

NCI DATA BRIEF

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What does NCI tell us about older adults with intellectual and developmental disabilities?

Life expectancy for persons with intellectual and developmental disabilities (ID/DD) has increased dramatically in recent decades and continues to rise. As such, the number of elderly people with ID/DD is also increasing. This data brief describes NCI findings for older adults with ID/DD, defined as ages 65 and older, in order to shed light on their experiences and to inform state policy and program design.

The 2009-10 National Core Indicators (NCI) Adult Consumer Survey Report included descriptive and outcome data on 11,599 adults from 17 states and one sub-state entity¹. Approximately 7% (833 people) were age 65 and older. The mean age for those 65 and older was 71.6 years, and the median age was 70 years.

The results described below were obtained through t-tests comparing adults ages 65 and over to those under 65. ***For the purpose of this Data Brief, only group differences that were significant at the $p < .05$ level are reported.***

PROFILE

Demographics

Adults with disabilities ages 65 years and older differed from those under 65 on several demographic characteristics. As shown in Figure 1, those 65 and older were more likely than those under age 65 to be white (85% vs. 72%) and less likely to be Black or African American (12% vs. 21%). A much higher proportion of individuals under 65 were male (57%) than female (43%); however, the proportion of males was lower than the proportion of females in the older adult group (49% male, 51% female).

There were significant differences between older and younger adults in terms of type of residence (see Figure 2). Those 65 and older were significantly more likely to be living in a group home (39% vs. 27%), a specialized institutional facility (25% vs. 20%), or a nursing facility (5% vs. 1%). Older adults were somewhat less likely to live in an independent home or apartment (9% vs. 11%). Not surprisingly, older adults were also significantly less likely to live in a parent's or relative's home (29% vs. 5%).

¹ 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.

