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What Do NCI Data Tell Us About the Characteristics and Outcomes of Young Adults Receiving Services?

By Stephanie Giordano and Valerie Bradley

Each year, over 20 million young adults enter college,¹ and others are securing their first job and moving out of their family home for the first time. These years can be both challenging and exciting. However, despite decades of federal policies that have promoted equal opportunity for people with disabilities,^a young adults with intellectual and developmental disabilities (IDD) do not share the same opportunities and experiences as their age peers, particularly with respect to education and employment.

Using National Core Indicators data from 2015-16 in-person surveys, this data brief examines the quality of life of young adults (ages 18 to 25) with IDD and provides suggestions to enhance the planning process used to support them as they transition to adult life—so they can gain skills that will help them maximize their autonomy and independence later in life.

^a Including the passage of The Education for All Handicapped Children Act (Public Law (PL) 94-142) in 1975 (reauthorized in 1990, and now known as the Individuals With Disabilities Act [IDEA]).

Findings

We analyzed data collected in 2015-2016 by the 35 states (and the District of Columbia) that participated in the National Core Indicators In-person Survey (formerly the Adult Consumer Survey) to explore the characteristics and outcomes of young adults ages 18 to 25 who are making the transition to adult services or have recently completed that transition. We compared the subsample of 2,726 young adults against the subsample of 14,732 adults age 26 and older (for more information on the study methodology, see page 10).

Compared to adults age 26 and older, young adults were more likely to be identified on the autism spectrum, to need some or extensive supports for behavioral issues, to live at home, and to have a guardian. They were less likely to have made choices about their daily schedule or the services or supports in their service plan, less likely to have a competitive job in the community, and less likely to participate in self-advocacy groups.

The younger subsample was more likely to self-direct their own supports than the adult group; however, they were also more likely to say they need more help to manage their budgets. Further, the young adults were more likely to indicate that family members or others close to them were directing their services.

Understanding the characteristics and outcomes of these young people can enhance the planning process used to support them as they transition to adult life. Notably, young people with disabilities experience lower high school graduation rates and more frequently complete high school with a certificate of completion rather than a traditional diploma.² In 2014-15, for example, national graduation rates reached a peak of 84%; however, students with disabilities fell far below this norm with a rate of 66%.³ ***Graduating without a standard diploma can hinder opportunities for continuing formal education as well as employment.***

NCI data suggest that the population of young adults who have most recently entered the adult support system have characteristics and outcomes that indicate they are still in transition to a self-determined adult life. These data underscore the need for a commitment—on the part of education, vocational rehabilitation, and public developmental disabilities staff—to a robust person-centered transition process both before and after these young people leave school.

Demographics

Some of the differences presented here may be attributable to the age differences in each group (e.g., lower mobility rates in the older cohort); others may suggest a changing landscape in the IDD field (e.g., higher rates of younger adults diagnosed on the autism spectrum).

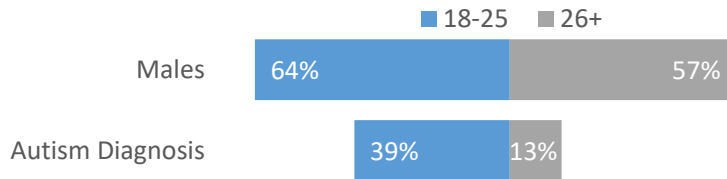
Residence

Two-thirds of the 18- to 25-year-old subsample lived in the family home compared to one-third of those 26 and older (66% compared to 32%). (Among the general population, the proportion of 25-year-olds living in the family home in 2012-2013 was 48.8%.⁴)

Gender

The young adult subsample had a significantly larger portion of males (64% compared with 57%). This may be explained by the fact that the younger cohort includes a larger proportion of individuals on the autism spectrum, who tend to be disproportionately male.

The younger subsample had both a higher percentage of males and a higher percentage of people identified as being on the autism spectrum.



Gender question: 18-25 (n=2,712), 26+ (n=14,621). Autism Diagnosis question: 18-25 (n=2,552), 26+ (n=13,598)

Race and Ethnicity

The racial make-up of the young adult and adult subsamples was similar: Most were identified as white (71% and 73%, respectively) or black (19% and 20%, respectively). However, a significantly greater proportion of individuals in the younger cohort was identified as Hispanic or Latino (6% compared to 4%).

