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## **Long-Term Care in the United States: Policy Themes and Promising Practices**

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*This analysis provides an overview of the major policy themes and promising practices emerging in recent years as policymakers and researchers struggle to design a long-term care system that meets the needs of an aging population. Themes that have dominated the long-term care policy debates include: recruiting and retaining a qualified long-term care workforce; devising financing mechanisms for those requiring long-term care; and moving away from an institutional-based long-term care system towards more home- and community-based services. Three promising practices that have emerged in the past few decades include: the culture change movement; service integration that combines medical and social care; and various forms of community residential care that bring together housing and services in a more home-like environment. It concludes with long-term care recommendations for policymakers.*

**KEYWORDS** *Long-term care, public policy, nursing homes, home and community-based services*

Long-term care policy is made up of a multitude of policies at the federal, state, and local levels that were created in response to demographic changes over the course of the 20th century, including the growth of the older adult population, greater longevity, and a shift from infectious diseases to chronic illnesses (R. A. Kane, Kane, & Ladd, 1998). In 1986, the Institute of Medicine (IOM) defined long-term care as "a variety of ongoing health and social services provided for individuals who need assistance on a

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continuing basis because of physical or mental disability” (p. 398). As implied by this definition, long-term care is more accurately described as a patchwork of different services and providers of care, rather than a comprehensive system. Long-term care includes *institutional care* (e.g., nursing home care), *in-home services* (e.g., home health aides), *community care* (including adult day health care), and *material supports* (e.g., wheelchairs and other assistive devices; Ikegami & Campbell, 2002). Long-term care also includes informal assistance by family and friends who provide the bulk of care to older adults.

Long-term care for older adults has long been a neglected issue among the media, policymakers, social workers, older adults, and their families. Perhaps due to wishful thinking, many aging Americans only contemplate long-term care when a health crisis leads to the need for assistance on an ongoing basis (R. A. Kane, 2001). Although older adults, rallied together by advocacy groups such as the American Association of Retired Persons (AARP), exert enormous political pressure on politicians who threaten to reduce Social Security benefits, very few put in a comparable effort towards long-term care reform, allowing politicians and policymakers to devote their energy to more politically pressing matters (R. A. Kane, 2001). With the exception of occasional tales of scandal and abuse in nursing homes, the media has paid very little attention to long-term care policy. As a result, long-term care has historically fallen below the policy radar in the United States.

In recent years, however, policymakers and researchers have recognized the vital importance of developing long-term care policies that will lead to adequate and appropriate care for the increasing number of Americans over the age of 65. First, research indicates that the long-term care system is inadequate to meet the current needs of older adults. Currently 4 out of 5 adults over age 50 in the United States, or 70 million individuals, have been diagnosed with at least one chronic condition (AARP Public Policy Institute [AARP PPI], 2009). According to the AARP PPI (2006), 40% of older adults in the United States in 2005 had a disability, although almost the same percentage of individuals age 75 and older lived alone. This data suggest that many older adults require some type of assistance and may not be able to depend on family members for the care they need. In 2008, approximately 10 million Americans received long-term care (Komisar & Thompson, 2007). This number may not include, however, all Americans who could benefit from long-term care, because one in five elders living in the community report they do not receive the care they need (Feder, Komisar, & Niefeld, 2000). These needs include performing activities of daily living (ADLs), such as bathing, dressing, eating, transferring from a bed to a chair, walking, and using the toilet (Katz, Ford, Moskowitz, Jackson, & Jaffe, 1963), or performing instrumental activities of daily living (IADLs), including preparing meals, shopping, managing money, using the

telephone, doing housework, and taking medicine (Lawton & Brody, 1969). Second, dramatic demographic changes will create a sense of urgency to do something about long-term care before the so-called *silver tsunami* hits this country. In 2000, approximately 1 in 8 Americans (12.4%) were age 65 and older, and by 2030 this ratio is expected to increase to 1 in 5 (20%; U.S. Census Bureau, 2004). This rise in the elderly population is due primarily to the aging of the baby-boom generation, the more than 80 million people born between 1946 and 1964 who will begin to turn 65 in the year 2011 (Frey, 2007). The baby-boomers have influenced public policy and public institutions throughout their life course, and it is expected that they will have the same effect on long-term care once they encounter the physical, cognitive, and/or mental decline that often accompany old age.

This analysis provides an overview of some of the major policy themes and promising practices emerging in recent years as policymakers and researchers struggle to design a long-term care system that meets the needs of an aging population. It begins with a discussion of three of the themes that have dominated the long-term care policy debates: (a) recruiting and retaining a qualified long-term care workforce; (b) devising financing mechanisms that provide adequate coverage for those requiring long-term care without bankrupting federal, state, and local governments; and (c) moving away from an institutional-based long-term care system towards more home- and community-based services. The analysis includes the description of three promising practices that have emerged in the past few decades: (a) the culture change movement that began in nursing homes and is now influencing community-based long-term care, (b) service integration that combines medical and social care, and (c) various forms of community residential care that bring together housing and services in a more home-like environment. It concludes with long-term care recommendations for policymakers.

