

BRINGING EMPLOYMENT FIRST TO SCALE

How is guardianship status related to employment status for people with IDD? Findings from the National Core Indicators Adult Consumer Survey.

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Key Findings from the RRTC on Advancing Employment

Introduction

Many individuals with intellectual and developmental disabilities, or IDD, have a legal guardian who assists them in making life decisions about housing, health, and employment. A recent analysis of data from the National Core Indicators (NCI) Adult Consumer Survey has found that people with IDD who were represented by a legal guardian were less likely to have paid employment than people who were their own legal guardians.

This finding may help us understand the role that legal guardians play in access to employment. If guardianship is a potential barrier to community-based work, then guardians need to be directly engaged in efforts to promote integrated employment.

Overview

This study examined data from a sample of 12,213 people with IDD who responded to the NCI Adult Consumer Survey in 2012-2013. The sample captures data from respondents in 26 states. The purpose of the study was to observe and describe different demographic characteristics among the respondents, and how those characteristics correlated to different outcomes.

One of the characteristics examined was whether or not an individual was represented by a legal guardian. In the NCI survey, this was a single-item question with three response categories: yes, full guardianship; yes, limited guardianship; and no, person is independent. For the purposes of this study, responses to the question were collapsed into two groups: has a guardian or does not have a guardian.

Four categories of employment settings were included in the data analysis for this study. These employment settings were 1) individual employment in the community, 2) group employment in the community, 3) facility-based work, and 4) no paid job.

The setting categories were created by combining two items from the NCI survey. The background information section of the survey includes a question about whether

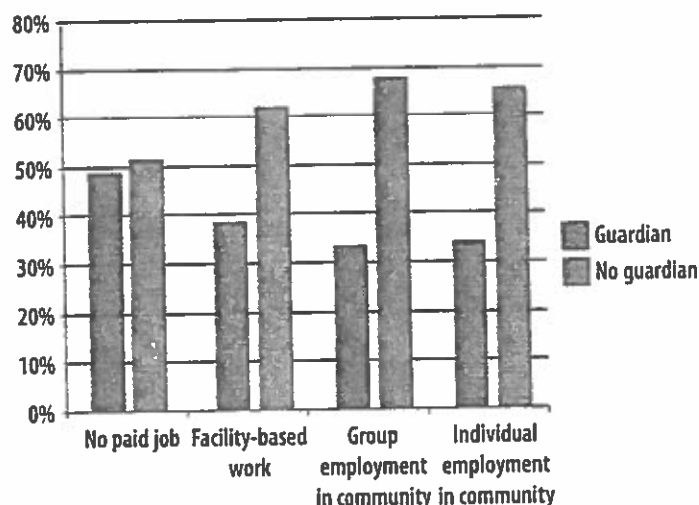
an individual has engaged in a paid job in a community setting, and this is followed up by another question about whether the job activity was done primarily by a group of people with disabilities.

If "yes" is marked for both questions, the individual was deemed to have a job in the community in a group setting. If the questions were marked "yes" to engaging in a paid community setting job, but not primarily with a group of individuals with disabilities, they were categorized as having an individual job in the community. If "engagement in facility work only" was selected, they were included in the facility-based work setting group. If the question did not indicate engagement in any of the employment groups, the individual was classified as not having a paid job.

Findings

The findings of this study showed a correlation between legal guardianship and employment setting for individuals with IDD. People who have a legal guardian were significantly less likely than people who were independent to have any kind of paid employment. Among those individuals without a paid job, there was an even split in guardianship status: 48.7% had a guardian, and 51.3% did not have a guardian.

Employment Setting and Guardianship



RRTC on Advancing Employment for Individuals with Intellectual and Developmental Disabilities
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In the paid employment groups, the rate of people represented by a legal guardian decreased significantly by comparison. People with a guardian represented about 39.1% of individuals in facility-based employment, and comprised only about a third of respondents who were employed in the community. About 32.8% of people in group community-based work settings and 33.7% of people in individual community-based work settings were represented by a legal guardian.

