SPECIAL  SECTION

TOWARD A NATIONAL CONTINUUM OF CARE

The Elderly Housing Coalition is made up of national organizations (including CHA), agencies, and individuals who work together to influence federal policies concerning suitable and affordable housing for the elderly. The following is a working document intended to provide recommendations to the U.S. Department of Health and Human Services (HHS) and the Department of Housing and Urban Development (HUD). It was distributed at a national meeting on elderly housing sponsored by HUD in early May. The Elderly Housing Coalition is grateful to James T. Sykes, assistant director, Institute on Aging, University of Wisconsin–Madison, who contributed greatly to the development of this report.

Only by Integrating Healthcare, Housing, and Services Can the U.S. Prepare for the Coming Wave of Frail Elderly

BY THE ELDERLY HOUSING COALITION

America's population is rapidly aging, with the fastest growth occurring among people 75 years and older. This is particularly true of residents of federally assisted housing, elderly people who are especially vulnerable because they are also frail and poor and have often outlived their informal support networks.

The demographics of our aging society are startling:

- Today there are 34.1 million Americans who are 65 and older; in 2010 the number will be 39.4 million.
- Two-thirds of elders living alone are widows. (In 1997 there were 143 older women for every 100 older men.) Researchers predict that, by 2020, poverty among the elderly will be confined primarily to women living alone.
- A growing number of Americans are reaching age 85. In 1992, 10 percent of the 65-and-older population group had reached 85. Between 1992 and 2000, this group increased by 50 percent; by 2010 the number of people over 85 will increase by another 29 percent.
- Those who live a long time face not only increasing disability but also a reduced income. The 1996 median income of households of people over 65 was $20,535, while that for households of people 85 and over was only $16,000. The incomes of residents of federally assisted housing fall far below even the latter figure.

The importance of these data is clear: Care in a nursing facility—although appropriate for persons recovering from an acute illness or having long-term, complex medical and nursing needs—is neither appropriate nor cost-effective for most frail older people. The rapid growth of the assisted living industry for those who can afford such accommodations has demonstrated the merits of supportive services and healthcare assistance in residential settings. Unfortunately, the cost of assisted living facilities is too high for elderly residents of federally assisted housing.

Nevertheless, the nation's need is growing for shelter with services for older persons who face illness, poverty, or the loss of family caregivers. A national long-term care policy that incorporates both health and housing polices is urgently needed to:

- Integrate health and housing programs
- Facilitate the retrofitting of federally supported housing
- Fund service coordinators
- Utilize federal, state, and local resources to pay for shelter, healthcare, and supportive services
- Create a "one window" access system for assisted living

Barriers to Affordable Continuum of Care

In this era of rapid growth of the aging population, there has been accompanying development of such services as home health, meals on wheels, transportation, congregate meals, and adult day care pro-

grams, and of such vocational roles as care managers, service coordinators, and personal aides. Although these services may not be available in all communities, most basic services are now widely available, thanks largely to Older Americans Act* funding and the ingenuity and dedicated service of nonprofit organizations. Nonetheless, there are barriers that keep the poor elderly in federally assisted housing programs from gaining access to a continuum of care essential to their independence, autonomy, and dignity.

Cost Cost is the major barrier, with the median market rate for assisted living facilities over $2,500 per month. Poor and frail residents of federally assisted housing simply cannot afford most assisted living facilities and many cannot afford the essential health and supportive services they need.§

Cost also poses a barrier to service providers trying to design housing and service programs for this population. Without government subsidies, the cost of developing and operating these programs exceeds the reach of those for whom the programs are intended.

Varying Eligibility Criteria Different service and entitlement programs have different eligibility criteria, which often makes it difficult for housing residents to access the services and programs intended for them and for providers to coordinate and deliver those services. An older person eligible for Medicare, Medicaid, Older Americans Act programs, and subsidized housing is treated by the government as four different entities. Most of these programs have discrete eligibility requirements, income limitations, disability criteria, regulations, and payment vehicles (Medicare has no limitations on income). The result is not only frustrating for the individuals involved; it also makes for inefficient and ineffective service delivery.

Fragmented Services Elderly residents of federally assisted housing who need health and social services, information on services, transportation, and medical care must turn to multiple sources for help. Although nearly everyone agrees that frail elderly persons benefit greatly from a holistic approach that includes a comprehensive and seamless continuum of care, this ideal is rarely achieved. Instead, we see fragmented services in which a provider knows neither which other services are being delivered nor whether needs are being met. This leads to duplication, major gaps in services, and an inefficient use of resources. Such a nonsystem of care is especially difficult to navigate for aged persons with cognitive or physical limitations.

