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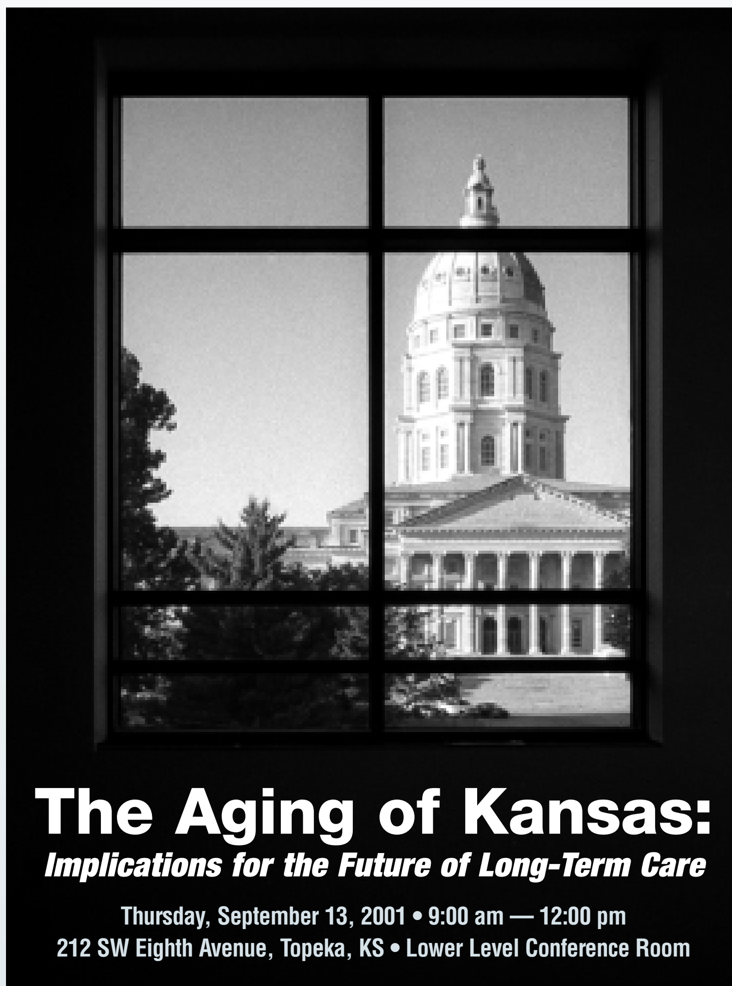
Forum Brief

Part 1 of a 2-part Brief

Kansas Health Policy Forums 2001

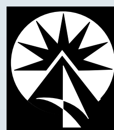


A DISCUSSION FEATURING

Robyn Stone, *Executive Director, Institute for the Future of Aging Services, American Association of Homes and Services for the Aging, Washington, D.C.*

Connie Hubbell, *Secretary, Kansas Department on Aging, Topeka, Kansas*

Rosemary Chapin, *Associate Professor, University of Kansas, School of Social Welfare, Lawrence, Kansas*



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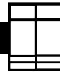

Kansas Health Policy Forums are presented by the Kansas Health Institute. Funding is provided by a grant from the Robert Wood Johnson Foundation, Princeton, NJ, and the Kansas Health Foundation, a Wichita-based philanthropy dedicated to improving the health of all Kansans.

Kansas Health Policy Forums are a series of interactive sessions for policymakers examining a broad array of health issues. Forums present a wide range of **expert views** on current health policy issues **followed by facilitated discussion** and dialogue in a non-partisan setting. **Forum Briefs** take an in-depth look at an issue, examine relevant data and information and are prepared in advance of each Forum.

The Aging of Kansas: *Implications for the Future of Long-Term Care* will examine key issues regarding the changing age demographics of the state and the development of a long-term care plan. **Part 1 of the Forum Brief (attached)** describes the current system of long-term care for the elderly and highlights the demographic changes that will impact the system in the future. **Part 2** presents key challenges and issues facing Kansas in addressing the future of long-term care for its aging citizens including:

- personal responsibility and informal supports;
- expanding home and community-based services;
- coordinating and integrating services;
- using public funds in strategic ways;
- concerns about quality; and
- public-private partnerships.

