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Home and Community-Based Services

A Synthesis of the Literature

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INTRODUCTION

Home and community-based services (HCBS) consist of a wide array of medical and social services which share the goal of helping people with disabilities live in the community and function as independently as possible for as long as possible (hcbs.org and Stone, 2000). These services include such long term care (LTC) services as home health care, personal care, homemaker services, adult day care, respite care, and assisted living. HCBS programs are financed by a mixture of State, Federal, and private funding sources, with Medicaid providing the bulk of the financing. Other public programs providing funding include the Older Americans Act (OAA), Medicare, Social Services Block Grant (SSBG), Rehabilitation Act funds, and State general revenues (Stone, 2000; Wiener and Tilly, 2003).

HCBS have grown in importance to the LTC system over the past two decades, and are increasingly used by older Americans (AARP, 2003; Polivka 1996). By 2002, Medicare and Medicaid HCBS LTC expenditures for those 65+ had grown to about \$18 billion (The Lewin Group 2003). In the coming years, it is likely that expenditures and utilization of home and community-based services will increase substantially for both demographic and policy reasons (Wiener, Illston and Hanley, 1994).

Demographic Trends

The demand for paid long-term care services, including HCBS, is largely a consequence of the prevalence of disability and the availability of informal care. The U.S. will become “gray” at a very fast pace. Although the proportion of the population over 65 actually declined slightly during the 1990s (US Census, October 2001), it is expected to rise as baby boomers reach age 65 (Kinsella & Welkoff, 2001). In 2000, people 65 years and older constituted 12.4 percent of the American population, and will reach 20 percent by 2030 (Gold et al., 1996). More than 4 million older people were over age 85 in 2000, and the numbers are likely to more than triple by 2040 (U.S. Census, October 2001; Federal Interagency Forum, Tilly, March 2001). This is the population most likely to need long-term care services. Older Americans will be mostly women, as their life expectancy has become significantly longer than that for men (US Census, 2002). Over time, the older population will also become more ethnically diverse, as non-Hispanic white populations decline from 84 percent to 64 percent of older people by 2050; the Hispanic population is expected to grow the fastest of any ethnic group (Administration on Aging, 2001; Federal Interagency Forum on Aging Related Statistics, 2000; U.S. Census Bureau, Sept. 2001, October 2001; Hobbs & Damon, 1996).

Estimates of the future rates of chronic disability among the growing older population are conflicting. Disability rates may be declining among those 65 or older. Manton and Gu (2001), for instance, found that in 1999 19.7 percent of Medicare beneficiaries 65 or older had difficulty carrying out at least one activity of daily living (such as bathing, dressing, toileting, transfer, continence, and feeding) or instrumental activity of daily living (such as preparing meals, shopping, managing money, using the telephone, doing housework and taking medication), down from 26.2 percent in 1982. Findings from the Survey of Income and Program Participation (SIPP) (Manton & Gu, 2001; National Institute on Aging, March 1999) and the Medicare Current Beneficiary Survey (MCBS) survey are consistent with these findings (Waidmann & Liu, 2000). Waidmann and Liu further suggest that if these trends continue, the ratio of

working-aged adults to disabled older people will not fall below current levels, even when the baby-boomers reach age 65.

These data may not be conclusive, however, because the different methods and definitions used by various surveys make estimates difficult to compare (Wiener et al., 1990). In particular, findings regarding self-reported ADLs are too mixed to support a consensus about declining disability rates, and the evidence regarding cognition is too limited to draw a conclusion (Freedman et al., 2002). There is also some concern that any decline in disability rates may also not continue in future generations, since rising rates of chronic disease among younger adults may lead to future cohorts of more disabled older people. One recent study which examined the National Health Interview Survey found that disability among 50-59 year old adults was on the rise, with asthma and diabetes the most likely causes (Lakdawalla et al., 2002).

The vast majority of care provided to people with disabilities is provided by informal caregivers—friends and relatives who provide care at no direct cost to the government. Despite a common perception that today’s families dump their disabled relatives into nursing homes, studies show that the vast majority receive informal, unpaid care from family, friends, or neighbors in the community setting (Spillman and Pezzin, 2000, Liu, et. al, 2000). An analysis of the 1994 National Long-Term Care Survey found that 78 percent of disabled elderly community residents relied exclusively on informal care (Spillman and Pezzin, 2000). Given today’s smaller families, the potential pool of family caregivers is not likely to keep pace with the growing need for care (Noelker, 2001). Greater education and work opportunities for women also have made informal caregiving more difficult to provide (Stern, 1995). Coupled with the growth of the older population, this potential decline in informal caregivers may lead to an increased demand for all types of formal long-term care, including HCBS.

Policy Interest in HCBS

From a policy perspective, creation of a more balanced long-term care delivery system by expanding home and community-based services is a major goal of the federal government and almost all states. Medicaid directed 73 percent of its LTC spending to institutional care in FY 2000, about \$49.4 billion. By FY 2002, this percentage had declined slightly to about 70 percent, but expenditures rose to about \$57.3 billion, leaving only about 30 percent, or about \$24.6 billion, for HCBS (Burwell, et al, 2003).

There are at least four rationales for expanding HCBS. First, older people strongly prefer HCBS to institutional care. In one study, 30 percent of older people indicated that they would rather die than move to an institutional setting, with an additional 26 percent ‘very unwilling’ (Mattimore et al, 1997). A 2003 study found that 81 percent of persons over 50 would prefer to avoid nursing home care even if they needed 24-hour care (AARP, 2003).

Second, community-based, disabled older people have substantial unmet needs for personal care and other HCBS services. This often leads to higher rates of adverse events, including discomfort, weight loss, dehydration, falls, burns, skin problems, missed meals, inability to follow special diets, missing doctor visits, and having to wear dirty clothes (Mitchell et al., 2004), factors that affect both quality of life and costs for the LTC populations.

Third, a key element in the preference of older people for HCBS is the assumption that it is superior in quality to institutional care. Numerous studies have cited substandard care in nursing homes (Institute of Medicine, 2001, U.S. GAO, 1998, 1999a, 1999b, 2000). In particular, people associate the ability to stay in their homes through HCBS with retention of independence and control over care decisions (AARP, 2003). However, remarkably little data is available about the quality of HCBS.

Fourth, and finally, a common element in policy makers' preferences for HCBS is the assumption that it is a less costly way of providing long-term care. Thus, the presumption is that HCBS can better meet the preferences of people with disabilities while achieving savings for States and the Federal government. As will be discussed below, however, the research literature in this area is less supportive of this contention than is commonly assumed.

The movement towards more HCBS programs has been further bolstered by the 1999 ruling of the U.S. Supreme Court in *L.C. & E.W. vs. Olmstead*, in which the court stated that "confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment" (*Olmstead v. L.C.*, 521 U.S. 581, 119 S.Ct.2176). Interpreting the Americans with Disabilities Act, the court ruled that states must make reasonable modification in their HCBS programs and activities to make these services available to those with disabilities. (Coleman, 2002) Although this right is not unlimited and may be bound by state fiscal limits, consumer advocacy groups across the country have used the court's decision to push for more HCBS (Wiener et al., 2000).

Paper Overview

The purpose of this paper is to review and summarize the vast research literature on HCBS in order to distill what is known and not known. To achieve that object, this paper is divided into three remaining sections. The first section presents background on home and community-based services, examining financing and utilization of services. The second section examines a number of themes on topics of importance in home and community-based services, including the workforce, quality of care, cost savings and cost effectiveness, substitution of formal for informal care, capitated approaches to HCBS, assisted living, consumer direction, assistive technology and caregiver support. The paper focuses on research that has been published in peer-reviewed journals, but includes other research when the importance of the material warrants it. Finally, the paper concludes with a proposed research agenda for HCBS.

BACKGROUND

Financing HCBS

The main sources of public funding for HCBS are Medicaid, Medicare, the Older Americans Act, the Social Services Block Grant and state and local programs. Table 1 shows the distribution of HCBS expenditures by funding source.

