they had met their case managers/service coordinators (95% vs. 92%), fewer of them reported that the case manager gets back to them “right away” after a request for contact (70%), or asks them what they wanted (84%), as compared to people without community jobs (76% and 86% respectively). There was no significant difference in the proportion of people who reported that they helped make their service plan. The findings could be interpreted as suggesting that case managers are less responsive to people with ID/DD who are working. Or, they could indicate that people who are working have higher expectations for their case manager in terms of responsiveness and supports received.

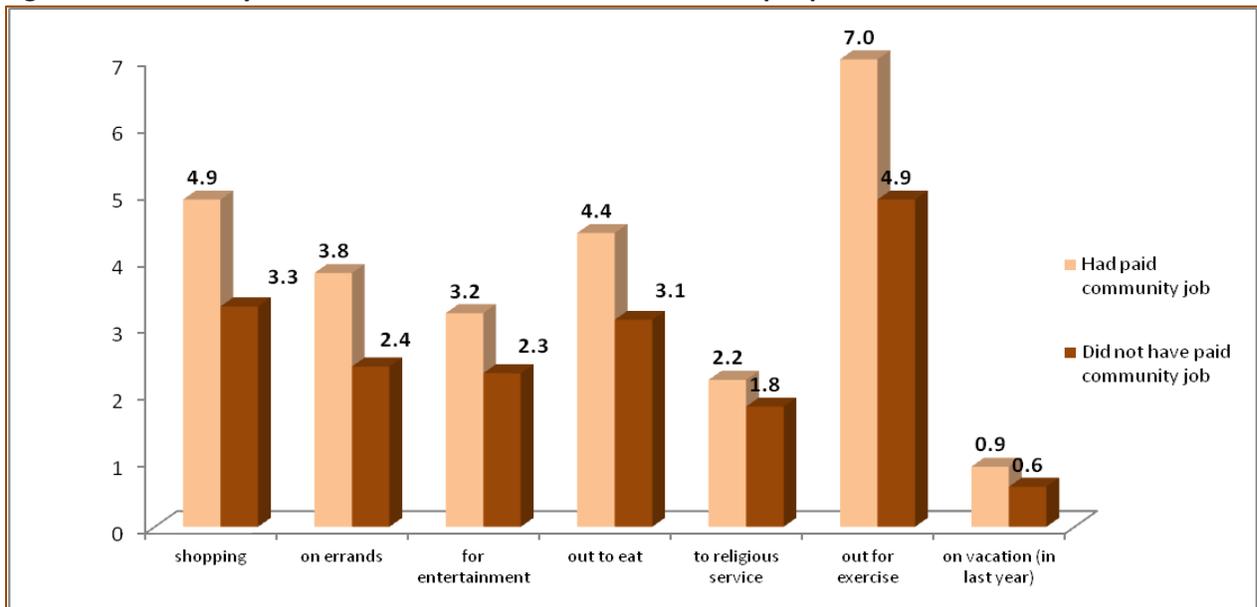
Figure 7. Service coordination



Community Inclusion

Not surprisingly, people with community-based employment tended to be more involved in their communities. On average, they participated in all types of community-based activities (that the NCI Adult Consumer Survey collects data on) more frequently than their counterparts without community-based employment. In the month prior to the interview, they went out shopping (4.9 times), on errands (3.8 times), for entertainment (3.2 times), out to eat (4.4 times), to a religious service of some kind (2.2 times) and out for exercise (7.0 times) more often people without community work (3.3, 2.4, 2.3, 3.1, 1.8 and 4.9 times respectively) (Figure 8). They also went on vacation in the past year more often (average of 0.9 times vs. 0.6 times for those without community work).

Figure 8. Community inclusion: Number of times in last month people went...



Choice and Decision-Making

People with community jobs also consistently exercised more choice in both life decisions and everyday choices. In terms of life decisions, they were more much more likely to have chosen their case manager (72%), where they live (65%) their work/activity during the day (83%), who they live with (59%), who helps them at home (78%) and at work/day activity (69%) than those without community based jobs (55%, 36%, 59%, 32%, 62% and 58% respectively) (Figure 9). They were also more likely to have looked at more than one home when selecting a residence (37% vs. 29% of those without community jobs) (not shown).

Similarly, those with community jobs on average exercised more choice in everyday decisions such as choosing their own schedule (95% vs. 78% of those without), choosing what to do with their free time (98% vs. 87%) and choosing what to buy with their money (97% vs. 85%) (Figure 10).