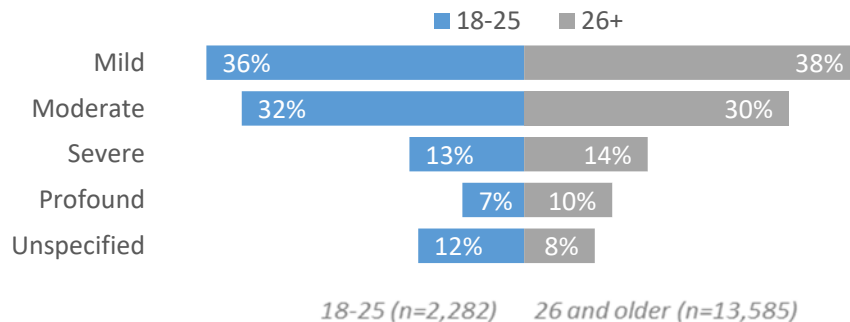
Communication

A greater proportion of the adult subsample used gestures or body language as their primary means of communication (19% versus 16% for young adults).

Diagnoses

Individuals ages 18-25 were significantly less likely than those 26 and older to have an intellectual disability reported (88% compared to 96%). Again, this may be a factor of the higher rates of autism diagnosis among the younger group (39% versus 13%).

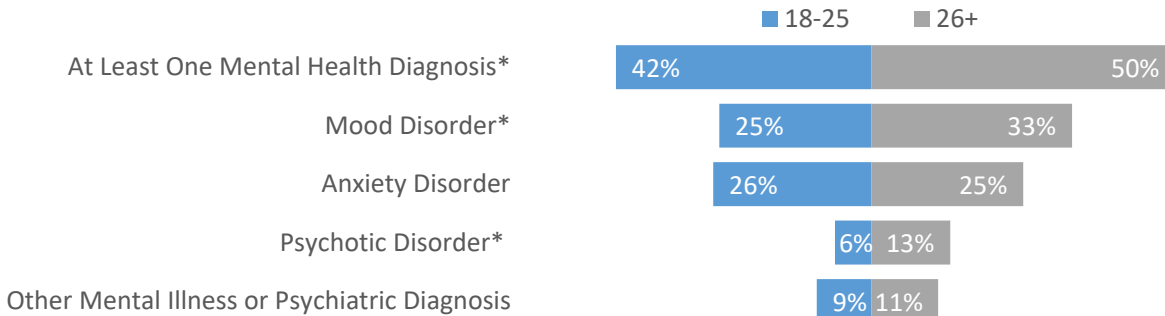
The younger subsample had higher percentages of people with an unspecified level of intellectual disability.



“Unspecified” level of ID means the individual had an ID diagnosis but the level of ID was unknown or not categorized. This category is most typically used by states that use functional assessments to determine eligibility.

Half (50%) of the adult cohort was diagnosed with at least one mental health condition compared to 42% among young adults. Individuals in the adult subsample were twice as likely to have been diagnosed with a psychotic disorder (13% versus 6%).

The younger subsample was less likely to have been diagnosed with a mood or psychotic disorder—and less likely to have been diagnosed with a mental health condition in general.



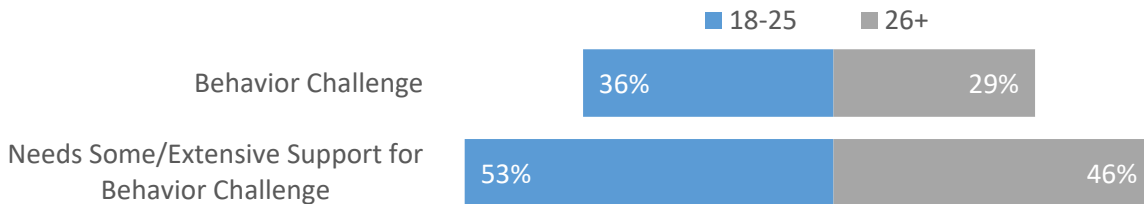
*Significant at .01

Note: Categories are not mutually exclusive therefore Ns are not shown.

