

Commentary: This is about nursing homes but the parallels are strong for all groups of people who desire freedom.

Item provided by:

Alliance of Disability Advocates  
Center for Independent Living  
[www.alliancecil.org](http://www.alliancecil.org)

~\*~

In 1999, the U.S. Supreme Court affirmed the right of individuals with disabilities to receive services in "...the most integrated setting." Since then, Centers for Independent Living (CILs) and other disability advocacy organizations have worked to transition adults with disabilities from inappropriate nursing home placements to community living.

## METHODS & RESULTS

In the summer of 2007, RTC: Rural mailed surveys to the 392 main CIL offices, including CILs that do not receive federal Title VII funding.

Research Progress Report # 39 describes CIL accomplishments in working on nursing home emancipation with 3,607 individuals in urban, rural, and very rural areas between October 2005 and September 2006. Survey respondents also reported barriers encountered in the emancipation effort and assigned each barrier a rating to indicate its severity. Table 1 lists these barriers and the average severity rating of each. Ratings were on a 5-point scale where "0" indicated the item was "not a problem" and "4" indicated that it is a "big problem."

## RATINGS OF BARRIERS TO NURSING HOME EMANCIPATION

<http://rtc.ruralinstitute.umt.edu/IL/NursingHomeEmancipationBarriers.html>

Lack accessible, affordable housing - 3.67

Lack accessible public or personal transportation - 2.91

Consumer concerned about finances (e.g. Social Security benefits) - 2.87  
Inadequate cash and resources to set up household - 2.86  
Fragmented programs and services - 2.66  
Consumer unaware of community options - 2.60  
Lack affordable, effective personal assistance - 2.44  
Difficulty working with nursing home staff - 2.40  
Consumer depressed or anxious - 2.22  
Consumer fears possible social isolation - 2.19  
Community lacks access to specialty medical services - 2.15  
Consumer fears being alone at times - 2.12  
Consumer characteristics (e.g., age, diagnosis, ventilator use) - 2.10  
Guardianship issues or third-party interference - 2.10  
Lack access to needed technology/equipment - 2.09  
Medication issues (access, misuse, abuse) - 2.07  
Consumer lacks clear community living goals - 1.95  
Consumer has fatigue or lacks stamina - 1.80  
Consumer anxious over managing chronic pain - 1.71  
Bowel/bladder problems (e.g., incontinence) - 1.59

It is not surprising that the top-rated barriers are basic needs such as shelter, transportation and money. It is noteworthy that health concerns, while not at the top of the list, also received relatively high ratings. These findings are illustrative, but must be interpreted with 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 (170, 43%), but may not reflect the experiences of non-responding centers. While affordable, accessible housing is the top barrier to nursing home emancipation, other listed barriers may be under-reported. If a CIL can't find housing for an individual, that person is likely to remain in the nursing home and other potential barriers will not pertain. If housing were available, some barriers such as personal assistance and secondary health conditions might have higher severity ratings.

NEXT STEPS

One goal of this line of research is to develop and test health promotion strategies that might assist in nursing home emancipation. Our first step will be to develop methods for assessing how secondary health conditions function as barriers to nursing home emancipation. Such an analysis will help us understand how to begin to target interventions to address those issues.

#### RTC: Rural Description

The Research and Training Center on Disability in Rural Communities (RTC:Rural) was established in 1988 as part of the Rural Institute at the University of Montana. RTC:Rural is funded by the National Institute on Rehabilitation Research to improve the ability of persons with disabilities to live independently in rural America.

<http://rtc.ruralinstitute.umt.edu/index.asp>