Figure 9. Life Choices

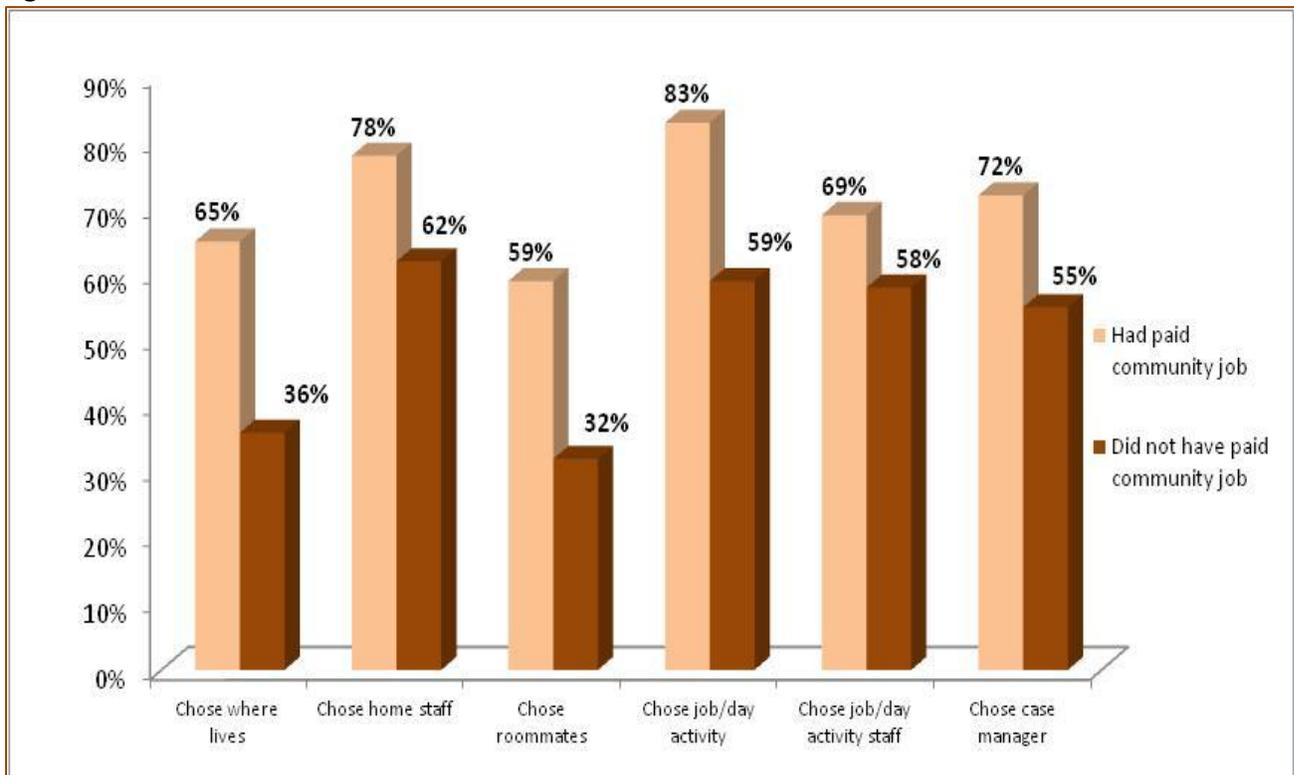