Table 1
Financing for Long-Term Care for Older People, 2002 (in billions)

	<u>Nursing Homes</u>	<u>Home and Community Based Services</u>	<u>Assisted Living Facilities</u>	<u>Totals</u>
Medicare	13 ^a	11.3 ^a	---	24.3
Medicaid	35.2 ^a	6.3 ^a	1 ^d	42.5
Administration on Aging	---	1.1 ^b	---	1.1
State-funded	---	1.1 ^c	---	1.1
LTC Insurance	1.4 ^d	0.3 ^d	0.5 ^d	2.2
Out-of-Pocket	18.3 ^d	1.6 ^d	7.7 ^d	27.6
Totals	67.9	21.7	9.2	98.8

^a Expenditures from The Lewin Group, Benchmarking the Long-Term Care Financing Model December 19, 2003

^b AoA FGS FY2002 Annual Allocation. Accessed at http://www.aoa.gov/about/legbudg/current_budg/doc/FGS_FY_2002_Annual_Allocation.pdf

^c AARP Public Policy Institute, State-Funded HCBC Programs for Older People, forthcoming 2004

^d LTC Financing Model projections from The Lewin Group, Benchmarking the Long-Term Care Financing Model, December 19, 2004

Medicaid

Medicaid was established to cover health care expenses for the poor and has become the single largest payer of LTC services (Stevens and Stevens, 1974; Senate Special Committee on Aging, 2002). Medicaid is jointly funded by the federal and state governments, with much of the policymaking done at the state level. In addition to the Federally-mandated services, each state program may cover optional services reflective of variations in the state's demographics, economics and political philosophies (Coleman, 2002). Medicaid spending on long term care services in FY 2002 totaled \$82.1 billion, including \$24.7 billion for HCBS for persons of all ages, about 30 percent of all Medicaid long-term care expenditures (Burwell et al., 2003). The percentage of Medicaid expenditures for HCBS varies widely by state.

While states must cover home health care, they can limit the amount, duration and scope of services. States may also offer a number of optional HCBS, including personal care, case

management, and adult day care (as a clinic service) as part of the regular Medicaid program (Smith et al., 2000, Wiener and Tilly, 2003).

Since 1981, states have been able to apply for home and community-based services waivers, which allow states to provide a wide range of services not otherwise covered (Smith et al., 2000, Wiener and Tilly, 2003). States must limit eligibility for the waivers to persons who need an institutional level of care. While a state plan Medicaid benefit must be in effect throughout an entire state (i.e., the amount, duration, and scope of coverage must be the same statewide), home and community based services (HCBS) waivers may target their offerings to selected groups and not offer all services covered under the waiver to all beneficiaries in the state. Under the waiver authority, states are allowed to provide services not usually covered by the Medicaid program if these services are required to keep a person from being institutionalized; case management, homemaker, home health aide, personal care, adult day health, habilitation, and respite care are specified in federal law as options. In addition, the Secretary of HHS is also authorized to approve other services requested by the state. Day treatment or other partial hospitalization services, psychosocial rehabilitation services, and clinic services (whether or not furnished in a facility) for individuals with chronic mental illness were added to the options in the late 1980s. These waiver programs are widely used, with expenditures of \$16.3 billion in FY 2002 (Eiken and Burwell, 2003). Under the waiver, states may provide Medicaid coverage to people with incomes up to 300 percent of the federal Supplemental Security Income level, which is the institutional eligibility level in many states. Waiver programs must be budget-neutral, with average Medicaid expenditures for beneficiaries no greater than they would have been without the waiver (Smith et al., 2000, Wiener and Tilly, 2003). In practice, the relevant comparison group for older people is Medicaid beneficiaries in nursing homes.

Medicare

Medicare was established to cover the acute care and short-term post-acute care needs of older people and some younger people with disabilities. Along with a limited amount of skilled nursing facility care, a medically-related home health care benefit is included in its benefits. Medicare home health is available to homebound beneficiaries who need intermittent or part-time skilled nursing or rehabilitation services (Wiener and Tilly, 2003; Gage, 1999).

While Medicare home health has historically provided short-term, post-acute skilled care, its role in LTC increased in the 1990s. As a result of relaxation of some of the Medicare coverage rules, Medicare home health utilization and expenditures skyrocketed, increasing at an annual rate of 29 percent between 1990 and 1995 (Prospective Payment Assessment Commission, 1996). Much of this increase was due to a large increase in the use of home health aide services (Ibid). Part of this growth also was due to state efforts to maximize Medicare reimbursement for home health, thus reducing Medicaid costs (Anderson, Norton and Kenney, 2003; Anderson, Kenney and Rabiner, 2003; Anderson, Norton and Dow, 2003; Kenney and Rajan, 2000; Kenney, Rajan and Soscia, 1998). Expenditures dropped by almost half immediately after the implementation of the Balanced Budget Act of 1997, which imposed an interim payment system as part of a transition to a prospective payment system (Knickman & Snell, 2002; Gage, 1999). With the implementation of the new prospective payment system, expenditures have increased again, reaching \$8.6 billion in 2001 (Cotterill and Gage, 2002; MedPAC, 2003).

Older Americans Act

The Older Americans Act established programs to promote the dignity and independence of older people, and to provide assistance and services to older individuals and their families through an Aging Network. The Aging Network consists of 56 State Units on Aging, 655 Area Agencies on Aging, 244 Tribal and Native organizations, and two organizations serving Native Hawaiians. These agencies receive federal funding for HCBS programs targeted to persons 60 and over, ranging from \$5.4 million in a number of states to \$104.7 million in California in FY 2002 (Wiener and Tilly, 2003, AoA, FGS 2002). Aging Network activities include information and referral services, nutrition programs, and social, volunteer, and legal services for older people. At the state and local levels, State Units on Aging and Area Agencies on Aging may also administer and coordinate programs funded by Medicaid, the Community Service and Social Service block grants, and programs supported by state and county general revenue funds, ranging from a single service, such as respite care, to a whole range of services, such as adult day care, adult foster care, meals, information and assistance, and service coordination (Gage et al., 2004(a); Kane et al., 1998). Aging network members also advocate on behalf of older persons at the state and local level (Wiener and Tilly, 2003).

Other OAA initiatives have been targeted to caregivers. The National Family Caregiver Support Program and the Alzheimer's Disease Demonstration Grants to States Program were created in 2000 to encourage the states to support informal caregivers by providing funding to the states to develop support systems for family caregiving (Feinberg et al., 2002). States who received these grants have established support activities, such as intensive case management services, voucher support, respite workers, day care facilities, with outreach to minority caregivers in rural and urban settings (Schulz, 2000).

Social Services Block Grant

Social Services Block Grant funds received by the states may be used for a wide range of social services, including LTC. There are no guidelines for spending these funds, and the proportion directed to LTC is unknown (Wiener and Tilly, 2003).

State Programs

States and counties may also fund HCBS services, and many do this. Wisconsin, for instance, operates a Community Options Program, which gives the state the option to cover services beyond those approved by Medicaid (Wiener and Lutzky, 2001). States may fund services through local public agencies, health and welfare departments, nonprofit organizations, or through the agencies of the Aging Network (Kane et al., 1998). Recent estimates suggest states contribute at least an additional \$1.1 billion to support state funded community services. (AARP, 2004).

Utilization of HCBS

Home care services can encompass both home health care (usually confined to skilled care) and a broad range of non-medical services. Services include personal care, homemaker services, adult day services, case management, respite services, skilled nursing care,

home-delivered meals, and companionship services. An analysis of the Medical Expenditure Panel Survey for 1998 found that approximately 12 percent of the older population used at least one home care service (AARP, 2003). There is, however, considerable variation across groups in the use of home and community-based services.

Cultural and Demographic Factors

Cultural and demographic factors which may affect the disabled elderly use of paid home care services include age, gender, race, residence in an urban or rural area, education, and access to informal supports. All these factors have been shown to have some influence in various studies, though none has emerged as having a consistent effect (Hanley et al., 1991). Nonetheless, a recent analysis of the Medical Expenditure Panel Survey for 1998 found that use of home care increased sharply with age (Table 2) (AARP, 2003).