Figure 1. Race/Ethnicity

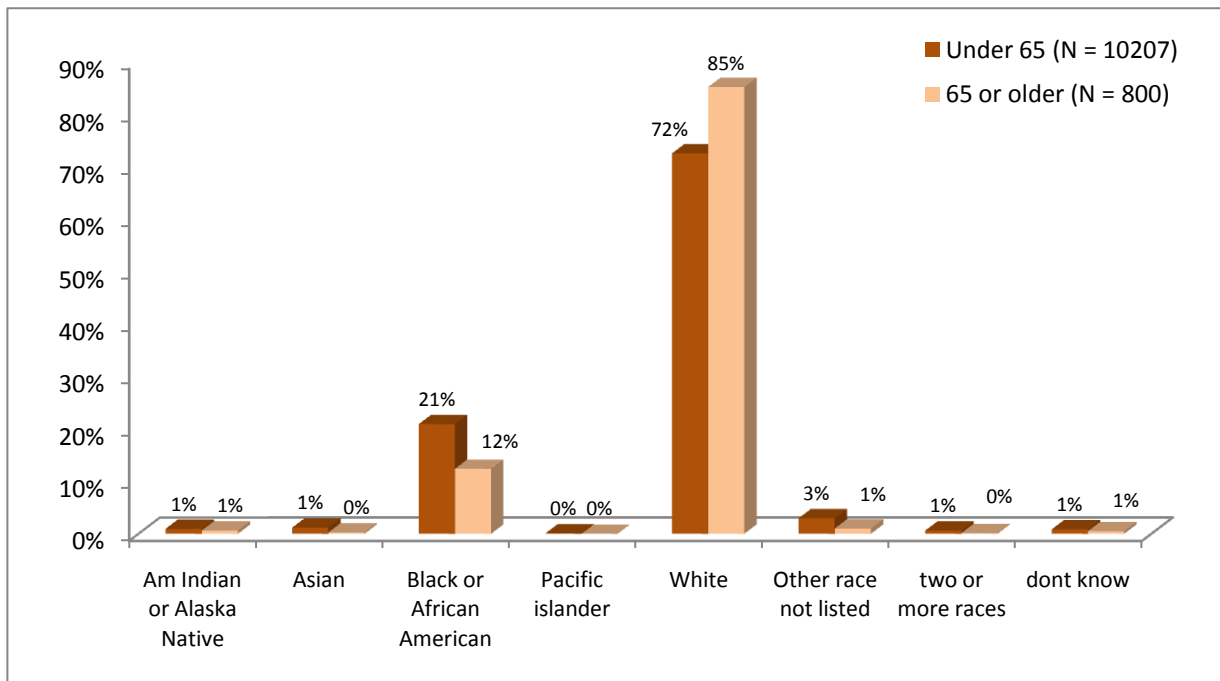
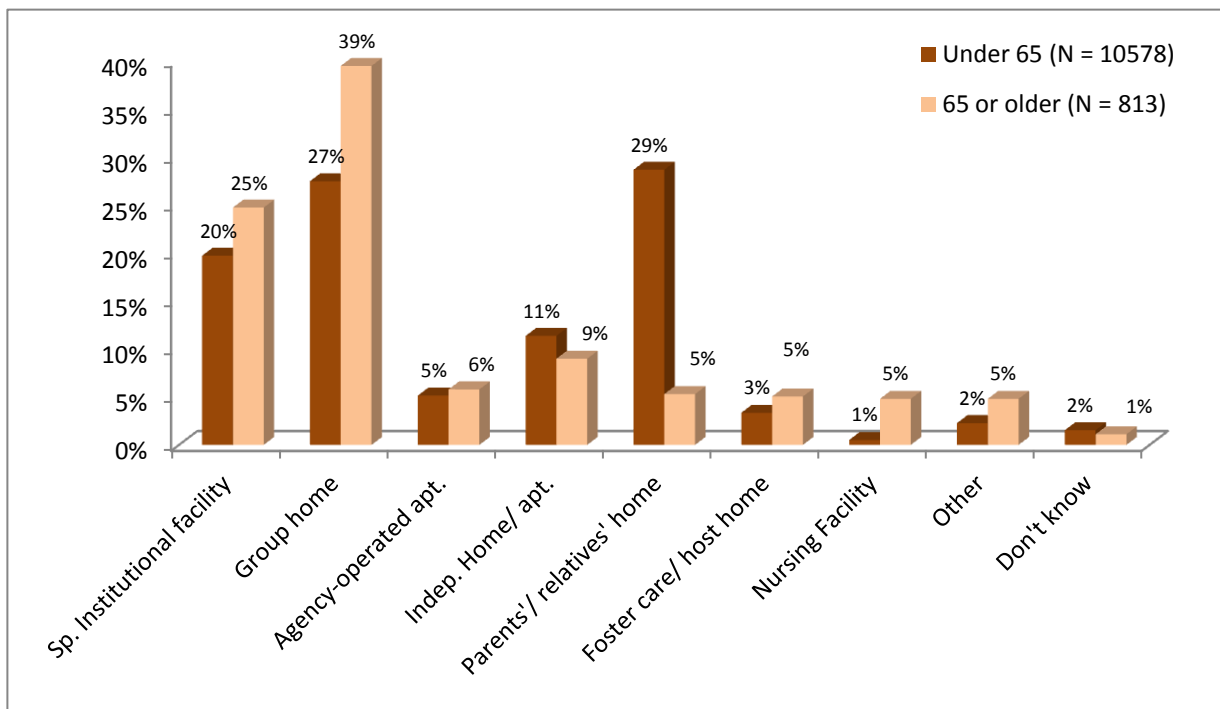
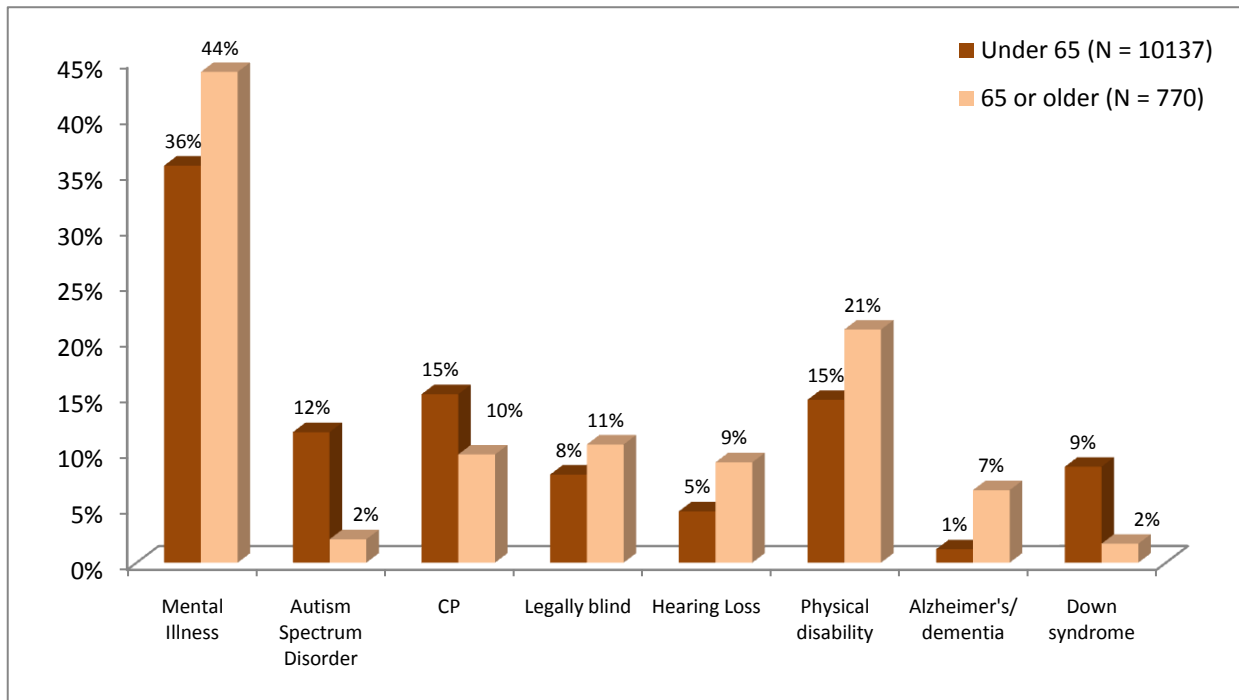