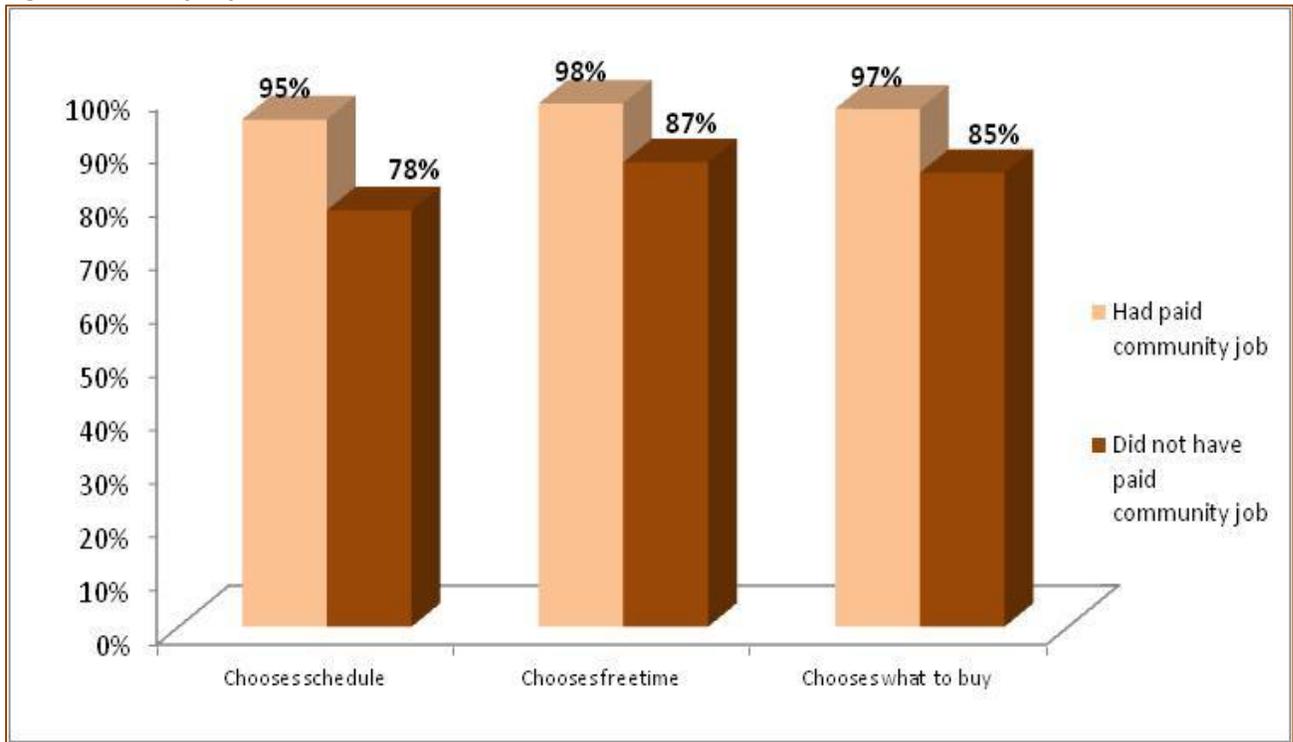