Lack of Family Care Providers The oldest residents of federally assisted housing, with few exceptions, live alone. Many have outlived their informal support systems and have no family or close friend to whom they can turn for help. Lacking such support, many poor elderly people must choose between moving to a nursing facility or being neglected. The cash equivalent of the care provided to the elderly by kin and other volunteers is estimated to be about $200 billion a year; unfortunately, residents of federally assisted housing seldom have family members or others who might provide such care.

Regulations The complexities of licensure and the cost of meeting regulations can create barriers to the effective development and delivery of support services by facilities serving the frail elderly. Regulations established by different agencies confound what should be a comprehensible and effi-

THE COALITION'S FINDINGS IN BRIEF

From their long experience in developing appropriate housing for older people, the members of the Elderly Housing Coalition have reached the following conclusions:

- Elderly residents of subsidized housing and recipients of housing vouchers are at risk of institutionalization or neglect because of declining health and the loss or absence of support and timely interventions. Residents who are in great need but possess few resources constitute a group to which supportive services can be delivered in an efficient and effective manner.
- Service coordinators in elderly housing projects have successfully assisted frail persons to access information, programs, benefits, and connections that promote their well-being and enrich the quality of their lives.
- The success of HUD's Congregate Housing Services Program and HOPE for Elderly Independence provide the foundation on which the nation could base supportive housing programs for its elderly.
- Delivery of services in federally subsidized housing is often fragmented because of multiple funding streams, conflicting regulations, and overlapping state and federal agencies. This fragmentation is not just costly; it also leaves serious gaps in the meeting of needs.
- HUD, HHS, and the various states participating in demonstration programs have creatively addressed problems associated with declining health, frailty, and poverty among the nation's elders. The use of Medicaid waivers to support community-based programs has been innovative and successful in serving frail citizens where they live and, thus, in reducing nursing home placements.

*The Older Americans Act of 1965 established the Administration on Aging as an agency of the U.S. Department of Health and Human Services. The agency administers programs that, among other things, provide supportive services to vulnerable older people who want to remain in their own homes.

§This article focuses on those vulnerable older persons who reside in federally assisted housing or are eligible for Section 8 vouchers. But millions of others face the same cost barrier.

cient system. For example, regulations that are appropriate for nursing facilities add to the cost of care and create an institutional atmosphere when applied to housing facilities. Although we of the Elderly Housing Coalition recognize that regulations are necessary to ensure high-quality care, we believe that those regulations should be appropriate for each setting in the continuum.

Space Limitations Residential facilities built for persons fully capable of independent living do not accommodate the needs of those who have physical limitations and need personal assistance, wheelchairs, or other assistive devices. Such facilities were not designed for persons needing nutritional or social supports; they lack adequate space for community kitchens, dining facilities required by health and safety codes, and for group recreation and socialization areas. Persons aging in place in federally assisted housing programs could benefit from on-site clinics, adult day care, PACE programs, and other co-located services that would help keep them well and minimize transportation needs.

THE COALITION'S RECOMMENDATIONS

The Elderly Housing Coalition urges the federal government to:

- Create a partnership between HUD and HHS to coordinate and maximize the benefits of federal housing and health programs for vulnerable residents. The government should authorize, finance, and administer programs that bring together shelter, healthcare, supportive services, and social services to help elderly residents remain independent as long as possible.
- Develop a continuum of care that offers supportive services to low-income elderly people whether they live in federally assisted housing projects that provide such services, or they receive a subsidy for their shelter and service needs.
- Give incentives and resources to federally assisted housing programs that encourage them to provide services and outreach not only to elderly residents but also to frail elderly people living in the neighborhood.
- Offer assisted living to frail elderly residents of federally assisted housing programs. Financial and other resources are needed to both add services and cover the structural modifications necessary to make affordable assisted living an option for elderly residents of subsidized housing.
- Find other funding sources for the conversion of federally supported housing to assisted living. Such funds should no longer be taken from allocations vital to the expansion of the Section 202 program, as they are at present.
- Establish HUD's Service Coordinator Program as an essential service authorized and adequately funded to ensure that every elderly resident of subsidized housing has access to a staff person knowledgeable about community services and sensitive to the needs of older people, especially the frail.

