ISSUES

EVERYONE AND HIS MOTHER

Families, Government, and Long-term Care in Pennsylvania

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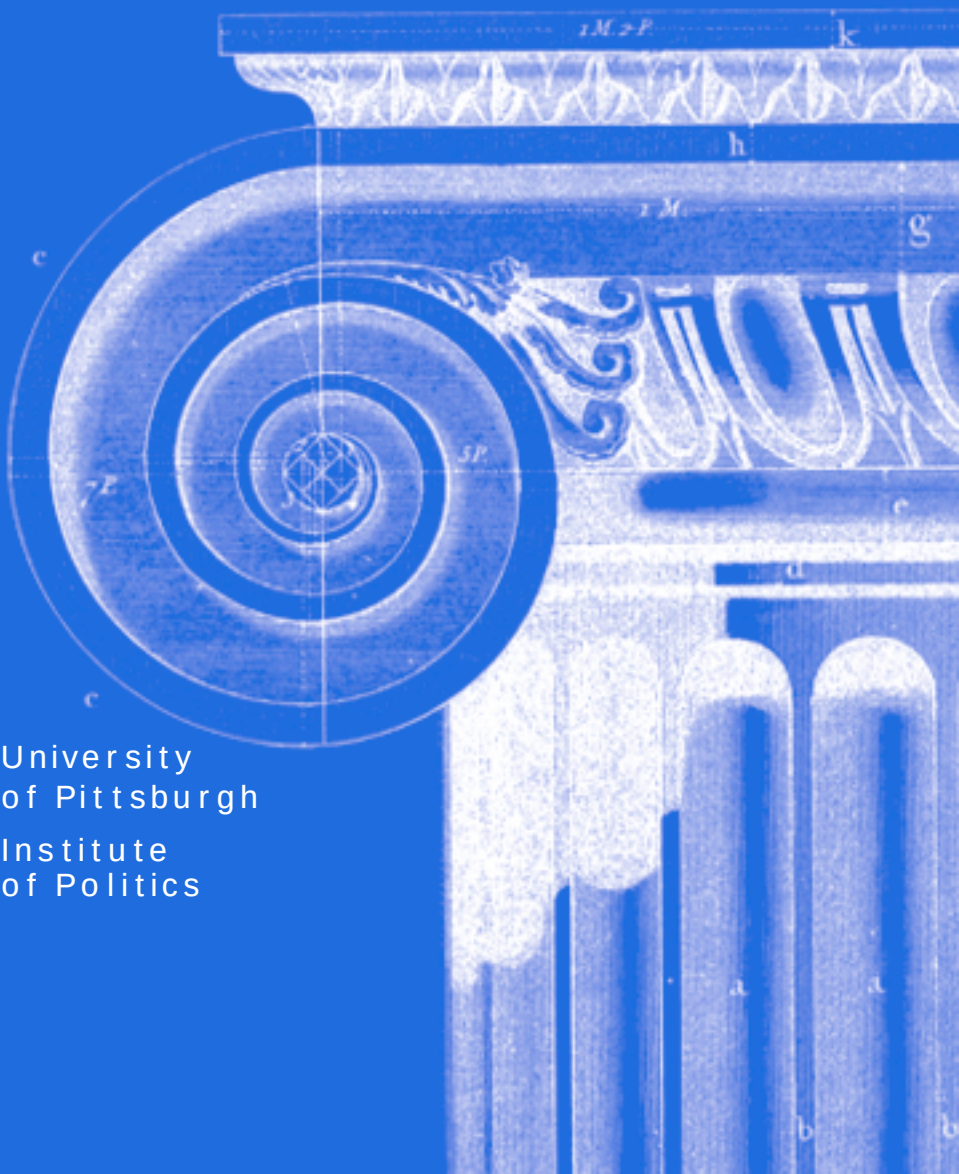

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Caring for Mother Louise

For the Smith family adult children gathered at John's home in Connecticut, the big question was: What to do about Mother Louise?

John in his methodical way had laid out in a letter the alternatives for their 80-year-old mother and asked each of the others to research one of them. "We all know what the problems are," he said to the others, grabbing a handful of pretzels. "None of us lives anywhere close to Pittsburgh ."

"And she has made it clear that she wants to stay in her house," Jim interjected, rising to his feet to walk around in a circle, as he had done from his childhood days.

"Right," John snapped, as if miffed at the interruption. "But the trouble is all our attempts at home care arrangements haven't worked out. It's harder to get good help in Pittsburgh—the *Post-Gazette*, when I was home with Mother, had an article reporting just that. You know that Allegheny County has the second highest number of elderly, ranking only behind Broward County in Florida. No wonder it's difficult. Besides, I think I can safely say just among us, she isn't the easiest person in the world to get along with. Mary, what have you found?"

Mary drew a long sigh. "I don't think anybody here will be surprised to learn that none of us wants to take Mother in. John asked me to check out your wives, and every one has a perfectly good reason that has nothing to do with Mother's disposition. I know everybody looks at me as the only daughter. But I can't give up, or even cut back, at my job, the way I'm moving up the executive ladder."

Tom muttered, "If Sarah were here, she'd say the same thing." The others knew why there was a grumble in Tom's voice. Sarah wasn't the only one miffed that John had deliberately confined his call to the siblings and not their spouses. Jim had complained of their eldest brother, "Same old control freak," but they'd gone along. Yet today they'd found John's son Harry included in the session on grounds he was an expert at trolling the Internet for information.

"Right! Well, that's narrowing our alternatives," John affirmed. "It may have to be Mother leaving our old home for some kind of long term care—assisted living, nursing home, whatever. Let's see, Jim, you were going to check out Medicare, right?"

Jim continued his little walking circle. "Well, Mother has Medicare A and B, but it's not really going to cover the kinds of cost we are getting into. It mostly covers the cost of acute medical care and for care required right after a hospitalization. And the truth is, Father's company didn't have a good pension plan. They should have had some kind of Medigap insurance, but didn't."

"And Medicaid, Tom?"

"I'm afraid that at this late date, we are in a real dilemma. You know,

we've always agreed with Mom to keep Dad's estate intact—"

"Not that Mother needed any urging," Jim broke in. "From growing up in the Depression, she's always been afraid of being poor."

"Right!" John said. "Go on, Tom."

"So now if she goes into any kind of place—assisted living, nursing home, whatever—they'll first use up that money before she can go on Medicaid. Her assets will have to be less than $2,000. Now, if we had faced this, say, three years ago, she could have parceled out the money to us as heirs and gone on Medicaid immediately. You have to do that divestiture 37 months ahead of turning to Medicaid."

"Right! But that's water over the dam now," John said.

Mary spoke up, "Here's something I meant to bring up earlier. You know that tobacco settlement the states have made with the cigarette companies. I read in the *Philadelphia Inquirer*—I have the clipping here—that Ridge, you know, Pennsylvania's governor, is already figuring how to spend Pennsylvania's share. I think I read it was something like $40 million for the first year. And one part of his plan is for it to go for funds on home care for elderly people who otherwise would need nursing home care."

John's face puckered in doubt. "Maybe, but that's a long way down the pike, if ever. And if enough. What else do we have?"

Harry, the 16-year-old, cleared his throat. "Dad, I've been checking on the Internet into long-term care insurance."

"Son, that was for us, not your Grandmother Louise. We're past that at her stage in life."

"Let him have his say," Tom asserted, flipping his hand as though discounting any hint of insubordination. "Getting into this problem has got Sarah and me to thinking about taking that out for ourselves...Like the rest of the baby boomers."

Harry eagerly began outlining his findings. A year in a nursing home costs an average of at least $46,000. The cost of home health care by someone outside the family costs about the same. And 76 million baby boomers will be retiring in the next few years, with the longest life expectancy ever, people living to their 90s or even to 100.

Next, Harry rolled out the statistics on premium costs he'd found from the American Council of Life Insurance. "If you buy a two year policy when you are between the ages of 45 and 49, it's $500 a year, or $734 a year for a five-year policy. Let's see, going down the list, it's $605 a year if you start buying between 50 and 54 and $905 for a five-year policy. Getting that two-year policy at 75 years old is $3,850."

