

# NCI DATA BRIEF

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## What does NCI tell us about adults with disabilities who live at home with their families?

The 2007-08 National Core Indicators Consumer Survey Report included descriptive and outcome data on 11,447 adults from 24 states<sup>1</sup>. Almost one-third of these individuals (3,559, or 31%) lived at home with their parents or other relatives, while the remaining two-thirds (7,888, or 69%) lived away from home in various residential settings, such as group homes, independent homes or apartments, institutions, and nursing facilities. It is increasingly common for people with intellectual disabilities to remain at home with their families and for longer periods of time. This data brief describes NCI findings for adults with ID/DD living in the family home in order to shed light on their experiences and to inform state policy and the design of services.

The results described below were obtained through t-tests comparing adults who lived at home to those who lived away from home. *For the purpose of this Data Brief, only group differences that were significant at the  $p < .05$  level are reported herein and displayed in the graphs.*

### PROFILE

#### Demographics

In several interesting ways adults with disabilities who lived at home were different from those who lived away from home. As shown in Figure 1, those who lived at home had a mean age of 35 and were on average over 10 years younger than those who lived away from home (mean age = 46). In addition, the group of individuals who lived at home was more racially and ethnically diverse. Compared with adults living outside the home, this group included significantly higher percentages of individuals who were non-white (19% Black/African American and 4% Asian) and Hispanic/Latino (11%). See Figure 2.

Figure 1. Average age

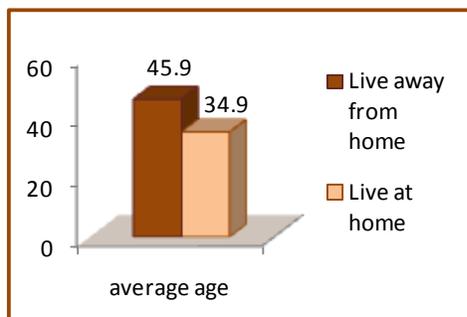
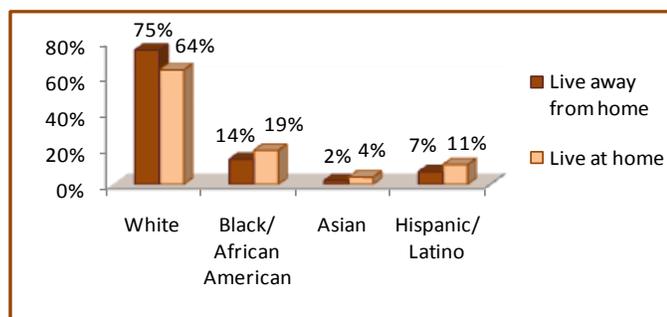


Figure 2. Race/Ethnicity



<sup>1</sup> The 2007-08 NCI Consumer Survey Report included: Alabama, Arkansas, Arizona, Connecticut, Delaware, Georgia, Hawaii, Indiana, Kentucky, Louisiana, Maine, Missouri, North Carolina, New Jersey, New Mexico, New York, Oklahoma, Pennsylvania, Rhode Island, South Carolina, Texas, Vermont, West Virginia, and Wyoming.

## Intellectual Disabilities and Medical/Psychological Disorders

This group of individuals also had a different profile with respect to level of intellectual disability and presence of other medical and psychological disorders. Figure 3 shows that individuals who lived at home were more likely to have diagnoses of no or mild ID (42%) or moderate intellectual disability (37%) and less likely to have a severe or profound disability (22%) than those who lived away from home (40%, 25% and 35%, respectively).

**Figure 3. Level of Intellectual Disability**

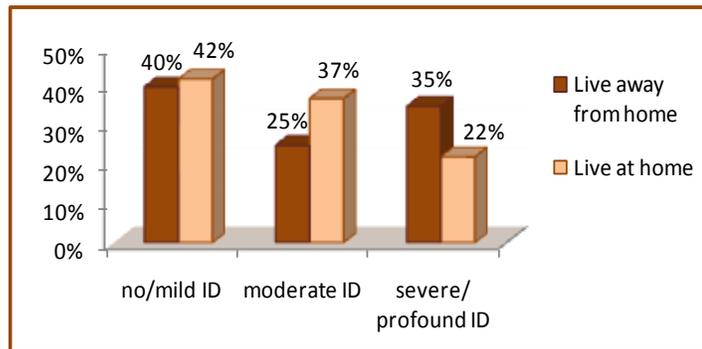
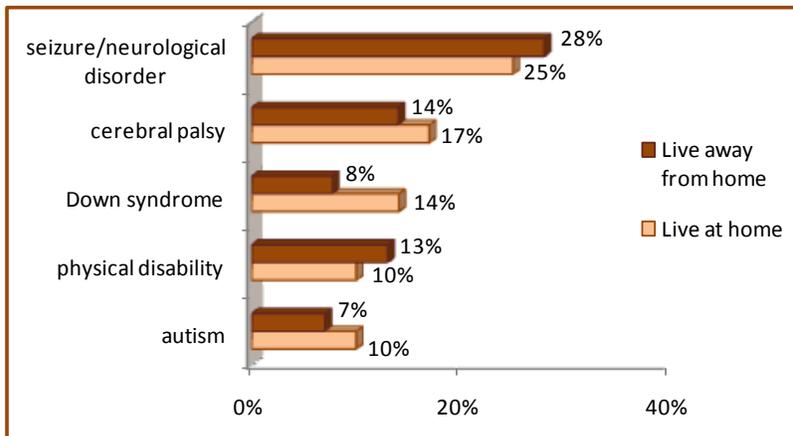


