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Research Brief

A Review of Disability Data for the Institutional Population

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Disability status for the non-institutional population in the United States has been substantially documented from national surveys such as the American Community Survey (ACS), the Current Population Survey (CPS), the National Health Interview Survey (NHIS), and the Survey of Income and Program Participation (SIPP). No comparable surveys have been fielded to collect information for the institutional population as a whole, however, including the large share of the institutional population having disabilities. In general, much less is known about the disability status of the institutional population than about the disability status of the non-institutional population, particularly for those of working age. In light of this gap in knowledge, we compiled and examined existing disability information for the institutional population to evaluate the implications of the exclusion of the institutional population from national surveys for disability statistics and research, with an emphasis on working-age people (She and Stapleton 2006). This research brief summarizes our key findings.

The Size and Distribution of the Institutional Population

According to the Bureau of the Census, institutional group quarters (GQs) include correctional institutions, nursing homes, and a lengthy list of other institutions, many of which exclusively house people with disabilities. The institutional population is a very small share of the entire population, but increased from 1.3 percent of the population in 1990 (3.3 million people) to 1.4 percent in 2000 (4.0 million people).[1] The increase was not uniform across institutional types, however. Nursing home residents, the largest institutional population in 1990, decreased from 0.71 percent of the total population to 0.61 percent, while the incarcerated population increased from 0.45 percent to 0.70 percent, surpassing the nursing home population in size. In 2000, about 98 percent of incarcerated persons were age 18-64, while about 90 percent of nursing home residents were age 65 or over.

The percentage of the institutional population that is of working age (ages 18-64) increased from 0.98 percent in 1990 (1.5 million people) to 1.3 percent in 2000 (2.3 million people), and working-age people accounted for a much larger proportion of the institutional population in 2000 (56 percent) than in 1990 (45 percent). In 2000, a large majority of the institutional working-age population (86 percent) resided in correctional institutions, and the remaining 14 percent were approximately evenly split between nursing homes and other institutions.

People with Disabilities Living in Institutions

When disability is defined as having self-care, mental, physical, or sensory disabilities[2] – 34 million (or 12 percent) of American people had disabilities, including 31 million (or 11 percent) of the household population, 2 million (or 54 percent) of the institutional GQs population, and 0.8 million (or 22 percent) of the non-institutional GQs population.[3] Thus, disability prevalence for the GQs population, especially for the institutional GQs, is much higher

[1] The statistics presented in this section are based on the 1990 and 2000 Census data.
[2] 2000 Census data on two additional disability types, employment disability and go-outside-home disability, are not valid. Based on the 2003 ACS, the prevalence of disability in the non-institutional population in 2000 would have been 1.5 to 2.0 percentage points higher had these two disabilities been included.
[3] Non-institutional GQs include group homes, college dormitories, military quarters, and a lengthy list of other non-household living situations.

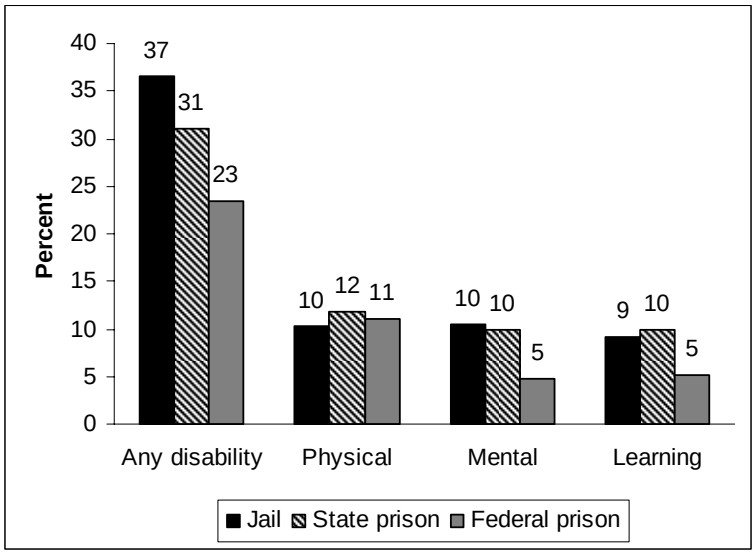
than for the household population. Even so, the vast majority of people with disabilities live in household units; 6.4 percent live in institutional GQs and 2.3 percent in non-institutional GQs.[4]