Understanding the complexities of the long-term care system, including a sampling of the issues under current policy debate and some of the promising practices that offer the hope of an improved long-term care system, will assist social workers engaged in direct and indirect practice with older clients. It is imperative that social workers become a part of these policy discussions and help shape the future of long-term care.

## MAJOR THEMES IN THE LONG-TERM CARE POLICY DEBATE

As policymakers and researchers have embarked on the challenge of creating a more comprehensive long-term care system, they have raised questions that focus on three areas: (a) the workforce shortage, (b) financing, and (c) moving from institutional to community-based care.

## Long-Term Care Workforce Shortage

The first theme involves recruiting and retaining qualified long-term care providers, particularly direct care staff. The health and long-term care workforce is currently inadequate to meet the needs of older adults. For example, only 1% of physicians specialize in geriatrics (Zieger, 2009), and according to the IOM (2008), 4% of social workers and less than 1% of nurses, physician assistants, and pharmacists have received training in geriatrics. In addition, the number of direct care workers in long-term care, including certified nursing assistants (CNAs) and home health aides, falls short of present demand (Stone, 2004). This demand will increase in the future, and the long-term care workforce will need to grow in response to the dramatic increase in the 65-and-over population over the next 30 years. According to a recent estimate, the long-term care workforce will need to expand by 2% a year from now until 2050, producing an additional four million new jobs (Friedland, 2004).

There are several reasons why recruitment and retention of frontline workers has become increasingly difficult. First, nursing facilities and home- and community-based service providers cannot find qualified, committed individuals to fill the available positions, which is, in part, due to low pay and benefits (Stone, 2001). Close to 30% of paraprofessional long-term care workers live at or below the poverty line, and they are less likely to receive health insurance or pensions than the average American worker (Institute for the Future of Aging Services, 2007). Second, the long-term care industry struggles with extraordinarily high rates of turnover. Experts attribute the high turnover rates to low wages and benefits, heavy workloads and difficult working conditions, feeling undervalued by employers and stigmatized by society, and a lack of qualified applicants, which has led many organizations to fill positions with so-called *warm bodies*, rather than individuals dedicated to the care of older adults (Stone, 2001).

In a 1999 survey on workforce issues, officials from 42 states designated recruitment and retention of workers as a high priority, and 30 states reported they had developed a workforce initiative (Stone, 2001). An example of a state initiative is the wage pass-through in which the state mandates that a portion of a reimbursement increase from Medicaid or other state funding sources be used to increase wages or benefits for frontline workers (Stone, 2004). Other policy recommendations include modifying state nurse practice acts to allow paraprofessionals to perform certain tasks that currently fall under the sole purview of RNs (Stone, 2004), hiring the friends and relatives of long-term care consumers to provide care (Simon-Rusinowitz et al., 2002), providing federal financial assistance to job candidates to complete certification or training requirements, and increasing federal and state investment in technology development that may lead to more efficient and effective ways to provide long-term care (Institute for the Future of Aging

Services, 2007). Perhaps the most important recommendation is for providers and local, state, and federal governments to work together to develop a comprehensive long-term care workforce policy that fits into the goals of the overall long-term care system (Institute for the Future of Aging Services, 2007). This will be a significant challenge because the long-term care system itself does not have an overarching goal or underlying set of principles from which to make policy decisions.

### Financing Long-Term Care

Long-term care costs in the United States totaled almost \$207 billion in 2005, representing a quadrupling from 1980 (Burman & Johnson, 2007). Some policy experts predict that costs could quadruple again between now and 2050 (Burman & Johnson, 2007), inspiring policymakers to devise a financing system that achieves a balance between public and private spending and contains rising costs.

Long-term care financing highlights the fragmented and reactionary nature of long-term care policy in the United States. Long-term care did not become widely available until the creation of Medicare and Medicaid, which (along with limited state programs) provide public funding for nursing homes, home health agencies, and other long-term care services (R. A. Kane et al., 1998). Medicare is a federally financed program that contributed 20% of the national spending on long-term care in 2005 (O'Brien, 2007). Medicare, however, is an entitlement program for older adults that is more focused on acute care than long-term care, and only covers the long-term care costs of older adults requiring skilled nursing care or rehabilitative treatment (O'Brien, 2007). Individuals who need custodial care in a nursing home for dementia or another chronic illness, or those who could remain in their homes with some assistance with personal care or other household tasks, do not qualify.

Long-term care is primarily financed by Medicaid and out-of-pocket spending, which accounted for 40% and 26%, respectively, of long-term care expenditures in 1998 (Feder et al., 2000). Medicaid is a health insurance program for impoverished individuals jointly funded by the federal and state governments. In 2005, Medicaid spent \$59 billion to cover nursing home care and more than \$42 billion for home care (Komisar & Thompson, 2007). The majority of elderly individuals does not enter into long-term care under Medicaid, but must *spend down* their life savings as private pay patients until they are eligible for Medicaid coverage (Kaiser Family Foundation, 2006).