Table 2
Use of Formal Home Care Services by Age, 1998

<u>Age</u>	<u>Number of persons</u>	<u>Percent of Population Segment</u>
65-74	970,000	5
75-84	1.9 million	16
85+	1.0 million	28
Total 65+	3.87 million	12

SOURCE: Project Hope analysis of 1998 MEPS for AARP Public Policy Institute as published in: AARP "Beyond 50: A Report to the Nation on Independent Living and Disability," Washington, DC 2003

One reason that usage of HCBS services increases with age may be that as people age they are less likely to have informal helpers such as spouses, adult children, or even parents to provide assistance. At older ages, one is more likely to have lost a spouse to death or divorce or to have a spouse who is unable to provide assistance (AARP, 2003). The AARP study also found that gender played a role, with women age 50 and older more likely than men to use home care services.

Disability and Health Factors

The impact of disability and poor health on long term care is generally measured by Activities of Daily Living (ADLs), such as bathing or dressing, and Instrumental Activities of Daily Living (IADLs), such as housekeeping or managing money. Another important factor is cognitive impairment. Several studies have shown that the likelihood of using home care increases with disability. ADL limitations and being cognitively impaired appear to be the most significant factors (Hanley et al., 1991). Another study found that those who needed assistance with mobility were more likely to be in HCBS until they were completely unable to move

without assistance, while those with cognitive problems were less likely to be in the HCBS population (Borrayo et al., 2002). Among persons with only IADL problems, 26 percent of the population was using home care services in 1998 compared to 48 percent of the population with ADL problems (AARP, 2003).

Gender and access to informal supports may also interact with disability and health factors (Borrayo et al., 2002). For instance, while in general those with chronic disease are found in HCBS rather than institutional care, women with chronic diseases are more likely than men to be in nursing care than assisted living, and as likely to be in nursing care or assisted living as in HCBS care. Among those with severe cognitive impairment, whites are more likely than minorities to use HCBS. Those not married and with more chronic disease are less likely to be in assisted living than HCBS, but those not married with severe cognitive impairment or ADL deficiencies are more likely to be in nursing home care than HCBS

Economic Factors

People with greater financial resources are more able to pay for formal home care, but studies have been mixed on the impact of income on increasing home care usage (Hanley et al., 1991). Medicaid and other public programs targeting lower income individuals may give them better access (Borrayo et al., 2002). For example, in 1998, 33 percent of home care users were in the lowest income quartile; only 14 percent of users were in the top income quartile (AARP, 2003) (Table 3).

Table 3
Use of Formal Home Care Services, Age 65+, by Income

<u>Income Quartile</u>	<u>Percentage of Formal Home Care Service Users</u>
Lowest 25%	33%
Middle 50%	54%
Top 25%	14%

(Percentages do not equal 100% due to rounding)

SOURCE: Project Hope analysis of 1998 MEPS for AARP Public Policy Institute as published in: AARP "Beyond 50: A Report to the Nation on Independent Living and Disability," Washington, DC 2003

THEMES IN HOME AND COMMUNITY-BASED SERVICES RESEARCH

Workforce

Paraprofessional long-term care workers, such as certified nurse assistants, home health aides and personal care attendants, are the backbone of the formal long-term care delivery system, providing the majority of paid assistance to people with disabilities. These "frontline" workers help people by assisting with activities of daily living, such as eating, bathing and dressing, and instrumental activities of daily living, such as medication management and meal preparation. The central role of these workers in providing "hands on" services makes them the key factor in determining the quality of paid long-term care (Stone and Wiener, 2001).

Defining the Problem

Researchers have identified at least three broad problems facing the long-term care direct care workforce. First, it is difficult to recruit and retain long-term care workers. In 2002, 37 states reported that direct care shortages were a "serious workforce issue" (Harmuth and Dyson, 2002). Home care turnover and vacancy rates are believed to be lower than for nursing homes, but still substantial. For example, annual home health aide turnover in Ohio ranged from 40 to 76 percent in the late 1990s (Straker and Atchley, 1999). Many individuals trained to provide long-term care do not stay in the industry. For example, in North Carolina, less than half of the individuals trained as certified nurse assistants over a ten year period were still working in this occupation at the end of the decade (Konrad, 1999). As a result of high turnover and vacancy rates, providers incur substantial recruitment and training costs (Leon, Marainen, and Marcotte, 2001; Pillemer, 1996; Atchley, 1996; White, 1994).

Second, the quality of long-term care services is likely compromised by the vacancies, high turnover and low-levels of training of long-term care workers. High turnover also means that continuity of care is reduced, with staff not having time to get to know the needs and preferences of individual consumers. Workers who are providing care in understaffed environments may experience high levels of stress and frustration, which may lead to high turnover and poor quality of care. The empirical literature, however, is weak in actually documenting these relationships.

Third, the low status of direct care jobs has negative implications for job satisfaction. Paraprofessional long-term care workers receive low wages and are often poor. Median earnings of personal and home care aides were only \$7.50 per hour in 2000. Because of the times when care is needed, many home care aides can only work part-time, further reducing their earnings. In addition, these workers have low rates of health insurance coverage and access to pension plans (Yamada, 2002; Crown, Ahlburg and MacAdam, 1995). In Los Angeles County, California, 45 percent of home care workers were uninsured in 2000 (Cousineau, Regan and Kokkinis, 2000). It is often argued that the low compensation package makes it hard to recruit and retain workers.

A final aspect of workforce satisfaction problems is that almost all of these long-term care jobs lack career ladders, making any job advancement unlikely. These direct care occupations are classic “dead-end jobs.” The lack of career ladder and respect derive, in part, from the fact that most paraprofessional long-term care workers have low levels of education and relatively little training (Yamada, 2002).

Interventions

There is a substantial research literature on interventions to address the problems of the HCBS workforce. However, most of this literature is descriptive, rather than evaluative (Stone and Wiener, 2001). These interventions can be grouped into four broad categories—recruitment, extrinsic rewards, training and career ladders, and organizational culture.

Recruitment - One strategy to address the workforce problems is to focus on the front-end of the process--finding and recruiting workers. Currently, we know little about what attracts workers to the long-term care field, other than the fact that many are drawn by their desire to help people (Pindus, Dyer, Ratcliffe, Trutko, and Isbell, 1997). This general approach includes public service announcements, worker registries, and advertisements designed to improve the image of long-term care as a career. One strategy that focuses on recruitment is to expand the labor pool from which workers are drawn by specifically targeting certain groups for recruitment to direct care jobs. Various interventions have sought to target older workers, family members, students, welfare beneficiaries, and immigrants (Stone and Wiener, 2001). For example, in 2002, four states reported welfare-to-work initiatives for long-term care occupations (Harmuth and Dyson, 2002). In many states, consumer-directed home care programs have allowed clients to choose family members, neighbors and other non-agency people as caregivers. A high percentage of clients choose family members to be their caregivers (Tilly and Wiener, 2001).

Extrinsic Rewards - Proposals to increase “extrinsic rewards,” such as wages and fringe benefits make a straightforward economic case. The argument is that better worker compensation packages and career opportunities could help draw marginal workers into the labor force. In addition, increases in the compensation of long-term care staff relative to other low-wage workers could reallocate the available low-wage workforce to long-term care (Holzer, 2001). To implement this approach, 20 states have adopted “wage-pass-throughs” for direct care workers over the last few years, where Medicaid or other public payment rate increases are earmarked to raise wages for long-term care staff (Harmuth and Dyson, 2002; and, North Carolina Division of Facility Services, 2000). However, the cost implications for public programs of rate increases may make even small wage increases difficult to implement at this time of fiscal crisis. (Ross and Cox, 2003). While standard economic theory would predict that increased wages and fringe benefits would reduce employee turnover, there is a lack of empirical research on this topic.

Training and Career Ladders - Several states are exploring the development of new career and training options for frontline workers (Harmuth and Dyson, 2002). States are developing new job categories, expanding the scope of duties under existing categories, and developing career ladders for direct care workers. For example, as part of a comprehensive, multi-year workforce strategy, Massachusetts has created an “extended care career ladder initiative” to support the development and implementation of career ladder programs using innovative caregiving and workplace practices. As part of their Systems Change Grants, a large

number of states, including Montana, Kentucky, North Carolina, Georgia, New Jersey, Oregon, Wisconsin, Arkansas, Arizona, Minnesota and Nevada are developing training materials for direct-care workers.