John interrupted, "Thanks, Harry. All those numbers are confusing, I know. I told Harry I thought a two-

year policy might not hack it for us at least, given the longevity of people these days, even after they go into some kind of long-term care facility. I'll bet that would be the case with Mother Louise. At least, I hope she has some years of life ahead. Anyway, I asked Harry to go back to the Internet to run some more numbers. Harry, on this you used your mom's insurance plan, didn't you?"

Yes, Harry replied. Since his mother was a teacher and was involved in something called Teachers SelectCare, underwritten by the Teachers Insurance and Annuity Association, he'd gleaned a set of comparison numbers. The basic format was the purchase of a seven-year benefit plan paying $300 a day maximum for nursing facility care. Starting a plan at age 35 would cost $3,420 annually; at 45, $3,450; at 55, $4,110; and at 65, $5,940. "And that doesn't pay for care provided by a member of the immediate family," Harry concluded breathlessly.

"Whew!" Tom said. "We've got college tuition coming up for our two; plus paying off the mortgage, plus saving something for ourselves. We'll have to think about that."

Jim sat down abruptly. "Damned tooting! But the more I get into this, the more I realize there's no one answer. Society has to find some solutions. It'll have to be some kind of combination. As I see it, government isn't going to do it alone, not when the cost of entitlement programs already is going through the roof. And companies aren't. So individuals are going to have to do a lot of it for themselves."

"Right!" John said. "I think that's something for us to work out in our own families."

"John," Mary interrupted gently. "I don't think we should pass over lightly what Jim is saying. What I've gotten out of this discussion this morning, besides thinking about Mother, is that Dale and I have to get serious about our own long term care. And I'd like to have us share information, starting with Harry's findings, so that all our families are on the right track. Especially when I see plans are so varied and so darned complex."

Jim was on his feet again. "Exactly. Otherwise, if I may say so, all our children—Harry and his cousins—will be facing the same problem with us not too many years down the road."

John held out his hands, palms down, as if quelling a revolt. "Right! But that doesn't help us with Mother Louise—the thing we need to get solved before everybody leaves for home. Folks, we have to buckle down and decide just what we are going to do. Any ideas?"

FACT SHEET

Demographics:

- Seventy six million American baby boomers will be retiring in the early years of the 21st century.
- By 2025, an estimated 69.3 million Americans, 20.6% of the U.S. population, will be enrolled in Medicare.
- In 2000, 17.9% of Allegheny County's population will be over 65, up from13.8% in 1980. These numbers are projected to continue to grow. In the United States, only Broward County, Florida has a greater percentage of residents over 65.
- Americans are living longer: The fastest growing group of Americans is comprised of those over 85.

Costs of Long-Term Care (LTC):

- A year in a nursing home costs an average of $48,000.
- Cost of care in the home varies, but average about the same as nursing home costs. However, most home care is provided "free" by family members (see "Costs of Informal Caregiving" below).
- In 1997, LTC expenditures in the United States reached $115 billion.
  Costs were covered as follows:
  a. Medicaid: 38% (but only covers individuals with total assets of less than $2,000)
  b. Medicare: 20% (but pays only for LTC in very narrowly defined circumstances, e.g., immediately following hospitalization)
  c. Consumers, out-of-pocket: 28%
  d. Private insurance: 7%
  e. Other sources: 7%
- Projected LTC costs are:
  a. 2020: $207 billion
  b. 2040: $346 billion
- In Pennsylvania in 1996, Medicaid expenditures on nursing homes alone totaled $2.2 billion, 30% of all Medicaid expenditures in the commonwealth that year. In 1995, the elderly represented 13.6% of the Medicaid population in Pennsylvania, but consumed 40% of total Medicaid expenditures.
- Medicare expending alone is predicted to rise from 2.7% of the gross domestic product (GDP) in 1998 to 5.3% in 2025. This increase corresponds to a 79% increase in the total number of beneficiaries.

FACT SHEET continued...

Costs of Informal (Unpaid) Caregiving:

- A conservative estimate of costs to employers in employees' lost time and productivity, increased health and mental health care, and replacement of workers who quit to attend to family members' LTC needs is $28 billion/year.
- An estimated 7 to 27 million Americans provide informal LTC to family members.
- The total economic value of informal caregiving is estimated at $196 billion/year.

LTC Insurance:

- Premium costs for private LTC insurance covering two years in a nursing home:
  a. $500/year for 45-49 old purchaser.
  b. $3,850/year for 75-year-old purchaser.
- LTC insurance policies vary significantly in services covered, benefits offered, and cost.

Compiled by the Jewish Healthcare Foundation of Pittsburgh.

Introduction
Everyone and his Mother

Building on the questions raised by the Smith family in considering the Mother Louise dilemma, let us discuss the various components in the following chapters.

First, this document does not pretend to cover all aspects of this highly complicated long-term care (LTC) field. Involved are consumers, providers, insurers, federal, state, and county governments, think tanks, and philanthropic foundations, among others. Inevitably, something will be left out that each of these groups considers important.

Figures compiled by the Jewish Healthcare Foundation of Pittsburgh show that the states and the federal government spend more than $50 billion a year on long-term care. In Pennsylvania, the elderly comprise 13.6 percent of the Medicaid population, but consume 40 percent of Medical Assistance spending, more than $2 billion a year. (In Pennsylvania, Medical Assistance is the governmental term used for Medicaid.)

Research suggests that two highly important cultural changes are at work here. One is the trend toward home- and community-based services (HCBS), something that citizens—and insurers—want in preference to nursing home care. Increasingly, this is an aim of government policies (including Pennsylvania's Ridge administration), with hopes for cutting costs a major reason. Specifically, the Ridge administration has set a goal of changing the present 95-5 ratio of money going to nursing homes to 60-40 by the year 2005—that is, 60 percent going to nursing-home care and 40 percent to HCBS.

But everyone is nervous about the parameters of HCBS. Would governmental funding include paying relatives for providing care for an elderly family member? At present, the answer is no. Does it include governmental funding for assisted-living facilities—the various alternatives between care in the home and a nursing home? Again, in Pennsylvania the answer is no, something the providers hope to change. And, naturally, nursing-home operators are concerned about the trends away from what some officials call the present "institutional bias."

The second cultural change is the demand on the part of workers in institutions for empowerment and recognition, such as through shared-work teams. This aspect is accentuated by the growing shortage of workers, especially in nursing homes. But it inevitably will affect cost, including any moves to HCBS. This subject will be discussed at further length in Chapter 6.

A result in all of this is a push in the LTC field for more individual foresight and enterprise in terms of buying LTC insurance. The idea is

that, given the costs, there is no way the governmental sector can or will provide all the answers for everybody. And, therefore, answers also will have to come through the private sector—insurers, employers, and individuals and families themselves. The objective of promoting LTC insurance, too, is fraught with uncertainties both on the side of the insurers and of the consumers.

Which brings us back to the Smith family's story. We will first look at the LTC dilemma from that family's viewpoint, namely that of the consumer. The consumer, of course, can be the aging person himself or herself; or the sons and daughters—and their spouses—faced with the care of a parent; or persons of any age deciding whether and when to purchase LTC insurance.

We shall be considering the various options. Medicare, Medicaid, home health care. The various types of institutional care and quality-of-life issues connected with them. The purchase of LTC insurance. The concept of businesses adding LTC insurance to health benefit packages, either directly or as an option—along with the question of portability. The pitfalls for insurance companies in determining risk with a still-small pool in an uncertain actuarial situation.

Here's a comparison to underline that last point. Purchasing and selling life insurance is one thing because everyone eventually will die and the probable lengths of life spans are well known, with actuarial tables built up over the past century and more. But LTC insurance, on the other hand, in one scenario is an obligation the insurer may never have to pay out if the consumer dies before needing institutional care. Or it may be an obligation that could go on for months and years. From the other side, the consumer faces the same uncertainty, a reason some people look at LTC insurance and feel the risk for them is not sufficiently strong enough to consider purchase.

Threaded through these discussions will be public policy considerations, whether at the federal or state level—not only for consumers but for LTC institutions.