The critics of the current financing system raise questions regarding the appropriate role of government in long-term care, pointing out that Medicaid produces a disincentive for older adults to plan or save for their future long-term care needs by depleting their savings before qualifying for any coverage (Johnson, 2008). To date, long-term care insurance has proven to be unpopular

with older adults. Although the number of policies sold increased from 1 million in 1987 to 9 million in 2002, that represented only 9% of adults age 55 and older, and private insurance accounted for only 4% of total long-term care spending in that year (Burman & Johnson, 2007). Long-term care insurance is expensive, costing an average of \$1,702 per year for a 60-year-old in 2005 (Gleckman, 2008). In addition, many private plans only provide benefits to those with severe cognitive and physical impairments (Burman & Johnson, 2007) and are not guaranteed to cover future innovative forms of care (Feder et al., 2000). To achieve a balance between public and private financing, policymakers can provide incentives for Americans to plan for their long-term care needs, create a different form of government financing, or some combination of the two (Gleckman, 2008; Johnson, 2008).

### Shifting the Emphasis From Institutional to Community-Based Care

A third theme in long-term care policy discussions over the past 25 years is the shift away from nursing homes toward home- and community-based care. Nursing homes have long been the dominant service providers in the long-term care system, even though the majority of older adults would prefer to remain at home (R. L. Kane, 2005). Nursing homes continue to be the primary setting in which older adults receive long-term care; in 2006, 75% of Medicaid long-term care spending was for institutional care (AARP PPI, 2008). There are significant barriers to caring for older adults in lower levels of care, including a lack of consensus among physicians on the appropriate care setting for different types of disease and disability; state regulations that dictate the types of clients that can receive treatment in less-restrictive environments (Spector, Reschovsky, & Cohen, 1996); and the absence of other community resources, such as meals on wheels and transportation, that are necessary to keep some older adults in their own homes (National Institute of Nursing Research, nd). Nevertheless, the use of nursing homes has decreased while the use of home- and community-based services has increased over the past few decades (Feder et al., 2000).

Both Medicare and Medicaid have increased spending for home- and community-based services over the past 25 years, but continue to dedicate more resources to nursing homes. Medicare beneficiaries of home health services must be homebound, have a physician to develop a plan of care, and have rehabilitative potential (R. A. Kane, 1995). The majority of Medicaid spending for home- and community-based care, through the optional Home and Community-Based Services (HCBS) waiver program or 1915c waivers, allow states to pay for in-home medical and support services for populations at risk of institutionalization, including the frail and disabled elderly (Kaiser Family Foundation, 2007; Summer, 2007). The majority of spending for HCBS waivers, however, is for individuals with mental retardation or developmental disabilities (AARP PPI, 2006). In 2002, Medicaid funded

more than three times the number of older adults in nursing homes as through HCBS waivers (AARP PPI, 2006).

Policymakers continue to promote the goal of helping older adults return to or remain in their own homes through the provision of home- and community-based services. They offer different rationales, however, for the movement toward home- and community-based care, including the cost effectiveness of such a strategy, the need to improve the quality of care and the quality of life of consumers, and the importance of honoring the preferences of older adults.

*Cost effectiveness.* Many policymakers view home and community-based services as a cost-effective alternative to nursing homes and have implemented policies designed to bring about a balance between institutional care and home-based care. Advocates of home- and community-based services point out that these services cost substantially less per recipient. The AARP PPI (2008) proposed that Medicaid can cover almost three older adults through the HCBS waiver program as compared to the cost of one older adult in a nursing home. There is little evidence, however, that a greater reliance on home and community-based care reduces overall long-term care costs (Grabowski, 2006) and may even have the opposite effect (R. A. Kane, 1995). Some potential explanations for the absence of cost savings include high front-end costs for assessment and developing care plans, providing unnecessary services, and legal requirements that only nurses can perform certain tasks (R. A. Kane, 1995). There is also the potential for an increased availability of home- and community-based care to increase the number of older adults receiving long-term care, rather than only substituting for nursing home care (Feder et al., 2000). Policymakers fear this so-called *woodwork effect*, in which older adults who would never consider entering a nursing home come *out of the woodwork* to enroll in the more attractive services that allow them to remain in their own homes (R. A. Kane, 2001).

To combat the impact of the woodwork effect and other factors contributing to the absence of cost savings of home and community-based services, policymakers have adopted various cost control strategies. Federal law permits states to impose eligibility requirements to limit the number of HCBS waiver recipients and reduce costs. In a recent survey of state Medicaid waiver programs by the Kaiser Family Foundation (2007), 23% reported that they use narrower financial eligibility limits for HCBS waivers than nursing home coverage, and seven states set stricter functional eligibility requirements for HCBS waivers than for nursing home care. States can also allot a certain number of waivers for each population at risk of institutional care, limit waivers to particular geographic regions, and impose hourly and expenditure caps. Finally, some states allow consumer direction, described in more detail in the following, in an effort to decrease costs (Kaiser Family Foundation, 2007).