Discussion

In addition to employment and guardianship, this study included a metric for capturing the respondents' degree of intellectual impairment, on a scale of five categories: none, mild, moderate, severe, and profound. Like guardianship status, severity of intellectual impairment had a negative correlation with the likelihood of having paid employment. Individuals who experienced a higher degree of intellectual impairment were also less likely to have any kind of paid job.

However, guardianship for people with IDD is a complex issue. In general, guardianship does not necessarily reflect or neatly correspond to an individual's degree of intellectual impairment. The current data set shows that rates of guardianship for people with IDD vary significantly across different states (Pettingell, 2017), and the requirements for guardianship vary according to state law (Whitenack, n.d.). Whether and why a guardian might be appointed depends on a given individual's circumstances, and may be dependent on the discretion and biases of the court system (Morgan, 2015; Jameson et al., 2015).

Guardians often have significant influence over the lives of people with IDD. Legal guardianship should be considered as a distinct phenomenon that potentially influences individuals' access to employment. To improve employment outcomes for all individuals with IDD, it may be necessary to explore whether and where legal guardians are able to access information about integrated employment, and whether there might be observable gaps or misalignment between guardians' expectations and individuals' employment goals.

Conclusion

The findings of this study highlight an important correlation between legal guardianship and employment for people with IDD. More research is needed to understand why people with legal guardians are less likely to attain community-based employment. Understanding why guardianship may represent a barrier to integrated employment can help providers, policymakers, and advocates engage with guardians to support improved employment outcomes for individuals with IDD.

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ADVANCING EMPLOYMENT AND OPPORTUNITY FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES

The Rehabilitation Research and Training Center on Advancing Employment for Individuals with Intellectual and Developmental Disabilities is a project of ThinkWork! at the Institute for Community Inclusion at UMass Boston. ThinkWork! is a resource portal offering data, personal stories, and tools related to improving employment outcomes for people with intellectual and developmental disabilities.

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Supported Decision Making is a constitutional and civil rights concept which recognizes that full guardianship is often not the least-restrictive alternative for adults who experience intellectual or developmental disabilities, communication impairment, or dementia. SDM can be best defined as relationships, practices, arrangements, and agreements of more or less formality and intensity that are designed to assist an individual with a disability to make and communicate to others decisions about the individual's life. The equal rights philosophy underlying SDM is that all people use support for making the important decisions of life; needing more, different, or structured help with getting information, setting goals, weighing options, exploring outcomes does not justify unequal treatment and removal of all rights to make a decision.

With the Council's work and vision, Alaska has joined 18 other states and the District of Columbia in implementing SDM at varying levels. The momentum toward legal recognition of written Supported Decision Making Agreements (SDMAs) has been championed by the American Bar Association and the U.S. Administration on Community Living through state WINGS grants. The Council supported the successful WINGS grant application for Alaska, and is a lead stakeholder in that collaboration along with the court system, the Long-Term Care Ombudsman, and the Office of Public Advocacy. The WINGS project objectives are to reform guardianship, improve court processes, and to provide less-restrictive alternatives to ensure that Alaskans with disabilities have as many options as possible to lead person-directed lives. Within the Council, there is also a work group that is facilitating a pilot project to develop and implement written SDMAs for several adults to replace or prevent full guardianships orders. The Council has presented on SDMAs to a wide variety of audiences and stakeholders this fall, and is creating more training for professional groups and agencies that are involved in adult guardianship or decision-making for others. The Council will also be working with the legislature, the court system, self-advocates, community partners, and state agencies to create processes, forms, professional standards, and institutional support for legally recognized SDMAs.

The American Bar Association considers SDM is constitutional right, under *Shelton v. Tucker* as articulated by *O'Connor v. Donaldson*; and a civil right under the "integration mandate" of *Olmstead v. L.C.* In August of 2017, the ABA adopted a Resolution on Supported Decision Making, at: https://www.americanbar.org/content/dam/aba/administrative/law_aging/2017_SDM_%20Resolution_Final.authcheckdam.pdf

Two states have enacted statutes providing legal requirements and recognition of SDMAs. An SDMA statute has passed both houses in a third state, and is awaiting enactment in 2018.