We expect to address as much as possible a question that will be uppermost for many persons, especially those in the baby boomer generation still in their earning years, and that is: When is the best age at which to buy LTC insurance?

So let us turn first to Medicare, the federal program that since 1965 has provided a measure of medical care for persons over 65. Although many people think of it as LTC insurance, the watchwords are "Not really" and "Beware."

Chapter 1
MULLING MEDICARE

Because Medicare since its 1965 enactment has done so much to lift from senior citizens the burden of worry over medical costs, it is seen by many as a long-term care (LTC) panacea.

Sorry. It's not quite that. Medicare is available only for acute care and, within limits, for post-acute care. Acute care is defined as hospital treatment necessary because of a sudden problem, such as a heart attack or stroke. Chronic, ongoing day-to-day problems such as diabetes or Parkinson's disease are not included in the definition.

Medicare is a health insurance program for people 65 years of age and older; for some disabled people under 65 years of age; and for people with End-Stage Renal Disease (permanent kidney failure treated with dialysis or a transplant). Medicare, the nation's largest health insurance program—covering 39 million Americans—is administered by the federal Health Care Financing Administration (HCFA).

Karen Wolk Feinstein, president of the Jewish Healthcare Foundation of Pittsburgh, succinctly laid out the outer limits of Medicare relating to LTC in an article in the *Pittsburgh Post-Gazette* (March 19, 2000) when she wrote:

"Most people are shocked to discover that government programs will cover only a portion of their long-term care needs. Medicare, for instance, pays for such services under only narrow circumstances, such as immediately following discharge from the hospital."

Modern Maturity, the magazine published by AARP (the American Association of Retired Persons), defines the rules this way: "By law, Medicare pays for only limited nursing-home care (which must follow a hospital stay of at least three days) and limited home health care."

Further, the federal 1997 Balanced Budget Act reduced reimbursements to Health Maintenance Organizations (HMOs). The result: Many HMOs are dropping plans that don't provide the profits they need to satisfy stockholders.

True, Medicare has made a dramatic difference in the lives of the elderly. A state-specific White House report entitled "*Pennsylvania: the Need for Medicare Reform,*" points out that poverty among the elderly in Pennsylvania has fallen to eight percent from 23 since Medicare was created.

In Pennsylvania, 1,874,000 seniors and 215,000 people with disabilities rely on Medicare. About 58 percent are women. Approximately 11 percent are age 85 or older.

Medicare is big business, with health care providers in Pennsylvania depending on $14 billion in Medicare dollars from the federal government. Indeed, Medicare pays for 24 percent

of all personal health care expenditures in the Keystone state. This is critical to 203 hospitals, 50,000 physicians, 769 nursing homes, and other providers.

But problems abound. For instance, roughly 16 percent of Pennsylvania's Medicare beneficiaries live in rural areas, with limited or no options for managed care or prescription drug coverage.

Furthermore, the White House report predicts that Medicare enrollment will surge as we move into the 21st century. The number of seniors in Pennsylvania will rise from 1,899,000 in 2000 to 2,659,000 in 2025. That means the proportion of Pennsylvanians who are elderly will increase to 21 percent from 16.

At present, only 22 percent of Pennsylvania firms offer retiree health insurance. And nationally, at least, the picture is turning gloomier, with 25 percent fewer firms offering retiree health coverage in 1998 than in 1994.

But what about Medigap insurance, the way many seniors can stretch their Medicare coverage, especially for prescription drugs?

The White House report has this answer: "The monthly premium for Medigap insurance including prescription drugs averages $142 in Pennsylvania, which is out of reach for many seniors." Moreover, "these plans are typically costly and their premiums increase dramatically with age." Only about 1 in 10 Medicare beneficiaries nationwide purchases Medigap with drug coverage, and the extra cost is about $90 per month.

What about Medicare managed care plans? About 1,918,911 or 81 percent of Medicare beneficiaries in Pennsylvania have the option of enrolling in a basic managed care plan that offers prescription drugs. However, nationwide, an increasing number of plans are capping their drug coverage at $1,000 or even $500. For those with unusual needs requiring high-priced drugs, such coverage doesn't go far.

Furthermore, 881,000 of all elderly in Pennsylvania are middle class (defined as those with incomes from $15,000 to $50,000) and would not be eligible for a low-income prescription drug benefit being urged by some advocacy groups.

At an April 14, 2000, Institute of Politics seminar on LTC, government officials present indicated strongly that any talk of establishing a vast new program of subsidizing prescription drugs for the elderly was whistling in the dark. Keeping abreast of present Medicare and Medicaid costs was said to be enough of a drain on tax dollars as it is, they contended.

Later in the year, of course, the question became increasingly and heavily entangled in the Presidential campaign, with candidates Al Gore Jr. and George W. Bush differing on what to do about it. So, despite predictions during the April seminar, the subject was bound to be high

on the agenda of the incoming 2001 Congress.

The bottom line on Medicare, however, is that it will fit certain narrow needs facing those now elderly or baby boomers in the future. But depending on it as an across-the-board LTC answer is folly.

Okay then. But what about that other government program inaugurated in 1965 that has been so helpful for many elderly, namely, Medicaid?

Chapter 2
MEDICAID MAZE

"If worst comes to worst, there is always Medicaid."

Yes, but...

Indeed, probably nowhere is there more misinformation in people's minds about long-term care than that concerning Medicaid.

First, a definition:

Medicaid is the nation's major public health-financing program, launched in 1965 to provide long-term care coverage to millions of low-income people. It has since been expanded beyond recipients of welfare assistance. In Pennsylvania, as noted previously, more than $2 billion of the state budget goes for Medicaid.

But some basic rules based on poverty principles continue to apply. And that's why Medicaid is not the easy answer for families like the Smiths.

Specifically, if Grandmother Louise goes into a nursing home at a cost of at least $4,000 a month, in a few years her savings will be gone. Only then, after her estate has been "spent down," in welfare jargon, will she be eligible for Medicaid, with the joint federal-state health program paying the bill.

But the inheritance will be gone. If she had intended any of that to go for her descendants' college education, that prospect is zapped. Nor, indeed, will there be much left for

any of her heirs—just a pitifully few exempt items. Examples of exempt items are life and burial insurance, up to certain limits, and, usually, an automobile.

The concept, obviously, is that Medicaid is not some escape hatch for everybody. No, the idea is that you must be poor to go on Medicaid.

Okay, how about having Grandmother Louise distribute her estate to John, Jim, Tom, and Mary, thus making herself legally "poor"?

Sorry, Congress thought of that, too.

So the Medicaid law contains a 37-month divestiture provision. That is, eroding the estate by donating it to heirs must take place at least 37 months before one can apply for Medicaid. No last-minute distribution in order to become poor enough to qualify for Medicaid help in meeting nursing home costs.

Not surprisingly, this dilemma has given rise to a host of estate planners, most scrupulous, but some not. For some, ethical as well as practical questions come into play.

First, is it morally right to be taking public tax dollars by circumventing rules designed to make Medicaid available only to the neediest?

The matter is bluntly put in a study conducted for the Health Insurance Association of America by SysteMetrics of Lexington, Massachusetts: "The objective of Medicaid estate planning is to avoid using private wealth to pay for nursing home care, and instead letting taxpayers pay for it through the Medicaid program."

However, as any family such as our Smiths going through the process of meeting the present and future needs of the extended family can attest, it's not that simple. There's the matter of college education that elderly persons want to assure for their grandchildren. There's the asset of independence that an accumulated estate gives an elderly person. Divesting one's assets this way throws the elderly person on the mercy of their children—remember Shakespeare's King Lear?

Finally, there is the Catch-22 aspect that the prospects for entering a good nursing home may depend upon having an estate. Operators are not anxious to have an applicant who is going immediately on Medicaid because of the low rates of Medicaid reimbursement. Better to take someone who has an estate to "spend down" at rates better matching the home's costs for several years before going on Medicaid.

However, two other warning signs concerning Medicaid are pointed out in a document from TIAA-CREF, the major pension system for educators. First, "you may not have much freedom to choose where you get services and from whom, since you must generally use Medicaid-approved providers and institutions."

