

Nursing home emancipation: A preliminary study of efforts by centers for independent living in urban and rural areas

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Abstract

Background: The U.S. Supreme Court's Olmstead decision affirmed the right of individual with disabilities to live in the community. 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 undesired nursing home placements to community living. There is, however, a paucity of published information about the nursing home transition process for adults with disabilities.

Objective/Hypothesis: The objectives of this research were to: (1) assess the levels of nursing home emancipation services and barriers to nursing home transitions, including the role of secondary health conditions, and (2) to assess nursing home transition policies and procedures.

Methods: We conducted 2 studies. First, we surveyed 165 CILs operating nursing home emancipation programs. Second, we reviewed the written transition policy and procedures documents of 28 CILs from 14 states.

Results: Respondents reported transitioning a total of 2,389 residents from nursing homes back to community living arrangements during the previous year, with only 4% of those returning to a nursing home for any reason. While most of the policies reflected many components of a standard model, several components appeared underrepresented.

Conclusions: Findings suggest the need to expand on established programs to build evidence-based practices. © 2011 Elsevier Inc. All rights reserved.

Keywords: Transitions; Olmstead; Return to community

Historically, people who experienced disability were often institutionalized in large facilities or in nursing homes [1]. Deinstitutionalization began in the late 1960s and continues. Despite a substantial reduction in the number of

people with disabilities living in nursing homes, many who could live in the community still remain institutionalized.

The Centers for Medicare & Medicaid Services [2] reported that 15,965 U.S. nursing homes participated in the Medicare and Medicaid program, and that they housed some 3.2 million residents. Individuals with disabilities (i.e., *consumers*) enter and remain in nursing homes for many reasons [3]. Forty percent of nursing homes are located in nonmetropolitan counties. While typically smaller in size, nonmetropolitan facilities serve about 35% of the nursing home population.¹ Unnecessary and inappropriate nursing home placement and difficulty transitioning back to community living may be particularly acute problems in rural areas [4]. Rural areas have fewer resources and

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¹ This is a higher per capita rate than the metropolitan population, as only about 18% of the population lives in non-metropolitan areas.

supports, and individuals must travel farther to access specialized services. When there are no apparent alternatives, rural Americans may perceive placement in a nursing home to be inevitable [5].

In 1999, the U.S. Supreme Court, based on the Americans with Disabilities Act, affirmed the right of individuals to receive services in “the most integrated setting,” which is usually the community [6]. Since then, centers for independent living (CILs) and other disability advocacy organizations have initiated a wide range of efforts to prevent nursing home placement and to emancipate (i.e., transition) adults with disabilities from inappropriate nursing home placements to community living [7,8]. Several national disability and aging organizations [9] place nursing home emancipation (NHE) high on their priority lists and propose that such efforts be legislated.

In response to the Olmstead decision and the efforts of disability advocates, the federal government and private foundations developed several national initiatives to prevent institutionalization in nursing homes and to promote transitions back to community living (see the [Appendix](#) for a brief history). For example, the CMS funded 33 Nursing Facility Transition Grants. CMS selected 9 of these programs for site review and independent outcome evaluation and found that approximately 3,605 individuals had left nursing facilities to live independently in the community during the grant period [10]. Unfortunately, very little data were collected to examine factors associated with successful community transitions. One study found that “poor health was the most commonly reported reason for not enjoying life” among 859 individuals who transitioned from nursing facilities.

While nursing homes have been considered an important element of the long-term care services system, there is also a history of public programs designed to both prevent nursing home entry and to promote return to the community after placement. For example, Medicaid established the 1915 (c) Home and Community-based Services waiver in 1981. However, community-based long-term support systems have been underappreciated and underfunded. CILs are a particularly important mechanism for delivering health education and support services [11].

Health and nursing home emancipation

People with disability often live with a smaller margin of health than do people in the general population [12]. One negative health-related event can more easily trigger a cascade of problems that affect an individual’s independence [13]. An individual with a significant impairment has a substantially greater risk of also experiencing secondary conditions (i.e., additional health complications) [14–16], which may affect nursing home transition in several ways. For example, a person with a spinal cord injury may develop a pressure sore that results in nursing home placement for treatment and care. Frustration over the pressure sore, nursing-home placement, and loss of

freedom may then lead to depression. Depression may lead the individual to doubt his or her ability to return to the community successfully.

Anecdotal reports suggest that CIL transition staff rarely consider secondary conditions when preparing a person to leave a nursing home or to manage the conditions when living in the community (M. Oxford, personal communication, April 14, 2005). An individual’s experiences with secondary conditions may increase his or her fear of being without the medical care expected to be available in a nursing home and affect the decision to transition to the community. Health behavior models that prevent and manage secondary conditions might help us understand this process. Several studies show that frail elderly nursing home residents who participate in health promotion programs improve their health, function, and life quality [17,18], but no studies have examined the use of such programs with adults who have disabilities and plan to leave a nursing home.

There is a paucity of published information about the nursing home transition process for adults with disabilities. While some community-based agencies, such as CILs, have long been providing nursing home transition services, and many others have now begun to do so, there is little understanding of the extent of these services. Further, the services have emerged organically from the field, and so, descriptions of the various approaches have yet to be compiled. The purpose of this research is to establish a baseline of nursing home transition services provided by CILs in the United States. Our first study assessed the levels of nursing home emancipation services and barriers to nursing home transitions. The second study reports on an assessment of CIL policies and procedures governing nursing home transition services.

Study 1: Assessment of NHE barriers and service outcomes

We 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 efforts as activities and services that directly help individuals living in nursing homes to relocate successfully to community 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

Proposal development

This study used community-based participatory research [19] and participatory action research [20] methods to

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