

Information for this review came from the interactive Research Information on Independent Living (RIIL) database at www.GetRIIL.org, which contains research summaries related to independent living with disabilities. A special effort has been made to include information that independent leaders in the field said they wanted, namely topics regarding accessible, affordable housing, effective advocacy for rural areas, effective transition from schools and nursing homes, accessible, affordable transportation, reaching underserved populations, policies that impede independent living, rural health care services, and Medicaid/Medicare regulations for durable equipment.

RIIL is a joint effort of the Research and Training Center on Independent Living at the University of Kansas and the Independent Living Research Utilization (ILRU) Program of TIRR.

Look up studies in:



www.GetRIIL.org

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Avoiding Nursing Home Care

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Bureaucratic regulations, federal funding bias toward the nursing home industry, and lack of community-based services have led many to reside in nursing homes as an unwanted, last resort.

Often individuals are placed in nursing homes because their families are overwhelmed or lack financial resources, housing, or daily living activities help. Individuals also may have had their financial assets taken to cover the cost of their nursing home stay. Once in, the more than 1.6 million Americans are bound by the practices, diet, and treatments ordered by the institution management.

It's hard to save the money to leave a nursing home because those receiving benefits can't save more than a set amount of benefits. Others lose their spirit and become engulfed in powerlessness. In one study, residents needing care and living at their own homes viewed themselves as competent and struggled for independence. Nursing home residents, in contrast, defined themselves as incompetent and thought their former lives ended when they entered nursing home residency.

Another drawback to nursing home care is its expense — about \$40,784 annually in 1999. On the flip side, ADAPT estimated that it would cost \$9,692 for the same person to live in the community with personal assistance services.

States have been slow to reduce their reliance on nursing home care. Oregon and some others are exceptions. In 1982, Oregon got approval to use Medicaid funding to provide home care, a move applauded by the independent living field.

Many people with psychiatric disabilities, too, were funneled into nursing homes when state mental hospitals began reducing their populations. But The 1987 Omnibus Budget Reconciliation Act of 1987 that mandated nursing home screening to admit only residents in need of nursing care, cut down on the admissions of people with a psychiatric disability diagnosis only.

Board members, staff and volunteers who have lived in institutions can convince medical professionals, family members and others that it is possible for people with severe disabilities to live independently in the community.

Centers can use these role models in all levels of the transition program and keep statistics for support.

Another need is to educate medical professionals about the independent living philosophy and develop relationships with hospital personnel so that they can help patients live in the community.

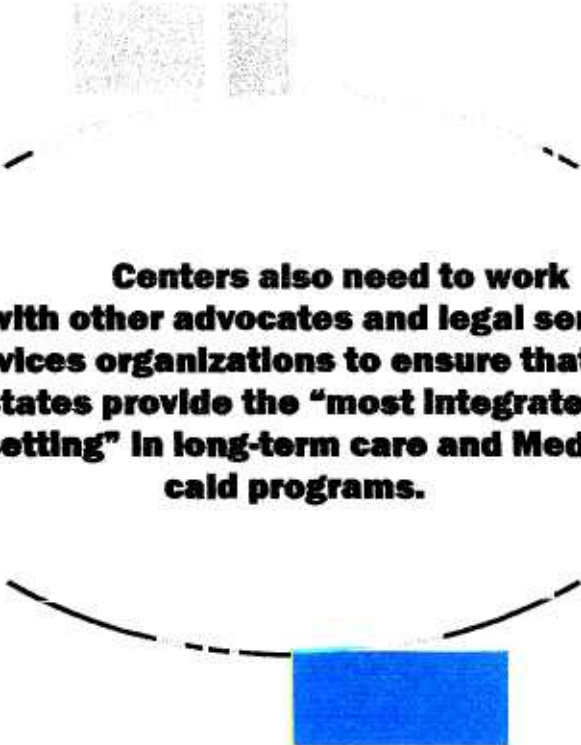
Today, research shows that nursing homes play a small role in mental health care except for elderly patients with dementia.

In the spirit of progress, the Independent Living Research Utilization Research and Training Center on Management of Independent Living Centers examined six centers for independent living that had moved people with disabilities into the community. One finding was the need for systems advocacy, including the expansion of Medicaid Waiver programs, in any transition program.

Centers also need to work with other advocates and legal services organizations to ensure that states provide the “most integrated setting” in long-term care and Medicaid programs.

Their boards, staff, and consumers, too, can benefit from learning about the nursing reform and how their states implement Medicaid Waiver programs.

They should also know the administrative requirement of funding agencies and be prepared with financial resources and personnel before starting a formal transition. — *Cindy Higgins, The Research and Training Center on Independent Living, The University of Kansas. This project funded by National Institute on Disability Rehabilitation Research grant #H133A980048.*



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