Organizational Culture - Initiatives to change organizational culture focus on such factors as the values that determine organizational behavior, the relationships among internal and external stakeholders, traditions, what is rewarded and punished in the organization, and the norms of behavior. The underlying hypothesis is that while extrinsic rewards may draw individuals into an organization to work, it is the satisfaction that they receive while on the job (i.e., the organizational culture) that causes them to remain (Bowers, 2002). A number of provider initiatives seek to change organizational culture by involving workers in decisions, empowering workers, providing more feedback and autonomy, and offering more ongoing training, but most have focused on nursing homes rather than HCBS (Stone, Reinhard, Bowers, Zimmerman, Phillips, Hawes, Fielding, and Jacobson, 2002; Reinhard and Stone, 2001; Thomas and Stermer, 1999; Barba, Tesh, and Courts, 2002).

Quality of Care

In light of increasing demand for HCBS services and rising public expenditures for them, high quality assurance for home and community-based care is increasingly important. Although people who use home care typically report high levels of satisfaction (Geron, 1996; Benjamin, 1998; Kane and Huck, 2000; Weissert et al., 1990; and, Montgomery and Kosloski, 1995), measuring and assuring quality of care in the HCBS setting is at a fairly early level of development, especially compared to nursing home care.

Federal/State Allocation of Responsibility

While the federal government sets standards for regulating home health agencies that participate in Medicare and Medicaid, states are almost completely responsible for regulating the quality of care provided by assisted living and home care agencies (GAO, 2003). Medicaid HCBS waiver services are somewhat more rigorously monitored as federal rules require states to have a quality assurance plan as part of these programs, but the content of those plans is left up to each state (Smith et al, 2000). However, in a review of Medicaid waiver programs for older people, GAO (2003) contended that there were quality problems in many of them. The Centers for Medicare and Medicaid Services introduced a new protocol in 2000 to assess state Medicaid quality assurance plans to assure that states fulfill basic procedures in assuring quality of care (Centers for Medicare and Medicaid Services, December 20, 2000).

Most states have modest quality assurance activities, and rely heavily on informal mechanisms to assure quality (Wiener, Tilly, and Alecxih, 2002). Case managers typically play a key role in quality assurance. In addition to developing service plans and arranging for and ensuring that providers deliver services, case managers monitor the quality of services, respond to complaints, and take action to resolve the problems with agencies and their workers. While most states have entry-level training requirements for paraprofessional workers and some level of criminal background check to weed out potentially abusive providers, not all states do, and most training requirements are minimal (Institute of Medicine, 2001).

Some states are conducting innovative quality assurance activities. For example, Wisconsin, Indiana, and Alabama, conduct consumer satisfaction surveys (Wiener and Tilly, 2003). The Family Care Program in Wisconsin is measuring outcomes through consumer interviews as well as site reviews (Alexih et al, 2003). In most consumer-directed programs, states consider the consumer who hires and fires the worker to be primarily responsible for quality assurance. In 2002, Delaware took legislative action to spell out staffing standards, permissible services and prohibited practices for home health care agencies. Rhode Island requires quality assurance programs for assisted living facilities (Coleman, et al, 2002).

Measuring Quality of Care

Developing standards for and measuring quality of HCBS is difficult, partly because of the special characteristics of HCBS (Wiener and Tilly, 2003). First, HCBS covers a very large number of disparate services—from highly technical, medical services to nonskilled homemaker services. Thus, some standards that would make sense for some services do not apply to others. Second, by definition, HCBS take place in large numbers of physically dispersed locations, making data collection difficult and expensive. Third, it is an open question as to the extent that providers should be held accountable for adverse client outcomes given that most home care workers spend only a limited amount of time in a consumer's home, unlike the situation in nursing homes (Kane et al., 1994). Fourth, satisfaction measures are poorly developed and collecting data from persons with cognitive impairments is difficult and expensive to do adequately. Fifth, states are reluctant to establish detailed standards for HCBS because they fear replicating the rigidity of the nursing home setting.

The earliest protocols for needs assessment in the community-living elderly concentrated on measurements of ADLs and IADLs. One of these, the Older Americans Resources and Services Multidimensional Functional Assessment, is widely used for community residing elders (Pfeiffer, 1975). Recent efforts in this area have concentrated on measuring quality outcomes, as opposed to structure, process or enabling indicators. An Adequacy of Care approach for home care builds on ADL and IADL measurement to obtain responses from professionals and care recipients regarding how well needs are met, although the ratings are subjective (Morrow-Howell et al, 1998). A more recent approach is the Quality of Circumstance protocol. This instrument seeks to quantify the immediate outcomes of personal assistance services, measuring impacts on such areas as safety, autonomy, and privacy as well as ADLs and IADLs (Caro, 2000).

Cost Savings and Cost Effectiveness

One of the common rationales for expanding home and community-based services is that it will cost less than the current financing and delivery system, which depends heavily on nursing home care. During the 1960s, 1970s, and 1980s, over 30 demonstrations were conducted and evaluated, often using very rigorous, randomized controlled trials to assess the effects of expanding home and community-based services. Most demonstrations provided case management and a range of services not otherwise offered by public programs, principally

Medicaid. The largest, best known and most extensively evaluated of these experiments was the Channeling demonstration in the early 1980s, which was sponsored by the U.S. Department of Health and Human Services (Kemper, 1988).

Several reviews of this literature have found that expanding home and community-based services does not reduce aggregate long-term care expenditures, although average per consumer costs are less than nursing home care in many studies (Kemper et al., 1987; Kane and Kane, 1987; Weissert et al., 1988; Wiener and Hanley, 1992; and Weissert and Hedrick, 1994). In fact, in most studies, expanding home and community-based services increased rather than decreased aggregate spending. For example, in the Channeling demonstration, the demonstration group that received additional home and community-based services had 18 percent higher expenditures than the control group (Thornton, Dunston and Kemper, 1988).

Older people's aversion to nursing homes explains this increase. Given a choice between nursing home care and no formal services, many older people will choose no formal services. But when the choice is expanded to include home care, many people will choose home care. Moreover, with few exceptions, demonstrations did not successfully target people with a high risk of institutionalization.¹ People receiving home and community-based services in the demonstrations would not have entered a nursing home without the services. In sum, the costs associated with a large increase in home care users more than offset relatively small reductions in nursing home and hospital use. An important methodological consequence of these findings is that overall expenditures can increase (because of higher home care utilization) even when average costs per person are lower than institutional care.

Since the mid-1980s, relatively few studies have been conducted on this topic. Most of the more recent studies have reanalyzed earlier data or have used far less rigorous methods than the earlier studies. A reanalysis of the Channeling data using a mathematical optimization procedure found that better screening and heavier use of more medical services might have resulted in cost savings (Greene, Ondrich, and Laditka, 1998; Greene et al., 1995; and Greene, Lovely and Ondrich, 1993). In a study of Oregon, Washington, and Wisconsin, the U.S. General Accounting Office (1994) found that average per person expenditures for nursing home care exceeded average expenditures for Medicaid home and community-based services waiver beneficiaries, even when Supplemental Security Income expenditures were included. However, the analysis did not address total spending, only average expenditures. In an application of simple simulation techniques, Alexih et al. (1996) analyzed long-term care expenditures in three states that had expanded home and community-based services--Colorado, Oregon and Washington. The study compared estimates of what long-term care expenditures would have been had the states not changed the balance between institutional and noninstitutional care and actual long-term care expenditures, controlling for a variety of factors. Although their projections are open to challenge, they found cost savings in all three states based on this comparison.

From 1989 to 1994, another large randomized, control trial demonstration studied the effect of case management services and a special Medicare community care service benefit on persons with Alzheimer's disease. The intervention had little or no effect on nursing home entry

¹ One exception was the South Carolina Long-Term Care Project (Capitman J, Haskins B, and Bernstein J, 1986).

rates, and treatment group members as a group were not found to have lower Medicare Part A expenditures than control group members of comparable health status. While some savings were observed for Medicare Part B expenditures these were more related to treatment site than to service level (Newcomer et al., 1999a, Miller et al., 1999, Newcomer et al., 1999b, Newcomer et al., 1999c).