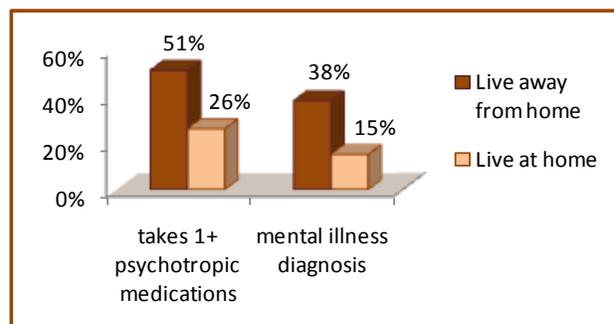
Figure 4 highlights the other disorders noted that showed significant differences between the two groups. Individuals who lived at home were more likely to have cerebral palsy (17%), Down syndrome (14%), and autism (10%) than individuals who lived away from home (14%, 8%, and 7%, respectively). However, individuals who lived at home were less likely to have a seizure or neurological disorder (25%) or a physical disability (10%) than those who lived away from home (28% and 13%, respectively).

**Figure 4. Other Disorders**



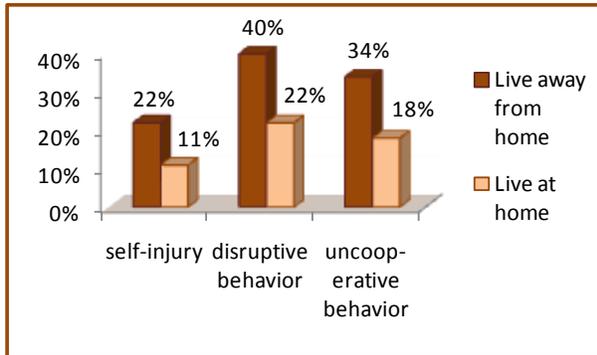
Individuals living at home were also less likely to have a mental illness diagnosis (26%) and to take at least one psychotropic medication (15%) than those who lived away from home (51% and 38%, respectively). See Figure 5.

**Figure 5. Mental illness and psychotropic medication**



## Challenging Behaviors

**Figure 6. Challenging behaviors**



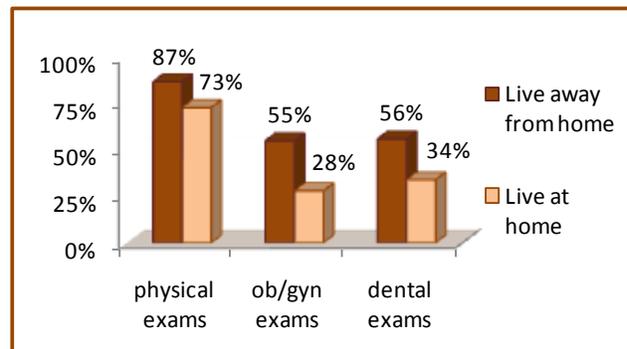
As shown in Figure 6, individuals who lived at home were roughly half as likely to require support to address three types of challenging behaviors (self-injury, disruptive behavior, and uncooperative behavior) than were individuals who lived away from home. Specifically, 11% of individuals who lived at home versus 22% of those who lived away from home needed support to prevent self-injury. Twenty-two percent (22%) of those who lived at home versus 40% of those who lived away from home needed support to prevent disruptive behavior. And, 18% of individuals who lived at home versus 34% of those who lived away from home needed support to prevent uncooperative behavior.