*Quality of care and quality of life.* Other supporters of the shift to home- and community-based services argue that they are preferable to institutional care because they can improve quality of care and quality of life. The quality of care in long-term care received scant notice in this country until a number of nursing home scandals (e.g. Medicaid fraud, resident abuse and neglect, and substandard care) caught the public's attention in the 1970s and 1980s. In response to a 1986 Institute of Medicine report, Congress passed the Omnibus Budget Reconciliation Act of 1987 (OBRA 87) that called for substantial reforms in the nursing home industry, including staff training and unannounced state inspections of facilities (National Institute of Nursing Research, n.d.). In 2001, however, the Institute of Medicine's Committee on Improving the Quality of Long-Term Care concluded that nursing facilities that have consistently violated OBRA 87 continue to operate and many nursing home residents experience poor quality of care. The same committee reported that, due to a lack of information about consumer outcomes and limited regulation, quality of care is also problematic in home- and community-based services. Critics of the emphasis on quality of care argue that measures of quality often reflect commonly held beliefs about how care should be provided rather than practices that have been shown to improve the quality of life of older adults in long-term care (R. L. Kane, 2005).

Quality of life, however, appears to be even more challenging to assess. There is little research on quality of life for older adults in nursing facilities and home- and community-based services because there is a lack of agreement on what comprises a good quality of life for such a population (R. A. Kane, 2001). In an effort to address this challenge, a group of researchers at the University of Minnesota proposed 11 domains of quality of life in long-term care that included: a sense of safety, security, and order; freedom from pain and discomfort; enjoyment; meaningful activity; reciprocal relationships; the highest level of functional competence possible; dignity; privacy; individuality and the ability to express one's identity; autonomy and choice; and spiritual well-being (R. A. Kane, 2001). It is likely that these 11 domains could also apply to individuals in other long-term care settings.

*Older adults' preferences.* Although the relationship between home care and cost savings or improvement in quality of care and quality of life has yet to be firmly established, research evidence supports the claim that older adults prefer to receive long-term care in their homes or the community (Weissert, Cready, & Pawelak, 1988). The 1999 Supreme Court Olmstead decision required that states provide long-term care for people with disabilities in the least restrictive setting possible (R. A. Kane, 2001). Long-term care policy discussions about older adults, however, often revolve around the trade-off between freedom and safety (R. A. Kane et al., 1998). Fears about the safety of older adults may lead policymakers and service providers to place them in a higher level of care than is necessary (R. A. Kane et al., 1998).

Honoring the preferences of older adults relates not only to providing more home- and community-based care but also to the types of home- and community-based care available. Consumer-directed care (allowing consumers to choose their agency-employed direct care worker and/or distributing a stipend with which they can arrange their own services) has become an increasingly accepted form of long-term care for older adults (Carlson, Foster, Dale, & Brown, 2006). For example, the In-Home Supportive Services (IHSS) program that started in California includes a consumer-directed model that allows recipients to hire, supervise, and fire their care provider, who could be an agency worker, family member, friend, or neighbor. In 2001, 62% of IHSS program participants were age 65 and older (Benjamin & Matthias, 2001).

Overall, it appears that consumer-directed care leads to equivalent outcomes compared to agency-directed care in terms of health and functioning (Grabowski, 2006), along with improved outcomes in terms of consumer satisfaction and well-being (Carlson et al., 2006). Although these results are promising, there are a number of concerns about the provision of long-term care to older adults through consumer-directed care. For example, IHSS offers very little in the way of training to consumers as to how to hire and supervise an in-home worker (Benjamin & Matthias, 2001). In addition, the beliefs of policymakers about the lack of interest in consumer-directed care among older adults may not be groundless. In their evaluation of IHSS, Benjamin and Matthias found that although older adults in a consumer-directed model were able to manage their own care, younger adults expressed more enthusiasm for consumer-direction than their older counterparts. Finally, research reveals that consumer-directed care may cost more than agency-directed care (Grabowski, 2006), a finding that could discourage states from experimenting with consumer-directed long-term care for older adults.

In summary, policymakers and researchers have not been able to resolve the important long-term care issues (e.g. workforce shortage, financing the growing costs of long-term care, and making the shift from institutional to home and community-based care) that have emerged over the past few decades. However, social reformers, policymakers, service providers, and older adults have been experimenting with some innovative practices that offer the promise of improved long-term care for older adults.

## PROMISING PRACTICES IN LONG-TERM CARE

Promising practices have emerged to offer an alternative to traditional long-term care based on institutionalization and the medical model. These promising practices include the culture change movement, service integration, and community residential care.

