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Connecticut Long-Term Care Needs Assessment

Focused Report I:

Financial Planning for Long-Term Care:
Individual Expectations and Plans ~

A Closer Look at
Long-Term Care
Insurance

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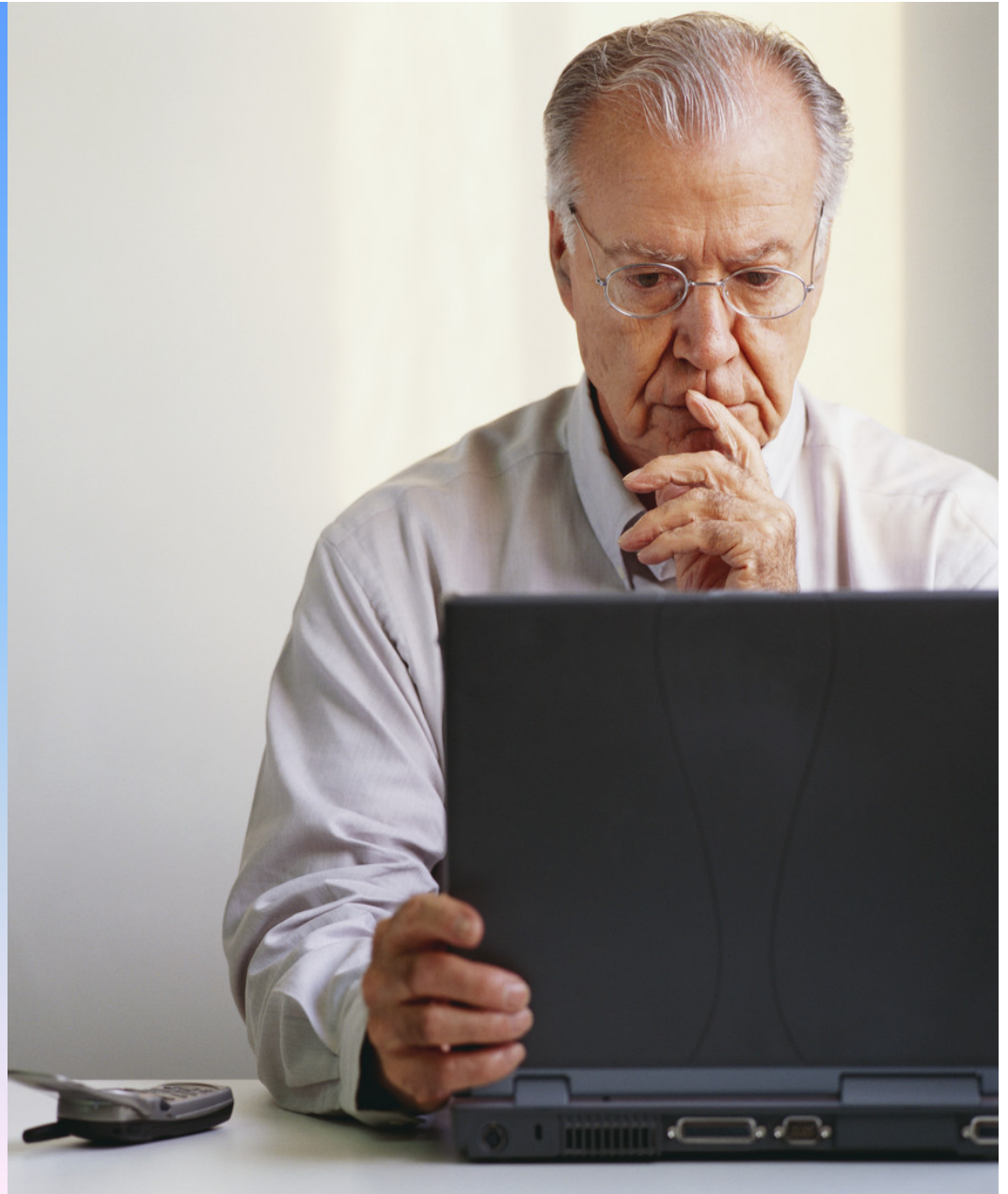
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Executive Summary

Current aggregate expenditures for long-term care are substantial and are projected to increase rapidly in the coming decades with the aging of the population. Nearly half of long-term care costs are paid by Medicaid, primarily borne by the states[1]. States are seeking to control escalating Medicaid costs in part by increasing greater private responsibility for paying for care. The 2007 Connecticut Long-term care Needs Assessment survey gathered information on individual plans to pay for long-term care, including a wide range of public and private sources. The present study was done in follow up to the needs assessment to generate additional insights into the concerns, motivations, preferences and expectations of Connecticut residents regarding paying for long-term care. Interviews and focus groups were conducted with Connecticut residents from across the state (32 interviews and 6 focus groups with a total of 40 participants).