Second, "once you begin receiving benefits from Medicaid, your state

is legally mandated to recover from your estate the cost of the benefits you received during your lifetime." In other words, you can just about forget about any estate remaining if you go this route.

For all these reasons, the Medicaid route for long-term care is a "yes but" for all but the neediest. Which, from the standpoint of the public purse, is as it should be.

But that still leaves the question for prudent families of how to face up to the problem of long-term care. And that brings us to one of the possible answers—long-term care insurance.

Chapter 3
INVESTIGATING INSURANCE

Increasingly, long-term care insurance is seen as one important answer for the problem of being prepared for the costs of long-term care when that becomes necessary in the aging process.

It certainly is a growth market. As Daniel Lebish of Highmark Inc. pointed out at the Institute of Politics seminar in April 2000, from 1988 to 1998, long-term care policies grew to 4.3 million from 1.1 million. Lebish is senior vice president, business development, for that insurer.

But the market continues to be risky, Lebish said, because the average age of the person who acquires LTC insurance is between 70 and 73 years of age. But insurance policies are based on risk, and policies are only profitable if the insurer can spread the risk of individuals collecting on benefits over a large number of people who are not using the benefits.

There are various types of services for the aging person, any of which may or may not be covered by long-term care (LTC) insurance. They include:

- Services in adult day-care centers or other community centers, usually for people still mobile. These offer respite for a family caregiver.
- Personal care in one's home or in a relative's home.
- Home health care, that is, care

provided by a professional or paraprofessional coming from outside the home.

- Services in assisted living facilities. These are institutions designed for people who can no longer handle routine daily activities by themselves but don't need the degree of support provided in a nursing home. Assisted living generally means long-term housing with private rooms, meals, social activities, and regular help with functions such as bathing and taking medications that residents can no longer perform for themselves.

The services range from ordinary clinic services in the early years of a person's stay to increases in additional services as the person becomes more frail and eventually needs full-time hospital-type care. By definition, persons in such facilities have the financial means to afford admission in the first place.

- Nursing-home care. A nursing home is a residence that provides a room, meals, recreational activities and help with daily living. Generally, nursing home residents have physical or mental impairments which keep them from living independently. They may need protective supervision.

LTC policies typically impose a maximum total benefit, and may state that benefit limit in years of coverage or in total dollars allowed. A policy also may include a waiting period, which is the length of time the patient must wait after beginning to use LTC services before benefits kick in. This means that the patient is responsible for all costs of LTC during this period. The length of the waiting period varies from policy to policy, with shorter periods typically requiring higher premiums.

A policy may also include inflation protection, which increases the daily benefit over time. Naturally, premiums will be higher for this policy asset.

For a majority of persons, the greatest attention goes to the prospect of nursing-home care at some point. Many dread it. Prudent planning for the possibility, however, constitutes one of the great arguments for LTC insurance, as well as proposals for governmental policy changes (see Chapter 7).

For the reality seems to be this: Statistics furnished by the United Seniors Health Cooperative of Washington, D.C. indicate that at age 65, a person has a 43 percent likelihood of being in a nursing home at least once during his or her lifetime. There is a 24 percent chance that the nursing home stay would be for more than one year, and a nine percent likelihood of staying more than five years. As the Cooperative puts it, "It is the long-term stay, with the associated catastrophic expense, against which insurance should protect."

Long-term care is expensive, whether in a nursing home, an assisted living facility, or in the home. A recent survey shows that the average annual cost of nursing home care is

$48,000. The American Council of Life Insurance projects that by the time the last of the baby boomers retires in 30 years, the cost of nursing home care will average about $190,000 annually.

Even less costly alternatives aren't cheap. The Health Insurance Association of America (HIAA) estimates that home care, which averages about $12,000 a year, can end up costing as much as a nursing home if care is needed around the clock. In fact, 24-hour home care now ranges from $480 to $720 a day. And, the HIAA adds, even if full-time care in the home isn't required, the average cost per visit for partial care can range from $50 to $100, depending on the type and level of care provided.

Hence the growing emphasis upon long-term care insurance. Such policies are offered with various basic options including the length of the benefit period, the daily benefit amount, options to increase the daily benefit amount, the care setting, and the elimination period.

In our story of the Smith family, it was obviously too late for the case of Mother Louise—unless very high premiums were paid. But it was equally apparent that it wasn't too late for her adult children and even grandchildren.

Self-evident though this "remedy" might seem, the concept is having to cope with numerous obstacles.

One, as described in the two previous chapters, is that many people assume—wrongly—that Medicare or Medicaid will provide the complete answer.

Second, it is easy to put off even thinking about the need for such insurance, let alone buying it. Regular life insurance is based on the idea that everyone someday will surely die. There is no such certainty about the need for long-term health insurance. One may never need to enter a nursing home; you might die first!

Also, there may be enough assets available by that time to obviate the need for an insurance backup. And, besides, there are so many more immediate pressures on the budget—college costs for the children, installment payments of many kinds, the cost of life insurance itself, and for some families without company-sponsored health insurance plans, the cost of individually purchasing that option. And some may assume that one way or another, the government will be persuaded to add that benefit to Medicare and Medicaid.

Third, all of these uncertainties weigh into the premiums that insurance companies feel prepared to schedule. With life insurance, actuarial tables based on the experience with death rates make premium-setting quite reliable. And the outlays at the time of death are fixed in the insurance policy itself.

But with long-term insurance, underwriting corporations face the uncertainties of "when" in a policyholder's life the need will arise and for

"how long." And there is uncertainty about the point at which the size of the "pool" of policy-holders is large enough to face these contingencies.

One possibility is for employers to include LTC insurance in their employee benefits package. Two factors are likely, however. The first is that it would be part of a "cafeteria" offering, along with dental care, child care, and similar opportunities. Second, the employee would have to pay the premium; the contribution of the company would be that with a company plan, premiums would be lower.

Given these factors, the likelihood is that with most employees, particularly younger ones, LTC insurance would be about the last item chosen from the "cafeteria menu." Still, this remains one of the likeliest non-governmental options arising in the coming years.

LTC insurance contracts necessarily contain restrictive definitions. Some important examples are highlighted in a February 2000 article in the *Exempt Organization Tax Review* written by Laura Kalick of Chevy Chase, Maryland, a lawyer and licensed independent insurance agent who specializes in LTC.

For instance, "chronically ill." For an individual to be considered "chronically ill, he or she must be certified by a licensed health care practitioner as unable to perform—without substantial assistance from another individual—at least two activities of daily living for a period of at least 90 days because of a loss of functional capacity. There also must be certification that the individual requires substantial supervision to protect him or her from threats to health and safety because of severe cognitive impairment."

Also "activities of daily living." The definition includes (1) eating—the ability to move food to mouth after food has been prepared; (2) toileting—the ability to get to the bathroom, to get on and off the commode, to perform needed functions, and to clean oneself afterwards; (3) transferring—the ability to move body weight such as from bed to chair; (4) bathing—the ability to wash the body in the shower or bathtub, including getting in and out; (5) dressing—the ability to put on and take off clothes that are worn daily; (6) and continence—the ability to voluntarily control bowel and bladder functions or to maintain personal hygiene with aid of equipment. Kalick also notes that any LTC insurance contract will have its own concise definitions in this sphere.

Given these realities of LTC, for the individual or family prudently looking to the long future, the inclusion of LTC insurance in planning makes eminent sense.

Yes, but at what age should one begin the process? Here even the experts can differ.

A helpful guide comes from TIAA-CREF, the major national pen-

sion fund for educators described in the opening narrative chapter. Its Teachers SelectCare Premium Calculator assumes the following:

Daily benefit maximum for nursing facility care
$300

Daily benefit maximum for home or community-based care
50%

Benefit period
7 years

Benefit waiting period
90 days

Inflation protection
5%

Now then, if you buy a policy at age 35, your premium would be $3,420, paid annually.

At age 45, your policy would cost $3,450, paid annually.

At age 55, the price rises to $4,110, paid annually.

And at age 65, the annual premium jumps to $5,940.

Here's where arguments can start even among the most disinterested observers.