## Culture Change Movement

The culture change movement aims to remold the way long-term care is organized and delivered. Proponents of culture change support the following values for long-term care: addressing the needs of the mind, body, and spirit; imbuing consumers with decision-making authority; accepting risk as a part of life; putting people before tasks; viewing consumers and staff as unique individuals; and believing that staff that are treated well will result in consumers that are treated well (R. A. Kane, 2001). In addition to improving the quality of care and quality of life, culture change can also improve staff recruitment and retention by creating better working conditions. The culture change process requires a substantial transformation in the attitudes and behavior of management and direct care staff to create a long-term care community that results in an improved quality of life for everyone involved (Rahman & Schnelle, 2008).

The culture change movement that was started by the Nursing Home Pioneers (now the Pioneer Network) in 1997 is still in the early stages of its development (Rahman & Schnelle, 2008). What began as a small grassroots movement gained momentum in 2005 when the Centers for Medicare and Medicaid Services (CMS) embraced the idea of nursing home culture change in the guidelines for state Quality Improvement Organizations to work with nursing homes to bring about an improved organizational culture (Rahman & Schnelle, 2008). The government's official endorsement, together with new instructional materials designed to help nursing homes and other long-term care providers implement culture change principles in their organizations (Rahman & Schnelle, 2008), suggests that this movement will continue to expand in the coming years.

Currently, there is little research evidence that culture change results in improved outcomes in older adults. Prior to the CMS endorsement, there were few efforts to rigorously evaluate culture change initiatives (Rahman & Schnelle, 2008). A recent evaluation of culture change in nursing homes in Kentucky, however, found that an increase in the number of culture change practices was associated with a decrease in the number of deficiencies identified in a state inspection, suggesting that culture change may lead to improved quality of care (Castellanos-Cruz, 2008). Another barrier to evaluating outcomes is the amount of time required to accurately assess the impact of culture change, the difficulty in achieving short-term improvements, and the complexity of the outcomes to be achieved (Angelelli & Higbie, 2005). For example, The Eden Alternative, one of the most visible examples of culture change in action, advocates for resident autonomy and interaction with children, animals, and plants that they believe will reduce the feelings of boredom, loneliness, and helplessness that often plague older adults in long-term care (Rahman & Schnelle, 2008). One recent year-long evaluation of a nursing home adopting the Eden Alternative, however, reported no

positive effect on mortality, functional status, or cognitive status (Coleman et al., 2002). It is possible that multiyear evaluations and more modest outcomes will yield more positive results.

There are many challenges facing the culture change movement. First, culture change requires a deep level of organizational commitment, and many culture change initiatives in the past have failed due to the absence of management buy-in (Angelelli & Higbie, 2005). Second, some policymakers and service providers resist the idea of transforming hospital-like facilities into more home-like environments, perhaps due to fears about older adult safety and their capacity to make decisions (Angelelli & Higbie, 2005). Finally, the culture change movement needs to provide more guidance to nursing facilities and other long-term care providers seeking to implement its principles. Without research evidence, however, it is difficult for the movement to identify evidence-based best practices (Rahman & Schnelle, 2008).

### Service Integration

Service integration involves connecting the components of the health care system, such as medical and acute care, with components of the social service system, including long-term care, education and training, housing, and psychosocial services (Leutz, 1999). Service integration also involves coordinating various funding sources and the types of services (Feder et al., 2000). Some efforts to integrate services involve combining Medicare (covering acute and skilled medical care) with Medicaid (covering long-term care; Feder, et al., 2000). According to Feder and colleagues (2000), however, “there is much more rhetoric than reality to service integration” (p. 51). In addition, they believe that although proponents of service integration claim that it will lead to improved quality of care, the true motivation behind such efforts is cost containment. Some proponents of service integration believe that it will reduce long-term care costs by substituting less expensive social services and preventive care for costlier acute medical care (Capitman, 2003).

Service integration concerns replacing the acute care model with the Chronic Care Model (CCM). Components of the CCM include supporting patient self-management, the use of interdisciplinary teams, and clinical information systems that provide data on individual patients and populations of patients (Wagner et al., 2001). The chronic care model would also require a change in financing for long-term care, as Medicare, Medicaid, and private insurance companies currently reimburse health care providers using fee-for-services payments that reward the quantity of services, rather than the quality of services (AARP PPI, 2009). For example, using a capitated system of payments in which health care providers receive a monthly fee for a long-term care patient might inspire them to improve the quality of care and contain unnecessary costs (AARP PPI, 2009).

One example of long-term care service integration is the nationwide Program of All-Inclusive Care for the Elderly (PACE) model developed by On Lok in San Francisco. A PACE site receives a monthly capitation payment from Medicaid and Medicare for each participant (Eng, Pedulla, Eleazer, McCann, & Fox, 1997). Each PACE center includes both an adult day health center and a full-service medical clinic, reflecting the model's emphasis on combining medical and social care. Each center employs an interdisciplinary team made up of primary care physicians, clinic nurses, nurse practitioners, social workers, occupational and physical therapists, dietitians, recreation staff, geriatric aides, home health nurses, transportation workers, and a program manager (Eng et al., 1997).