Summary of Key Findings

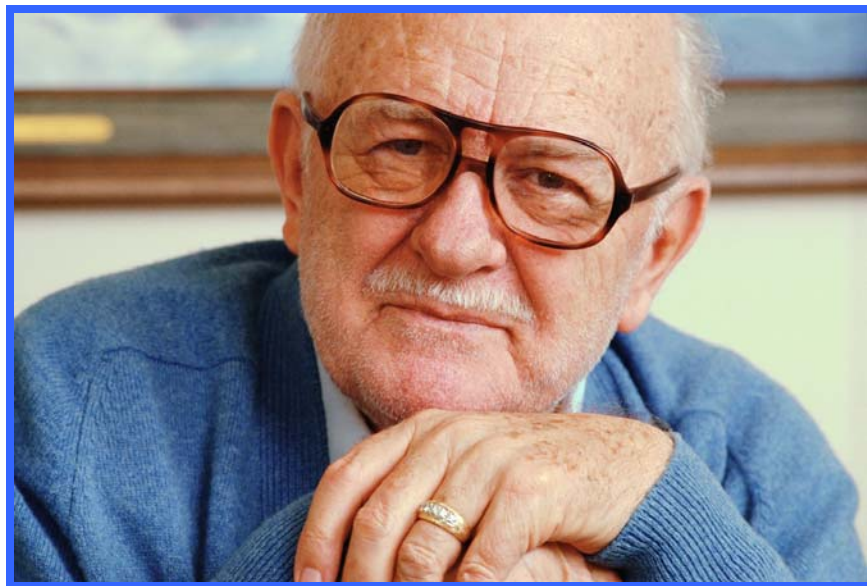
The focus group discussions and individual interviews generated a substantial amount of information related to individuals' expectations and motivations for financing their own long-term care in the future.

1. Participants described a wide range of strategies or approaches they plan to use in order to pay for long-term care should they need it in the future. Options included using their own current assets in various forms, taking out a reverse mortgage, relying on the Medicaid program, pursuing alternative housing arrangements and buying long-term care insurance.

2. There was extensive discussion regarding the potential role of long-term care insurance in people's financial plans. Participants described assessing tradeoffs among multiple competing factors when considering whether or not to purchase long-term care insurance. Those who had purchased a policy or were considering a purchase reported a wide range of benefits and motivations for buying a policy, while others described considerations important to them in their decision not to buy a policy. They also discussed possible incentives that might encourage greater interest in long-term care insurance.

3. Discussions highlighted a number of factors that influence individual considerations regarding the most appropriate plan for their circumstances. A number of factors were identified by participants as influencing their planning efforts, including affordability of long-term care insurance (addressed above), their own individual planning style, psychosocial factors, family and peers, considerations regarding Medicaid quality of care, and individual preferences for a care setting.

4. Participants described the source and nature of information about long-term care financing alternatives currently available. Participants identified a number of issues related to information about the full range of long-term care financing alternatives. Sources of information are quite limited or are unknown to the general public and many available informational sources lack credibility for potential consumers. Information that is available is frequently confusing and overwhelming. The one exception to this was the Partnership for Long-term care, which participants uniformly perceived as trustworthy, neutral and unbiased.



Recommendations

There are four primary recommendations as a result of this study.

1. Continue and enhance multiple efforts to educate the public about the full range of long-term care financial planning alternatives

The 2007 Connecticut Long-term care Needs Assessment concluded that education for state residents about many aspects of long-term care financing must be a key priority for state policymakers [3]. This study explored the views of residents who were somewhat more financially sophisticated than the general population and found that the need for education persists, even among this group. One of the strongest themes from the discussions was the critical need for objective, clear, accessible information about the full range of long-term care financing options.

The content of educational programming should be comprehensive in providing information about the full range of long-term care financing options to both people in the planning stages and people confronting an immediate need for services who may not have done adequate planning. To the greatest extent feasible, the information should use clear, direct language readily understood by the general public. A comprehensive planning tool setting forth a clear and concise review of the entire menu of options and identifying possible sources of neutral, objective information is strongly recommended.

