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Nursing Home Emancipation: Barriers Reported by Centers for Independent Living

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**Nursing Home Emancipation:
Barriers Reported by Centers for Independent Living**

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 and Results

In the summer of 2007, RTC: Rural mailed surveys to the 392 main CIL offices, including those 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 was a "big problem."

Table 1. Ratings of Barriers to Nursing Home Emancipation

Lack accessible, affordable housing	3.67	Community lacks access to specialty medical services	2.15
Lack accessible public or personal transportation	2.91	Consumer fears being alone at times	2.12
Consumer concerned about finances (e.g. Social Security benefits)	2.87	Consumer characteristics (e.g., age, diagnosis, ventilator use)	2.10
Inadequate cash and resources to set up household	2.86	Guardianship issues or third-party interference	2.10
Fragmented programs and services	2.66	Lack access to needed technology/equipment	2.09
Consumer unaware of community options	2.60	Medication issues (access, misuse, abuse)	2.07
Lack affordable, effective personal assistance	2.44	Consumer lacks clear community living goals	1.95
Difficulty working with nursing home staff	2.40	Consumer has fatigue or lacks stamina	1.80
Consumer depressed or anxious	2.22	Consumer anxious over managing chronic pain	1.71
Consumer fears possible social isolation	2.19	Bowel/bladder problems (e.g., incontinence)	1.59

Conclusions and Limitations

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.

Resource: Steve Gold's *Treasured Nuggets of Information* at <http://www.stevegoldada.com/>

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