Behavior Challenges

The younger subsample was more likely to have been identified as having behavior challenges (36% compared with 29%).

A significantly greater proportion of the younger subsample required support for self-injurious, destructive, and/or disruptive behavior.



Guardianship

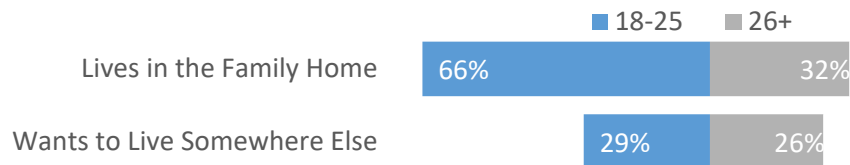
Young adults were significantly more likely than their older counterparts to have a legally appointed guardian/conservator (a person who is legally granted partial or full authority to make decisions on behalf of the individual) and to be under full guardianship or conservatorship (57% compared to 50%). The data do not tell us whether this is influenced by the fact that the younger cohort is more likely to live at home and/or the fact that a number of the individuals in the young adult subsample were still in the education system, which may identify parents as legal guardian until graduation. Most frequently, when reported, a family member served as guardian or conservator to the person.

Outcomes

Satisfaction with Residence

As noted previously, a significantly greater proportion of young adults were living at home with family and were more likely to want to live somewhere else.

Young adults tended to be as satisfied with where they lived as the adults (91% vs. 89%), but they were also significantly more likely to report they wanted to live somewhere else.

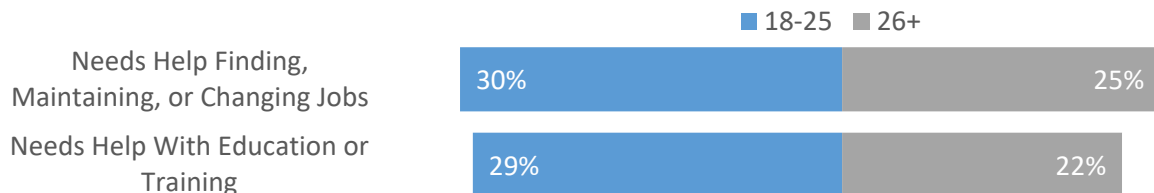


Family Home question: 18-25 (n=2,698), 26+ (n=14,502)
Live Somewhere Else question: 18-25 (n=1,622), 26+ (n=9,697)

Employment

Young adults were much more likely to report taking classes and being enrolled in training courses to get a job or a better job (33% versus 22% among those 26 and older); this may be explained in part by the fact that some of the young adults are still in school. They were also more likely to report needing support with regard to employment or education/training.

Greater proportions of young adults say they need assistance finding, maintaining, or changing jobs and with education/training.

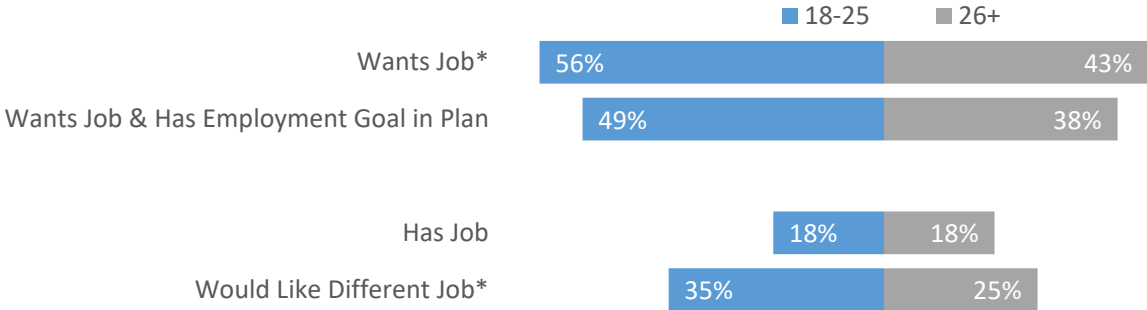


Help Finding/Maintaining/Changing Job question: 18-25 (n=403), 26+ (n=1,558)
Help With Education/Training question: 18-25 (n=1,338), 26+ (n=6,139)

Employment outcomes back up this need for support: Just 18% of young adults were currently employed in community employment, the same percentage as for those 26 and older. (NCI determines community employment based on three employment categories: 1) individual job without publicly funded supports—an individual job in which the person does not receive state or other funded supports; 2) individual job with publicly funded supports—an individual job in which the person receives state or other funded supports; and 3) group-supported—a job that takes part in an integrated setting but is done with a group of individuals with disabilities, a work crew for example. Group-supported jobs may or may not receive publicly funded supports.)

