

## Employment and Income Status of Adults With Developmental Disabilities Living in the Community

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### Abstract

A comprehensive national portrait of employment and income status of adults with developmental disabilities was estimated through secondary analyses of the 1990 and the 1991 Survey of Income and Program Participation. Results indicate that the majority of adults with developmental disabilities had very limited economic resources, even when earnings from employment and benefits from governmental income support programs were both included. The minority, who worked in a variety of occupations, were earning higher incomes than previous estimates. The overwhelming majority were unemployed. Implications of the low-income profile and potential underutilization of employment services was discussed.

The present study represents the first population-based profile of the employment and income status of adults with developmental disabilities. The intent of the profile is to provide a clearer understanding of the economic status of adults with developmental disabilities at the national level and the roles of employment and governmental income support programs on income status.

Over 15 years have passed since federal legislation relating to persons with developmental disabilities began to place a high priority on employment-related services. The 1984 Developmental Disabilities Act Amendments (1984), for example, set the employment services as a major priority area (Rusch & Hughes, 1990). Supported employment programs, that were authorized by the Rehabilitation Act Amendments (1986), have been a common employment option to sheltered employment (e.g., Wehman, Revell, & Kregel, 1998). Federal legislation, such as the Americans With Disabilities Act (1990) and the Rehabilitation Act Amendments (1992), continues to emphasize employment opportunities for people with a disability. Most recently, the reauthorized Developmental Disabilities Assistance and Bill of Rights Act (2000) maintains the emphasis on employment as a life goal activity area.

Despite the priority, we know very little on a

national basis about the employment status of Americans with developmental disabilities. For a variety of reasons, the available literature provides only limited information. Of the available large-population research, the core samples have been those people already in the service system (e.g., Butterworth, Gilmore, Kiernan, & Schalock, 1999; Mank, Cioffi, & Yovanoff, 1997; Wehman et al., 1998). Those who were not known to the system were excluded from the studies. Relatedly, the substantial research literature on employment outcomes has been conducted on specific programs, typically with small sample sizes (e.g., Levy et al., 1994) or a limited geographical coverage (e.g., Blanck, 1996). Only a few studies (e.g., Butterworth et al., 1999; Wehman et al., 1998) allow us to generalize findings to a national level. Finally, researchers typically devoted minimum attention to the impact of employment on an individual's overall income status. A significant number of persons with developmental disabilities utilize income support programs (Boggs, 1994; Braddock, 1987; U.S. General Accounting Office, 1995). Outcomes of employment programs are, however, often reported as the change in earned income associated with a particular type of employment training (e.g., Kregel, Wehman, & Banks, 1989; Schalock, McGaughey, & Kiernan, 1989; Thompson, Powers, & Houchard,

1992) rather than change in the overall economic status of an individual.

Our central purpose in the present study is to address this gap in our understanding of the employment and income status of adults with developmental disabilities at the national level. A population-based profile can better highlight points of concern and focus our national service priorities with greater clarity.

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## Method

### *Data*

In the present study we utilized the 1990 and the 1991 data from the Survey of Income and Program Participation, a nationally representative longitudinal household survey of noninstitutionalized adults in the United States (U.S. Bureau of the Census, 1991). Interviewers visited sample households between October 1991 and January 1992 and collected information on each resident age 15 and older. The information collected included demographics, income, employment, use of government programs, and detailed questions on the resident's functional limitations and disability status during the 4-month period prior to the interview. A proxy response was allowed when a sampled household member was not available at the time of the interview.

Although more recent Survey of Income and Program Participation data are available, there were several advantages using the 1990 and the 1991 data sets. First, the 1990 data included an oversampling of low income and minority households that were more likely to include a family member with developmental disabilities (e.g., Fujiura & Yamaki, 1997). Second, the 1990 and the 1991 data provided a larger sample size than did the more recent Survey data sets, an important consideration when evaluating lower prevalence populations, such as individuals with developmental disabilities. Third, the 1990 and the 1991 data included detailed information about the functional limitations of respondents, which has not always been included in the recent data sets. Consequently, the combination of 2 years of data in the present study represents monthly information from a total of 91,234 individuals in 33,802 households across the nation during the 7-month period from June 1991 to December 1991.