HUD's policies requiring the building of as many residential units as the capital budgets could provide resulted in projects with little common space. To add spaces such as communal kitchens and dining rooms, small clinics and offices may require converting residential units into program spaces. A comprehensive plan to enable residents to age in place may require that apartments be converted to common space in order to accommodate new services.

Lack of a Systems Approach Barriers to a coordinated, comprehensive, comprehensible continuum of care are the result of decades of piecemeal legislation. Although each legislated component has a specific function, together they are haphazard and uncoordinated. In an era devoted to reinventing government and containing healthcare costs, it is apparent that an interagency and interdepartmental effort must be employed to develop a continuum of care. Innovative efforts by various states and the federal government have been successful in overcoming some of the barriers described here. Some of these innovations are discussed in the sections below.

FEDERAL INITIATIVES: HOUSING

The three HUD programs described here emphasize the fact that, for more than 20 years, the department has administered programs promoting independence among frail residents. The Congregate Housing Services Program, Service Coordinator Program, and HOPE for Elderly Independence Demonstration Program, although modest in their reach, provide evidence of the effectiveness of strategies that enable frail elders to age in place.

Congregate Housing Services Program (CHSP) Since 1978, CHSP has made modest grants to public housing agencies and other federally assisted housing projects to cover the costs of meals and supportive services for frail elderly and nonelderly disabled persons. Eligibility is based on a functional assessment that identifies those residents who are eligible for assistance. Services include one meal per day, housekeeping, personal assistance, social programs, transportation, and the support of a service coordinator.

Evaluations of CHSP indicate that the program reaches residents seriously in need, providing services that enable them to age in place. It thus directly addresses the needs of a large and growing number of frail elderly residents. HUD's administration of CHSP demonstrates that it can effectively administer, and local authorities can competently manage a services component to a housing program.

However, as a grant program with minimal

funds, CHSP fails to serve most of the people who could benefit substantially from it. A CHSP grant covers only 40 percent of its services' costs. Unfortunately, most resource-poor public housing authorities and other sponsors of federally assisted elderly housing projects are unable to provide the remainder. The few projects that are awarded CHSP grants must therefore develop substantial local resources to sustain the program.

The CHSP program shows what can be achieved, at a relatively low cost in a federally assisted elderly housing project, to enable elders to age in place. Meals, housekeeping, and personal assistance constitute the minimal services that should be available to low-income, at-risk residents when age-related infirmities compromise their ability to live independently. We believe that lessons learned from CHSP should be applied to a national strategy for developing a continuum of services for elderly residents in federally supported housing.

Service Coordinator Program (SCP) This is another example of an effective strategy to assist residents to remain independent. In it, service coordinators are hired by projects to help frail residents gain access to supportive services in the community and to help them manage their care, especially in times of stress. The program is an approved expense in all federally subsidized housing programs serving older persons and younger persons with disabilities. In addition, the Supportive Services Program in Senior Housing, a demonstration funded by the Robert Wood Johnson Foundation through state housing finance authorities, allows certain private sector elderly housing projects—those developed with tax exempt bonds but without direct federal support payments—to employ service coordinators.

Service coordinators in elderly housing projects make it possible for frail residents to get services that enhance their independence. Knowledgeable about community resources and state and federal programs, the service coordinator is a confidant and friend of residents, a key actor in a continuum of care strategy.

Unfortunately, SCP, like CHSP, is underfunded. Although the number of coordinators across the nation is growing, the gap between the number in place and the number needed is huge. We believe that service coordinators—a first line of support for the nation's frail residents of subsidized housing—should be funded for every senior housing project.

HOPE for Elderly Independence (HOPE IV) This is another well-conceived HUD initiative carefully targeted to a specific population within public housing. Unfortunately, it is no longer funded.

The CHSP program shows what can be achieved to enable elders to age in place.

HOPE IV incorporated essential elements of supportive services and individual resident care management to enhance the quality of life of frail, very low-income residents in an independent living environment. The target recipients were primarily women over 75, living alone, impoverished, in poor health, and without close friends or family to care for them.

Evaluations of HOPE IV reported that the program helped frail persons remain in their public housing apartments. The program's most helpful services, evaluators found, were housekeeping, home health aides, meals, and transportation. A care manager was identified as an important key to the success of the program. Unfortunately, local housing authorities had some difficulty in finding candidates for the program.