For working-age people with disabilities, the share of males living in institutional GQs is much larger than the share of females (7.7 percent versus 1.7 percent), mostly reflecting the fact that over nine out of ten inmates in correctional institutions are male. Working-age people with disabilities residing in institutional GQs are also disproportionately African American (38.6 percent of those ages 18-49 and 22.4 percent of those ages 50-64). Unfortunately the Census 2000 Public Use Microdata Samples (PUMS) files do not allow us to generate statistics by type of institution.

Disability in the Incarcerated Population

Based on data from three Department of Justice (DOJ) surveys, about 37 percent of jail inmates, 31 percent of state prison inmates, and 23 percent of Federal prison inmates report a disability of some sort (Exhibit I). Mental and learning disabilities are particularly prevalent in the jail and state prison populations. The prevalence of disability in the incarcerated population, almost all of which is of working age, appears to be two to three times as high as in the household working-age population, although exact comparisons based on published data are problematic due to different definitions of disability and differences in demographics.[5]

Exhibit I: Prevalence of Disabilities in the Incarcerated Population, 1996/1997



Source: She and Stapleton (2006).

[4] Due to a data collection problem, the 2000 Census statistics may overstate the share of the population with disabilities that lives in institutional or other GQs.

[5] Based on the 2003 ACS, disability prevalence among all persons aged 25 to 61 not living in GQs is 11.9 percent, including 7.5 percent with a physical disability and 4.0 percent with a mental disability. Young adult males account for a disproportionately large share of the incarcerated population; only about one percent of the incarcerated population is over age 65.

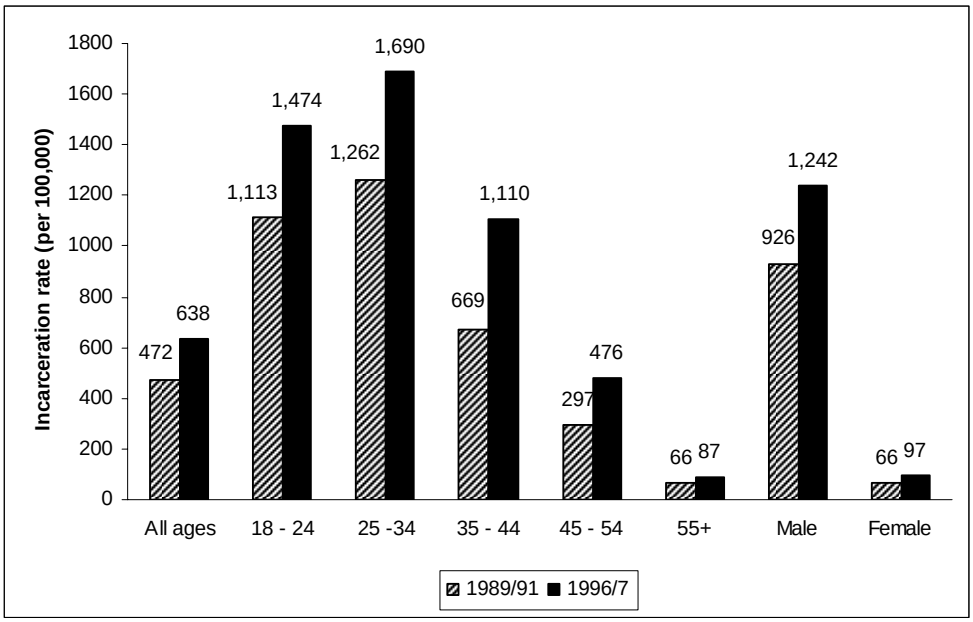
Disability in the Nursing Home Population