Similar to culture change initiatives, there have been few studies that examine older adult outcomes or other potential benefits associated with service integration. The PACE model appears to result in positive health outcomes (e.g. lower mortality rate) for frail elders (Eng et al., 1997). Another study reports that although PACE participants have higher rates of disability and disease compared to all older adults receiving Medicare, they have similar hospitalization rates (Weiland et al., 2000). In general, however, it has been difficult to show that integrating social and health care has a beneficial impact on the physical, mental, or cognitive functioning of older adults (Capitman, 2003). It has also been difficult to demonstrate that lower cost services are replacing higher cost services to reduce long-term care expenditures (Capitman, 2003). Service integration must overcome a number of challenges before there can be a determination as to whether this model of service delivery will improve long-term care for older adults. First, organizations often compromise as they attempt to integrate services, focusing on either a private pay or low-income population or engaging in service coordination rather than integration (Leutz, 1999). Second, service integration requires large administrative start-up costs along with initial service costs that may discourage organizations and policymakers interested in cost containment (Leutz, 1999). In addition, service integration requires investment in staff training and support, as it requires health care and social services professionals to work together to provide long-term care (Leutz, 1999). Although service integration may be viewed as a promising practice, it is too soon to tell whether it will become a best practice in long-term care.

### Community Residential Care

Over the past few decades, a major development in long-term care for older adults is the growing interest in community residential care that combines group housing with various health and supportive services (Hedrick et al., 2003). Community residential care gives residents more privacy and autonomy than that afforded by nursing homes while maintaining the economies of scale that are more efficient than providing services in individual homes

(R. A. Kane, Kane, Ilston, Nyman, & Finch, 1991). Community residential care generally serves a population that is less impaired than those living in nursing homes but more impaired than those still living in their own homes (Hedrick et al., 2003). The two models of community residential care that emerged in the state of Oregon are assisted living and adult foster care.

The term *assisted living* was first used in 1985 in a pilot study in Oregon that experimented with providing services to nursing home residents in a more residential setting, and by the early 1990s the concept of assisted living had spread across the country (Wilson, 2007). States view assisted living as a cost-effective means of providing long-term care, because Medicaid covers only services in assisted living but covers rent, food, and services in nursing homes (Carder, Wright, & Jenkins, 2006) and the majority of assisted living residents are private pay and not dependent on the public financing system (Hedrick et al., 2003). Assisted living became the fastest growing type of senior housing by the late 1990s (Hawes, Phillips, Rose, Holan, & Sherman, 2003).

According to early proponents, assisted living needed to include three components: (a) a home-like environment that provides privacy and control over personal space; (b) supportive services offered in a way that meets residents' preferences; and (c) a governing philosophy emphasizing independence, choice, dignity, and privacy (Hernandez, 2006). The term *assisted living* is now applied to a wide variety of settings. The state of Oregon, for example, classifies institutions as assisted living if they offer personal care and health related services; 24-hr supervision; social activities; and furnish each resident with a private living unit that includes a kitchenette and wheelchair-accessible bathroom (Oregon Department of Human Services, 2005). In contrast, Florida and North Carolina define an assisted living facility as any type of residential care setting that is not a nursing home (Hernandez, 2006). The lack of uniformity among assisted living facilities raises concerns as to whether they can deliver on their promise of maintaining the dignity and privacy of their residents while providing adequate services to help them age in place (Wilson, 2007).

Adult foster care is another model of community residential care designed to keep older adults out of nursing homes. Adult foster care also began in Oregon in the early 1980s, and today exists in states across the country. Adult foster homes are typically a private residence in which a live-in manager, often the owner of the home, provides personal assistance, housekeeping, and congregate meals to a small number of older adults (Hedrick et al., 2003). Most adult foster care providers are not health care or social service professionals (Nyman, Finch, Kane, Kane, & Illston, 1997), but they can access additional health and supportive services provided by home care agencies (R. A. Kane et al., 1991). As with assisted living facilities, many adult foster home residents are private pay and have a higher level of physical and cognitive functioning than individuals living in a nursing home (R. A. Kane et al., 1991). As with most promising practices in long-term care,

there is little empirical evidence of the benefits of community residential care compared to nursing facilities. One major obstacle to rigorous evaluations of these care settings is the lack of uniformity in the definitions of community residential care (Wilson, 2007). For example, in a national survey of assisted living administrators, Hawes and colleagues (2003) found that although residents of assisted living have more privacy and control than residents of nursing homes, a significant portion of facilities do not adhere to the principles of assisted living. In addition, although early proponents of assisted living viewed it as a way to prevent nursing home admission for those who seemed destined for such an institution (Wilson, 2007), this same survey reported that a substantial percentage of facilities refuse to admit or retain those who need nursing home services (Hawes et al., 2003).