Speaker Bios

Robyn I. Stone, Dr.P.H., is a noted researcher and internationally recognized authority on health care and aging policy. In June 1999, she joined the Washington, D.C.-based American Association of Homes and Services for the Aging to establish and oversee the Institute for the Future of Aging Services. She is the Institute's executive director.

Dr. Stone has held senior research and policy positions in both the U.S. government and the private sector. She was an appointee in the Clinton Administration, serving in the U.S. Department of Health and Human Services as Deputy Assistant Secretary for Disability, Aging and Long-Term Care Policy from 1993 through 1996 and as Assistant Secretary for Aging in 1997. In the 1980s and early 1990s, she was a senior researcher at the National Center for Health Services Research and at Project HOPE's Center for Health Affairs. Dr. Stone was on the staff of the 1989 Bipartisan Commission on Comprehensive Health Care (the Pepper Commission) and the 1993 Clinton Administration Task Force on Health Care Reform.

Dr. Stone is a distinguished speaker and has published widely in the areas of long-term care, chronic care for the disabled and family caregiving. Her doctorate in public health is from the University of California, Berkeley.

Connie Hubbell, was appointed Secretary on Aging on November 12, 1999. Prior to accepting this position, she served as the Assistant Secretary for Health Care Policy at the Kansas Department of Social and Rehabilitation Services (SRS).

Secretary Hubbell's previous professional experience includes: elementary and secondary educator; elected member of the Kansas State Board of Education, serving ten years, and as Chair for two years; Commissioner of Income Maintenance and Employment Preparation Services for SRS; Commissioner of Substance Abuse, Mental Health and Developmental Disabilities for SRS; President of the National Association of State Boards of Education; and Public Policy Monitor for the YMCAs of Kansas.

Rosemary Chapin, Ph.D., Associate Professor, University of Kansas, School of Social Welfare, has extensive teaching, research, policy and program development experience in the long-term care arena. She directs the Office of Aging and Long-Term Care in the School of Social Welfare. For the past 12 years, Dr. Chapin has been involved in doing research and providing technical assistance to states to help craft more effective state long-term care policy. She has published widely in the area of long-term care policy and recently co-authored a handbook on strengths-based care management for older adults.

Brief Author and Forum Facilitator

Anthony Wellever is President of Delta Rural Health Consulting and Research, a firm specializing in providing technical assistance to rural health policy makers, providers, and communities. Mr. Wellever has written and spoken widely on the topics of rural health networks, managed care in rural areas, alternative model rural hospitals, and the meaning and consequences of local control of health care services. Previously he served as a Research Fellow and Deputy Director of the University of Minnesota Rural Health Research Center and as Senior Vice President of the Montana Hospital Association.

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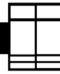
The Kansas Health Institute is an independent, non-profit health policy and research organization based in Topeka, KS. Established in 1995 with a multi-year grant from the Kansas Health Foundation, the Kansas Health Institute conducts research and policy analysis on issues that affect the health of Kansans.



Overview

Long-term care is a general term for an array of supportive services provided over an extended period of time to people who need assistance with a variety of activities. People of all ages consume long- term care (LTC) services, but the primary users are elderly persons.

What You Need to Know

- The population of Kansas elders age 85 or older is projected to grow from 52,700 in 2000 to 63,800 in 2020, increasing the demand for long-term care services.
- Approximately 60 percent of long-term care (LTC) services are financed currently by Medicaid and Medicare; Medicaid is the single largest payer of LTC services.
- The shortage of health care workers is a potential barrier to access to long-term care services.

The demand for LTC services will expand greatly in the coming years. As illustrated by the chart to the right, between 2000 and 2025 the population of Kansans age 65 or older is expected to grow by more than 246,000 persons, a growth rate seven times that of the population age 25-64. On average, persons age 85 years old or greater are more likely to use LTC services. Between 2000 and 2020 the 85+ population of Kansas is expected to grow by approximately 11,000 persons or 21 percent, a rate more than double the under age 65 rate. Many of the age 85+ population reside in rural areas of the state. Smith County, the most extreme example among rural counties, has the highest percentage of age 85+ residents in Kansas and ranks fourth among all counties in the United States.