2. Review current long-term care insurance agent training to identify potential areas of improvement

This study suggests some professionals advising clients on long-term care financing issues do not consistently provide current, comprehensive and objective information. Current standards for training of professional financial advisors should be reviewed and enhanced as needed. Other states should be surveyed to determine whether there are best practices that Connecticut might adopt.

3. Address affordability of long-term care insurance at multiple levels

Affordability of long-term care insurance should be examined from the perspective of insurers, the state in its role of ensuring high quality insurance products, and potential consumers who may be misinformed about important facts when assessing the risks and benefits of long-term care insurance. If the state is seeking to encourage the purchase of long-term care insurance among suitable candidates, perceived affordability persists as a major impediment to attracting purchasers. This study revealed the complexity of the primary stated reason for non-purchase: it is too costly. In fact, consumers weigh a number of financial, personal and family-related factors when assessing whether a long-term care insurance policy is worth it.

4. Consider recommendations made by study participants

Participants were eager to offer their views on a wide range of potential financing alternatives, as well as modifications to existing options such as long-term care insurance. The suggestions of study participants should be considered in a public forum such as a regular meeting of the CT Long-Term Care Advisory Council or CT Long-Term Care Planning Committee.



Overview

Current aggregate expenditures for long-term care are substantial and are projected to increase rapidly in the coming decades with the aging of the population. Nearly half of long-term care costs are paid by Medicaid, primarily borne by the states[1]. States are seeking to control escalating Medicaid costs in part by increasing greater private responsibility for paying for care. Major policy initiatives are intended to provide incentives to purchase private long-term care insurance, to limit the practice of Medicaid estate planning and to enhance enforcement of estate recovery programs.

The 2007 Connecticut Long-term care Needs Assessment survey gathered information on individual plans to pay for long-term care, including a wide range of possible public and private sources of funding. Primary findings indicated that many Connecticut residents erroneously assume Medicare will pay for long-term care, do not have sufficient means to pay privately for long-term care, and have few additional plans in place. Detailed analyses presented in the needs assessment final report examine differences in financing plans by age, disability level, income, and race/ethnicity.[2] In follow up to the needs assessment, the present study explored perspectives regarding long-term care financial planning in greater depth. Qualitative methods, including focus groups and in-depth interviews, were used to generate additional insights into the concerns, motivations, preferences and expectations of Connecticut citizens regarding paying for long-term care. This report presents findings from this study.





Background

Long-term care provides supports to people who need assistance with the activities of daily living over an extended period due to disability or chronic illness and includes a broad range of medical and non-medical services and supports as well as informal, unpaid care provided by family and friends.

There are two broad sources of financing for long-term care: personal resources and public programs. Personal resources include informal care donated by family and friends, out-of-pocket spending and private insurance. Public funding sources include the Medicaid and Medicare programs, and state-funded programs such as those administered through the Older Americans Act. The monetary value of care donated by family and friends (informal care) was recently estimated to account for approximately 52 percent of total long-term care costs [3]. This estimate includes both in kind care and financial contributions. Although clearly significant, the financial contribution of informal care providers is not typically included in expenditure estimates. Accordingly, the data presented in this overview of long-term care financing do not include informal care as a source of funding.

Background (Cont.)

With Congressional support, states are seeking to minimize the escalating pressures on Medicaid programs through the following policy mechanisms intended to increase private responsibility for paying for care.

- Many states are interested in stimulating the purchase of long-term care insurance generally, and there is considerable interest in implementing Partnership for Long-term care models in particular[4-6].
- States are devoting attention to reducing the practice of Medicaid estate planning through increased penalties for certain asset transfers, as well as a variety of enforcement mechanisms. [7, 8]
- Although estate recovery programs are mandated across the states, the degree to which they are enforced varies widely. There is substantial federal interest in the potential for estate recovery programs to recoup some Medicaid long-term care expenditures. [9, 10]
- Finally, some states are beginning to explore the political feasibility of enforcing existing laws regarding the filial responsibility of children toward indigent parents, in which children are responsible in part for the costs of care for a parent.[11]

One challenge policymakers face in attempting to increase private responsibility is the significant misunderstanding of the role of public programs in paying for long-term care. For instance, one national study by AARP found that 50% feel not very or not at all prepared to handle the costs of long-term care. That same study found 29% of respondents believed they had purchased long-term care insurance. Yet, existing data estimate about 9% have long-term care insurance, suggesting many individuals believe they may have insurance when in fact they do not and are confusing long-term care insurance with disability insurance provided by employers or

with Medicare. In addition, respondents consistently and dramatically underestimated costs of various kinds of long-term care services [12] Information is also overwhelming and inaccessible, particularly for long-term care insurance [13, 14].