Federal Initiatives: Healthcare

Several federal initiatives promote healthcare for the low-income elderly outside nursing homes.

Medicaid Waivers In a limited number of states, the Health Care Financing Administration (HCFA) grants waivers for exploring improved ways to finance services for low-income elderly persons. There are two types of waivers:

- *1115 Waivers* These allow the states that have them to use Medicaid resources to "assist in promoting the objectives" of Medicaid. Projects usually include a research methodology and an independent evaluation. Most projects run for a period of several years, after which they may be renewed.
- *2176 Waivers* These, which are also known as 1915(c) and 1915(d) waivers, allow the states that have them to offer community-based, long-term care services to persons who would otherwise require nursing home care or other forms of institutional care. Programs using these waivers provide a broad range of home and community-based services to elderly, mentally retarded, disabled, and chronically ill persons. (See also **Box,** p. 48.)

Program of All-Inclusive Care for the Elderly (PACE)

PACE is a national demonstration model integrating care for frail elderly persons who, although eligible for nursing facility care, prefer to live in the community. To enable them to do so, the program uses case management, adult day-care and other community-based services. Evaluations show that PACE reduces hospital and nursing facility use while improving the quality of life of participants. The program's sites receive monthly capitation payments from Medicare and Medicaid.

Several PACE programs have been located in

federally assisted housing sites, including HUD 202 buildings. These are often developed in partnership with hospitals or other healthcare organizations, which thereby take responsibility for the medical aspects of participants' care. As a result of the Balanced Budget Act of 1997, PACE became a permanent program and the number of potential sites was greatly increased. This will make it possible to extend access to PACE to residents of federally assisted housing programs throughout the nation.

Older Americans Act The Older Americans Act (OAA) provides limited funds for various programs and services that are important to residents of federally assisted housing programs. These funds, funneled through state offices, have been used to provide elderly people with congregate meals, companions, housekeeping, transportation and escort services, health promotion and disease prevention programs, and access to information and referral services.

Responsibility for identifying the needs to be met by such funds lies with local officials. They then develop a plan and submit it to the state and the Administration on Aging. Contracts with local agencies—including senior centers, home health agencies, and transportation providers—ensure that limited resources are effectively distributed. Nearly all OAA-funded agencies use volunteers, thereby providing maximum services to targeted populations. Whether those services reach residents of subsidized housing depends on local assessments of needs, service capacities, and delivery priorities.

These HUD- and HHS-sponsored national programs are focused on those in greatest need, administered at the state or local level, and sustained through modest federal grants or budget allocations. They are highly successful in what they attempt to do, providing evidence that HUD and HHS effectively manage important health, shelter, and social service programs.

Unfortunately, these programs are also limited in scope and funding and have almost always operated in isolation from each other. Nevertheless, evaluations of them persuasively suggest that we know what to do to enable frail elderly to age in place—the goal articulated by members of Congress and succeeding administrations for more than 20 years.

State Initiatives

States have provided laboratories for testing ways to advance the goal of independence for frail persons. Most states have been pushed by the dramatic increase in their Medicaid budgets as larger numbers of frail, medically indigent older persons were destined for nursing homes. Some states began years ago to identify ways to divert persons from costly nursing home beds into community programs.

The wisdom of using Medicaid waivers to fund community initiatives spread from state to state. Two states, Wisconsin and Oregon, have pioneered programs that created community options to reduce, or at least slow, the rate of nursing home admissions. Florida, faced earlier than the rest of the nation with this profound demographic shift, has examined policy options and is planning for the growing needs of its aging residents.

Wisconsin For more than 20 years, Wisconsin has sought answers to the questions: How, where, and at what cost should state governments provide care for those least able to care for themselves?

In 1981 the state developed the Community Options Program (COP). The program's two central concepts are, first, placing eligible frail persons at the program's center and, second, bringing the services and support they need, tailored to their special needs, to their homes. Key features of COP include an assessment of the recipient's needs and capacities and a care plan developed and executed with the participation of the recipient himself or herself.

COP is a partnership between the state and county governments, between federal Medicaid funds and state general-purpose revenues, and between recipients and care providers. Support for the program has grown through different administrations, both liberal Democratic and conservative Republican, and changing leadership in the houses of the state legislature. This long-term care program proves that older persons can be well served when they are put in charge of their own care, when community resources are mobilized, and when agencies make the commitment to care for those in greatest need. In addition, COP has delivered impressive savings over the cost of other alternatives.