LTC services are provided in a variety of home, community, residential, and institutional settings. Most LTC is provided informally by family members and friends, but approximately 21,000 Kansans resided in nursing homes in the year 2000.

Medicaid and Medicare nationally finance approximately 60 percent of LTC services (nursing facility and home health only). Medicaid is the single largest purchaser of LTC services. According to the Kansas Department on Aging, the Kansas Medicaid program paid $318.5 million for nursing home and home and community based services in state fiscal year 2000. The second largest purchasers of LTC services are individuals who pay out-of- pocket for their own care.

Total annual LTC expenditures are difficult to estimate because of the large number of delivery sites and the lack of available financial data. A broad estimate extrapolated from known sources of LTC spending indicates that, in 2000, total LTC spending from all sources in Kansas easily topped $1 billion.

TABLE OF CONTENTS

Users of Long-Term Care Services 3

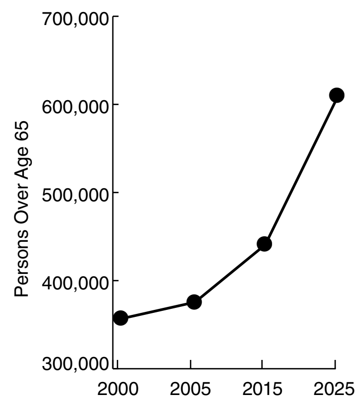
Providers of Long-Term Care Services 4

Long-Term Care Quality and Culture 4

Financing Long-Term Care Services 5

Developing a Long-Term Care Policy 6

Number of Kansans Aged 65+ 2000-2025



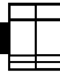
Source: U.S. Census Bureau, Population Division, Population Projections Branch, "Projections of the Population by Age and Sex, of States: 1995 to 2025", www.census.gov/population/projections/state/stpjage.txt.

These statistics suggest that the aging of Kansans will place greater demands on state and local governments and health care and social service systems statewide. Demographic projections of the aging of the population inform us that a public policy problem will unfold slowly during the next 20 to 30 years. Population projections provide an opportunity for policy makers, consumers, and providers to consider, in a calm and deliberative manner, enhancements or other changes to the LTC system that will enable it to provide care for the anticipated increase in frail elderly Kansans.

Users of Long-Term Care Services

LTC services are needed and used by people who have limitations on their ability to perform or manage the activities of daily living. Activities of daily living (ADL) include the ability to eat, dress, walk, per-

This brief is Part 1 of a two-part Forum Brief prepared for an upcoming Kansas Health Policy Forum entitled **The Aging of Kansas: *Implications for the Future of Long-Term Care,*** scheduled for September 13, 2001 in Topeka. Part 1 of the Forum Brief sets the stage by describing current long-term care systems and presenting relevant demographic information about Kansas. Forum Brief, Part 2 will build on this information and discuss critical policy issues and challenges facing the state in dealing with the future of long-term care for the elderly.



form personal care and grooming, and maintain bowel and bladder continence.

Another functional measurement that determines the need for LTC services is called instrumental activities of daily living (IADL) and includes handling monetary affairs, telephoning, grocery shopping, housekeeping, and transportation.

The elderly are the largest users of LTC services. Current research suggests that after age 65, almost one-half of all Americans will spend some time in a nursing home, and almost three of four will need some home care. Demand for LTC services will continue to grow as the "Baby Boom" generation enters this age category beginning in 2011. Because demand for LTC increases with age, the largest surge in demand may not begin to appear until 2031.

The Baby Boomers may differ from previous generations in several ways. For example, the proportion that has purchased LTC insurance is likely to be greater than preceding generations. However, smaller numbers of offspring and the decline of the nuclear family may reduce the network of informal care givers available to elderly Baby Boomers.

Providers of Long-Term Care Services

Unlike the acute care system, which seeks to cure patients of illnesses and injuries, the goal of the LTC system is to provide required medical, social, and environmental support services that enable persons to maximize their functional independence.