Although the existing research literature consistently suggests that home and community-based services do not save money, many observers argue that the relevance of these findings to the current environment is limited. They note that the research is based on old data, almost all of which was collected at least 20 years ago. Over the last two decades, long-term care has changed dramatically and states have learned a great deal about how to efficiently manage home and community-based services. For example, a variety of new services with a cost savings potential, including assisted living facilities and consumer directed home care, are now available. Most importantly, the increasing dominance of Medicaid home and community-based waivers has probably increased the potential for cost savings. These waivers encourage states to target a more severely disabled population with a higher risk of institutionalization, place a cap on average expenditures for persons receiving waiver services, and cover a wide range of lower-cost services (Wiener and Tilly, 2003). No methodologically rigorous recent research, however, has empirically tested how these changes affect the cost-effectiveness of changes in home and community-based services.

In light of strong support among advocates, policymakers and older people for the expansion of community-based alternatives to nursing home care, future research should focus on assessing the relative cost-effectiveness of various strategies for providing community-based care. The organizing objectives of this research should be the generation of cost and outcome information that policy makers can use in making decisions about the most efficient allocation of resources for the expansion of home and community-based programs. Outcome measures used in these future studies should include relative levels of nursing home use, quality of care and quality of life (consumer preferences and satisfaction) indicators.

Substitution of Formal for Informal Care

A concern of policy makers is the potential impact of paid HCBS care on the level of informal caregiving by family and friends. Some officials fear that formal services would discourage informal care providers and substitute for rather than supplement their efforts (Shanas, 1979). A companion belief is that providing formal care would undermine self-reliance and the values of personal responsibility which underlies the emphasis on family and personal responsibility in long term care (Penning, 2002). The implications of such a substitution are vast, with the value of informal caregiving in the U. S. estimated be \$257 billion in 2002 (Arnol., 2002).

Limits on the Availability of Informal Care

Although informal care still accounts for the overwhelming majority of long-term care, its provision has declined somewhat in recent years (Spillman and Pezzin, 2000). For those people with disabilities who have potential family caregivers, the proportion who actually received family informal care declined from 78.7 percent in 1984 to 71.9 percent in 1994

(Spillman & Pezzin, 2000). Personal, demographic and economic factors encourage these trends.

Caregiving can be an arduous responsibility. Depressive symptoms are twice as common among caregivers as among the general population; over half of all caregivers reported that their caregiving responsibilities have a negative impact on other aspects of their lives, and one third of those helping the most impaired older people experience physical or mental health problems (The Henry J. Kaiser Foundation, 2002). Half of all informal caregivers find caregiving to be “frequently” or “sometimes” too much to handle and almost a quarter report feelings of isolation that are “sometimes” or “frequently” too much to handle. Many caregivers also complain of emotional stress in addition to the physical and financial pressures (Bethell, et al., 2002).² These pressures are particularly high for caregivers of people with Alzheimer’s disease (Schulz, 2000).

Demographic and economic issues are also a factor. Women have been more likely than men to serve as caregivers (Johnson and Lo Sasso, 2000a), and the availability of education and work opportunities for women has increasingly led them to jobs outside of the home (Stern, 1995). Employment among married women rose from 36 percent of those ages 45 to 64 in 1960 to 65 percent in 1997 (Johnson and Lo Sasso, 2000b). A recent analysis found that for adult children aged 53-65 engaged in substantial informal care, women cut back their hours of paid work by 43 percent and men cut back their hours of paid work by 43 percent (Johnson and Lo Sasso, 2000a).

The Impact of Formal HCBS Care on Informal Care

The research literature is mixed on the issue of the impact of formal care on informal care. However, the bulk of the research literature suggests that the overall level of informal caregiving does not decline significantly when formal HCBS are provided, or if it does fall, the amount of the decline is small (Hanley, Wiener and Harris, 1991; Penning and Keating, 2000; Penning, 2002). For example, using Channeling data, Christianson (1988) found that informal care declined after paid home care was provided, but the reduction was not large and concentrated among neighbors and friends rather than family members.

More recent studies in Canada are consistent with these findings. A 2001 economic analysis of continuing care in Alberta from 1991-1995 found that formal and informal care rose at almost exactly the same rate among care recipients, and that the presence of formal resources encouraged the provision of informal care (Fassbender, 2001). A study of care recipients in 1997 found no evidence that use of greater formal HCBS care was associated with less use of informal care (Penning, 2002). This was true for both the sample as a whole and for users of publicly and privately provided care.

Capitated Systems of HCBS

People with disabilities currently receive care in a splintered and uncoordinated financing and delivery system (Wiener and Skaggs, 1995; Wiener, 1996; Leutz, Greenlick and Leutz, Greenlick, and Capitman, 1994). Financing for acute care is largely the responsibility of Medicare and the federal government, while long-term care is dominated by Medicaid and state governments. Within long-term care, financing comes from a variety of sources, including

² These statistics relate to caregivers in general and are not limited to caregivers of the elderly.

Medicare, Medicaid, the Older Americans Act and a number of state-funded programs. In terms of service delivery, fragmentation exists both within and between the acute care and long-term care systems.

Because of the growing awareness of the inadequacies of the current system, there is increasing policy interest in finding ways to integrate the acute care and long-term care or just long-term care services and financing into a single system (Rudolph and Lubitz, 1999). Almost all of these initiatives depend on managed care to achieve this integration. Under these models, capitated organizations (i.e., they receive a per capita payment) have financial incentives to avoid both the functional decline that can result from unmet needs and the unnecessary costs associated with providing services in needlessly expensive settings. The hypothesis is that this coordinated approach will produce savings in acute care because lower cost long-term care services will substitute for more costly hospital and physician services and that home care will substitute for more expensive nursing home care (Leutz, Greenlick and Capitman, 1994).

A number of demonstrations or pilot programs are under way to test various approaches to integrating financing and services through managed care (Rudolph and Lubitz, 1999). The best known and most extensively researched of these projects are the Social Health Maintenance Organizations (S/HMOs), the Program of All-inclusive Care of the Elderly (PACE) and the Arizona Long-Term Care System (ALTCS), but other examples include Texas' STAR+PLUS program, the Minnesota Senior Health Options (MSHO), New York's Medicaid Long-Term Care Capitation Program, and Wisconsin's Family Care program (Rudolph and Lubitz, 1999; Kane et al, 2003; Liu et al, 2001; and Alexih et al, 2003).

Social HMOs extend the traditional concept of HMOs by adding a modest amount of long-term care to the benefits covered (Leutz, Greenlick and Capitman, 1994; Harrington and Newcomer, 1991). Nursing home and home care coverage, while generally available from Medicare HMOs, is limited. A coordinated case management system authorizes long-term care benefits for those who meet the established eligibility criteria. Social HMOs are intended to serve a cross section of the older population, including both functionally impaired and unimpaired people. While all enrollees are eligible for Medicare, relatively few Medicaid beneficiaries are enrolled. After the original four-site demonstration, Congress authorized a "second generation" of demonstrations that are designed to provide more extensive long-term care benefits and to have more of a "geriatrics" orientation (Kane et al, 1997). Only one second generation site has started (Newcomer, Harrington and Kane, 2002).

Social HMOs do not appear to have had a dramatic impact on the care of the older people enrolled in the programs. Although the findings were contested by the demonstration sites, the degree of integration of acute and long-term care achieved appears to have been limited (Harrington, Lynch and Newcomer, 1993; Leutz, Greenlick and Capitman, 1994). There was enormous variation in financial performance as well as utilization of both acute and long-term care services across demonstration sites (Harrington and Newcomer, 1991). For the first year of full risk, two of the sites had expenditures that were higher than the fee-for-service system and two sites had expenditures that were lower than the fee-for-service system (Newcomer et al., 1995). Not surprisingly since Social HMOs covered these services, nonskilled home care expenditures in all sites was higher than in the fee-for-service system in all sites.