### *Screen*

Adults with developmental disabilities were identified using the following criteria. They were between the ages of 22 and 65, had a childhood-originated condition that resulted in work limitation, and had either any of the categorical labels associated with the old definition of developmental disabilities or functional limitations in two or more of the six life activity domains (i.e., self-care, language, learning, mobility, self-direction, and independent living) as described in the current developmental disabilities definition in the Developmental Disabilities Assistance and Bill of Rights Act (2000).

A work limitation that results in limitations in the economic self-sufficiency domain is used as a key indicator when defining severe disability (e.g., Kaye, 1997; Rehabilitation, Comprehensive Services, and Developmental Disabilities Act Amendments, 1978) and utilized to define adults with developmental disabilities (e.g., Boggs & Henney, 1979). Thus, the presence of a childhood condition that generates a work limitation was central to our definition.

The intent of using both functional and categorical screens was two-fold: to minimize the underreporting bias of stigmatized labels (i.e., mental retardation) and to include a population who might not have categorical labels included in the earlier definition of developmental disabilities but meet the functional limitation criteria of the current definition. The presence of categorical conditions associated with the earlier definition was determined using three questions in the Survey of Income and Program Participation. One question asked the respondent if he or she has "mental retardation" and/or a "developmental disabilities such as autism or cerebral palsy." The other two questions allowed the respondent to choose up to 3 conditions, from a list of 30, as a cause of their functional and/or employment limitations. Included in the list were cerebral palsy, epilepsy, and mental retardation.

Summarized in Table 1 are selected examples of the Survey of Income and Program Participation questions that addressed functional limitations in the six life activity domains used for the screen. Although the 1978 amendments to the Developmental Disabilities Act introduced a functional approach to defining developmental disabilities, it did not operationalize specific functional activities

**Table 1** Sample SIPP Questions on Functional Limitations in the Developmental Disability Screen

Life activity domain	SIPP questions
Self-care	Does _____ need the help of another person with taking bath or shower?
Language	Does _____ need the help of another person with dressing?
	Does _____ have any difficulty hearing what is said in a normal conversation with another person (using a hearing aid if he/she usually wears one)? Because of a health condition or problem, does _____ have any difficulty having his/her speech understood?
Learning	Does _____ have any difficulty using the telephone?
	Does _____ need the help of another person with keeping track of money and bills?
Mobility	Has _____ used (a cane, crutches, a walker, or a wheelchair) for six months or longer?
	Does _____ have any difficulty climbing a flight of stairs without resting?
Self-Direction	Does _____ need the help of another person with going outside the home, for example to shop or visit a doctor's office?
	Does _____ need the help of another person with keeping track of money and bills?
Independent Living	Does _____ need the help of another person with doing light house work, such as washing dishes, or sweeping floor?
	Does _____ need the help of another person with preparing meals?

*Note.* SIPP = Survey of Income and Program Participation.

for each of the life activity domains employed in the definition. Employing operational definitions developed in previous research (i.e., Boggs & Henney, 1979; Janicki & Jacobson, 1982), we grouped 20 Survey of Income and Program Participation questions on functional limitations to represent each of the six domains used for the screen. Some questions represent multiple domains. Difficulty in using the telephone, for example, represents both the learning and independent living domains because the cause of the difficulty could be either cognitive or physical. A subject indicating a difficulty in one or more activities in a given life activity domain was considered to have a limitation in that area and was screened if reporting limitations in two or more domains.