Most of the needs of people living in the community who require support and assistance with ADL and/or IADL are fulfilled by unpaid, informal care givers — family, friends, and neighbors. According to the AARP Public Policy Institute, approximately 64 percent of older persons with "severe disabilities" who reside in the community rely exclusively on help from family and friends.

Examples of LTC Services

Home and Community-Based

Adult day care ▲
Home health care ▲
Transportation
Case management
Congregate meals
Meals-on-Wheels
Emergency response system
Information and referral

Residential

Retirement centers (senior housing)
Assisted living centers ▲
Residential health care facilities ▲
Homes plus ▲
Boarding care homes ▲

Institutional

Nursing facilities (Medicaid funded) ▲
Skilled nursing services (Medicare funded) ▲
Nursing facilities for mental health ▲

▲ *Services licensed by the Kansas Department of Health and Environment (KDHE)*

If the needs of LTC clients are too great or the resources of the informal care system are too slim, the formal LTC delivery system begins to fill the gap. The formal LTC delivery system is composed of a variety of community-based, residential, and institutional services. The box above highlights key services in each of these areas.

Although the services referred to in the box are often considered a continuum of care, they are not necessarily used sequentially. A person may enter the system at any level and use services of multiple levels simultaneously. For example, a resident of an assisted living facility may use an elder care transportation service to attend functions at the local senior center. Similarly, a resident of an assisted living facility may be admitted temporarily to a nursing facility following a surgical procedure and be discharged from the nursing facility back to the assisted living facility.

The nature of services provided (medical and social), their independent funding sources, and the increasing number of alternatives available makes coordination of LTC services difficult. Assessment and case management services that identify a person's needs and help the person navigate the formal LTC system also are in short supply.

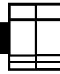
Supportive housing options are among the newest innovations in LTC. They offer residents moderate assistance in performing daily activities. Older people who are not able to live independently in their homes, and do not require the medical services of a nursing facility have a range of residential services to choose from. Although supportive housing options are growing, 37 counties in Kansas have neither assisted living nor residential health care beds.

Nursing home care is the most complex and typically most expensive of the services offered in the LTC continuum. Nursing home residents usually have multiple activity limitations and/or chronic conditions which cannot be managed in the community and whose conditions are too complex for residential care providers. In Kansas, the annual Medicaid cost of skilled nursing facility care per resident in state fiscal year 2001 was approximately $34,000, exclusive of drugs, supplies, and other medical therapies (based on the average Medicaid daily rate). The overall average, including private pay, would be somewhat higher because facilities cannot charge a higher rate for Medicaid funded individuals than for private pay.

If the proper home, community, and residential supports are available, admission to a nursing home may be forestalled for a considerable period of time. To help certain low-income elderly receive these supports, the Kansas Medicaid Program pays for certain home and community based services through the Home and Community Based Services (HCBS) waiver for the frail elderly.

Long- Term Care Quality and Culture

The Kansas Department of Health and



Hospice and End-of-Life Care

Hospice and end-of-life care are special cases in the long-term care continuum. An interdisciplinary team offers hospice services to terminally ill persons in both home and institutional settings. Viewing death and dying as something natural and personal, hospices provide palliative care to people who are dying.

Palliative care is intended to relieve a patient's symptoms. Although pain management with drug therapies is a primary aspect, palliative care also includes psycho-social and spiritual counseling for the patient and family. Hospices care for the entire person — body, mind, and spirit — in a way that few other health care providers do.

Longer-term end-of-life care is provided, of course, in nursing homes as well as hospices. End- of-life care is an emotional issue that has ramifications for public policy in terms of professional and facility practice regulations, third-party payment rules, and health profession education curricula.

Environment (KDHE) licenses several LTC services for the state and certifies them for Medicare. In the box on page 4, a triangle indicates the services licensed by KDHE (▲).

Licensing and certification are initial controls on the quality of services provided. Repeated, periodic inspections of LTC services by KDHE (also called "surveys") help ensure that services continue to be provided appropriately and that the safety and rights of clients are preserved. Although quality oversight is provided by the state at all levels of care, institutional and residential services receive the most scrutiny.