Figure 2. Residence



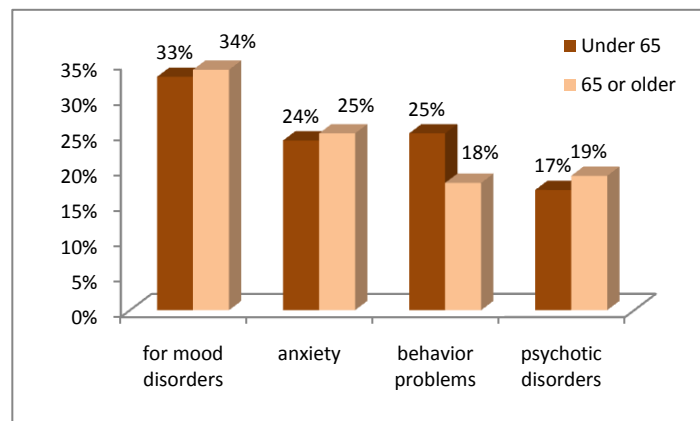
Older individuals with ID/DD had a somewhat different profile with respect to the presence of other medical and psychological conditions than did individuals less than 65 years of age (see Figure 3). Older adults were more likely to have a diagnosis of Alzheimer’s disease or other dementia (7% vs. 1%). They were also more likely to have a physical disability (21% vs. 15%), hearing loss (9% vs. 5%), or be legally blind (11% vs. 8%). Interestingly, they were also significantly more likely to have a diagnosis of mental illness or a psychiatric disorder (44%) than those less than 65 years of age (36%). On the other hand, they were significantly less likely to have a diagnosis of Cerebral Palsy (10% vs. 15%) or Down syndrome (2% vs. 9%). They were also less likely to be diagnosed with Autism Spectrum Disorder (2% vs. 12%) than those under 65 (12%).

Figure 3. Other Disorders



Even though the older group was significantly more likely to be diagnosed with a mental illness, they were no more likely to take various types of psychotropic medications (see Figure 4) than were adults under 65 years of age. In fact, they were less likely to take psychotropic medications for behavior problems than the younger group (18% vs. 25%). Approximately 52% of the older group and 51% of the younger group took at least one kind of psychotropic medication.