These misperceptions were also reflected in the Connecticut Long-term care Needs Assessment study, where 38% of all respondents (34% of boomers and 46% of older adults) wrongly believed that Medicare would pay for their long-term care needs.

Substantial attention is being directed at the potential for long-term care insurance to reduce public expenditures. Three primary strategies of governmental intervention to increase the number of people with private long-term care insurance include:

- Providing individuals with tax incentives that encourage purchase of long-term insurance policies by reducing the net price of such policies,
- Encouraging employer-based private long-term care insurance through tax incentives and through the federal and state governments serving as role models for private employers by providing governmental employees, retirees, and their dependents the opportunity to purchase insurance, and
- Waiving some or all of the Medicaid asset depletion requirements for purchasers of qualified private long-term care insurance policies, allowing them to retain more of their assets and still qualify for Medicaid [15].

This third strategy is used in long-term care partnership insurance models, such as the program operational in Connecticut. Under the Connecticut Partnership for Long-term care, private insurance companies competitively sell long-term care insurance policies that satisfy specific requirements. These policies offer benefits to pay for



long-term care costs, as well as provide dollar-for-dollar protection of assets in the qualification for Medicaid in Connecticut. For individuals who have exhausted the benefits of a Partnership policy, the state will disregard some or all of their assets in determining Medicaid eligibility.

Developing policies to increase private responsibility must take into account individual expectations and views regarding the government's role in ensuring access to long-term care. Substantial tensions exist around enforcement of government policies on estate recovery, Medicaid estate planning, and filial duty laws[16]. While these programs are intended to limit government expenditures for long-term care, they are controversial and raise important ethical questions about the respective duties of individuals and the government in the assurance of access to long-term care. One recent study found that, though mandated by the federal government, estate recovery programs are enforced variably across the states, and collections represent a very modest savings to the state Medicaid programs [10]. The role of the Medicaid program in shaping financing decisions is complex.[17] Some argue that

the existence of Medicaid as a safety net acts as a disincentive for individuals to purchase long-term care insurance or otherwise plan for private financing of care.[18] Others suggest that accessing Medicaid coverage is not a desirable strategy, due to perceived lower quality of care for Medicaid beneficiaries and limited access to preferred care settings.[19] A recent review of filial responsibility statutes indicates a renewed interest in the potential for these laws to reduce Medicaid expenditures. Though rarely enforced, filial duty laws exist in 30 states, and the only estimate of savings available (done in 1983) suggested enforcement could reduce Medicaid spending by \$25 million, an amount likely to be significantly higher today.[11] Despite these attempts by states to influence individual long-term care financial behaviors, there is limited evidence regarding their impact to date.

Given this political and economic context regarding long-term care financing, it was determined that the Long-term care Needs Assessment should be supplemented by the current study in order to enhance its findings. We explored individual perspectives regarding long-term care financial planning in greater depth, using focus groups and in-depth interviews with Connecticut citizens. We asked them to share their concerns, motivations, preferences and expectations regarding paying for long-term care.