## Medical Exams and Received Services

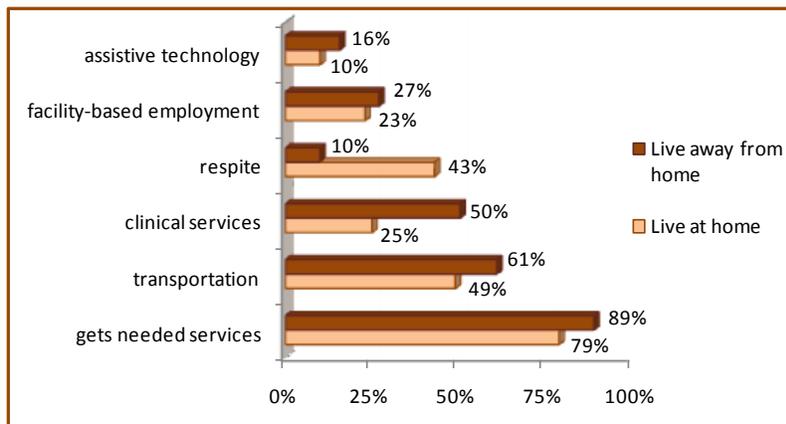
Figure 7 shows that adults with disabilities who lived at home were less likely to have had a physical exam (73%) or ob/gyn exam (28%) in the past year and a dental exam (34%) in the past six months than those who lived away from home (87%, 55%, and 56%, respectively). This represents an area of concern.

In addition, individuals who lived at home were less likely to have received assistive technology, facility-based employment support, clinical services, and transportation support. This group was more likely to have received respite or home support than were individuals who lived away from home. Another troubling finding is that individuals who lived at home were less likely to report that they received the services they needed (79%) than were those who lived away from home (89%). See Figure 8 below.

**Figure 7. Medical Exams**



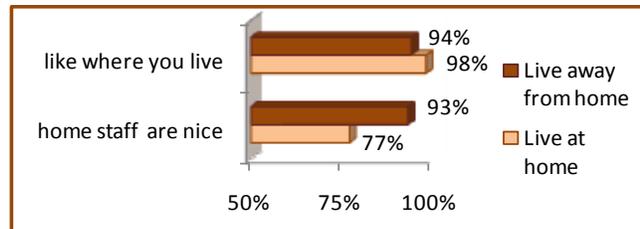
**Figure 8. Received Services and Supports**



## Satisfaction with Residence

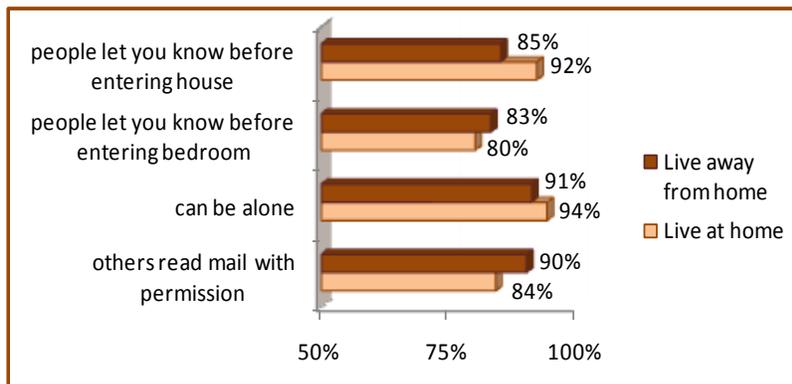
Individuals who lived at home were slightly more likely (98%) to report that they liked where they lived than were those who lived out of their family home (94%). See Figure 9. However, they were less likely to feel that their home staff were polite and respectful (77%) than were individuals who lived away from home (93%).

**Figure 9. Home Satisfaction**



## Privacy and Respect

**Figure 10. Privacy and Respect**



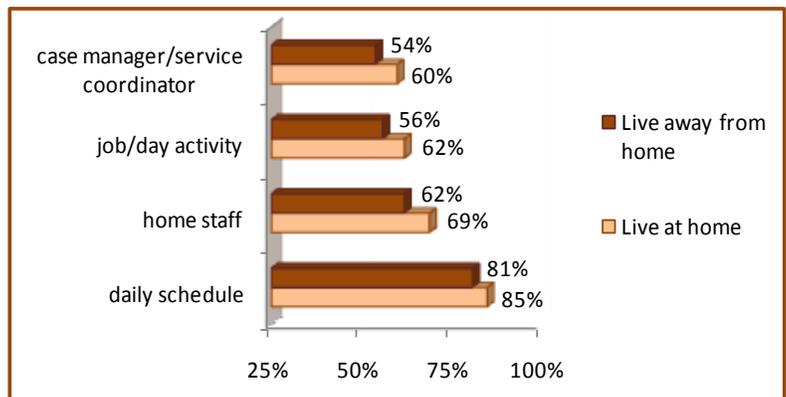
There were also mixed results regarding privacy and respect (see Figure 10). Individuals who lived with their families were more likely to be alerted before other people entered their home (92%) and were more likely to report that they could be alone and have privacy (94%) than were individuals who lived away from their families (85% and 91%, respectively). However, individuals who lived at home were less likely to be alerted before others entered

their bedroom (80%) and to have others ask them for permission before reading their mail (84%) than were those who lived away from their families (83% and 90%, respectively).