*Status Variables*

Seven status variables in the Survey of Income and Program Participation data were used to profile employment and income characteristics: (a) employment rate, (b) job title, (c) full- or part-time employment status, (d) earned income, (e) total income, (f) reciprocity rate of income support programs, and (g) benefit amount from income support programs. Respondents who indicated that they had a job in a given month, regardless of the number of weeks they actually worked, were operationally defined as *employed* and included in the employment rate calculation. Workers who had a job for an entire month and worked over 35 hours per week were defined as *full-time workers*. Those who worked less than 35 hours per week in any of the weeks in a month or held a job for only part of a month were labeled as *part-time workers*. *Earned income* consisted of wages, salaries, and income from self-employment; *total income* included 51 different income sources, including earnings from employment, income from assets, welfare benefits, pension money, and other miscellaneous income sources (e.g., contributions from charitable organizations or money from relatives or friends). The *use of income support programs* was defined as reciprocity rate and the amount of benefits received from the Social Security program and the Supplemental Security Income (SSI) program, the most common income support programs for the developmental disabilities population (e.g., Boggs, 1994; Braddock, 1987; Kiernan, Mc-

Gaughey, & Schalock, 1988; Social Security Administration, 1993; U.S. General Accounting Office, 1995).

*Analysis*

National-level monthly estimates were calculated using weights that reflected each sample member's representation of the noninstitutionalized population of the United States by age, race, and gender for each given month (U.S. Bureau of the Census, 1991). The 1990 and the 1991 Survey of Income and Program Participation overlapped in their data-collection period. Thus, the 7 months that both surveys were being fielded provided 14 separate monthly estimates; 2 each for the months of June through December 1991. Each pair of month-specific estimates was combined into a single averaged estimate. Finally, a national monthly estimate was computed by averaging these seven averaged estimates. Standard error of the estimates was computed using SUDAAN, a statistical software package designed to analyze survey data with stratified, multistage sample designs (Shah, Barnwell, & Bieler, 1997). Using 95% confidence intervals, we made population comparisons between subjects with and those without developmental disabilities.

**Results**

*Population Profile*

The average monthly estimate of the U.S. non-institutionalized adult population between ages 22 to 65 was 142 million. Of those, 1,748,900, or 1.23%, were estimated to have developmental disabilities. Table 2 summarizes demographic characteristics for the population with developmental disabilities, the general population, and the corresponding disability prevalence estimates. The distribution of the population is reported in terms of percentages, which are more reliable than the corresponding numerator estimates (U.S. Bureau of the Census, 1991).

Compared to the general population, Whites were underrepresented and African Americans were overrepresented in the developmental disabilities population. There were no differences by gender or age cohort between the developmental disabilities population and the general population. As shown in the table, males had a slightly higher prevalence rate of developmental disabilities than did females, but the difference was not statistically

**Table 2** Breakdowns of Population With Developmental Disabilities (DD), the General Population, and Prevalence Rate by Demographic Variables

Variable	DD population <sup>a</sup>		General population <sup>a</sup>		DD prevalence	
	%	SE	%	SE	%	SE
<b>Gender</b>						
Male	53.3	2.4	48.9	.1	1.34	.08
Female	46.7	2.4	51.1	.1	1.13	.09
<b>Race</b>						
White	72.5 <sup>b</sup>	2.3	78.2	.3	1.14	.08
African American	17.6 <sup>b</sup>	1.9	10.0	.3	2.15 <sup>c</sup>	.22
Hispanic	7.9	1.2	8.1	.2	1.21	.18
Other	2.0 <sup>d</sup>	.6	3.7	.2	.65	.19
<b>Age group</b>						
22 to 34	36.9	2.6	37.6	.3	1.21	.10
35 to 44	24.8	2.0	27.6	.3	1.11	.11
45 to 54	19.6	1.8	18.5	.2	1.30	.12
55 to 65	18.8	1.6	16.3	.3	1.41	.15

*Note.* Averaged monthly estimates between June 1991 to December 1991.

<sup>a</sup>Breakdowns are reported in percentages within each population. <sup>b</sup>Proportion is significantly different compared to the general population using 95% confidence interval. <sup>c</sup>Prevalence is significantly higher than other groups using 95% confidence interval. <sup>d</sup>Estimate is unreliable (SE > 30% of estimate) and not included for statistical comparison.

significant. African Americans had the highest prevalence rate of developmental disabilities (2.15%, SE = .22).