For example, does it make sense to start buying LTC insurance at 35, when it costs little more to commence at age 45? And thereby avoiding 10 years of premiums in a period when a family is moving toward the college years?

What about the same argument for waiting until age 55? Or does the possibility of life-debilitating illness in those midlife years—stroke, extreme heart condition, the early onset of cancer—suggest folly in waiting too long?

Any quick answer can be tempered for a given family by the prospects of employer-subsidized LTC insurance, a subject we will be discussing in Chapter 6.

But it's a complex gamble any way you look at it, as the Smith family in our introductory tale was finding out.

That's why many experts are thinking beyond individually-financed LTC insurance to supplementary approaches involving employers and changes in governmental policies (see Chapter 7). Hopes for the latter have been heightened by Congressional passage in September, 2000 of a law under which federal workers and members of the military may buy insurance to cover the cost of caring for elderly and ailing relatives. The legislation authorizes the federal Office of Personnel Management to negotiate with private insurers to offer LTC insurance to as many as 13 million government employees, retirees and their families (Reuters News Service story printed in the Sept. 20, 2000, issue of the *Pittsburgh Post-Gazette*).

In many LTC programs, the federal government sets the guidelines. But the states then make the decisions as to how the programs will be run, including licensing provisions and reimbursement formulas.

Therefore, it is important that we next consider the policies of Pennsylvania state government under the aegis of Governor Ridge.

Chapter 4
PENNSYLVANIA POLICY

The trend in Long-term care (LTC) away from institutions such as nursing homes is nowhere better illustrated than in current policies of the Pennsylvania Department of Public Welfare (DPW).

At an Institute of Politics seminar on LTC in April 2000, Dr. Peg Dierkers outlined that Ridge Administration policy. She is deputy secretary in the Office of Medical Assistance Programs. Dierkers said the goal is to alter the present ratio of LTC money going to nursing home care from 95-5 to 60-40 by the year 2005. That is, the Medical Assistance money going to alternatives encompassed in home and community based services (HCBS) will jump from 5 percent to 40 percent. (Medical Assistance is the term used in Pennsylvania for the federal-state Medicaid program.)

One rationale is that most people dread the idea of a nursing home and will welcome the alternatives of services that will allow them to retain a degree of independence, including staying in their own homes. But clearly another factor emphasized by Dr. Dierkers is that at present 38.8 percent of Medical Assistance funds are going to LTC, even though its recipients are only 12.5 percent of the Medicaid-eligible population. The rest are mostly women and children. (Her presentation was based on

1996-97 data.)

In elaborating upon DPW policy, James Pezzuti says, "We would like to have the services attached to a consumer, not to a provider. This is not an anti-institution move because many people will want to stay there." Pezzuti is director of the division of Long Term Care Client Services.

"We are seeing sicker people in nursing homes and that's appropriate and showing there is a need for them still. Yet the overall institutional occupancy rate is on a steady three-year decline."

Pezzuti elaborates, "But we want the consumer to have a choice, and we'll support them where they want to go. At present, many consumers are required to go to an institution to get services, even though that means living by the rules of the institution," Pezzuti says. "We prefer that the consumers have a choice to get those services wherever they want to have them. That means encouraging the expansion of home and community based services so the money can follow the client."

Consumers are more sophisticated now, Pezzuti says, and are aware of available programs—and want them. "They tend to avoid nursing homes, if possible, so that the nursing homes are losing market share, as we are offering consumers a choice of services."

The possibilities include what are called "hard services," ranging from having a nurse come by the home periodically to more complete staffing. Then there is respite care to give a break to the caregiver relative (daughter, wife, husband). That can include having someone come in for an afternoon while the caregiver goes shopping, for instance. Or it may mean a person going to a nursing home for a week or two while the caregiver is on vacation.

Under the DPW plan, decisions on these matters come via a case-by-case assessment that is done by a case manager.

However, this doesn't mean opening wide the treasury door.

For instance, the amount of money spent on a consumer utilizing HCB services cannot exceed the cost if he or she were in a nursing home. That is, there is a gross dollar basis for spending, with spending caps per individual set by the DPW. Rates per individual service are set by the local Area Agency on Aging.

And these HCB services are non-entitlement programs, Pezzuti said. "We are not trying to create new entitlements."

The DPW also has launched a new initiative called the Community-Based Fall and Risk Prevention Program, which is starting in Philadelphia. The intent is to provide intervention services to elderly persons identified for risk or falls and/or failure to take their medication appropriately. Experience has shown that falls often can incapacitate a person to the

point that going to a nursing home becomes inevitable. Also, of course, such falls among the frail elderly (such as those in their 80s) can lay the person open to illnesses that lead to death.

An obvious question: How about paying the relative who is the caregiver? Pezzuti stated there are severe federal restrictions on any such payment. But he added that this is a subject of discussion at the state and federal level, with some states trying tentative experiments.

Further, at this point the DPW does not pay for waiver services in a personal care home. "Waiver" refers to action by the federal Health Care Financing Administration (HCFA) waiving specific federal rules on Medicaid reimbursements, a way to effect changes without engaging in the cumbersome and risky process of going to Congress to rewrite the law.

Pezzuti notes, "However, we are currently looking at the possibility of allowing a consumer in a personal care home to stay there and get additional services. This would require action by the state legislature."

A personal care home is a sort of successor to the old boarding home for elderly people. On the scale of services, it ranks higher than in-home care but below assisted living and nursing home facilities.

What the DPW is adamantly opposed to is having more "bundling." That's where one service encompasses a range. A nursing home, for example, is a bundled service, providing lodging, food, medical care, chore services, etc. Pezzuti says that other agencies want to offer "bundles" that could include home health care, chore services, etc.

But the DPW doesn't want to go that route because it contravenes the idea of individual care plans. It opens the door for an agency to provide and pay for an array of services beyond what an individual wants or the DPW is willing to pay for. Moreover, it can entail moving service dollars to capital for constructing or improving buildings—as the DPW has learned from its experience with nursing homes.

Individual service plans allow a consumer to choose a variety of services from a variety of providers. "They might like X for chore services, but shouldn't have to take other services from that same X provider," Pezzuti explains.

This view undergirds DPW resistance to putting money into assisted living, because their apartment-and-service packages represent a bundling of services for the person or couple moving in. In particular, Pezzuti says, the DPW has no interest in bundling housing with services, as an institutional setting does. It wants to stick with funding services, rather than financing capital projects.

An assisted living facility may become a provider of waiver services and receive reimbursement for those services as long as the service is ordered by the case manager and the

consumer chooses the facility to provide the service.

As the experience with nursing homes shows, "A provider would like to have a guarantee when he builds a facility that Medical Assistance then would have to pay him when a consumer moves in. So there are moves to have Medicaid pay for a bundled assisted living package. But this displacement of consumer choice is exactly what we don't want. We don't want to force consumers to move to such a place in order to get services."

Needless to say, as described in Chapter 6, this is causing considerable concern among operators of nursing homes and assisted living facilities.

Finally, at play in the LTC picture is the tobacco settlement.

Pennsylvania has garnered $11.2 billion from the settlement the tobacco industry made with the attorneys general of the states, who had sued on grounds the deleterious effects of smoking on many smokers had impacted their Medicaid budgets. The money is to be received over a 25-year period.

So far Pennsylvania has received $463 million of its settlement share. But any use of it was stalled in the 2000 State Legislature where differences of opinion rose over Governor Ridge's proposals for spending it.

The governor wanted the money to provide low-cost health insurance for state residents without coverage, anti-smoking programs, reimbursements to hospitals for unpaid care, health research—with a significant 15 percent going for HCBS for senior citizens. In addition, he proposed a non-health component—the creation of a public-private investment fund to help fledgling biotech firms.

But Democrats in the House of Representatives countered with moves to carve out $91.8 million to boost the PACE program to help more low-income seniors pay for health coverage. PACE in this instance stands for Program of All-Inclusive Care for the Elderly.

As of the time of publication of this *Issues* brief, the matter is unresolved.

At this point, let's take a look at a PACE program already in place.

Chapter 5
THE PACE PROSPECT

To glimpse the future of Long Term Care of the elderly, take note of the newly established Community LIFE institution in McKeesport, Pennsylvania.