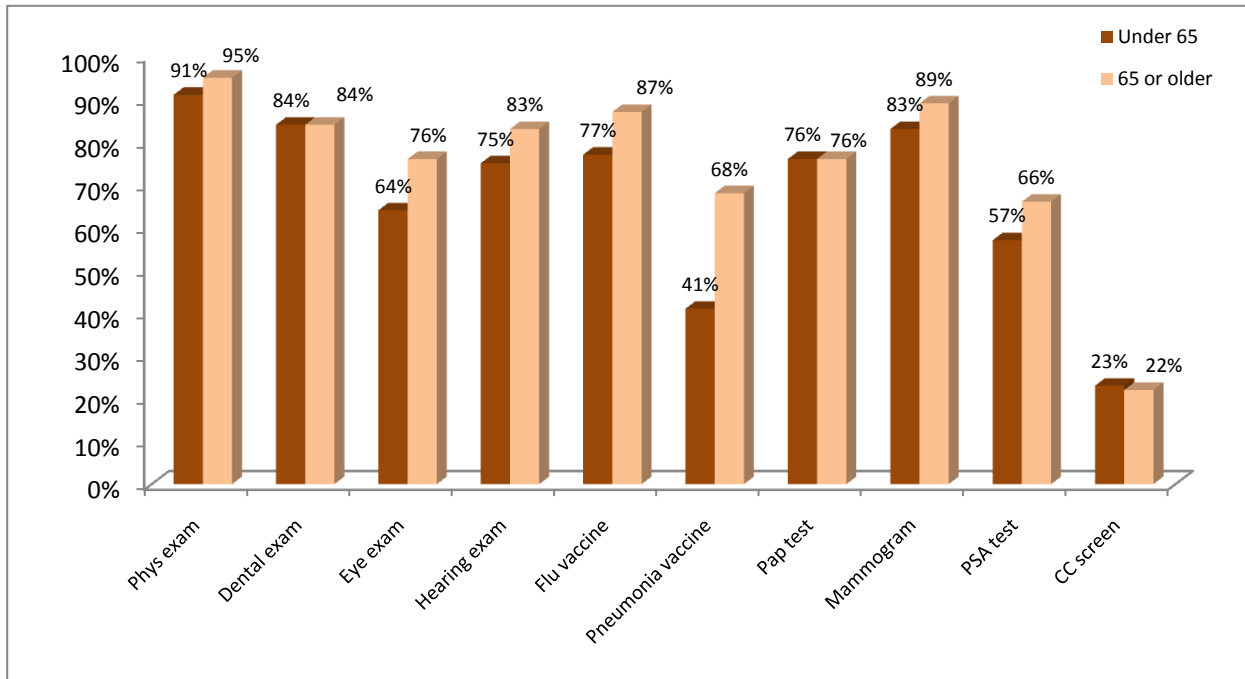
Figure 4. Psychotropic medication



Medical Care

As described in Figure 5, adults with disabilities who are 65 years of age and older receive some preventive health care procedures at slightly higher rates than those under age 65 years. They were somewhat more likely to have had a physical exam in the past year (95% compared to 91% of those under 65), and significantly more likely to have had vision (76% vs. 64%) and hearing (83% vs. 75%) exams. Older adults were also significantly more likely to be vaccinated for the flu in the past year (87% vs. 77%), and pneumonia over their lifetimes (68% vs. 41%).

Figure 5. Medical Exams



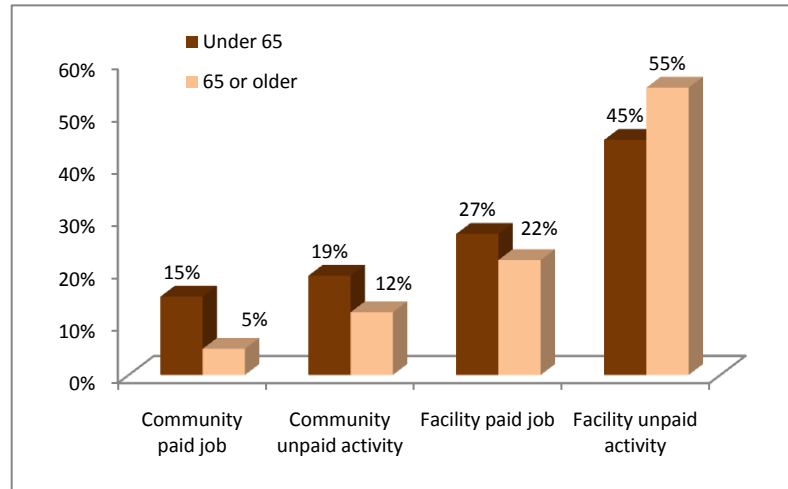
Overall, the older group received medical care at higher frequencies than the younger group. Thirty-nine percent of those 65 years and older accessed medical care at least once a month, compared to 21% of the younger group. Older adults were also somewhat more likely to be receiving clinical services (48% vs. 45%). Furthermore, adults 65 and older received assistive technology services and transportation services at higher rates (30% vs. 20%, and 71% vs. 67% respectively). They were also more likely to report that they received needed services (94%) than were the younger group (86%).