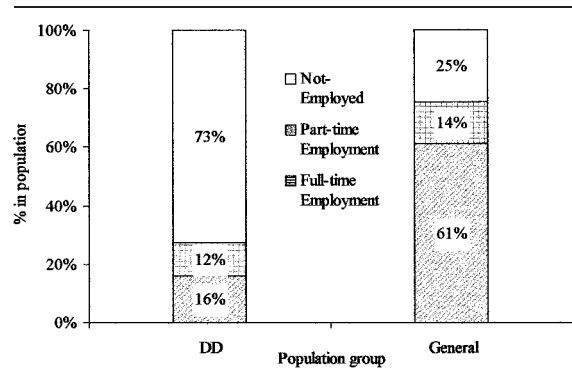
Seventy-one percent of the population with developmental disabilities reported conditions associated with the older categorical definition. Including those with other secondary conditions, 41% reported having mental retardation, and 30% reported having conditions other than mental retardation (i.e., cerebral palsy, epilepsy, and autism). Other conditions that were cited as the source of limitations included back/spine prob-

lems, heart-related conditions, head or spinal cord injury, mental/emotional problems, and hearing impairments.

*Comparisons Between Individuals With and Those Without Developmental Disabilities*

Table 3 is a summary of comparisons between the population with developmental disabilities and the general population average based on five economic status variables. Only 27.6% of adults with developmental disabilities had a job in any given month in comparison to 75.1% for the general adult population.

Figure 1 graphically illustrates differences in full- or part-time work status between the two groups. Just over one half of the employed workers with developmental disabilities were full-time em-



**Figure 1** Employment status for the population with developmental disabilities and the general population.

**Table 3** Employment and Income Status of Adults With and Without Developmental Disabilities (DD)

Economic status variable	DD population		General population	
	Estimate	SE	Estimate	SE
Employment rate <sup>a</sup> (%)	27.6	2.1	75.1	.3
Earned income <sup>a,b</sup> (\$)				
Mean	1,298	95	2,206	12
Median	787	65	1,649	9
Total income <sup>a</sup> (\$)				
Mean	764	40	1,740	10
Median	471	21	1,374	10
Income support reciprocity <sup>a</sup> (%)				
Mean	57.6	2.4	7.0	.2
Benefits amount <sup>a,c</sup> (\$)				
Mean	460	11	529	4
Median	424	3	487	8

*Note.* Income status averaged monthly estimates between June 1991 to December 1991.

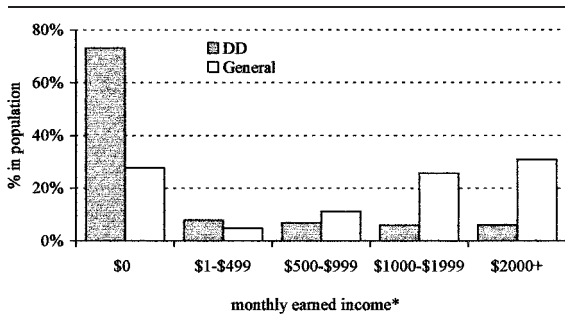
<sup>a</sup>Difference between the population with developmental disability and the general population is significant using 95% confidence interval. <sup>b</sup>Earned income was estimated only for those who reported earned income. <sup>c</sup>Benefits amount was estimated only for those who received income support programs.

ployees; 4 out of 5 workers in the general population were at full-time status.

The majority of the employed workers with developmental disabilities engaged in either service occupations (23%) or laborer jobs (29%). Janitor was the most frequently reported job title (10%). The majority of the population of employees without developmental disabilities, in contrast, were in technical, sales, or administrative support positions (27.7%) or managerial or professional positions (24.4%). Manager/administrator and secretary were the most commonly reported occupational titles, at 5.4% and 3.5%, respectively.

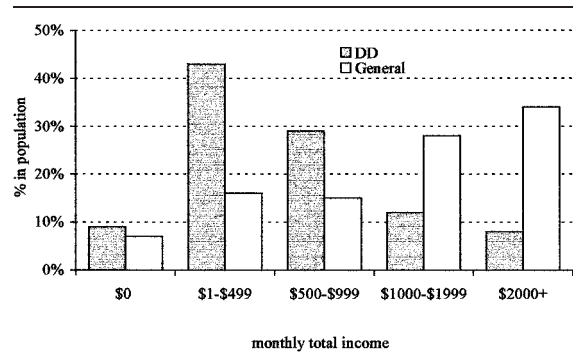
Estimates for mean and median earned income were derived only for those who reported earnings; those without jobs were excluded from the analysis. As shown in Table 3, monthly earned income for workers with developmental disabilities was significantly lower than that for workers without developmental disabilities. Distribution of earned income for both groups is shown in Figure 2. In contrast to Table 3, the figure includes individuals with no earned incomes in order to highlight the aggregate income status of the population with developmental disabilities. Of those persons with developmental disabilities who worked, more than half earned less than \$1,000 per month. In contrast, only one in five workers in the general population fell within that range.