## Choice

Overall, individuals who lived at home tended to have more choice in their lives than did those who lived away from home (see Figure 11). Specifically, individuals who lived at home were more likely to have chosen their case manager/service coordinator (60%), their job or day activity (62%), their home staff (69%), and their daily schedule (85%) than were individuals who lived away from home (54%, 56%, 62%, and 81%, respectively).

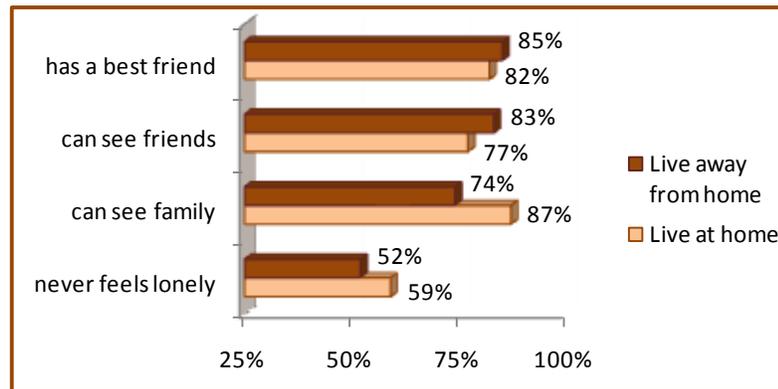
**Figure 11. Choice**



## Relationships with Friends and Family

The results regarding relationships, displayed in Figure 12, were also mixed. Individuals who lived at home were more likely to see their families whenever they wanted to (87%) and to never feel lonely (59%) than were individuals who lived away from home (74% and 52%, respectively). However, people who lived at home were less likely to have a best friend (82%) and to see their friends whenever they wanted to (77%) than were those who lived away from home (85% and 83%, respectively). These group differences may be explained by the closer proximity of individuals living at home to their families and individuals living away from home to roommates who may also be friends.

**Figure 12. Relationships**



## ADDITIONAL ANALYSES

The differences described above between adults with disabilities who live at home with their families and adults who live away from home could be explained by significant and large group differences in various key background variables, such as the state in which individuals lived, their age, their likelihood of having a mental illness or psychiatric diagnosis, and their receipt of clinical services, frequent medical care, and 24 hour on-site staff support. To determine whether these key background variables accounted for any of the observed group differences described above, we conducted a series of regression analyses to examine differences between the two groups' responses to the NCI survey questions while controlling for these six key background variables. Analyses indicated that all of the group differences described in the charts above held true even after controlling for differences in the aforementioned key background variables. In other words, the group differences described above in this report cannot be explained by group differences in individuals' ages, the places where they lived, their disabilities, or the supports and services they received.

Though not reported herein, employment outcomes also varied for individuals living at home and those living outside the home. Several new employment variables were added to the 2008-2009 NCI Consumer Survey in order to gather additional data on this key policy issue. Future analyses will be performed to examine group differences in community employment outcomes by residence type, and these findings will be reported in a separate Data Brief.

## SUMMARY OF FINDINGS

National data collected on the health, support and services, behaviors, and outcomes of individuals with disabilities in 2007-08 by the National Core Indicators survey revealed some significant differences between adults with disabilities who lived at home with their families and adults who lived away from home in other residential settings.

Overall, compared with individuals who lived away from home, individuals who lived at home tended to:

- ❖ have less severe intellectual disabilities
- ❖ have lower rates of seizure/neurological disorders, physical disabilities, and mental illness, and were less likely to be taking psychotropic medications
- ❖ have higher rates of cerebral palsy, Down syndrome, and autism
- ❖ be less likely to need support to prevent challenging behavior

The data suggest that individuals who live at home fare better in some areas than individuals who live away from home. For example, people living at home:

- ❖ have more choice in several areas of their lives
- ❖ are more likely to see family
- ❖ are less likely to feel lonely, although loneliness remains a concern across both groups

However, the data also indicate that individuals who live away from home score higher on several important indicators. Specifically, they are:

- ❖ more likely to have and see friends
- ❖ more likely to have regular medical exams
- ❖ more likely to receive several types of supports and services
- ❖ more likely to feel they received the services they need

As state policy makers expand services to people living at home and with their families, it is important to understand the needs of this group of individuals. For instance, although the rates of neurological disorders, mental illness, challenging behaviors, and physical disability are lower among this population than those living in out of home settings, they are still considerable. Services and supports must be adequate to meet their needs and tailored to address each person's individual characteristics. The strengths of the family home environment should be recognized, honored and nurtured. The risks, especially concerning access to medical care and adequate services, on the other hand, require attention and careful planning.