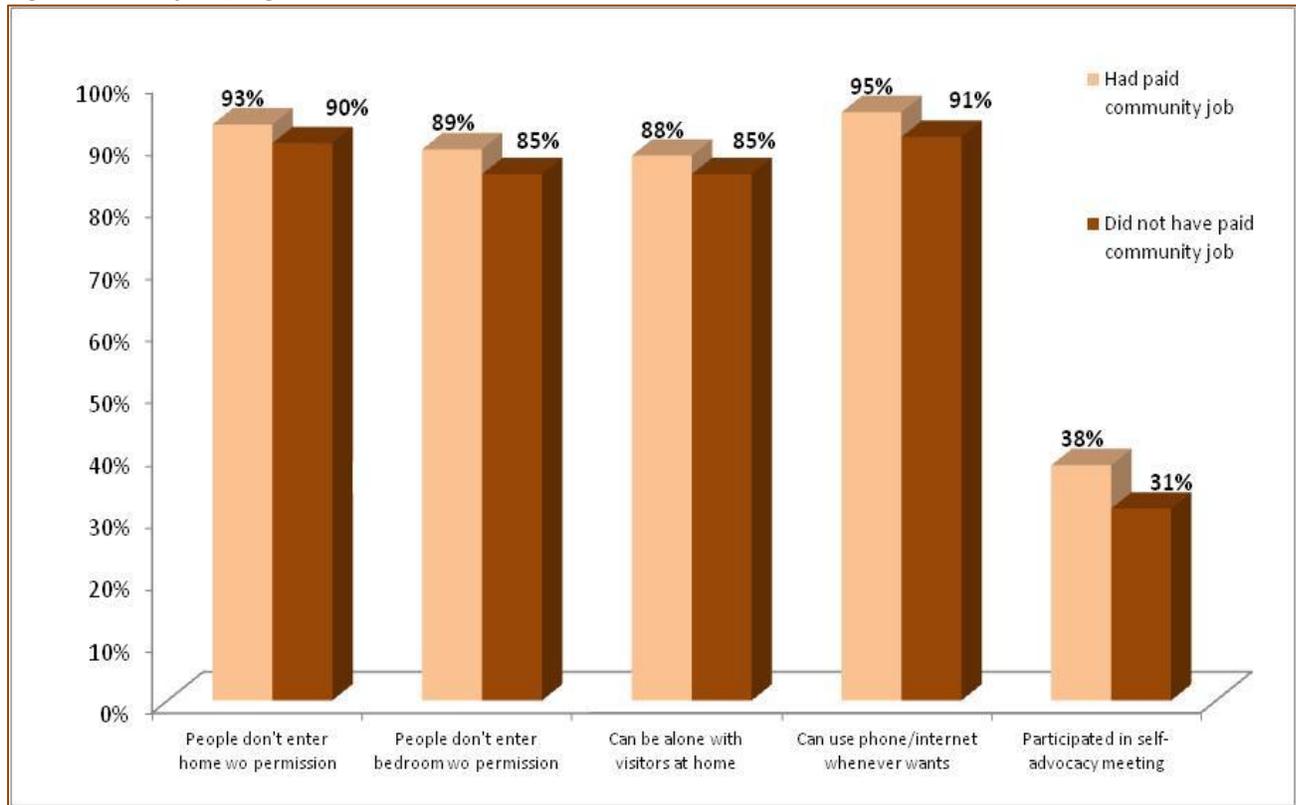
Figure 10. Everyday Choices



Respect/Rights

People with community employment were also somewhat more apt to report that their rights and privacy were respected than were people with ID/DD who were not employed in the community. More people with community jobs reported that their home (93% vs. 90%) and their bedroom (89% vs. 85%) was entered with permission only, that they can be alone with visitors at home (88% vs. 85%) and that they can use the phone or the internet without restrictions (95% vs. 91%) (Figure 11). As with some of the other outcomes, these differences are not large, but they are statistically significant. A higher percentage of those with community employment reported that they had participated or had an opportunity to participate in a self-advocacy meeting (38% vs. 31%).

Figure 11. Respect/Rights



ADDITIONAL ANALYSES

The analyses presented above are descriptive in nature comparing outcomes of people with ID/DD who are employed in community-based jobs with outcomes of individuals with ID/DD without community-based jobs. As found in previous analyses and described in one of the other employment data briefs in this series (Issue 6, 2011), there are other differences between these two groups with respect to age, disability, other diagnoses, etc. It is possible that some of the differences found here are due at least in part to other factors besides community employment. This may be particularly relevant for preventive health care indicators, for which, based on previous analyses, the likelihood of receipt is heavily depended on type of residence. People living in more restrictive environments are more likely to receive preventive health care, controlling for other factors. Since those who have community jobs are more likely to live in community-based settings, this differential may account for most of the observed difference in health care receipt. We will perform additional analyses to control for factors other than having a community-based job and will publish the results in a peer-reviewed journal.

SUMMARY OF FINDINGS

Data collected in 2009-10 by the NCI Adult Consumer Survey revealed a strong pattern of significant differences in outcomes between people who had community-based jobs and people who did not.

Overall, compared with individuals without community-based jobs, people who had them were more likely to:

- ❖ Be satisfied with where they live and more likely to talk to their neighbors
- ❖ Have friends, be able to date, be able to see their friends and family
- ❖ Feel safe at home, at work or in their neighborhood
- ❖ Have someone they can go to for help if they feel afraid
- ❖ Have met their case manager
- ❖ Have chosen their case manager, where and with whom they live, where they work or go during the day, and who helps them
- ❖ Make everyday choices such as choosing their own schedule, choosing what to do with their free time and choosing how to spend their money
- ❖ Have their rights respected
- ❖ Have participated in a self-advocacy meeting.

The data also showed that people in community-based employment are less likely to:

- ❖ Feel that their case manager is responsive in terms of calling them back right away or asking about what they want
- ❖ To receive most preventive health care exams and services.

The data illustrate the important impact that employment has on the personal and social lives of people with ID/DD in state developmental disabilities service delivery systems as demonstrated by a clear trend of differences in outcomes between people with ID/DD who work in community-based jobs and people with ID/DD who do not. Across all outcomes other than those relating to service coordination, people with community jobs reported having a greater quality of life compared to those not working in community jobs. Although, as previously noted, other factors may contribute to differences between the groups (e.g., age, level of disability, other diagnoses, type of residence), the results of this analysis suggest that working in a community job has a strong role to play in a person's overall well-being.