Essentially all nursing home residents have some type of disability. Based on data from the 1999 National Nursing Home Survey (NNHS), the two most common activity limitations are for bathing (94 percent) and dressing (85 percent), and about three quarters of the nursing home residents received help with three or more such activities of daily living (ADLs). The prevalence of various disabilities is generally lower among those under age 65, with one exception: mental disorders other than Alzheimer's disease – 21 percent for those under 65 versus 17 percent for those 65 and over.

Growth in the Incarcerated Population

The incarcerated population more than quadrupled from 1980 to 2003, from a half million to more than two million. Although this growth partly reflects underlying population growth, the main reason for growth is increased incarceration rates. From 1989-91 to 1996-97, the incarceration rate for the working-age population grew by 35 percent (Exhibit II). The change in the incarceration rate is greatest for those age 25 to 44, although relative change is greater for those age 35 to 54. Further, the change in the incarceration rate is much greater for males than for females, although the relative change is somewhat larger for females. These statistics, along with the relatively high prevalence of disability in the incarcerated population, suggest that the growth in incarceration could have had a substantial impact on prevalence of disability in the household population, and possibly on the characteristics of the household population with disabilities, especially for working-age males.

Exhibit II: Change in Incarceration Rate by Age and Sex, 1989/91 to 1996/97



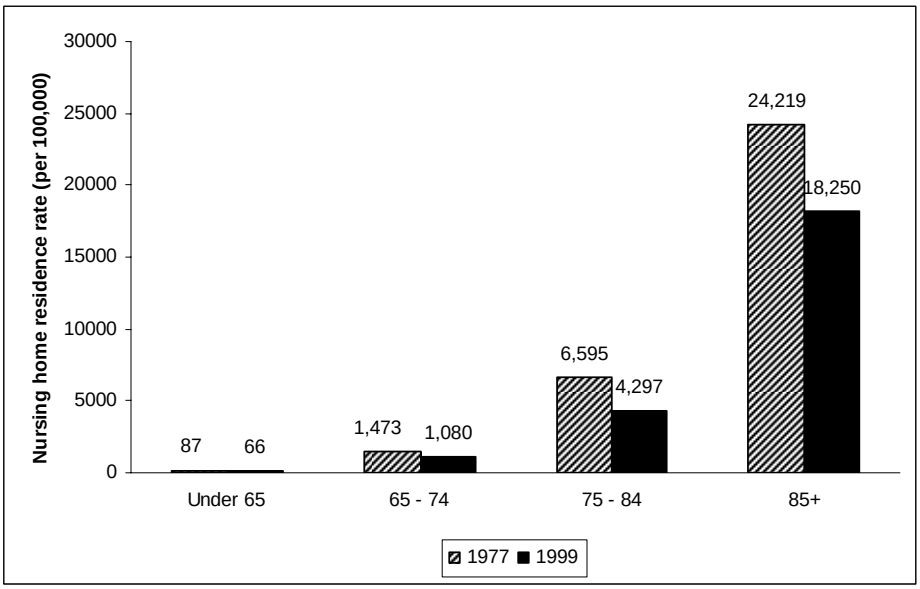
Source: She and Stapleton (2006).

Relative Decline in the Nursing Home Population

The nursing home population has been growing slowly in absolute terms, and, as previously indicated, has been declining relative to the size of the entire population. From 1977 to 1999, the nursing home residence rate (the number of residents per 100,000 population)

declined for all age groups (Exhibit III). For those under 65, the decline is small, but would be much more substantial if measured relative to the size of the population with disabilities. The decline was especially large for those age 85+, almost 6 percentage points. We do not know the extent to which this decline represents a decline in disability among those 85 and older versus a change in the living arrangements of people with disabilities (e.g., the rise of assisted living).