Recent trends in LTC services have been to increase the independence and autonomy of clients and to provide services in community settings whenever possible. Both of these trends are associated with improving quality and client satisfaction. Several new models of service delivery and financing that promise to reform the culture of LTC services have been proposed. These models include:

Program of All Inclusive Care for the Elderly (PACE):
PACE began as a federal Health Care Financing Administration (HCFA) demonstration project. The Balanced Budget Act of 1997 made PACE a permanent federal Medicare provider and a state option under Medicaid. Kansas will implement its first PACE site in Sedgwick County later this year.

PACE is a form of managed care in which the provider accepts a fixed monthly payment for each enrolled person and agrees to provide services to that person regardless of cost. Services to be provided range from hospitalization to home and community based services. PACE providers have a financial incentive to maximize the functional independence and general well-being of their enrolled population. PACE providers are responsible for managing care as well as providing LTC and acute care services. The integration of health services is expected to improve coordination and timely access to appropriate levels of service.

Most of the experience with PACE at demonstration sites around the country is favorable. According to a review of PACE research studies by Robyn Stone (Milbank Memorial Fund, 2000), some evaluations of PACE experiments report improvements in health status, quality of life, and the cost of care. Other studies suggest that first-generation experiments did not integrate long-term and acute care successfully.

The Eden Alternative:
One of several approaches to redesigning nursing home care, the Eden Alternative stresses elimination of loneliness, helplessness, and boredom (which it claims account for the majority of suffering in the elderly) by creating "vibrant and vigorous habitats for human beings."

This new paradigm of care delivery integrates pets, plants, and children into the environment, reduces hierarchical staff relationships, and encourages resident autonomy and spontaneity. Although formal evaluations of the Eden Alternative have not been performed, anecdotal evidence suggests that it reduces medication use, infection rates, and mortality; it also reportedly reduces staff turnover. Seven nursing homes in Kansas currently subscribe to the Eden Alternative approach.

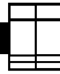
Other innovative approaches include designing the physical space of nursing facilities to reduce institutionalization and more closely duplicate a home environment.

Financing Long-Term Care Services

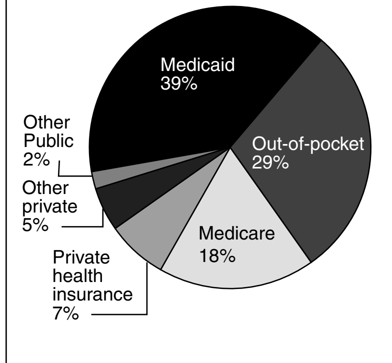
A range of private and public sources funds LTC services. Private individuals pay for many of the services provided. The informal delivery system relies exclusively on unpaid "workers" who, in addition to the value of their labor contribution, incur other expenses providing care, such as the cost of disposable supplies and remodeling of homes to improve mobility and safety. The value of the assistance provided by the informal care system, although great, is difficult to quantify.

With few exceptions, individuals pay for services provided in supportive housing options. They also are responsible for paying for the nursing facility care they receive. If they "spend down" their assets and no longer can afford to pay for nursing home care, they may become eligible for Medicaid.

The chart on page 6 shows the sources of funding for all LTC services nationally including nursing home services and home and community-based services.



Sources of LTC Funding Nationally, 1998



Source: HCFA Office of the Actuary, 2000

Looking at nursing home services alone, individuals paid 33 percent of all costs out-of-pocket in 1998 on a national basis. An additional 5 percent was paid by private insurance. LTC insurance becomes increasingly expensive to purchase as the age of the beneficiary increases. At least partly due to cost issues, fewer than 10 percent of seniors own LTC insurance policies to finance their nursing home care.

Medicare has a limited nursing home benefit, paying only for skilled nursing care following an acute care episode. Medicare accounted for approximately 12 percent of national nursing home revenues in 1998.