PACE also provides a comprehensive set of acute and long-term care services in an integrated financing and service setting (Eng et al., 1997). It replicates the On Lok program in San Francisco. While Social HMOs target a broad range of people with and without disabilities in order to pool risk, enrollment in PACE is limited to people who are disabled enough to meet nursing home admission criteria. Because expenditures per person are so high, very few people can afford to pay an actuarially fair premium. As a result, almost all enrollees are dually eligible for Medicare and Medicaid. PACE sites operate as geriatrics-oriented, staff model HMOs, with primary care physicians as employees of the organization. A hallmark of the program is heavy use of adult day health programs, which are integrated with primary care.

A CMS-sponsored evaluation of PACE found that the program had positive effects on enrollees, although the external validity of the findings may be limited by the fact that enrollees and the comparison group were not randomly assigned (Chatterji et al, 1998). Compared to people who qualified for PACE but decided not to enroll, PACE enrollees had fewer hospital admissions, hospital days and nursing home days. PACE enrollees also had short-run improvements in quality of life, satisfaction with care, and functional status. Moreover, PACE enrollees lived longer and spent more days in the community.

In terms of expenditures, the evaluation also found that in the initial year after enrollment, the PACE capitation payments were a savings for the Medicare program, but additional costs for Medicaid (White, 1998). Combined Medicare and Medicaid PACE capitation payments in the first year after enrollment were roughly 4 percent higher than fee-for-service expenditures, after excluding two nonrepresentative sites.

The Arizona Health Care Cost Containment System (AHCCCS) is a statewide demonstration project that finances medical services for the Medicaid population through prepaid contracts with providers (McCall, 1996). Beginning in 1989, the Arizona Long-Term Care System (ALTCS) program incorporated Medicaid long-term care services into the AHCCS program (Weissert et al., 1997). Arizona is the only state to provide for capitated acute and long-term care services on a statewide basis. Participation is limited to individuals who are certified to be at risk of institutionalization. ALTCS covers Medicaid acute care services (but does not include Medicare payments), as well as nursing facilities, intermediate care facilities for the mentally retarded, and home and community-based services. Under the ALTCS model, the state contracts with one entity in each county to assume responsibility for covered services to eligible elderly and physically disabled people. In the overwhelming majority of cases the contractor for older people and persons with physical disabilities is the county government.

An evaluation of potential cost savings from ALTCS found that the program appeared to save the Medicaid program money, although the synthetic estimates of what expenditures would have been in the absence of the program are open to criticism (Weissert, 1997). The use of home and community-based services was cost-effective in the view of the evaluators. The researchers attributed the findings to limiting eligibility to people at a high risk of institutionalization, a capitation payment methodology that forced managed care contractors to hold down average HCBS costs, and the blending of HCBS and nursing home costs in the capitated rate so that plans that failed to place clients in HCBS and used more nursing home care than the capitation rate allowed would lose money.

While Social HMOs, PACE, and ALTCS seek to integrate acute and long-term care services and financing, Wisconsin's Family Care Demonstration focuses solely on integrating long-term care, including both a wide range of home and community-based services and institutional care (Alecxi et al., 2003; Justice, 2003). Operating in five counties, Family Care has two major components—aging and disability resource centers and care management organizations, both of which are run by the counties. The resource centers offer a wide range of information and counseling on long-term care services and providers, conduct functional assessments for Family Care and, if appropriate and chosen by the client, assist with enrollment into a care management organization. The goal is for the resource centers to be a “single point of entry” into the entire long-term care system for persons of all income levels.

Care management organizations serve as capitated, managed care organizations for institutional and home and community-based long-term care services. Funding for long-term care from Medicaid state plan services, the Medicaid home and community-based services waivers, and state and county-funded programs are consolidated into a single monthly capitated payment to care management organizations. The goal is one “pot” of money that can be used to create a seamless system in which individuals' needs dictate service provision, rather than program demarcation. The capitation payment is related to the individual's levels of functional disability. The state and the care management organization share financial risk. To consumer advocates, a major advantage of Family Care is that it provides an entitlement to an array of flexible home and community-based services to everyone who meets certain criteria. Thus, its goal is to end Wisconsin's long waiting lists for HCBS.

A state-funded evaluation of the early implementation of Family Care found that the program had substantially met its goal of increasing choice and access and improving quality measured by social outcomes (Alecxi et al., 2003). Not surprisingly given the way the program operated, waiting lists were eliminated. On a wide variety of quality of life indicators, including measures of choice, self determination, and community integration, enrollees rated Family Care better than the Medicaid waiver. However, in terms of a number of objective health outcomes, such as presence of decubitus ulcer, hospital and emergency room use, and mortality, there did not appear to be significant differences between Family Care enrollees and the rest of the state. While the evaluation contended that it was too early to draw conclusions regarding spending, the increased enrollment in CMOs relative to the growth in enrollment in the rest of the state meant that aggregate spending for the Family Care program increased faster than if it had not been implemented.

Assisted Living

Recognizing that there are certain economies of scale in residential settings that are lacking in traditional home care where services are provided one-on-one, many states and older people are exploring the potential role of residential care alternatives to nursing home care, including adult foster care, board and care homes, and assisted living facilities (Wiener and Stevenson, 1998; Mollica, 2002). Policymakers and older people hope that these facilities will be able to provide services in a more home-like environment that provides greater personal autonomy and more personal choice than nursing homes. These settings may be particularly useful for persons who do not need a large amount of hands-on care, but do need a lot of supervision, such as persons in the early or middle stages of Alzheimer's disease or other

cognitive impairments. While the count is incomplete, as of 2002, state licensing agencies reported over 36,000 licensed assisted living and board and care homes with over 900,000 units or beds (Mollica, 2002).

Although residential care facility residents mostly pay privately, Medicaid and Supplemental Security Income are increasingly important sources of payment (O’Keeffe and Wiener, 2004). The number of Medicaid beneficiaries receiving long-term care services in group residential settings outside of nursing homes increased from 40,000 in 1998 to 102,000 in 2002 (Mollica, 1998; 2002). In 2002, 40 states and the District of Columbia covered services in residential care facilities under Medicaid; 27 states under home and community-based services waivers; five states under the personal care option, and eight under both options. While services may be covered through the personal care option or through HCBS waivers, room and board may not be reimbursed by Medicaid.

The National Study of Assisted Living for the Frail Elderly found that most assisted living residents are less impaired than the typical nursing home residents, although the study also found that a third of assisted living facility residents had cognitive impairment and a quarter had three or more ADL problems (Hawes, et al., 1999). Pruchno and Rose (2000), studied individuals who were generally better functioning than typical nursing home residents but worse functioning than typical assisted living residents, and hence eligible for admission to either setting. They compared groups of these individuals in assisted living facilities to groups of similar individuals in nursing home care, and found no significant differences in mortality, relocation, cognitive status, functional ability, depression or self-reported health. A similar lack of difference in outcomes, including psychological measures, was noted in a comparison between assisted living and nursing home residents in Oregon (Frytak et al., 2001).

States increasing use of residential care settings face at least four major issues (O’Keeffe and Wiener, 2004). First, should states wanting to expand residential care under Medicaid use the personal care option, HCBS waivers, or both? Under personal care, states may serve people with modest disability levels, but cannot expand financial eligibility and must provide only a relatively narrow set of services. Under Medicaid HCBS waivers, states must limit eligibility to people with a nursing home level of care, but may expand financial eligibility and may finance a very broad set of services.

Second, are room and board payments and Medicaid service reimbursement rates adequate to provide good quality care? Failure to assure that the combination of service payment and room and board payments are adequate may make it difficult to attract high quality providers and to assure that resources are available to provide needed care. Unless payments are at a level that good quality providers will accept, Medicaid beneficiaries may be either unable to find service providers or they will have to utilize a substandard provider.

Third, does the existing supply of residential care facilities provide the autonomy and privacy on which the expansion of use is premised? Many facilities currently participating in Medicaid are board and care homes that have been renamed “assisted living,” but lack the philosophical and physical plant characteristics of facilities serving private pay residents. Substantial portions of Medicaid beneficiaries reside in facilities where they must share rooms and bathrooms, just as in nursing facilities (O’Keeffe, O’Keeffe, and Bernard, 2003). Because of

the enormous variability that exists among residential care providers, the public, including Medicaid beneficiaries, have little useful guidance in deciding whether this type of care can meet their needs.