Research studies have found generally high levels of satisfaction among assisted living residents, particularly in terms of the comfort and privacy of their rooms and their treatment by staff (Hedrick et al., 2003; Mitchell & Kemp, 2000). The few research studies that have been conducted on outcomes, however, have produced mixed results. One study reported that residents of nursing homes and assisted living facilities do not differ in outcomes related to physical functioning, psychological functioning, and pain and discomfort over the course of a year (Frytak, Kane, Finch, Kane, & Maude-Griffin, 2001). Data from another study, however, show that residents living in adult foster care experience more functional decline over 12 months than their nursing-home dwelling counterparts (Stark, Kane, Kane, & Finch, 1995). Community residential care does appear to reduce nursing home use. In Oregon, for example, the 1980s witnessed the rise of assisted living and adult foster care beds with a concurrent decrease in the number of nursing home beds (R. A. Kane et al., 1991).

A number of current and future challenges to community residential care have yet to be addressed by policymakers and service providers. First, there is no indication that the lack of uniformity in the definition of community residential care will change anytime soon (Hernandez, 2006). Second, there is debate as to whether these settings should develop quality of care standards similar to those legally required for nursing homes. Some state officials now view assisted living as a “disaster waiting to happen” (Hernandez, 2006, p. 16) and are developing standards of care that mirror those that have proved less than successful in nursing homes (Wilson, 2007). Others believe that community residential care will lose its distinctive components, including an emphasis on privacy and dignity, if nursing home regulations are transferred to these settings (Carder et al., 2006). Finally, some advocates fear that assisted living and other forms of community residential care serve primarily older adults of a high socioeconomic status. Assisted living is much more affordable than a nursing home, yet few low- or middle-income older adults can afford to privately pay the room and board fees.

## Promising Practices in Action: The State of Oregon

The state of Oregon, recognized as a pioneer and innovator in long-term care (Hernandez, 2006), provides a model for improving the residual approach to long-term care. What is known as the *Oregon Model* emphasizes community residential care as an alternative to nursing homes and the importance of service integration.

In 1980, Oregon received funding from the US Department of Health and Human Services to develop a comprehensive state plan for the provision of long-term care to older adults (Kutza, 1994). At the same time, Oregon carried out a four-county demonstration project to develop alternatives to nursing home care (Kutza, 1994). The result of both of these projects was the creation of the Senior Services Division (now the Senior and Disabled Services Division or SDSD) in 1981 that oversees the state long-term care system (Kutza, 1994). The SDSD funds and supervises four types of programs: cash assistance to older and disabled adults; long-term care; Older Americans Act programs; and protective services (Kutza, 1994). After consolidating funding for all aging and long-term care services into one entity, Oregon designated Area Agencies on Aging (AAA) as the single point of entry for all services (Kutza, 1994).

The goal of the Oregon Model is to provide long-term care in a wide array of settings from which the consumer can choose the site that best meets his or her long-term care needs (Hernandez, 2006). Early on, Oregon's Medicaid HCBS waiver could be used for services in community residential care facilities, including adult foster care homes and assisted living facilities (Kutza, 1994). In addition, SDSD employed a number of strategies to increase access to these types of settings. For example, to spur on the development of adult foster care in the early 1980s, SDSD instituted minimal licensing requirements to assist in recruitment, employed resource development specialists to identify potential foster homes in communities, and implemented a nursing home diversion policy in which case managers would evaluate Medicaid nursing home residents to determine if they could be better served in adult foster care (Nyman et al., 1997). Similarly, Oregon used low-interest loans and a high Medicaid payment to motivate developers to create more assisted living facilities (Hernandez, 2006). These policies appear to have been successful. In 2004, Oregon had achieved a better balance of long-term care options than most states (e.g., 30% of long-term care beds in nursing homes, 30% in assisted living, 19% in adult foster care and 21% in other residential facilities; Hernandez, 2006).

## THE FUTURE OF LONG-TERM CARE

Although these three innovative ways of designing and delivering long-term care provide potential solutions to important challenges in long-term care,



they do not address the absence of a comprehensive long-term care system complete with underlying principles and goals from which to develop future policies. Benjamin (1993) proposed that the lack of consensus on the principles and goals of home care policy stems from the residual nature of these services, in that they are delivered to individuals who do not have the potential to benefit from other types of services. One could argue that the same problem plagues long-term care policy in general. The key to a comprehensive long-term care system, therefore, lies not only in developing policies to improve the traditional residual system of long-term care but also combining policies with a preventative approach that aims to reduce the number of older adults requiring long-term care. Long-term care policy would then be guided by two complementary goals: (a) improving the health and well-being of individuals of all ages to reduce the need for long-term care in old age and (b) providing accessible and appropriate long-term care to older adults who require assistance due to physical, psychological, and/or cognitive impairment. The achievement of both of these goals is dependent on the willingness of federal and state governments to provide funding for experimental and innovative approaches to long-term care.