Additionally, a significantly greater proportion of young adults (56% versus 43%) reported that they were not working and wanted a job. Among those employed in paid community employment, young adults were more likely to report they would like to work somewhere else.

Significantly higher percentages of young adults reported they want a paying job in the community and have it as a goal in their service plan.

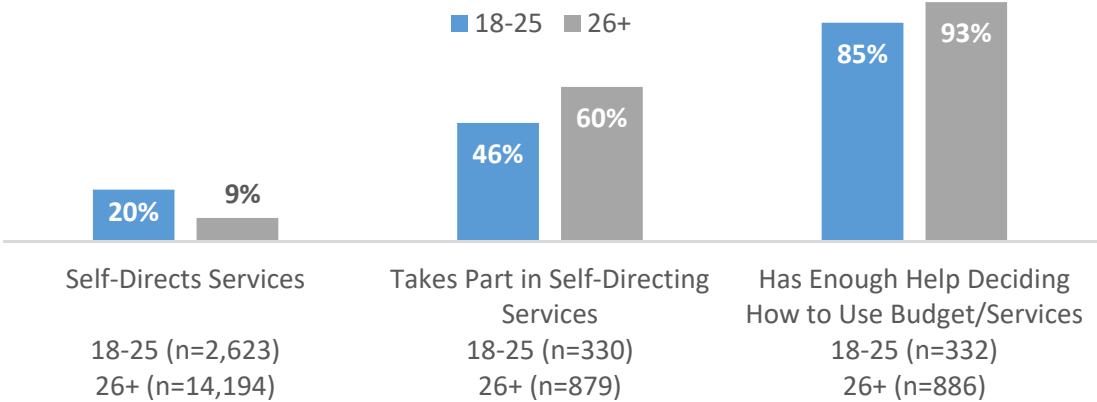


*Significant at .01

Choice and Planning

The young adult subsample made fewer choices about schedules, free time, and spending money than the adult subsample: 82% compared to 85% chose or had input in their daily schedule; 91% compared to 93% chose or had input in how to spend free time; and 86% compared to 88% chose or had input in how to use their spending money. Some of the differences in choice may have to do with the fact that some of the young adults are in school until age 22, where choices may be limited.

Young adults were more than twice as likely to self-direct their services, but fewer than half took part in making decisions about how their service budget was spent—and they were less likely to report they had enough help deciding how to use their budget/services.

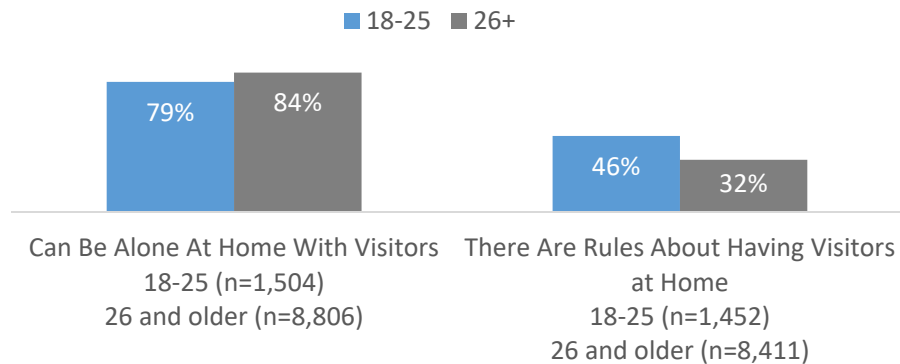


In a similar vein, young adults were less likely than those 26 and older to have chosen services as part of their service plan (75% vs 78%).