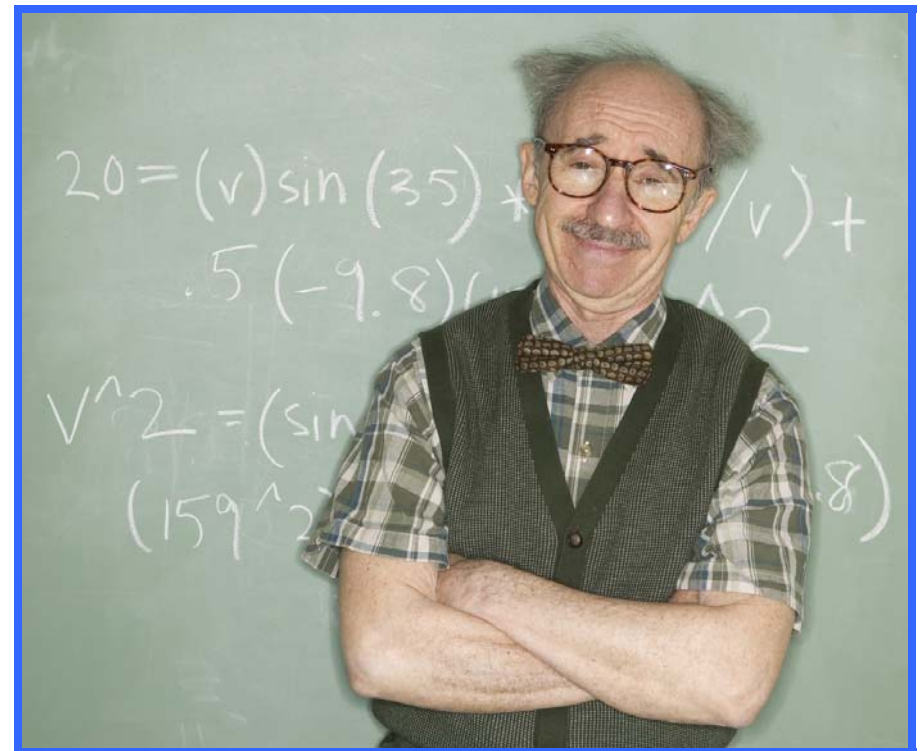


Methods

Purposeful samples were developed for both the interviews and the focus groups, in order to include individuals who had knowledge or direct experience relevant to long-term care financing decisions (Mays and Pope, 1995). Potential participants were chosen from two sources: a random sample of people who registered for one of three educational forums held by the Connecticut Partnership for Long-Term Care and a random sample from a subset of the Connecticut Long-Term Care Needs Assessment survey responders. Since the goal was to understand financial planning decisions for future long-term care needs, people currently using long-term care services were excluded from the sample. The sample size for the interviews and focus groups was determined by the principle of 'theoretical saturation.' This is the point at which no new concepts emerge from reviewing of successive data from a sample that is diverse in pertinent characteristics and experiences (Glaser and Strauss, 1967; Strauss and Corbin, 1998). A total of 32 telephone interviews were completed (12 with Partnership forum registrants and 20 with survey respondents). Six focus group sites were chosen in three different counties across the state: Hartford, New Haven, and Fairfield, with two focus groups held at each site: one for older adults and one for boomers. A total of 22 older adults and 18 Boomers participated in the focus groups. Interviews and focus groups were conducted by a trained member of the research team. Topics explored included plans to pay for long-term care in the future with a particular focus on long-term care insurance, views on individual and government responsibility for long-term care, including policies regarding Medicaid estate planning and estate recovery. The complete focus group discussion guide and telephone interview guide are included in Appendices A and B.

Audiotapes of the interviews and focus groups were transcribed and the documents were imported into qualitative analysis software (Atlas.ti) to facilitate data organization and retrieval. In the first stage of analysis, codes were created

and defined as concepts emerged from the data in an inductive fashion (21, 22). Members of the coding team independently line-by-line coded transcripts and then met as a group to negotiate consensus when needed. Using the constant comparative method of qualitative analysis (21, 22), coded text was compared to identify novel themes and expand existing themes, refining the codes as appropriate until a final coding structure defining all codes comprehensively was established (22, 23). This code structure was systematically applied to each of the transcripts. Primary recurrent themes were generated through review and interpretation of coded data. Additional detail regarding the sampling and analysis methods is provided in Appendix C.



Results

The focus group discussions and individual interviews generated a substantial amount of information related to individual expectations and motivations for financing their own long-term care in the future. First, participants described how they are (or are not) planning to pay for long-term care. Second, there was extensive commentary regarding long-term care insurance in general and the Partnership for Long-term care in particular; those findings are presented in a separate section below. Third, discussions highlighted a number of factors that influence individual considerations in deciding the most appropriate plan given their circumstances. Fourth, participants described the source and nature of information about long-term care financing alternatives currently available, with frequent expressions of frustration as to the accessibility and trustworthiness of information. These findings are reported in detail in the following section, with illustrative quotations provided for each. The report concludes with recommendations generated by the study findings.

How do people plan to pay for long-term care?

Participants who have given thought to the matter described a wide range of strategies or approaches they plan to use in order to pay for long-term care should they need it in the future. Options included using their own current assets in various forms, taking out a reverse mortgage, relying on the Medicaid program, pursuing alternative housing arrangements and buying long-term care insurance (see Table 1).