Fourth, how should facilities be regulated to assure adequate quality yet allow older people to age in place? In most cases, current state standards are minimal and vague. While many persons in assisted living have relatively light long-term care and medical needs, a significant minority are quite severely disabled. The use of Medicaid home and community-based services waivers complicates this issue because eligibility is limited to persons with disabilities who need nursing home-level care. The difficulty is that federal and state regulatory structures are built on the concept of a continuum of care in which individuals move from one level to another as they become more disabled. In contrast, the whole notion of aging in place means bringing services to individuals in their “homes,” wherever they may be, as they become more disabled. The issue is how to allow aging in place without making these facilities into unlicensed nursing homes.

Consumer Direction

A key issue in the design of home and community services programs is the extent to which clients control their services. A major innovation in long-term care in the United States and Europe is the development of publicly-funded, consumer-directed home care (Wiener, Tilly and Cuellar, 2003; Coleman, 2003). These programs give consumers, rather than home care agencies, control over who provides services, when they are provided, and how these services are delivered. Typically, consumer-directed programs allow the consumer to hire, train, supervise, and fire the home care worker (DeJong, Batavia and McKnew, 1992). In some programs, beneficiaries receive cash payments, enabling them to purchase the services they want (Wiener, Tilly and Cuellar, 2003; Cuellar and Wiener, 2001; Doty, 1998).

Consumer-directed home care has slowly become an international policy trend. A number of countries, including France, the Netherlands, the United Kingdom, Austria, and Germany, have implemented programs to give beneficiaries more control over their home care services (Wiener, Tilly and Cuellar, 2003; Coleman, 2003; Tilly, Wiener and Cuellar, 2000; Cuellar and Wiener, 2000; and, Coleman, 2001). In addition, a growing number of American states are incorporating consumer direction into their home care programs, including California, Michigan, Oregon, Washington, Wisconsin, and Vermont (Tilly and Wiener, 2001, Wiener, Tilly and Alexih, 2002; Gage et al 2003, Coleman 2003; Benjamin, 1998). Moreover, the U.S. Department of Health and Human Services and The Robert Wood Johnson Foundation are sponsoring “cash and counseling” demonstrations in Florida, Arkansas, and New Jersey, where Medicaid beneficiaries of all ages are being given the opportunity to receive cash budgets rather than agency-directed personal care services (Doty, 1998; Dale et al, 2003; Foster et al., 2003).

Older Persons' Preferences about Consumer Direction

Although predominantly associated with younger people with disabilities, older people use the consumer-directed option as well. A key issue is whether older people want to take on these responsibilities. Several studies suggest a significant minority of older people are interested in consumer-directed care, although substantially less than among younger persons with disabilities (Glickman, Stocker and Caro, 1997; Desmond et al 1998; Mahoney et al., 1998;

Simon-Rusinowitz et al, 1998; Tilly and Wiener, 2000). For example, a study of beneficiaries of the agency-directed Massachusetts Home Care Program found that only 18 percent of older respondents said they wanted “more involvement in determining the amount and type of services” received (Glickman, Stocker and Caro, 1997). A major limitation of these studies is the very low survey response rate.

Quality of Care

The quality of consumer-directed services is probably the most controversial issue facing policymakers. Traditional home and community-based services programs for older people attempt to assure quality of care by relying heavily on agency supervision by professionals, training requirements for paraprofessional staff, and government regulation. Although requirements vary, almost all of these mechanisms are lacking in publicly-funded consumer-directed care. Despite fears about poor quality, the limited quantitative research uniformly finds that consumer-directed services provide quality of care and life that is at least comparable to agency-directed care, if not better (Tilly and Wiener, 2000; Benjamin et al., 1998; Taylor, Leitman and Barnett, 1991; Foster et al, 2003; and, Dale et al., 2003). However, these results relate mostly to measures of consumer satisfaction and not to other measures, such as delay of functional decline or absence of avoidable hospitalizations, which may be important indicators of quality.

In a study of the California’s In-home Supportive Services Program, consumer-directed respondents reported more satisfaction with their services and the freedom to select them, higher perceived quality of care, and higher emotional, social and physical well-being than did agency-directed clients (Benjamin, 1998). Consumer-directed clients also reported greater satisfaction with the providers’ ability to assist them do things inside and outside of the home than did agency-directed clients. Other differences in outcomes between the two groups were not statistically significant.

In the Arkansas Cash and Counseling Demonstration, of those beneficiaries who received the cash option, satisfaction with paid caregivers’ performance was significantly higher than for those in the traditional program control group, and reports of unmet needs were significantly lower (Foster et al., 2003). Care provided was at least as safe as agency-provided care, according to reports of disability-related adverse events, health problems, and general health status. Of those participating, 82 percent reported that the program had improved their lives, and 93 percent said that they would recommend the program to others.

Workers in Consumer-Directed Programs

Limited research suggests that consumer direction most likely improves individual workers’ relationships with beneficiaries and working environments, but leaves workers at an economic disadvantage compared with their agency counterparts. Paid family caregivers and friends play a key role as independent workers, accounting for a majority of providers (Tilly and Wiener, 2000; Wiener, Tilly and Cuellar, 2003; Benjamin 1998; Foster et al., 2003; Dale et al., 2003). In California’s In-home Supportive Services Program, about 75 percent of individual workers knew the consumers before they started work versus only about 7 percent of agency workers (Benjamin, 2003). Family caregivers were more likely to feel close to beneficiaries, but

reported more emotional burden than other individual providers. In the Arkansas Cash and Counseling Demonstration, among treatment group members, about two-thirds hired family members, and most others hired friends or acquaintances (Dale et al., 2003).

The California study illustrates the typical compensation problems facing home care workers, with virtually all individual providers reporting no fringe benefits. In contrast, about 40 percent of agency workers received health benefits, paid sick leave and paid vacation, and about 60 percent of these agency workers received paid holidays and payment for travel costs (Benjamin 1998).

Assistive Technology

Most long-term care involves hands-on human help. However, more than 75 percent of older adults with disabilities use some kind of assistive device, usually to help with mobility (Russell et al 1994). These devices have demonstrated their utility in enabling many older persons to supplement and to some degree replace human assistance, through retaining mobility and avoiding injury from falls.

Assistive technology may range in scope from the use of a cane to facilitate mobility to major modifications to a dwelling. An analysis of survey data from the Disability Supplements to the National Health Interview Survey of 1994 and 1995 found a 37 percent increase in use of canes, a 70 percent increase in use of walkers and an 83 percent use of wheelchairs since 1980 (Allen et al 2001, Allen, 2001). The study found that users of assistive equipment relied on human help for fewer hours than non-users. For example, use of canes was associated with one less hour of formal care help and four less hours of informal help per week. There were also apparent savings in out-of-pocket costs for supportive services among cane and crutch users. Another study based on data from the Disability Supplements examined the effect of assistive technology on pain, fatigue, and time intensity, and found that the assistive technology users reported less unmet need for personal care even though the technology produced no specific benefit in these areas (Agree and Freedman 2003).

Assistive technology may also involve changes in the physical environment. One study showed that minor bathroom modifications significantly promoted independence for older people by increasing their ability to bathe (Kochera, 2002). Most research in the area of environmental modification has focused on falls, which are a major cause of disablement in the over 65 population, with a majority of falls occurring inside the home (Kochera, 2002). Researchers at the Lewin Group (2000) analyzed the potential impact of home modifications such as handrails, grab bars, widened hallways, ramps, door handles and other modifications. They concluded that, if such modifications were implemented among the 2.4 million older people with mobility limitations, over 250,000 falls would be prevented, saving approximately \$2.7 billion in medical costs in 2000. Such an intervention would cost \$4.8 billion, but if home modifications could be performed more cheaply, such as during construction of the dwelling, and perhaps with better targeting, the net costs could be reduced (Lewin Group 2000).