Additionally, a significantly lower proportion of older adults were reported as being obese (22%) as compared to the proportion of younger adults (30%), though older adults were much less likely to be independently mobile (54% vs. 76%).

Work and Day Activities

As shown in Figure 6, adults with disabilities 65 years and older were less likely than those under 65 to participate in community-based jobs, facility-based jobs, and community-based unpaid activities. They were, however, considerably more likely to be engaged in a facility-based unpaid activity during the day (55% vs. 45%). While this figure may include people who go to generic activity centers for seniors, it is likely that the majority are in sheltered day/workshop programs geared specifically towards people with intellectual and developmental disabilities.

Figure 6. Work and Day Activities

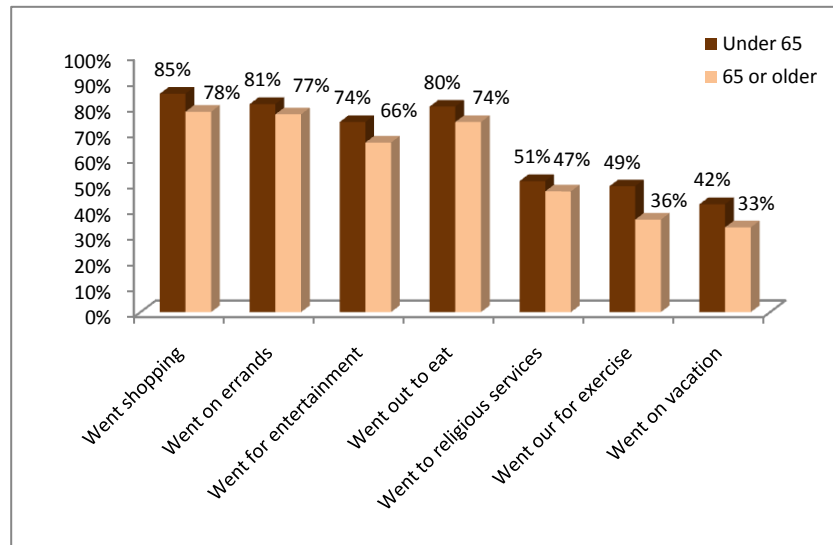


Of people who report not having a community job, only 25% of those 65 and older said they wanted one, as compared to 47% of those under 65.

Community Inclusion

Older adults with disabilities were consistently less likely to take part in integrated community-based activities such going shopping, out for entertainment, or out to eat (Figure 7). Seventy eight percent (78%) reported going shopping in the community in the last month, compared to 85% of those under 65. Only 66% reported going out for entertainment in the last month, and 74% reported going out to eat or to a coffee shop in the same time period (compared to, respectively, 74% and 80% of younger adults).