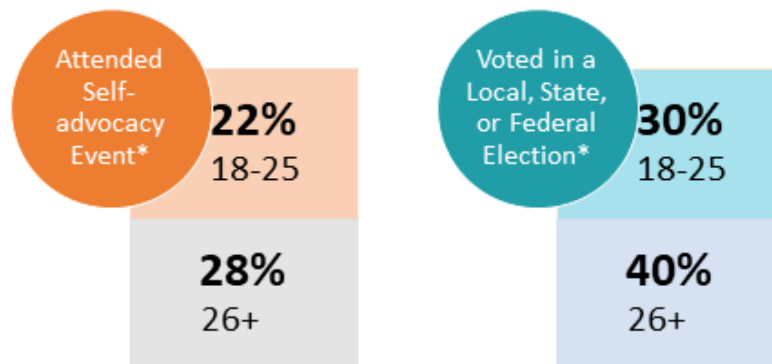
Rights, Rules and Restrictions

Young adults tended to experience greater levels of restrictions in their personal lives than those 26 and older. (This may be a function of the larger number of individuals in this group who live with families.) Compared with those 26 and older, significantly smaller proportions of individuals ages 18-25 reported having a key to their home and that others ask before coming into their bedroom; the younger cohort also reported higher rates of restrictions with visitors.

Young adults tended to experience greater levels of restrictions in their personal lives.



Young adults were significantly less likely to have attended a self-advocacy event. They were also significantly less likely to have voted in an election—though this is also the case in the general population.⁵



Summary of Findings

Compared to individuals age 26 and older, young adults (ages 18-25) were:

- More likely to be male, to be Latino, to use spoken language, and less likely to have mobility challenges
- More likely to have an autism spectrum diagnosis, less likely to have a mental illness diagnosis, and more likely to require some or extensive support for behavioral issues
- More likely to have a guardian
- More likely to live at home
- More likely to express a desire to live somewhere else
- More likely to be involved in training or classes in preparation for a job, to want a job if they don't have one, to need more support if they currently have a job, and to want a job somewhere else.
- Less likely to make everyday choices, such as daily schedule; and less likely to make choices regarding the services in their plan
- More likely to self-direct, but also more likely to say they need more help to manage their budgets
- More likely to experience restrictions about having visitors, and less likely to be involved in self-advocacy organizations.

Study Limitations

There are several limitations to this study that are important to consider when interpreting the results described in this data brief. The aggregated data analyzed here were collected from 35 states and the District of Columbia. However, aggregated results can mask what may be substantial variations among those states in demographic breakdowns and the achievement of specific outcomes. States have unique policies, practices, and requirements that strongly influence results. Further, states may vary in terms of the proportion of young adults served. Additionally, differences in the demographic make-up of each state (e.g., average age and level of ID, cultural makeup, etc.) have an impact on results. Given underlying state differences, these data should be used as a first step to providing context around the emerging cohort of individuals entering the IDD system.

With respect to the data on guardianship, differences among states regarding the proportion of people with guardians, may be attributable to variations in policies regarding guardianship and the availability of alternatives. There was also missing data in many states suggesting that the legal status of participants is not always available. The n for this analysis only included yes or no responses, not “do not know.”

Discussion and policy questions

The findings regarding the characteristics and outcomes of young adults with I/DD receiving services and supports suggest that the young cohort currently transitioning out of school aged services has support needs that do not appear to be present to the same degree in those who are older. The analysis also suggests that many of these young people have not yet fully transitioned into activities that typically signify adulthood, especially with respect to rights, employment, decision-making, and civic involvement. State programs interested in further understanding the experience of young adults transitioning to their service system may want to explore the following questions about state practices.

With respect to transition . . .

- Do you begin the transition from school to adulthood as early as possible – even prior to 16 (which is the age required in the IDEA)?