One of the efforts to determine the potential for assistive technology for older people in the community setting was the Massachusetts Assistive Equipment Demonstration, a collaboration between the Massachusetts Executive Office of Elder Affairs and the Gerontology Institute of the University of Massachusetts, Boston. This project investigated the effectiveness

of extending formal home care services by making a \$150 allowance available to purchase a wide range of assistive devices. The demonstration utilized the statewide network of aging services to train and assign case managers, who in turn, trained and advised beneficiaries on the use of the equipment. Devices purchased by clients included those aiding with food preparation (e.g., oversized handles and grippers), dressing, bathing, mobility or leisure activities, with the meal preparation devices being the most used. The demonstration showed the feasibility of integrating available assistive devices into a system of aging services. Overall savings in service expenses were not realized, in part due to a lack of accurate appraisals of clients' individual needs. Despite this problem, individuals reported 63 percent of the devices they had purchased to be "very helpful," and on a task-specific basis the project was able to demonstrate that the equipment did lead to savings in staff effort. The evaluators concluded that with active help from case managers, increased use of such devices represented a potentially cost-effective addition to home and community based services (Gottlieb & Caro 2000a, Gottlieb & Caro 2000b, Caro & Gottlieb 2001, Gottlieb & Caro 2001).

Caregiver Support

Informal caregivers provide the bulk of LTC in the community (Spillman and Pezzin, 2000). Substituting informal care with paid long-term care would almost triple long-term care expenditures (Arno, Levine, and Memmott, 1999). Public and private programs provide a number of supports for informal caregivers, including information and training, respite care, tax benefits and payments, regulation of businesses to allow for caregiving, and initiatives by private organizations (Wiener, 2003). An underlying premise of many of these programs is that the provision of these services or cash payments to informal caregivers will enable them to do a better job, that they will experience less stress, and that they will be able to provide care for a longer period of time.

Much of the research into caregiver burden and the need for support has focused on caregivers of recipients with dementia, who operate under some of the most difficult caregiving situations (Schulz, 2000). Researchers have attempted to devise interventions to address the causes of stress among caregivers. One of the most ambitious of these has been the Resources for Enhancing Alzheimer's Caregiver Health (REACH) program, a multisite trial of multiple interventions to support caregivers established in 1995. REACH employs a battery of home visits and interventions from professionals to help train caregivers to be able to provide more effective care, and to 'treat' the caregivers themselves for the risks of depression and injury due to the time and effort involved in caring for relatives with difficult and debilitating conditions (Pearlin et al, 1995, Schulz, 2000). Among these interventions have been behavioral skills and management training, a telephone-based intervention of automated monitoring and personal support services, family therapy, mood management classes, and environmental skill-building support (Schulz, 2003). Study findings have indicated significant reduction in caregiver burden and depression and various aspects of the program have been replicated in a second wave of interventions (Gitlin et al, 2003; University of Pittsburgh, 2002). The study also demonstrated that involving patients and families through interventions tailored to the caregivers' needs was an important element in producing positive results (Brodaty et al., 2003).

Other studies have identified adult day care services, increased social support, respite services, and formal service support as other helpful interventions (Chappell and Reid 2002, Zarit et al 1998). According to a recent study of the National Family Caregiver Support Program, caregivers most often identified respite services, along with assistive devices, supplies and home modifications for those in their care as the interventions that would be most helpful to them (Feinberg, 2002).

A RESEARCH AGENDA FOR HCBS

Research on long-term care, especially home and community-based services, has come a long way over the last 25 years. While a great deal of research has been done, much remains to be learned. Moreover, some issues which were researched in earlier periods deserve to be revisited because of changing circumstances. While there are numerous possible areas for research, a research agenda for home and community-based services would focus on the following issues:

Quality of Care

Much of the policy preference for home and community-based services is based on the assumption that the quality of care and quality of life for people receiving these services are better than for people in institutions. There is, however, little evidence on the quality of care and quality of life of home and community-based services to either support or challenge this contention. In addition, few states have made monitoring quality of care and quality of life a major priority, adding to the knowledge and policy gap. Potential research questions include:

- What are the current quality assurance systems that states use for home and community-based services?
- How can quality of care and quality of life for home and community-based services be measured?
- How does quality of care and quality of life for home and community-based services compare to institutional care?
- What is the relationship between reimbursement/costs and quality of care?
- Does training affect quality of care?

Workforce

A research strategy on long-term care paraprofessionals should address the problems of the long-term care workforce, including recruitment and retention, quality of care and life as it relates to the home and community-based services workforce, and the quality of life of those workers. Ongoing research is needed to provide current information about the basic characteristics of the home and community-based services workforce and to document policy,

provider, and consumer initiatives to address the problems. In addition, research is needed that rigorously evaluates the impact and costs of different interventions. Some of the potential research questions are:

- What are the trends in the demographic, social, and economic characteristics of long-term care workers?
- What are the vacancy and turnover rates in nursing homes, home care (including both agency-directed and consumer-directed care), and nonmedical residential facilities?
- What are the trends in the characteristics of long-term care jobs in terms of wages, hours worked, income, and fringe benefits?
- What initiatives are federal, state and local governments, providers and consumers taking to address the problems of the long-term care workforce?
- What is the impact of raising wages, providing fringe benefits, changing organizational culture on recruitment and retention, quality of care, quality of life, and public and private costs?
- What is the effectiveness of initiatives to expand the labor pool by recruiting welfare beneficiaries, older workers, family members, immigrants and students?

Cost-effectiveness and the Outcomes of Care

Although a great deal of research has been conducted on the cost effectiveness of home and community-based services, the current validity of the findings is questionable. Virtually all of the research is old, using data from the late 1970s and early 1980s, more than 20 years ago. Over this time period, states and providers have learned a great deal about providing lower-cost and more efficient services. In addition, the increasing dominance of Medicaid home and community-based services waivers has given states the tools they need to develop more cost effective systems of care. Moreover, new modalities of care have been developed which are less expensive than earlier models. As a result, it is critical that the potential cost savings role of home and community-based services be revisited. Potential research questions are:

- Controlling for disability level and other characteristics, how does the average cost per person differ between serving a person in the community and serving that person in a nursing home?
- Does expanding home and community-based services increase or reduce aggregate long-term care expenditures? Public long-term care expenditures? Federal expenditures? State expenditures?
- Does expanding home and community-based services reduce the use of nursing home care, acute care services, or informal care?

- What is the impact of expanding home and community-based services on quality of life, consumer satisfaction, disability level, and caregiver burden?
- What are the system characteristics necessary to produce cost-effective home and community-based services?

Promising Innovations

States, providers, consumers and others have developed several new service modalities, including assisted living, consumer-directed home care services, capitated organizations, assistive technology, and caregiver support programs. Very little research has been done on these service approaches. Potential research questions include:

Assisted Living

- What are the characteristics of assisted living facilities and of the people who live in them? How do these facilities measure up against the philosophy of autonomy and choice advocated by the assisted living movement?
- What is the quality of care and quality of life in assisted living facilities?
- How do states regulate assisted living facilities?
- How can residents be allowed to “age in place”?

Consumer Direction

- What proportion of people with disabilities would like to direct their own care?
- What is the quality of care of consumer-directed home care? How does it compare to agency-directed care?
- What supports do persons with disabilities need to use consumer-directed home care?
- What is the role of informal caregivers in consumer-directed home care?

Managed Care Organizations

- How well do managed care organizations integrate long-term care services or integrate acute and long-term care services?
- Do capitated organizations reduce the use of nursing homes and increase the use of home and community-based services?
- Does the integration of acute and long-term care in managed care organizations reduce acute care use and expenditures?

Assistive Technology

- To what extent can assistive technology replace hands-on services?
- How can computers and other new technologies increase the independence of people with disabilities?
- Can assistive technologies reduce the cost of care?

Caregiver Support

- Do caregiver support programs reduce caregiver burden?
- Do caregiver support programs improve the health of caregivers and reduce “burnout”?
- Do caregiver support programs reduce nursing home or acute care use?
- Do caregiver programs change the way people with disabilities receive care?

These are but a few of the questions that need to be addressed in the coming years. The American population is aging while younger families have fewer children to act as the future caregivers. Advances in medicine and technology and innovations in service systems have also increased the opportunities for long term care populations to remain independent longer, possibly reducing the need for institutional care. Understanding the future demand for services and developing effective, low cost ways to meet those needs in the community will be important as States and the Federal governments respond to ever increasing fiscal constraints. Much research is needed to address these issues and develop cost-effective long term care options that meet both the policy makers concerns and the preferences of the older people and persons with disabilities.

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