Figure 7. Community Inclusion

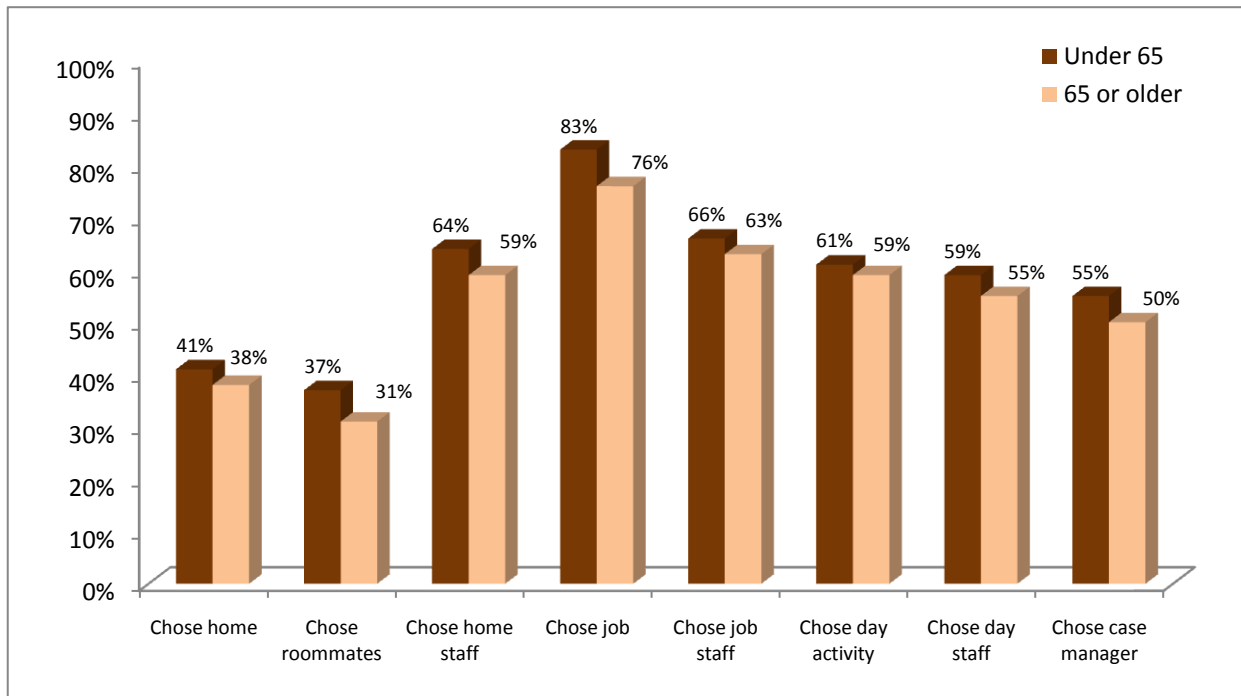


Forty seven percent (47%) reported going to community-based religious services, and only 36% said they went out for some sort of exercise or sport. Only one third (33%) of people 65 and over reported going on a vacation in the past year, compared to 42% of those under 65.

Choice

Overall, individuals 65 and older tended to make fewer choices in their lives than do those under 65 (see Figure 8). Specifically, older individuals were less likely to choose their home (38%), roommates (31%), case manager/service coordinator (50%), their job (76%), their home (59%) and day staff (55%) than were younger individuals (41%, 37%, 55%, 83%, 64%, and 59%, respectively).

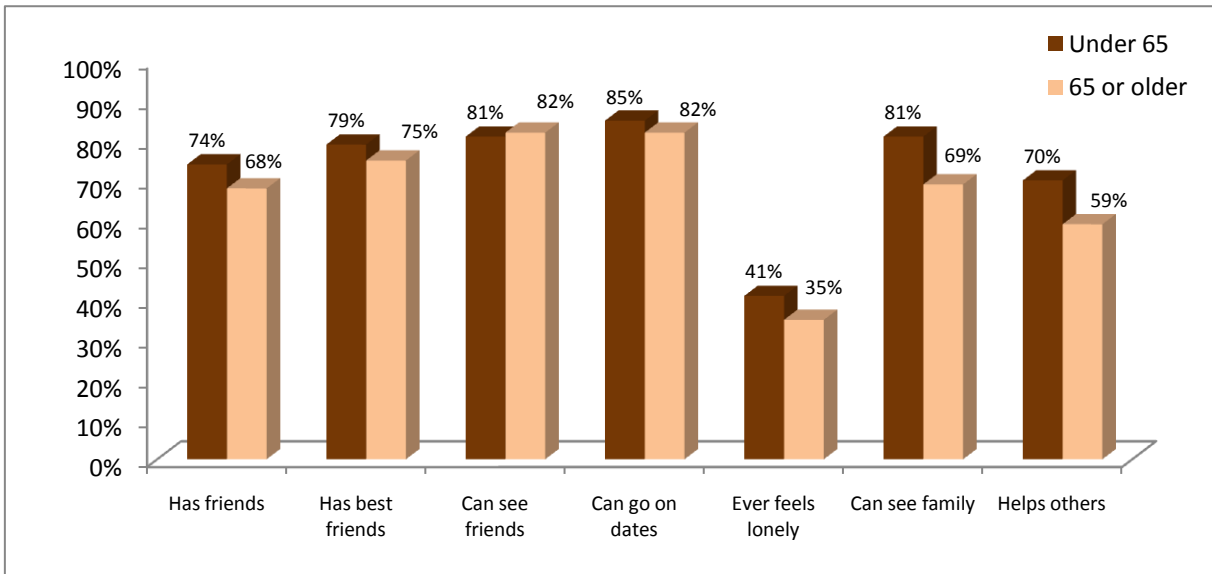
Figure 8. Choice



Relationships with Friends and Family

The results regarding relationships, displayed in Figure 9, also reveal some differences between older and younger adults. Individuals 65 and older were less likely to report having friends (68%) or a best friend (75%), and less likely to be able to see their families when they wanted to (69%) than were younger individuals (74%, 79%, and 81%, respectively). They were also less likely to report helping others (59% vs. 70% of people under 65). Interestingly, however, the older group was more likely to report never feeling lonely (65% compared to 59% of the younger group).

