

## **U.S. Department of Health and Human Services: Assisted Living for Americans**

*To develop tools and materials that help assisted living consumers, and consumer intermediaries (e.g., local Aging agencies) obtain uniform information on the characteristics, services and costs of individual AL/RC facilities -- to aid consumers in determining which AL/RC community best meets their priorities and needs. Now known collectively as the AL Disclosure Collaborative (ALDC), the ALDC members -- representing ~ 25 national organizations -- have agreed to develop the tools (and eventually disseminate ALDC endorsed tools/materials) using a voluntary consensus process in partnership with AHRQ, the latter providing the research support to insure the resulting tools are based on sound scientific methods.*

### **Lead Agency:**

U.S. Department of Health and Human Services, Agency for Healthcare Research and Quality (AHRQ)

### **Agency Mission:**

The mission of the Agency for Healthcare Research and Quality is to improve the safety, quality, effectiveness, and efficiency of health care for all Americans.

### **Principal Investigators:**

D.E.B. Potter, M.S. (2005-present)  
Senior Survey Statistician  
Agency for Healthcare Research and Quality  
540 Gaither Road, Suite 500  
Rockville, MD 20850

William Spector, PhD (2003-2005)  
Senior Social Science Researcher  
Agency for Healthcare Research and Quality  
540 Gaither Road, Suite 500  
Rockville, MD 20850

### **Partner Agencies:**

AARP  
Benjamin Rose Institute  
University of Minnesota, Minneapolis (Division of Health Policy  
and Management, School of Public Health)  
University of Massachusetts (Gerontology Institute)

Jessie F. Richardson Foundation (Clackamas, OR)  
National Academy of State Health Policy  
Texas A&M Health Science Center at College Station (School of  
Rural Public Health)\*  
University of North Carolina at Chapel Hill  
VA Puget Sound Health Care System (Health Services Research  
and Development)  
Westat, Inc  
University of Pittsburg (Center for Research on Health Care)  
National Academy of State Health Policy  
Harvard Medical School, Massachusetts  
RAND, California  
American Institutes for Research  
Texas A&M Health Science Center at College Station (School of  
Rural Public Health)

### **General Description:**

Assisted living/residential care (AL/RC) is an important care option for people with health needs and functional impairments, especially for frail elders needing protective oversight, but not continuous nursing care. The typical assisted living resident is an 86 year old woman who needs help managing medications and is in need of assistance with approximately two activities of daily living (i.e., help with bathing, dressing, toiling, transferring, or eating; NCAL, 2008). With the capacity to serve over a million residents (Mollica et al, 2007), AL/RC is gradually approaching the size of the nursing home resident population (1.4 million residents; AHCA 2008).

Currently, differences in State requirements and a wide variety of services and amenities offered by AL/RC providers make it difficult for consumers to obtain uniform information to determine which AL/RC setting best meets their priorities and needs. This is in contrast to information that is provided to nursing home and home health consumers on the national Medicare.gov web site (and maintained by U.S. Centers for Medicare and Medicaid Services), in part, as a result of federal regulations.

The goal of the Agency for Healthcare Research and Quality's Assisted Living Initiative is to help AL/RC consumers, and consumer intermediates (e.g., local Aging agencies, hospital discharge planners), differentiate between individual AL/RC facilities to determine what best meets the consumer's priorities and needs.

Phase I of the Initiative began by funding a working conference of AL researchers, consumers, providers and Government officials. The 2004 meeting developed a national AL research agenda (see references in Question II.5 for agenda); a key conclusion from the conference was "Consumers lack information for making informed decisions concerning AL" (Kane, Wilson and Spector, 2007).

Subsequently (Phase II of the Initiative), AHRQ funded a research scan of available AL/RC consumer measures and state consumer tools, and conducted consumer and provider focus group research. Findings from these efforts were assessed and presented at a second AL/RC stakeholder meeting. The 2006 group recommended the development of uniform information that would describe the services and characteristics of individual AL/RC communities.

Phase III of the project began late in 2006 with the establishment of a partnership between AHRQ and the Center for Excellence in Assisted Living. Jointly they invited key AL/RC stakeholders to work collaboratively through a voluntary, consensus process to develop a uniform instrument (based on evidence when available) that would be used to describe individual AL/RC communities. Efforts are focusing on: services available; pricing information for services; move-in and move-out criteria; staffing information (RN staffing, 24/7 staffing, staff training and turnover); dementia services; and resident rights, house rules and life safety. Known as the Assisted Living Disclosure Collaborative this national voluntary consensus body is now composed of 22 member organizations (with expectations of more) and several ad hoc federal and national organizations. Once the uniform instrument is developed (planned for fall 2009), a formal testing period (small and large scale) will ensue with consumers and providers, followed by dissemination of the ALDC endorsed instrument, associated materials and information.

***Excellence:*** What makes this project exceptional?

The AL initiative from its outset has been a public private partnership that involved key assisted living stakeholders in the AL research process. The research community, the AL provider community, organizations that advocate for older Americans and the disabled as well as consumers, have all voiced their need for consumer information on AL/RC.

What is **exceptional** is that for very little federal investment and no federal regulation -- in contrast to the spending and regulation required to obtain uniform public information about individual nursing homes and home health agencies -- the resulting AL/RC tools (based upon science when available) could (after development and dissemination) aid consumers in their informed choice of an AL/RC communities by providing information on the characteristics, services and costs of individual AL/RC residences.

***Significance:*** How is this research relevant to older persons, populations and/or an aging society?

The average age of an assisted living consumer is 85 years old (NCAL, 2008). The population age 85 and older is the fastest growing segment of the US population, expected to grow from 8.5 million in 2006 to almost 21 million by 2050 (Federal Interagency Forum on Aging Related Statistics, 2008). AL/RC is an important care option for people with health needs and functional impairments, especially for frail elders and those with dementia related problems not requiring continuous nursing care. Informed consumer choice, especially a choice that diverts older Americans from more

costly care alternatives (while simultaneously meeting their needs and priorities), has the potential to reduce the pace of public long-term care spending (62 percent of nursing home care in 2005 was financed by either Medicare or Medicaid; Komisar and Thompson, 2007).

***Effectiveness:*** What is the impact and/or application of this research to older persons?

The goal of this project is to aid consumers and consumer intermediaries (e.g., local Aging agencies, hospital discharge planners) in their **effective** identification and choice of AL/RC residence(s) that meets their priorities and needs. Uniform information about the characteristics and costs of health care providers is an essential element of informed consumer choice. The tool in development is to be designed to obtain uniform information on the characteristics, services and costs of individual AL/RC facilities, using evidence based information when available.

***Innovativeness:*** Why is this research exciting and newsworthy?

Information (based on a national standard) about individual nursing homes and home health agencies was made available to the public, in part, due to federal regulation. The efforts of AHRQ's Assisted Living Initiative have the potential of providing consumers with uniform information as the result of a voluntary consensus process of key AL/RC industry stakeholders (see Question I.5 for a list of project partners) that work in partnership with the Federal government, i.e. AHRQ – supporting the development of AL/RC tools that are based on sound research principals that inform consumer decision making.