Table 1: Options considered for financing long-term care

Own assets ('self insurance')	Annuities
	Trusts
	Reverse mortgages
	Other savings
Private insurance	Long-term care insurance
	Partnership long-term care insurance
Alternative living arrangements	Continuing care retirement community
	Move abroad
	Other congregate/communal living
Government programs	Medicaid, Veteran's Administration

The following is a collection of selected quotes from the focus groups and interviews with Connecticut residents.



1. Personal assets

Personal assets included annuities, trusts and other forms of savings that would enable an individual to pay for some or all of their care. While some participants appeared confident that they would be able to cover future costs of care, others referred to plans to use personal assets with hesitancy or anxiety (such as hoping for the best).

I have been thinking that I would use my own assets. I would love to be able to leave a large amount of money to my two daughters but I believe you have to pay what you owe....I have not done much research in terms of insurance and I probably should, although I am mid fifties too, and whether I could find something affordable I don't know. My wife and I are doing what we can to build a sizable estate so we will have money available. I'm hoping that does not wind up all being spent for long term health care but we are prepared to do that.

Umm, (laughs), we're kind hoping that we have saved enough at this point so that we can put some money into like an annuity account or something like that, and then have that pay for it or have some type of payment plan.

2. Reverse mortgage

There were a number of discussions about the use of reverse mortgages. Reverse mortgages are predominantly a federal Housing and Urban Development authority program. This financing technique is considered separately because of the detailed comments concerning its use, although in essence it is another way of using one's own assets to pay for care. Discussions reflected a range of sophistication about this tool, from those who appeared well informed to those who had very limited anecdotal, sometimes incomplete or incorrect information.

We have friends that have taken out a reverse mortgage to enable them to stay in their house. They have health problems, they're having problems with their legs. It was a two story house with the laundry facilities in the basement. With this reverse mortgage they could build a room on with the laundry and yes, live on the first floor, so now they can stay in their house where they would have had to sell it and go to an apartment or a condo or something that was on one floor.

E: Well, you also have options as to how much you are going to take a month or if you just want one lump sum.

S: Right, see that's the things that I don't know about.

E: That could be a pitfall- take the whole bundle and go up to Foxwoods. The whole idea is to get more money every month to pay all your bills and meet all your obligations.

3. Alternative housing arrangements

Participants described plans to access long-term care through a variety of living arrangements, including continuing care retirement communities, innovative models of communal living to share long-term care expenses, and plans to move abroad, where they perceive that long-term care (particularly community-based care) is readily accessible, of good quality, and more affordable.

I'd actually like to see something to pair people up. Do you know what I mean? Certainly one caregiver can take care of 1 or 2 people. I can see in the future that if 2 people needed a small amount of help they would say come to my house and we will get a live-in and he'll care for the two of us.

I'm not sure how else to do it- it's either the insurance or going ahead with the plans to live overseas and so forth where labor is cheap-it's labor that makes LTC expensive.



4. Rely on government programs

The role of government programs in individual decisions was discussed by participants, including Medicaid and the Veteran's Administration. While there were relatively few statements referring to intentions to engage in Medicaid estate planning or otherwise access Medicaid covered services, the issue was mentioned.

I am getting to the point where I am feeling lazy and I am saying 'I don't want to spend money for LTC' and I want to take my house out of my asset program, give it to the kids and let me become a ward of the state if I need LTC.

I have had long-term care insurance for about a decade and my wife is strongly considering it at the moment...I think that it only lasts for a couple years, but those are the most crucial periods. I think that if I go beyond that then I have another great savings for CT because I'm going to have my wife dump me at the VA and I'm eligible for LTC service there. I'm thinking about things and that's what all of us need to do is to consider what our options and possibilities are. It's not a shame to be on Title 19 or Welfare because you don't have anything - because you did at one time but you lose everything...

Long-Term Care Insurance

There was extensive discussion regarding the potential role of long-term care insurance in people's financial plans. Each focus group and interview examined long-term care insurance in a fair amount of depth. There were four primary topics addressed by participants. First, participants described assessing tradeoffs among multiple competing factors when considering whether or not to purchase long-term care insurance. Second, those who had purchased a policy or were considering a purchase reported a wide range of benefits and motivations for buying a policy. Third, participants who had contemplated purchasing a policy, or who had looked into insurance, described considerations important to them in their decision not to buy a policy. Finally, participants discussed several possible incentives that might encourage greater interest in long-term care insurance.