Figure 9. Relationships



ADDITIONAL ANALYSES

The differences described above between older (age 65 and over) and younger (under 65) adults with disabilities could be explained in part by significant and large group differences in various key background variables, such as the state in which individuals lives, their likelihood of having a psychiatric diagnosis, frequency of medical care needed, mobility, and type of residence. To determine whether these factors accounted for any of the observed group differences described above, we will be conducting a series of regression analyses to examine differences between the two groups' responses to the NCI survey questions while controlling for the key variables. The results of these analyses will be published in a peer-reviewed journal.

SUMMARY OF FINDINGS

Data collected on the health, support and services, behaviors, and outcomes of individuals with disabilities in 2009-10 by the National Core Indicators Adult Consumer Survey revealed some significant differences between older adults and adults who were under 65 years of age.

Overall, compared with younger individuals, older adults with intellectual and developmental disabilities tended to:

- ❖ have lower rates of Autism Spectrum Disorder, Down syndrome, and Cerebral Palsy
- ❖ have higher rates of a psychiatric diagnosis, Alzheimer's or other dementia, vision or hearing problems, and physical disability
- ❖ be more likely to live in provider-based settings (group homes, specialized institutional facilities, and nursing homes)

The data suggest that older adults fare worse in some areas than younger individuals. Specifically, older adults:

- ❖ were less likely to make choices in several areas of their lives, such as choosing their homes, roommates, jobs, service coordinators, and staff
- ❖ were less likely to have friends or be able to see family
- ❖ were less likely participate in community-based leisure activities, such as shopping, eating out, or going out for entertainment
- ❖ were less likely to have paid work
- ❖ were much more likely to be engaged in unpaid facility-based activities

However, the data also indicate that older individuals score higher on other important indicators. As a group, people over 65 years are:

- ❖ more likely to report never feeling lonely
- ❖ more likely to have regular medical exams and vaccinations
- ❖ more likely to report that they received the services they need

Although older adults were more likely to have a mental illness or psychiatric diagnosis, there was little difference between the two groups in terms of rates of psychotropic medication use for mood, anxiety, or psychotic disorders. In fact, both groups had similar and remarkably high rates of using at least one psychotropic drug (just over 50%).

The NCI data indicate that 55% of adults 65 and over participate in facility-based programs engaged in non-work activities during the day. It is not clear whether they are given an option to retire. Admittedly, the concept of retirement is a complicated one for people with ID/DD, particularly since the program model people with ID/DD typically retire *from* is no different from the model that people without disabilities typically retire *to*. This is an issue that will be receiving increasingly more attention as the population ages.

These findings should be considered in light of the fact that people who are older and have ID/DD face two sets of challenges. First, like people without ID/DD, they experience functional and cognitive declines during the aging process that limit their ability to actively care for themselves and engage in community life. Second, because of the nature and scope of their existing disabilities, people with ID/DD may require more comprehensive supports during the aging process.

It also is important to emphasize that some of the differences found between older and younger adults could be due to factors other than age itself. For example, the NCI data indicate that people living in more institutional-type settings are more likely to receive preventive health care than those living in the family home. Since older adults are more likely to live in institutions and group homes, this may account for at least some of the observed greater likelihood of their receiving needed medical exams and vaccinations.

The differences between older and younger individuals with ID/DD receiving services reflect a number of variables, as noted above, not the least of which are those related to the characteristics of different

state DD systems. People who are older tend to have been served by state systems for longer periods of time, and the fact that greater numbers are being served in more traditional day and residential programs may reflect past placement and service provision practices, rather than a planned approach to serving older individuals.

It also needs to be considered that people growing older in the near future will have had very different life experiences than the current 65+ cohort, especially in terms of experiencing institutionalization, family relationships, and self-advocacy. The data underscore the need to carefully track services and service outcomes for older individuals with ID/DD to ensure that supports are tailored to address quality of life areas that are of particular importance to older adults, including opportunities for the exercise of personal choice and control, participation in community activities, maintaining friendships and relationships with family and friends, and providing meaningful options for people of retirement age.