As shown in Table 3, total income, which includes earned income, for the population with developmental disabilities was less than half of total income for the general population. Figure 3 illustrates the distribution of total income for the two



\* Includes all persons with or without reported job earnings.

**Figure 2** Distribution of earned income for the population with a developmental disabilities and the general population.



**Figure 3** Distribution of total income for the population with a developmental disabilities and the general population.

groups. Graphically shown is the skew toward lower income groups for persons with developmental disabilities. After including all sources of income, more than half of Americans with developmental disabilities reported monthly total incomes less than \$500 in 1991 dollars; 81% (SE = 1.5) reported less than \$1,000. In contrast, only two fifths of adults in the general population had monthly incomes below \$1,000.

More than half of all adults with developmental disabilities were recipients of income support programs compared to only 7% for the general population. The difference in the participation rate reflects the low-income profile of the developmental disabilities population. A breakdown of recipients by program shows that those with developmental disabilities evenly divided between the SSI program and the Social Security program; 23% used SSI alone, 23% used Social Security alone, and 11% used both programs concurrently. In contrast, the majority of recipients in the general population (6.1%), including those who used both programs (0.3%), used the Social Security program.

In summary, adults with developmental disabilities were less likely to be employed, and many of the few wage earners were employed part-time. In terms of earned income, there appeared to be two groups: a majority earning only a moderate income and a small minority whose earned income was comparable to that of individuals in the general population. Though a significant number of individuals with developmental disabilities utilized income support programs at a far greater rate than

those in the general population, their total income was far less.

### Discussion

Interpretation of the estimates reported in the present study requires some caveats. Population size and prevalence rates estimated were likely to underrepresent the developmental disabilities population. The Survey of Income and Program Participation uses community households as its sampling unit, and persons with developmental disabilities who lived in residential programs were excluded from the survey. When the 346,870 individuals who utilized out-of-home residential services in 1992 (Braddock, Hemp, Bachelder, & Fujiura, 1995) are added to the total, estimates of population size and prevalence rate increase to 2.1 million, or 1.5% of the 1991 adult population of the United States. These estimates fall into the lower end of the values projected by previous estimates; 2 to 4 million, or 1.5% to 1.7% (e.g., Developmental Disabilities Assistance and Bill of Rights Act, 1994; Institute of Medicine, 1991). Second, the study included only individuals of working age. Compared to other age cohorts, children have a higher prevalence of developmental disabilities (e.g., Kiernan & Bruininks, 1986; Larson, 1999).

Contemporary data may yield less discrepant findings than the 1991 data presented here. These data were collected in the middle of an economic recession. During the period between July 1990 and June 1992, the number of individuals who were unemployed increased 46%; the national unemployment rate rose 2.3 percentage points

(Gardner, 1994). The number of Americans who lived in poverty increased to 33.9 million, or 13.6% of the population in 1991 (Shea, 1995). During the past decade, however, the nation's economy has vastly increased job opportunities (Deavers & Hattiangadi, 1998). It is possible that the employment profile of individuals with developmental disabilities has expanded as well.

Results of recent studies, however, suggest that the employment and income status of the population with developmental disabilities has not changed significantly. Butterworth et al. (1999) found that earned income for workers with developmental disabilities, who participated in state/federal vocational rehabilitation service systems, had not improved over the past 10 years. Average weekly wages increased slightly, from \$143 in 1985 to \$148 in 1995. When they adjusted for inflation, however, researchers found that wages had declined over 40% in real dollar terms. For individuals using supported employment services, of which approximately two thirds reported having mental retardation as a primary disability, wages increased modestly, from \$102 per week in 1990 to \$114 per week in 1995 (Wehman et al., 1998).