1. Tradeoffs considered in making a decision whether to purchase long-term care insurance

One of the most frequent observations from both interviews and focus groups was that long-term care insurance is too expensive. Beyond the face value of that comment, however, the salient feature of many remarks concerned the concept of tradeoffs, such as balancing cost vs. benefit, risk vs. reward, and consumption now vs. consumption later. Participants described fairly sophisticated thinking about the tradeoffs made in deciding whether to purchase long-term care insurance, and in particular whether the premiums are too high. It is commonly believed that long-term care insurance is unappealing because of its cost, but participants gave some insight into the question: Too expensive compared to what? They compared the cost of long-term care insurance to many other important considerations and made decisions between them, for example: other current expenses, the level of current assets, the timing of purchase/age at purchase, policy features such as the length of waiting period, and the cost of nursing home care.

To be honest we are on the cusp where we are not sure if we are going to pay either out of pocket rather than pay the premium and I would just as soon pay the premium in the chance that I would have to spend many, many thousand dollars in LTC. I would rather give that to my kids. I'm not trying to build up money for my children, but I would rather give it to my children than to the nursing home.

A major factor in the decision whether to buy insurance is the likelihood of need and perception of risk. Respondents are making tradeoffs between certain payments now and uncertain payments later, between their current health and the likelihood of their future health, based on the probability of using long-term care services.

With a lot of insurances you stop and think about how likely you are to need to use it or not use it. I think sometimes about like auto insurance, of course you have to have it and of course it's easy to have an accident, very easy to have an accident, so you are likely to use it. Or umbrella insurance, you are less likely to use it but it saves everything that you own. But LTC insurance is a little more difficult to make the decision about because you are using money you might put away for retirement – you are not sure if you will have to use it.

Participants also expressed concerns about the stability of the insurance company and likelihood that the company will be viable in a future time when the benefit might be needed.

In some ways it makes more sense if you have a really fine policy, if you have very fine company because companies go out of business and companies are acquired. GE, which is a big provider in this field, sold out all of its insurance operations, so you no longer have the AAA/GE company behind you. They are still rated highly, but I don't know what they are going to be in 20 years.

That's my biggest fear. Will they be here to pay the bills when I need them to? I truly believe that either they will still be here or someone will have bought that contract.

In discussing the tradeoffs that go into the insurance purchasing decision, a set of issues emerged related to the classic economic dilemma of current vs. future consumption, the notion that the money spent on premiums might be spent on other things that are more enjoyable in the present, such as supporting children or a charity.

I have looked into it a couple of times and I have chosen not to get it. I have really chosen to go to the route of maybe thinking about putting aside or investing my own money my own funds for it. Probably also because there is a certain amount of denial in thinking well I can use that money for other things and that would be more enjoyable.

Finally, people described considerations in the context of retirement planning, and the importance of future savings in maintaining a certain standard of living in their later years. For instance,

As we get older it gets more pricey, so I thought I want to get in now in my forties. Then my husband and I were talking to some people and they said just sink that money into the market and it will grow and it'll grow. But it may not grow to the point of the coverage that you would be entitled to fast forward twenty or thirty years from now, so I'm at a bit of a dilemma with it.



2. Reasons for purchasing long-term care insurance

A number of specific reasons were offered for purchasing long-term care insurance. These included: to protect assets, to avoid becoming impoverished, to ensure choice in the type of long-term care, to assume personal responsibility for one's care needs and avoid burdening family members, to provide security for those living alone, and to obtain even partial coverage for future services (see Table 2).

Table 2: Reasons for purchase of insurance

Protect assets for self, spouse, children
Avoid impoverishment
Control choice of setting/type of care
Personal responsibility
Single/ no one to rely on for care
Ensure at least partial coverage for care

a. *To protect assets for themselves, their families or heirs*

Although there were highly divergent views regarding the importance of passing on assets to one's spouse or children, this emerged as a primary motivation among those who had purchased long-term care insurance. Those who had purchased a Connecticut Partnership for Long-term care policy mentioned this explicitly.

Since I do have people that I might like to leave my money to, then I'd rather not have a urine-stenched nursing home take all the money that I would rather leave to my kids. I kind of think that motivates me in a way for LTC insurance.

Participants who had considered purchasing a policy through the Connecticut Partnership for Long-term care talked explicitly about the goal of protecting assets. They described the importance of specific policy features such as inflation protection. They also felt the state's endorsement provided necessary assurances regarding both the quality of the product and protections against possible future insolvency of the insurer. Although the cost was perceived as high by some purchasers, others felt the policy was a wise investment.