Community LIFE (acronym for Living Independently for Elders) embodies the principles of a nationwide movement called PACE. In this case, PACE stands for Program of All-Inclusive Care for the Elderly—to be distinguished from such other uses of the PACE acronym as relating to prescription drugs, alternative schools and the like.

Community LIFE (CL) is, in effect, "a nursing home without walls," providing a comprehensive service package for individuals with Medicaid and Medicare benefits who are faced with the prospect of entering a nursing home. CL allows an individual to remain in the community, despite medical and functional frailty, rather than moving to a nursing facility. CL arranges a full array of health and social services 24 hours a day, 7 days a week, 365 days a year.

The PACE concept is based on the On Lok model developed in San Francisco's Chinatown community in the early 1970s. PACE now has the backing of Congress through the 1997 Balanced Budget Act. It has accomplished the bureaucratic miracle of achieving agreement from both the Medicare and Medicaid programs for a joint approach in rules, regulations, and the funneling of funding.

On Lok is Chinese for "peaceful, happy abode." Citizens of Chinatown, noting the increasing numbers in their community of aged persons, particularly the frail elderly, sought ways in which in a modern, scattered family environment, they could provide services to keep their seniors out of nursing homes and in their own homes as long as possible. They came up with a system of home and community based services that eventually caught the attention of LTC experts and then the appropriate governmental agencies.

To enroll in Community LIFE, one must be 60 or older, have or be eligible for Medicare and Medicaid, be able to live safely in the community with the services provided, be deemed eligible by the Allegheny County Area Agency on Aging for nursing home placement, and live in one of 32 zip codes in the southeastern third of Allegheny County.

A tour through the CL facility on McKeesport's Fifth Avenue with its executive director, Ransom Towsley, demonstrates the breadth of activities.

Coming in through the front door are a dozen elderly persons, transported in a CL van from their own homes, some on crutches or in wheelchairs. Depending upon their condition, most of these enrollees—as they are called—will go to a community room where the regimen will be much

like the usual adult day care center: bingo, card games, Bible study, lunch. There will be occasional outings, such as a recent CL trip to Kennywood, which to many brought back memories of good times there long ago.

Persons with dementia go to a separate, secure part of the facility.

Those with a medical need will be referred to the on-site clinic, which has available for routine as well as some emergency care a team consisting of a physician, nurse, nurse practitioner, physical therapist, dietitian, pharmacist, social worker, and nurse aide. Starting with the time of first enrolling, the participant will be meeting with this team to decide what services are to be provided.

If hospitalization is necessary, the participant will be taken across Fifth Avenue to the UPMC McKeesport Hospital. (CL is housed in a renovated warehouse formerly used by the McKeesport Hospital—now UPMC McKeesport.)

Important components of CL that might not occur to the outsider are showers and a whirlpool bathtub. This is a help for elderly people having difficulty in managing a bath or who don't have adequate facilities at home. Rowena Lynch of the CL staff recalls that a woman who was asked during her enrollment interview what she would particularly like replied: "Some water coming down over me." It turned out that she had had only sponge baths for the previous five years.

"We scrubbed her down, washed her hair, and she stayed under the shower for two hours; she was so gleeful," Lynch recalls.

All told, the range of services available at CL includes medical care and diagnostic tests and prescriptions; nutritional counseling; social services; physical, occupational and speech therapies; dentistry; optometry; podiatry; transportation; and—in the home—skilled and personal care, Meals on Wheels, home safety and energy assessments, and minor modifications.

Towsley explains that the whole purpose of CL is to make it possible for enrollees to live in their own homes as long as possible, through having available the medical and socialization care they need. As their aging progresses, they are prepared for any end-of-life hospitalization, hospice care, or nursing-home care. Implicit is acceptance of the idea that even today's high-tech medical system will not cure everything or sustain life indefinitely. The idea is a continuum of personalized care on a case-by-case basis to enhance the independence and quality of life of the participant to his or her highest functional ability, Towsley explains.

Significantly, the writer of this monograph was urged to visit Community LIFE both by officials of the Pennsylvania Department of Public Welfare and by spokespersons for providers—two groups often at odds over what should be done in LTC and how

it should be financed.

Indeed, how is all this possible financially? The answer started with a 1980s federal demonstration process with On Lok, leading to a 1983 Congressional act making possible six demonstration projects across the country, whose success has led to a significant expansion of PACE, with 12 sites in Pennsylvania including McKeesport's Community LIFE.

The key is the federal legislation to allow a blending of Medicare, Medicaid, and private dollars to make possible capitation grants to institutions such as CL. Capitation means a set payment per enrollee.

The legislation was designed to overcome the "never-the-twain-shall-meet" barriers between Medicare and Medicaid disbursements. The federal Balanced Budget Act of 1997 established PACE as a permanent type of provider under Medicare and as a state option under Medicaid.

Towsley explains the result as a "win-win" proposition for everyone. For governmental agencies, it is a risk-free proposition with the cost a known quantity per person per month. In Pennsylvania, the capitation formula, while complex, is based on a percentage of the amount of Medicaid dollars provided by the State Department of Public Welfare to nursing homes, currently $3,216 per patient per months. Under the PACE arrangement, CL has received 95 percent of that amount for the first year, 90 percent the second year and 85 percent from then on.

Likewise, for PACE providers like Community LIFE, the capitation system means it knows how much money it has to work with, based on its enrollment. (As of September, 2000, CL had 240 enrollees.) If the provider spends more overall, it's the loser. But if it comes out ahead, as a nonprofit agency, it will put the profit into a special fund against unexpectedly large costs, such as paying for a hip replacement for an enrollee.

But most important, Towsley maintains, it is a win-win for the enrollee. He or she has a "wrap-around" arrangement meeting all needs but without having to navigate the system to find one agency for one need and another for something else.

That's because the new enrollee and his or her caregiver—daughter, son, other relative—sit down with a CL caseworker to decide just what is needed from among the array of services available. That evaluation is kept up to date as conditions change for the enrollee.

How does this differ from the "bundling of services" which the DPW resists? (See Chapter 4.) The answer is that the PACE offerings do not include lodging and board, the key element in the programs of many other kinds of facilities which the DPW is determined to fight off.

Why McKeesport? Not only is it the center of the southeastern third of Allegheny County, but it is a town hit by demographic changes with the

downturn of the steel industry in the early 1980s. Its 35 percent population loss included the exit of many younger families, leaving their elderly relatives without the family caregivers they had expected to have in their declining years.

Note: Community LIFE is the provider for one of three PACE catchment areas in the county—territory in 32 ZIP codes in the Mon Valley and the southeastern suburbs, edging into Wilkinsburg and Pittsburgh's Squirrel Hill and Shadyside neighborhoods. Another PACE facility in the Greentree suburb, LIFE Pittsburgh, is also a going concern, serving the South Hills as far as Mt. Lebanon and Upper St. Clair and reaching into Pittsburgh's West End, Northside and Hill District. A third PACE facility for the rest of the county is in the planning stage.

Instrumental in getting Community LIFE off the ground has been the Pittsburgh Care Partnership, Inc., a nonprofit 501 (c) (3) agency sponsored by the Jewish Association on Aging, Presbyterian SeniorCare, and UPMC Health System.

The next step for CL is a joint effort with the Allegheny County Housing Authority to establish a PACE unit in a public housing project in Homestead. This coincides with a renovation venture there under the Hope 6 program of the U.S. Department of Housing and Urban Development (HUD) to make more apartments handicap-accessible and otherwise more usable for longtime residents now aging into frailty. The idea, Towsley explains, is to allow people to stay as long as possible in the place where they have lived, rather than having to go to a county-run Kane Hospital or a nursing home.

As can be seen, the PACE facility goes a long ways toward (1) meeting the expressed wish of elderly persons to stay in their homes as long as possible and (2) providing for them in one place a range of service choices—something the DPW has as a goal.

That suggests that in the future a great deal of attention—and government financing—will go in the direction of PACE. The consequences for nursing homes, personal care homes, and even some assisted-living institutions may be considerable. Certainly, the PACE process offers a modicum of hope as a societal answer for the ever growing number of elderly persons in the forecast, particularly the frail elderly in their 80s and 90s.