Oregon Oregon's leadership in integrating shelter, services, and healthcare into a simple comprehensible, effective program for low-income elders has been widely acknowledged. Faced with a rapid increase in the demand for nursing home beds, Oregon decided to pursue alternatives to the institutional bias found in the allocation of Medicaid and other funds. The state developed what is called the Oregon Plan, which provides needy elderly with financial assistance for shelter, support, and services—with, in short, assisted living.

An analysis of Oregon's long-term care expenditures and its use of Medicaid waiver funds is instructive. A Lewin Group analysis of Oregon's experience reports the following:

> Wisconsin and Oregon have pioneered programs to reduce the rate of nursing home admissions.

• In 1994, through its use of home- and community-based care rather than nursing home facility care, Oregon saved $49 million. Since receiving its Medicaid waiver, the state has had total cost savings of $278 million.

• Oregon spends $638 per person aged 65 and older, compared with a national average of $1,047.

• The number of persons Oregon serves in community settings has increased from 6,000 to 17,000—in less than 10 years.

• Despite an increase in its elderly population, Oregon's nursing home census declined by 15 percent among persons aged 75 and older between 1981 and 1994.

A state strategy to improve the quality of life of elderly poor persons by offering them shelter with services has paid huge dividends—for older persons, for their care providers, and for the state's taxpayers. With this strategy Oregon has, since 1987, tripled the number of persons receiving less expensive community-based services in settings of their choosing. In the process, Oregon has developed a long-term care infrastructure and policy base that promises high-quality care and lower costs for more persons in the years ahead. A close examination of Oregon's policies and experience provides strong evidence that a long-term care policy that integrates shelter, services, and healthcare into one system makes good sense for all involved.

Florida This state offers, first, a compelling case for integrating shelter with services for low-income elderly impaired persons, and, second, a strategy for achieving it.

With over 18 percent of its population aged 65 and older, Florida is a snapshot showing the rest of the nation how it will look in the near term. The state urgently needed a long-term care system filling three needs:

• High-quality, affordable, appropriate shelter with services for those least able to care for themselves

• Support for their care providers

• Relief for those who pay, directly or indirectly, for the care

Florida encouraged the state agencies involved to study models of care developed in other states and create demonstration projects that would test concepts and practices based on them. The agencies then made six recommendations that have met wide approval from rent-subsidized housing organizations and service providers. Florida was urged to:

• Fund additional service coordinators within rent-subsidized facilities

• Create incentives for rent-subsidized facilities to provide services that help older tenants to age in place

• Develop partnerships to expand supportive services to elder residents in rent-subsidized facilities

• Articulate the state's commitment to the development of a well-organized and comprehensive long-term care system featuring the growth of home and community-based programs

• Integrate and expand medical care (through the use of home health nursing and home health aides) into home- and community-based programs

• Expand its Extended Congregate Care program to absorb those who would otherwise be placed in nursing homes

A long-term care policy that integrates shelter, services, and healthcare into one system makes good sense for all involved.

Toward a National Policy for a Continuum of Care

Having examined several national and state strategies, we find that there is a significant body of thought, experience, and knowledge to guide our nation in its response to older persons who face the triple jeopardy of poverty, chronic illness, and living alone. For the segment of the population living in federally assisted housing, a continuum of care that brings together shelter, social services, and healthcare is a sensible, cost-effective solution.

We now know *who* needs care. We know *where* they prefer to receive it. We know *which services* are needed. And we know *how* to provide them—through an integrated, comprehensive, affordable system.

The Elderly Housing Coalition is recommending the adoption of a national policy that will ensure the right of elderly low-income persons to decent, safe, affordable housing with appropriate services. This would translate core values of the American people into a policy that protects vulnerable elders with appropriate and affordable shelter, supportive services, and health care to enable them to live independently in their homes and communities.

Achieving this goal will require the development of a continuum of care: an integrated system of housing, health, and support services. A continuum of care includes an array of services that are accessible, affordable, and coordinated for older persons who live in federally supported housing. It would be developed utilizing the experience of past successes and demonstrations which show that federal, state, and local services and funding must be coordinated to achieve results and efficiencies, and to ensure quality health and housing programs for the nation's vulnerable elderly persons. □

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