In terms of the first goal, the idea of creating a *livable* or *aging-friendly* community offers a preventative approach to long-term care. An aging-friendly community is defined as “a place where older adults are actively involved, valued, and supported with infrastructure and services that effectively accommodate their needs” (Alley, Liebig, Pynoos, Benerjee, & Choi, 2007, p. 5). In addition, an aging-friendly community is designed to meet the needs of individuals at all stages of the life course and all levels of ability (Alley et al., 2007). Although the mix of specific policies, programs, and infrastructure, and the relative importance placed on each component, will vary depending on the needs of the community (Alley et al., 2007), the major components of an aging-friendly community include: (a) community design, (b) adequate housing options, (c) a wide range of transportation choices, (d) access to health care and supportive services, and (e) opportunities for community involvement (Partners for Livable Communities and the National Association of Area Agencies on Aging, 2007).

The goal is to create communities across the United States that support their residents of all ages and allow people to achieve a high quality of life and an individually determined level of independence. This goal requires the involvement of individuals and organizations that have not traditionally engaged in long-term care policy debates. The creation of a truly aging-friendly community requires the dedication of policymakers, service providers, private businesses, and community residents of all ages and the development of new policies and practices at the local, state, and federal levels.

To date, there has been little research investigating the relationship between characteristics of an aging-friendly community and long-term care outcomes such as health, well-being, or reduced costs of care. Some local

governments, nonprofit organizations, and community advocates, however, are working to create more aging-friendly communities. For example, in Atlanta, the Atlanta Regional Commission's Lifelong Communities Initiative is working with local communities to achieve three primary goals: promote housing and transportation options, encourage healthy lifestyles, and expand information and access (Atlanta Regional Commission, 2008). Other aging-friendly community initiatives are in various stages of development in Boston; Charlottesville, Virginia; Boulder County, Colorado; and New York City.

In terms of the second goal, as described, the state of Oregon provides a model for improving the residual approach to long-term care. Oregon is showing that long-term care need not be restricted to a model in which services are provided in a hospital-like nursing home where social needs are subservient to medical needs, and dignity and independence are neglected in favor of safety and dependence. The Oregon Model provides a basic framework on which other states can build. The Oregon Model takes the promising practices of culture change, service integration, and community residential care and puts them into action. The major components of the Oregon Model include: (a) a single point of entry for all long-term care and aging services; (b) a single state agency or department responsible for funding and supervising all long-term care and aging services; (c) a combination of local, state, and federal funding for community residential care and other innovative forms of long-term care; and (d) active state involvement, such as through tax incentives and nursing home diversion policies, in the development of community residential care and other innovative forms of long-term care.

Most important, the Oregon Model provides an example of a state-planned long-term care system, rather than a cobbled together patchwork of services. This may be the most important lesson for policymakers and service providers as they attempt to anticipate the future needs of the older adult population. The federal government provided funding to Oregon to develop a comprehensive plan for the provision of long-term care back in 1980, and it took many years of demonstration projects, legislative debates, federal waiver applications, and other time consuming activities before that plan could be institutionalized. It is imperative that the federal government provide all states with the same opportunity, and that each state work with their local governments to develop and implement a comprehensive long-term care plan.

Both the creation of aging-friendly communities and the development of a comprehensive long-term care system will require federal and state funding at the same time that the government is facing a fiscal crisis. The government will be increasingly reluctant to provide financial support to programs and policies that have not yet been shown to reduce long-term care costs or improve the quality of care and quality of life of older adults. As highlighted, there is little research evidence for the effectiveness of

innovative long-term care programs, including the components of aging-friendly communities and the Oregon Model. Therefore, state agencies, local governments, and social service agencies should seek out federal waivers to pilot test innovative programs. On Lok, for example, pursued Medicare and Medicaid waivers as they were developing the PACE service integration model in the early 1980s (Zawadski, Shen, Yordi, & Hansen, 1985). Once On Lok demonstrated that they could provide quality care to frail older adults under capitated financing, they received additional waivers to replicate their model in sites across the county, and today PACE providers are eligible to become permanent Medicare and Medicaid providers. The policies and programs described in this analysis could potentially achieve the same level of success by following a similar path.

Developing long-term care policies that will lead to adequate and appropriate care for the growing number of older Americans is a daunting, but not impossible, task. Current long-term care policies evolved in a piecemeal fashion over the 20th century in response to demographic, regulatory, and policy changes. Future policies should be based on extensive planning and research, and involve the perspectives of a wide variety of stakeholders, including social workers, city planners, transportation providers, home developers, business leaders, and older adults. In addition, the future long-term care system must combine policies that aim to prevent the number of older adults requiring long-term care with policies that provide adequate social and medical support to those who need assistance.

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