The various problems facing providers of services for the elderly constitute our next subject.

Chapter 6
PROVIDER PREDICAMENTS

For provider institutions in the long-term care field, times are all topsy-turvy.

Two trends outlined by Mary Anne Kelly are altering the LTC landscape in ways discomfiting to just about everybody in the field. Kelly is executive director of Southwestern Pennsylvania Partnerships for Aging, commonly nicknamed Swippa.

The first is the trend toward keeping elderly people in the home as long as possible. Not only is this the preference of most elderly people, Kelly explains, but the dread for many of going to a nursing home is well-known in the field. This has led to increased attention to a category called Home and Community Based Services.

Also, the state government is pushing hard in that direction, both for humanitarian and for financial reasons. As explained in the Chapter 4, the State Department of Public Welfare is working to change the ratio of Medicaid money it allocates to nursing homes down to 60-40 from the present 95-5.

Certainly, there is room for change. A 1996 University of Minnesota survey showed Pennsylvania at the absolute bottom of the states in the ratio of Medicaid clients receiving HCB services (4.37 percent), as against a national average of 64.05 percent. (New York state topped the list with 87.61 percent.) Even in the proportion of all LTC cases that are HCBS clients, Pennsylvania at 55.75 percent was second only from Tennessee's percentage at the bottom of 46.53.

The second trend is the growing shortage of workers in institutions for the elderly, particularly nursing homes. As Kelly puts it, "When you can make more money putting candles on the shelf for Target than handling bedpans and changing diapers, it's no wonder."

Beyond the question of salaries is the matter of low self-esteem and the feeling of workers of being disregarded by management and their supervisors, Kelly reports. This, in turn, is propelling institutions to a system of "shared work teams" in which the opinions of workers at all levels are valued. Administrators, physicians, nurses all need to realize that although it is the bedside worker who spends the most time with the client, often she or he is the least valued, the least likely person to be asked for an opinion. Yet, Kelly notes, that person is the one the client most often cites to relatives.

"The empowerment of staff is crucial, including mentoring programs," Kelly contends. "We have found that what attracts people to the field is not necessarily the money or even the closeness to home of the job but, instead, the relationship with the rest of the staff and with the

clients themselves."

Institutions for the elderly range all the way from adult day-care centers through personal care homes, assisted-living institutions, nursing homes and hospices to acute-care wings in hospitals. (For fuller descriptions, see Chapter 3.)

Day-care centers usually concentrate upon recreation and socialization, valuable for the lonely elderly. They also perform the important function of providing respite for caregivers in the families of the elderly—hours when they can be free to do other things for themselves. These adult living centers are licensed by the State Department of Aging. Their income derives from county disbursements and from private pay, often by relatives welcoming the respite opportunity.

The personal care home category covers a wide mix of institutions, roughly everything between day-care centers and nursing homes. They receive no state DPW reimbursement. Often housed in converted homes or convents, they can be faith-based or "mom and pop" operations. They are licensed by the state DPW to assume responsibility for three or more persons unrelated to the provider. In a sense, they are the successors of the old boarding homes, providing lodging and meals for a small group of persons. In many states they are still officially called boarding homes. There are an estimated 1,800 personal care homes in Pennsylvania; including 800 in the 10-county southwestern corner of the state.

A 1998 survey by the Albert Einstein Hospital Network and the Philadelphia Corporation for Aging determined that Pennsylvania has 31,508 persons living in personal care homes, with 27,724 (88 percent) over 60 years of age.

One of the efforts of provider groups is to obtain state recognition for reimbursement purposes, both of the special problems and of the possibilities of utilizing personal care homes for dementia patients and for the frail elderly, as an alternative to nursing homes.

The assisted-living category usually caters to more well-to-do elderly because of price, and therefore receives no state DPW reimbursement. Indeed, these facilities have sprung up in recent decades precisely as a way for people who could afford it to avoid a nursing home. As noted in an earlier chapter, the American Association of Retired Persons (AARP) defines assisted living facilities as "designed for people who can no longer handle routine daily activities by themselves but don't need the degree of support provided in a nursing home."

The general concept is that a couple or person pays up front for continued care. They have an apartment of their own, with one or two meals a day in a common dining room. A medical facility is available. In some assisted-living institutions, the care

can continue as the person becomes frail or needs full-time care—nursing home care, in effect.

In recent years, some assisted-living institutions have had to add dementia units for Alzheimer's patients.

This brings us to nursing homes (around-the-clock nursing care available), with one "intermediate" exception. That is the new Program for All-Inclusive Care for the Elderly (PACE) as a step short of the nursing home. This example of an institution offering HCB services was discussed in Chapter 5.

As to nursing homes, the public perception becomes a factor. For instance, from time to time, stories appear in the media about abuse of patients in nursing homes by caretakers or about corruption in management.

Unquestionably, these incidents are a blight upon society and require not only sensible regulations but oversight to be sure they are followed. In Pennsylvania, this responsibility lies with the State Department of Health. The involvement of the DPW also is crucial in that it dispenses the Medicaid funds which are essential to the fiscal structures of many nursing homes.

But these outrages may cause the public to overlook another aspect: What would society do if the nursing homes went out of business?

While such a cataclysm is unlikely to occur, in Pennsylvania as elsewhere there are pressures on the providers that are diminishing their ranks and raising policy questions in both the private and public spheres. These are coming at a time when people are living longer, with an increased amount of dementia putting more demands upon personnel and facilities—paralleling the problem for assisted-living institutions.

Recognition of this quandary came in a September 16, 2000 radio address by President Clinton in which he noted that half of U.S. nursing homes do not have adequate staffing levels. He proposed a $1 billion investment over five years to improve nursing home quality. Replying for the Republicans, U.S. Rep. J.C. Watts of Oklahoma said Clinton had ignored the problem of a legal system "run amok. . .forcing many nursing homes to shut down because trial lawyers sue at every turn."

According to experts such as Kelly, in Pennsylvania two factors are at work:

First, as noted above, in the current low-unemployment situation, it is increasingly difficult to attract and hold workers, regardless of wage offers, for what is often a thankless, drudge job in dreary surroundings. At the same time, 85 percent of care is now done by certified nurse assistants. This is a change from the days of the licensed practical nurse (LPN); many LPNs have gone on to become registered nurses. An obvious answer—pay higher wages—in turn is undercut by

a second factor, described as follows:

Officials of provider institutions complain that the low rates of reimbursement, whether from Medicaid or from private insurers, mean an increasing cost squeeze. The variety of assisted-living facilities that have sprung up has also hurt in terms of competing for higher-paying clients.

Competition is forcing nursing homes to look different; to be more residential rather than "warehousing;" to do away with such hospital-like fixtures as nursing stations; to "edenize" with flowers and color and animals rather than drabness—in effect, a scale more human. So to keep up to date, operators find they need newer or renovated buildings. But many of them can't afford even to change what they now have, often requiring a resort to double-occupancy of rooms, negating the human-scale concept.

This particular squeeze has come because the DPW since 1983 has resisted providing money for capital improvements—bricks-and-mortar—a daunting factor for providers, considering that the current capital cost for a "bed" is $100,00 to $120,000. That DPW moratorium position is taken largely on grounds that there are too many nursing-home beds already (see Chapter 4). Not surprisingly, the combination of these reimbursement and moratorium policies has nursing-home operators "scared to death," in the phrase of one LTC expert.

To be sure, one remedy proposed is the privatizing of such institutions. But under present circumstances, observers such as Kelly ask: Who would want to buy them—particularly if it means picking up the debt service?

Private insurers, too, are concerned about the state's reimbursement policies because of worries about cost-shifting. That phrase is the term for a provider practice of higher billings for private-insurance clients to make up for the "shortfall" in government reimbursements. And, as noted in Chapter 3, for insurance companies there are pitfalls in determining risk with a still-small pool in an uncertain actuarial situation.

Still up in the air is the concept of private businesses adding LTC insurance to health benefit packages, either directly or as an option.