- Do you carry the transition process beyond the person’s graduation from school to ensure a seamless move from adolescence to a productive and empowered adulthood? A seamless transition planning requires collaboration of multiple state entities to be successful.
- Do you include person-centered expectations regarding community and civic involvement, post-secondary education, vocational education, employment, self-direction, and exercise of rights as foundational elements in the transition process?⁶
- Do you address family expectations during transition? A study from 2012 found that young adults with significant disabilities whose parents expected them to work after graduation were more than five times as likely to have paid community employment within two years after exiting.⁷
- Do you make provision for work experience even before the preparation of the transition plan to enhance the possibility of post-graduation employment?⁸ Experience in paid work during high school years has shown a strong correlation to getting or retaining paid work into adulthood.⁹

With respect to guardianship and rights . . .

- Are alternatives to guardianship are explored during the transition process?
- What is the frequency of guardianship among young adults, and how does that compare to other states?
- Is information about supported decision-making broadly disseminated? (There is a federally funded resource center – <http://www.supporteddecisionmaking.org/> – that provides information about this promising practice).
- Are there opportunities for decision-making for all individuals supported by I/DD systems, and have you identified promising practices and supports that may benefit individuals living with families?

With respect to Autism Spectrum Disorder . . .

- Are you analyzing your state’s NCI data to find out how the proportion of individuals on the spectrum compares to national data?
- Are you assessing current services and supports to understand whether they are responsive to the specific needs of individuals on the spectrum given the growing numbers of younger individuals with an ASD diagnosis?¹⁰
- Are you tracking results on the NCI Child Family Survey to detect trends in the numbers of children diagnosed with autism (2015 – 2016 data indicate that 56.2% of children are on the spectrum)?

Conclusion

It will be important to keep a close eye on the subtle and not so subtle differences in the characteristics of young adults with IDD entering the public system, including the trend toward more adults living at home with families. Public systems and IDD service providers may see opportunities to ensure that these individuals can be significant actors in their own lives and that they can experience independence and personal autonomy. NCI data provide a way for state IDD systems to analyze and track trends in their own data on 18- to 25-year-olds and to compare their outcomes with those of older individuals. Any significant differences in life experiences between the two groups can point toward potential opportunities to explore changes in policy, services, and models of support.

Background and Approach

The data in this brief are from the 2015-2016 administration of the National Core Indicators (NCI) In-person Survey. All individuals surveyed were age 18 or over and were receiving at least one service in addition to case management. The total sample includes data from 35 states^b and the District of Columbia.

The questions analyzed for this data brief come from the Background Information Section and Sections I and II of the NCI In-Person Survey. The Background Information Section contains data on individual demographics and characteristics (including living arrangements and employment) that are most likely found in agency records or information systems and is generally completed prior to a face-to-face interview with the person receiving services. Section I of the survey solicits information on interviewee satisfaction with a range of services and situations and can only be answered by the participant. In Section II, individuals (proxies) who know the person well can respond, such as a family member or a staff person, if the interviewee is unable or unwilling to respond. Case managers or service coordinators cannot respond on the individual's behalf.

The Background section includes the date of birth that was used to create the sub-sample of individuals 18 to 25 years old. For this cohort, we examined the differences in personal characteristics and outcomes for those individuals who were 18-25 and those who were 26 and older. Individuals for whom age was not reported were excluded from analysis. The total number of individuals in each group was: 2,726 in the 18-25 age range and 14,732 who were 26 and older for a total sample of 17,458 individuals.

Chi-squared analyses were conducted to assess whether significant relationships existed between the groups of individuals who were 18 to 25 years old and those who were 26 and older. All reported differences in this data brief are significant at the $p < .01$ level (unless otherwise noted). Statistical significance means that the result cannot be attributed to chance but in fact is a true reflection of actual differences.

^b Participating states included: AL, AR, AZ, CO, CT, DE, FL, GA, HI, IL, IN, KS, KY, LA, MA, ME, MI, MN, MO, MS, NC, NV, NY, OH, OK, PA, RI, SD, TN, UT, VA, VT, WA, WI, WY.

Questions? Comments? Contact Us

For additional information on the National Core Indicators (NCI) initiative, public reports, and past data briefs, please visit: www.nationalcoreindicators.org.

We welcome your feedback and questions. If you want to discuss this report or have questions about the NCI project, please contact: Dorothy Hiersteiner, NCI Project Coordinator, at dhiersteiner@hsri.org

References

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- ³ EDFacts Data Groups 695 and 696, School year 2015–16; October 25, 2017.
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