Exhibit III: Change in Nursing Home Residence Rate by Age, 1977 to 1999



Source: She and Stapleton (2006).

Gaps in Survey Coverage

In the past, the four major household surveys – ACS, CPS, NHIS, and SIPP – have all excluded the institutional population in their sampling frames, and varied in their coverage of persons living in non-institutional GQs. Further, public use files often fail to identify type of living quarters. Survey information is also very limited for the homeless population and the military population. The homeless population is either not covered at all or covered to an unknown extent in major national surveys. Only the March Supplement of the CPS claims to routinely include the military population, but we found no studies providing CPS-based estimates for the military population. Incomplete coverage for the non-institutional GQs population is more problematic for the working-age population than for the elderly population.[6]

The NNHS provides extensive information on nursing home residents, and the three DOJ surveys provide information about the incarcerated population. We found no surveys covering the institutional population not living in correctional institutions or nursing homes, except the Census long-form survey. This component now represents 9 percent of the institutional population, and 7 percent of the working-age institutional population. Further, it is apparent that those with disabilities in this population represent a much larger, although unknown, share of the population of people with disabilities.

[6] Based on the 1996 National Survey of Homeless Assistance Providers and Clients, 80 percent of homeless clients are 25 to 54 years old.

Infrequent Collection

In the past, the one survey to collect data on the entire population, the Census, has been conducted only once per decade – in contrast to the annual collection of data on the household population via four major government surveys. The surveys of specific institutional populations are conducted less frequently and less regularly. The DOJ surveys are fielded roughly every five years. The NNHS was fielded biennially from 1995 to 1999, but no information has been available since 1999.

Disability Definitions

The disability information included in the surveys varies. Currently, the Census and three major non-institutional surveys (ACS, NHIS, and SIPP) all contain information on sensory disabilities, functional limitations, mental disabilities, limitations in ADLs, limitations in instrumental activities of daily living (IADLs), and work disabilities, although definitions vary. The CPS only contains information about work disabilities. The NNHS does not ask respondents about work disability, but this might reflect an implicit assumption that all respondents either have work disabilities, or that almost all are too old for work to be considered a relevant topic. The surveys on inmates do not ask questions on ADLs and IADLs, but do include questions on learning disabilities that are absent in most household surveys. Conceptual definitions of disability in these surveys are substantially in agreement, but there are substantial operational differences in the collection of information for each conceptual definition.

Conclusion

It is apparent from the data available that the size and composition of the institutional population has changed very substantially in the last 25 years. Those changes have been especially important for the population with disabilities, because of the relatively large number of persons with disabilities who live in institutions. Growth in the incarceration rate is especially important for the working-age population, and raises many disability policy issues, such as: how public policies affect the participation of people with disabilities in criminal activity; the provision of equal access to justice; appropriate treatment of, and supports for, prisoners with disabilities; and support for the transition from prison into the household population. The decline in the nursing home residence rate, especially for the elderly, is also very substantial, and raises a host of questions about the reason for the decline and the implications for public policy.

Disability information on the entire population is scarce. That situation is changing; if the Bureau of the Census follows its current plan, the ACS will continuously and consistently provide annual data for the population living in most GQs, including the major institutional GQs, from 2006 forward.[7] This information will be particularly valuable for disability research and statistics, especially for the working-age population, given the large gaps in currently available information.

[7] As of 2006, ACS data collection excludes the following GQs: domestic violence shelters, soup kitchens, regularly scheduled mobile food vans, targeted non-sheltered locations, natural disaster shelters, transient locations (such as RV campgrounds, marinas, and military hotels), dangerous encampments, and maritime vessels.

Reference:

She, P and D.C. Stapleton (2006). An Inventory of Disability Information for the Population Living in Institutions. Rehabilitation Research and Training Center on Disability Demographics and Statistics, Cornell University, Ithaca, NY.

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