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Nursing Home Emancipation: Accomplishments of Urban and Rural Centers for Independent Living

In 1999, the U.S. Supreme Court established a legal precedent, based on the Americans with Disabilities Act, to help adults with disabilities leave institutional settings and return to community living (Olmstead v. L.C.). This established the right of individuals to receive services in "...the most integrated setting," which is generally the community. Since then, centers for independent living (CILs) and other disability advocacy organizations have initiated a wide range of efforts to emancipate (i.e. transition) adults with disabilities from inappropriate nursing home placements to community living.



Photo by Tom Olin

Nursing home emancipation is high on the priority lists of several national organizations and it is even proposed that such efforts be legislated. Despite the efforts of many emancipation programs and services, little research has addressed institutionalized individuals' return to community living.

Historically, people who experienced disability were often institutionalized in large congregate facilities or in nursing homes (Braddock & Parish, 2001). In the late 1960s, deinstitutionalization began and still continues. Despite a substantial reduction in the number of disabled people living in nursing homes and other institutions, many who could live in the community still remain institutionalized.

Rural transitions:

There are 17,253 U.S. nursing homes housing 1,590,126 residents (Phillips, Hawes, & Leyk, 2004). Forty percent of nursing homes are located in non-metropolitan counties. While typically smaller in size, non-metro facilities serve about 35 percent of the nursing home population. Unnecessary and inappropriate nursing home placement, and difficulty transitioning back to community living may be particularly acute problems in these rural areas (Forti, Funk, Bellamy, Ivory, & Heady, 2001). Rural areas have fewer resources and supports, and individuals must travel farther to access specialized services. Nursing homes may even be perceived as acceptable rural residential arrangements because there are no apparent alternatives (Hawes, Phillips, Holan, & Sherman, 2004).

RTC: Rural researchers conducted a national survey of CILs as the first step in a larger study of secondary health conditions as risk factors for nursing home placement and as barriers to nursing home emancipation. The purpose of this baseline survey was to assess the status of CIL nursing home emancipation resources, issues, practices, and accomplishments. We defined nursing home emancipation or transition, as "...activities and services that directly assist individuals living in a nursing home to relocate successfully from a nursing home to community based living arrangements." Activities and services include counseling; financial assistance; assistance with securing housing, moving and setting up a household; and assistance with arranging transportation and attendant services.

Methods and Results

In the summer of 2007, we mailed surveys to all 392 main CIL offices, including those that do not receive federal Title VII funding. Initially, 170 centers (43%) responded. Respondents' net operating budgets averaged \$6,180,398, but several centers with very high budgets skewed the average; we also calculated a median budget. Half of respondents reported budgets of less than \$672,500. Most respondents (89%) reported providing services that directly support individuals in relocating from nursing homes to community-based living arrangements. Respondents reported working on nursing home emancipation with a total of 3,607 individuals from October 2005 to September 2006. Sixty-three percent (2,277) of those individuals successfully relocated from a nursing home to a community-based living arrangement. Two percent of emancipated individuals (n = 88) returned to a nursing home during this same period.

Table 1 shows the total reported number of institutionalized consumers across urban, rural, and very rural areas whom CILs attempted to emancipate, the number successfully relocated, and the number who returned to a nursing home during the reporting period.

Table 1. Institutionalized Consumers Served, Emancipated, and Returning to Nursing Homes by Type of Area, October 2005-September 2006.

	Urban Areas*	Rural Areas**	Very Rural Areas***
Total number of institutionalized consumers served	2,518	1,021	68
Average number of institutionalized consumers served per CIL	17.25	7.04	.47
Total number of consumers successfully relocated to community	1,416	819	42
Average number of consumers successfully relocated per CIL	9.63	7.04	.29
Total number of consumers returning to nursing homes	55	28	5
Average number of consumers returning to nursing homes per CIL	.38	.19	.03

***Urban Areas:** Cities with populations over 50,000 plus immediate surrounding area

****Rural Areas:** Towns of 2,500-49,999 plus immediate area

*****Very Rural Areas:** Towns of <2,500

Thirty percent of consumers served were in rural or very rural areas – somewhat fewer than might be

expected – but 37.8 percent of those who successfully moved to the community lived in rural and very rural areas.

On a 5-point scale where "0" was inadequate and "4" was very adequate, respondents rated the adequacy of their budgets for providing the four core independent living services (independent living skills training, peer mentoring, advocacy, information & referral) and nursing home emancipation services. Average ratings of budget adequacy were low: 2.03 for core services and 1.27 for emancipation services. On average, respondents (n = 127) reported allocating an average of 10.1 percent of their overall operating budgets to nursing home emancipation services and supports. Only 46 percent of respondents reported receiving additional funding specifically to provide nursing home emancipation services. Respondents estimated that a center would need an average annual budget of \$398,303 to operate an effective nursing home emancipation program.

Limitations

These findings must be interpreted with some caution because they are based on the initial responses to, and preliminary analysis of, a national survey. They represent about half of all centers for independent living, but may not reflect the emancipation services of non-responding centers. There may also have been a bias in responding. For example, one large center for independent living did not initially respond to the survey because it was being conducted by a rural research center. Therefore, they thought only rural centers were expected to respond. While this center eventually did respond, other non-rural centers may not have done so.

Conclusions and Next Steps

This line of research is designed to improve practices associated with nursing home emancipation services. Overall, these data illustrate that centers for independent living are successfully helping people with disabilities return from nursing homes to community-based living. It is particularly noteworthy that only about 2 percent of those emancipated return to nursing homes for any reason.

In the 20th century, nursing homes became the accepted base of the nation's long-term care system. They are an expensive entitlement. The majority of people requiring long-term care prefer to live independently with community-based services and supports. Such services and supports provide a higher quality-of-life for individuals and appear to be less expensive in the aggregate.

The next steps in this research include collecting and analyzing CIL policies governing nursing home emancipation services. We will also begin to explore the role secondary conditions and other barriers play in nursing home emancipation.

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