Results from the present study clearly underscore the fact, not likely changed in the past decade, that the majority of Americans with developmental disabilities have very limited economic resources. The median annual income for adults with developmental disabilities computed from the monthly estimate was 20% below the 1991 poverty threshold for a single person under age 65 (U.S. Bureau of the Census, 1999). Three out of four Americans with developmental disabilities fell below the low-income threshold (i.e., 150% of the poverty line), a criterion often used as a realistic poverty standard (e.g., Kim, 1998). These findings are consistent with previous research in disabilities generally. Shea (1995), for example, reported that adults with disabilities were twice as likely to be at or below the poverty level than those without a disability. The Harris Survey (Louis Harris & Associates, 1998) reported that only 31% of Americans with disabilities were employed in 1994 and 29% in 1998.

The employment profile revealed in the present analysis is different than in previous studies (e.g., Kiernan & Ciborowski, 1986; Mank, Cioffi, & Yovanoff, 1998; Wehman et al., 1998). Workers with developmental disabilities in the present study were more likely to (a) work in a wide range

of occupations, (b) be employed full time, and (c) have a higher income level. Perhaps because we employed a less-biased community sample, we found a more diversified employment profile. Employment ranged from an individual with mental retardation in part-time food preparation earning \$50 per month to a computer programmer with epilepsy earning \$3,000 per month. Although these individuals had common life-long functional limitations and significant support needs, the impact of the impairment on their employment and income capacity varied widely.

Even when including benefits from income support programs and other miscellaneous income sources, we found that an overwhelming majority of the population with developmental disabilities in 1991 still reported their incomes near or below the poverty level. This is consistent with Boggs' (1994) assertion that the amount of benefits received from federal Social Security and the SSI programs was too low to move individual's income beyond the level of poverty.

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## Implications

Individuals with developmental disabilities are likely to continue to depend on family support (e.g., Fujiura, 1998). Thus, the low economic profile of such individuals, as suggested in the present study, may not be dismal. The presence of family members with developmental disabilities, however, may impose financial burdens on supporting families, a particular concern because the incomes of these families are often lower than the United States average (e.g., Fujiura, 1998; Fujiura & Yamiki, 1997). Though there is a considerable literature on the service needs of families supporting adult members with developmental disabilities (e.g., Black, Molaison, & Smull, 1990; Heller & Factor, 1991; Smith, Majeski, & McClenny, 1996), there is limited information on the financial needs of supporting families.

The low rates of employment found in the present study underscore the continuing importance of employment services. A significant finding of the present analysis was the substantial gap between the estimated size of the population and the numbers served by state vocational and MR/DD agencies (e.g., Butterworth et al., 1999). It is clear that the community household survey data used in this analysis likely includes many who do

not use publicly funded services, a finding reported in other national studies of developmental disabilities services (e.g., Fujiura & Braddock, 1992; Hayden & DePaepe, 1994; Olney & Kennedy, 2001). The circumstances of these individuals who neither work nor use employment services may be of special interest. Do they choose not to seek employment and to continue to rely on other resources? Are there simply not enough services available? Additional information on the status of this unserved segment of the developmental disabilities population is needed.

For the few individuals who are employed, earnings are severely limited. Vocational rehabilitation researchers have paid far too little attention to the economic impact of employment opportunities that are largely minimum wage entry-level positions with limited earning potential. Employment does not directly equate to economic self-sufficiency. The national profile presented here, though dated, suggests that greater attention should be paid to issues of economic well-being, of which employment and training models are but one facet.

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*Received 7/15/99, first decision 8/12/99, accepted 4/2/01.*

*Editor-in-charge: Marty Wyngaarden Krauss*

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*Preparation of this article was supported in part by Grant HB133B980046 from the National Institute on Rehabilitation Research, U.S. Department of Educa-*

*tion, and funding from the Rehabilitation Research and Training Center on Aging with Developmental Disabilities, University of Illinois at Chicago, through the U.S. Department of Education.*

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