Medicaid is the primary payer for nursing home services. Unlike Medicare, Medicaid pays for care provided to nursing facility residents with chronic disabilities. In 1998, Medicaid's share of the total nursing home bill nationally was 46 percent. In Kansas, Medicaid nursing home expenditures grew from $215.7 million in 1995 to a projected $292 million in 2001, an annual growth rate of almost 6 percent.

Home and community based LTC services are also financed by a wide range of federal, state, local government, individual, private, and faith-based sources.

The Kansas Medicaid Program operates under a waiver from the federal Centers for Medicare and Medicaid Services (or CMS, formerly known as HCFA), allowing it to pay for certain home- and community-based services (HCBS) provided to Medicaid-eligible consumers as an alternative to nursing home care. HCBS expenditures projected for 2001 are $49.8 million, representing an annual growth rate of 28.4 percent between 1998 and 2001. The bulk of this increase in expenditures is due to the number of clients served. During the period 1998 to 2000 the increase in the number of clients seeking "alternative services" averaged almost 20 percent per year. In state fiscal year 2001, the rate of growth slowed to 13.4 percent.

According to the Office of the Actuary, CMS, Medicare was the largest payer of home health care nationally in 1998, responsible for approximately 36 percent of home health providers' revenues. Individuals contributed 21 percent out of pocket; Medicaid, 17 percent; private insurance, 14 percent; and other public and private sources, 12 percent.

Kansas is among a group of states that has attempted to improve coordination of LTC services for the elderly by consolidating them in a single agency. In 1997, the Legislature voted to transfer the Medicaid nursing facility and home and community based programs from the Department of Social and Rehabilitation Services to the Department on Aging, which administers other programs for the elderly, such as Meals-on-Wheels.

Developing a Long-Term Care Policy

"Who gets what, when, and how," is a famous definition of politics. It also could be applied to public policy making. To answer these questions in regard to LTC, it is necessary first to set goals and determine priorities for the financing and delivery of LTC services. Issues to be considered include:

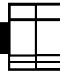
- Projected changes in the population of Kansas over the next 10 to 30 years;

Work Force Issues

Work force issues cut across many levels of LTC employment but certain positions are affected to a greater degree than others. Certified nursing assistants (CNAs) are employed in greater numbers by LTC providers than any other position. New delivery sites and the increased intensity of nursing home care have increased the demand for CNAs dramatically. The Kansas Department of Human Resources rates nursing aides and orderlies as the fifth fasting growing occupation in the state, measured by the projected creation of new jobs, between 1996 and 2006 (Kansas Occupational Outlook 2006).

It may be difficult to fill all of the projected positions. According to one estimate, the percentage difference between budgeted and filled positions (i.e., vacancy rate) of LTC CNAs in Kansas in 2000 was 11.2 percent. This means that approximately 1,500 CNA jobs in Kansas nursing homes and home health care agencies alone were unfilled on any given day in 2000. The annual CNA turnover rate is estimated at 110 percent. The vacancy rate for the foreseeable future is not expected to diminish as the need for new positions will grow at the same time that existing positions remain unfilled.

Among the many problems related to the work force crisis is the inability of LTC providers to increase salaries to attract new workers due to low third-party payments and the high proportion of residents whose care is paid for by Medicaid and Medicare. To help overcome this limitation, the Kansas legislature adopted a direct care "wage pass-through" in 2000 that increased Medicaid payments to nursing homes and earmarked them for increases in wages and benefits.



- The capacity of the LTC delivery system to meet increased demand for services;
- The capacity of the State of Kansas to finance LTC services;
- The personal responsibility of Kansans for their financial and health status;
- The appropriateness and quality of LTC services; and
- Maintenance of the independence and dignity of older residents of the state.

In addition to considering these factors, a long-term care policy for Kansas would define the role of government in determining what services should be delivered, to whom, when, and how. Implicit in this assessment is exploration of the potential for public-private partnerships to satisfy the growing need for services.

The second part of this Forum Brief will discuss, challenges facing the long-term care system including:

- Building on the importance of family and the informal delivery system;
- Expanding community-based and home health care services;
- Coordinating and integrating the spectrum of LTC services;
- Using public funds in strategic ways;
- Addressing concerns about quality of LTC services; and
- Planning for long-term care public private partnerships

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