And the question of portability for employees changing jobs. Meanwhile, Congress has taken no action on a proposal by Sen. Ted Kennedy of Massachusetts to add to the federal insurance system a Medicare C component comprising LTC insurance.

Third, the mounting costs of drugs is hitting LTC institutions hard. As a hospital consultant said at an April 2000 Institute of Politics seminar on LTC, "Nobody's looking at the consequences down that road." State Senator Tim Murphy of Upper St. Clair echoed, "With the prescription drug problem, we are headed for a train wreck."

One result—a growing number of nursing home bankruptcies—was cited at the Institute of Politics seminar by Judy Fitzgerald, chief judge of the U.S. Bankruptcy Court in Pittsburgh. In many cases, it's smaller nursing homes unable to pay back bricks-and-mortar loans.

However, Richard Browdie, Pennsylvania secretary of aging, suggested at the seminar that the reason many LTC institutions are in such trouble is because of mergers and acquisitions, not operational costs.

Hanging over the entire scene is the impact of managed care. This works both ways. For managed-care organizations, there is the challenge of making financially viable the burgeoning of clients moving into the LTC category. For providers in the HMO frameworks, there are the added rules they have to follow, the increased paper work all around, the decreased reimbursement.

Even the turn to home care heralded by most people in the field has its question marks. An enthusiast, Charles W. Pruitt Jr., nevertheless cites some "gap areas." He is president of Senior Care Solutions, consultants. One instance was the decision of the Visiting Nurses Association of Allegheny County in April, 2000, to go out of business, with reimbursement cutbacks as a major reason.

In today's job market, finding persons to provide home care is a problem, and especially if the patient has Alzheimer's, Pruitt adds.

The DPW is cautious about providing reimbursements for home care, not wanting to open wide the treasury door. And there is a definite "No" at this point to the idea of paying relatives to furnish the care. (See Chapter 4.)

Interviews with Kelly, Pruitt and other knowledgeable persons suggests there are policy questions galore from the viewpoint of providers.

Clearly, the reimbursement question is high on the list. If institutions at various levels are to humanize, requiring capital expenditures in many cases, the federal and state governments may need to reassess policies on that score.

Coming over the horizon is the question of public housing projects, where many clients are becoming older. If they are to stay there where they've lived for years, rather than going to a nursing home, new approaches may be needed, such as providing meals. Can Meals on Wheels suffice? The same considerations may have to be taken into account in high rises for the elderly. (See Chapter 5 for an approach being launched in Homestead, Pennsylvania.)

Finally, Pruitt raises the question of where responsibility can lie for addressing Pennsylvania's LTC needs when power is now shared among three departments. Although the DPW controls finances through the Medicaid reimbursement system, it

is the state Health Department that licenses nursing homes and the state Department of Aging that licenses adult care centers. Left out of the licensing equation are assisted living facilities and home care organizations.

It stands to reason that if a continuum of care is desirable, there needs to be some overall umbrella entity, if not an overarching authority. If nothing else, the present system leads to uncertainty and confusion on the part of providers and insurers, not to mention the elderly themselves.

We now turn to some final observations.

Chapter 7
AMONG THE ALTERNATIVES

As long term care for the elderly is a many-pronged problem, so will it require many answers—from government, from the private sector, especially employers—and from individuals.

An abundance of material and proposals is available from such organizations as the Southwestern Pennsylvania Partnership for Aging (724-779-3200); the Pennsylvania Intra-Governmental Council on Long Term Care (717-783-1550); and the Jewish Healthcare Foundation (412-261-1400).

First, let it be said that the moves toward home and community based care are all to the good. That's what most elderly citizens want in preference to nursing homes. And government officials see it as a way to curb the rocketing share of the state budget that Medicaid (Medical Assistance in the state's parlance) is taking.

But the State Legislature and the state Department of Public Welfare (DPW) need to realize that this approach is not some kind of tax-saving bonanza. For instance, as pointed out in Chapter 6, for the home and community based services (HCBS) approach to work, there will need to be infusions of funds. If it is to be humane, there will need to be adequate money for obtaining, training, and retaining competent personnel.

Second, even by the ratio the Ridge administration and DPW hope to achieve on nursing homes versus home-based care, the former still will be the majority service. As described in Chapter 4, the goal is to cut the ratio of money from 95-5 in favor of nursing homes to 60-40.

Well and good. But what about the quality of the nursing homes that still will carry the load? Here's where the question of inadequate reimbursement formulas comes into play. Of course, the DPW's determination not to spend money on bricks-and-mortar sounds good. But what if the cost of humanizing nursing homes, both in terms of renovations and of better salaries, drives too many of them out of business? What have we gained?

Both the DPW and experts in the provider field seem enthusiastic about the (PACE) experiments around the state (see Chapter 5). They provide choice and don't involve the cost of lodging and board that the DPW eschews. Note: This PACE program is to be distinguished from the better known program with the same acronym—PACE for Pharmaceutical Assistance Contract for the Elderly.

And any consideration of meeting the requirements of all needy Pennsylvanians must include those living in public housing projects. Here the extension of Community LIFE, the PACE project located in McKeesport, into a public housing community in Homestead is a refreshing venture.

But talk for a moment about bricks and mortar! Can money for the facilities for all the PACE projects needed eventually to service the elderly around the state come from the private investment sector?

Likewise, there may need to be new thinking about the provisions against Medicaid reimbursements for certain aspects of personal care homes and even assisted living institutions. One can understand the apprehension of state officials and the Legislature about opening a bottomless pit.

But, again, if these institutions continue to fail, the burden will fall on the state—with more cost likely in the end.

Broadening that effort to other housing projects will require working with the federal Housing and Urban Development (HUD) agency, something that state officials should push.

This suggests the need by state government to take a long-view look at the totality of long term care and what it will take. Deplorable as the thought is, if that requires an increase in taxes, that may be better than a penny-wise pound-foolish approach that really costs a lot down the road.

Moreover, what more appropriate use for tax dollars than to ease the final years of the citizens who carried this state through the Depression, fought its wars, and suffered the downturns of deindustrialization, a process which caused the exodus of younger relatives who otherwise might be their caregivers today?

And while the Legislature is about it, members should give a thought to remedying the present troika system of governance. As explained in Chapter 6, while the DPW manages the Medicaid reimbursements, the state Health Department licenses nursing homes and the state Department of the Aging licenses the adult day care centers.

It's hard to see how this trifurcated, to coin a phrase, system can make possible any concentrated approach to the problems outlined in this *Issues* brief. Ideally, authority and responsibility for LTC should be housed in one agency.

Finally, LTC insurance. Here the primary responsibility lies with the individual and family, with purchase during the earning years obviously the best solution for most people. Different experts prescribe what they consider the best age. Most treatises on the subject urge the earlier the better, in terms of obtaining the best premium rates.

But that may not seem practical to families facing the cost of college education for their youngsters. Therefore, from a sensible viewpoint, the best time would seem to be in their 50s, a maximum earning time when the task of paying for the children's college education is largely past and before the costs of paying for elderly parents begin to burden family finances. For the baby boomers who soon will be entering the senior scene, that means starting the process now.

But because of the actuarial vagaries of LTC insurance, a workable solution would be for the corporate community to include it as an option offered in health-benefit programs. A precedent in many corporation packages is that of offering term-life-insurance as an option. Even if the employee pays the entire premium, the cost would be lower because of the pooling effect, as well as the possibility of employers banding together to access the insurance at reduced rates.

To make LTC insurance plans for employees more appealing to business, federal legislation for some kind of tax credits may be necessary. A benchmark program may be evolving with the announcement (discussed in Chapter 3) of an LTC insurance option to be offered to federal workers.

Again, the appeal to members of Congress would be that any loss to the federal Treasury in the short run would be more than made up in the long haul with insured citizens able to pay for their own long term care without hitting the public dole.

Who is to engineer all of this? Ideally, it would come through the political process.

One hates to call for yet another study. But it may take a coordinated survey by or supported by philanthropic foundations to work through the maze of conflicting turf interests and lay out the pathways for federal, state, community, and individual

action. After all, as one of the oldest proverbs has it, "A stitch in time..."

THE END

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