I got mine before I turned 60 so it's not very expensive. I dropped my life insurance. You get to the point in life that you don't need life insurance, so what you do is you replace it with long-term care. I did that because of the Partnership program. You only have to spend down your assets until a certain point, that way there are assets left for [my wife] if something happens to me.



b. To avoid impoverishment

Another motivation to purchase long-term care insurance was to avoid impoverishment in the event that long-term care is needed. Having had a prior experience with someone who exhausted their assets in obtaining long-term care, or hearing similar stories from peers was a major factor that motivated some individuals to purchase a policy.



I am a social worker, so I am often put in that position of helping people look into what they have and begin to decide when to use it, so that has influenced me, seeing how beneficial it [long-term care insurance] can be...My dad is 95 years old and in a nursing home and they spent all of their money taking care of each other. My mother died when she was 89 but now he's, as he says 'I'm a pauper' and he hates it and I don't blame him. So I don't want to end up like that.



c. To control choice of care setting and type of care

Other participants described purchasing long-term care insurance as a way to ensure they would have control over the setting and type of care they received. This issue was frequently raised in connection with concerns about the quality of care provided to individuals with Medicaid as a source of payment.

I have a friend who is a nursing home administrator so I asked her some questions too. She of course is very much for long-term care insurance. She said that there is a real advantage in having it because then you have more choices as to the type of care, as to where you get the care and you would be definitely more readily accepted into a nursing home of your choice. Let's say I knew of a nursing home that I really liked and I had experience with other people being and, gee, if I had to go to a nursing home I would really like to go there - but lets say if I didn't have a LTC insurance, I might not necessarily be able to be accepted into it whereas having the policy, you are more likely to gain access rather than being another Medicaid patient. So that is another question as to whether you get better care having long-term care insurance.

d. Personal responsibility

Another reason given for buying a policy was to assume personal responsibility for one's potential long-term care needs in the future. Some participants expressed strong views about the importance of making the necessary financial arrangements to ensure independence in the event they needed long-term care. This was often, but not always, discussed in relationship to wanting to avoid placing burden on one's children.

I did buy a long-term care insurance policy about 4 years ago. This has been such a difficult decision, to make it in the beginning and it is still not resolved in my mind. I have a lot of emotional issues surrounding it as well. I am not certain if I really can afford it because I am certainly not wealthy and I don't have a lot of assets to protect. On the other hand, I bought into the presentation 'oh you don't want to be a burden to your children' so they certainly emphasize the guilt factor, the responsibility to society, and I want to do what's right for everybody.

e. Live alone

A number of participants reported that they currently live alone and would not have anyone available to care for them if they needed assistance. These individuals described feeling more secure having a long-term care insurance policy in place.

I don't have children and I don't have a spouse so if something were to happen to me, I don't have anybody to take care of me like a lot of people do. So that was part of my decision to go with it.

f. Ensure partial coverage

There were interesting comments regarding the value of having even partial coverage through a long-term care insurance policy. Some purchasers stated they felt there was value in having a policy, even if it provided only 6 months of coverage. Others responded they felt that such policies may provide false assurances and that the risks of substantial financial burden remain with partial policies.

Long-term care insurance isn't always the answer; it depends on what kind of [policy] you buy. Long-term care insurance can be so expensive that most people don't buy full coverage. They buy partial coverage and the balance can be devastating too.



3. Reasons not to purchase long-term care insurance

A broad and diverse range of reasons for not purchasing insurance were offered by participants. Reasons included: the policy premium was too high, they were skeptical of insurance companies, the individual or spouse was not a suitable candidate due to asset levels or an uninsurable medical condition, policies are too complex to evaluate and may be of poor quality (See Table 3).

Table 3: Reasons for non-purchase of insurance

Premium 'too high'
Skeptical of viability of insurance company
Not suitable (too many/too few assets to protect), uninsurable medical condition
Policies too complex to assess

a. Premium too high

As noted previously, high premiums were frequently mentioned as a reason not to buy insurance. Discussions revealed the complexity of this reason, however, as participants described the tradeoffs inherent in assessing whether insurance is too costly. Noting the increase in cost with later age, participants talked about carefully targeting information to reach individuals at the appropriate age and income/asset levels.

My general feeling is that it is much too expensive for most people...Some people don't need that policy for 30 years, if they start at 54, 55. You are paying a hell of a lot of premiums and for a long period of time.

b. Skeptical of insurance companies

Participants who had not purchased long-term care insurance described several concerns regarding insurance companies and agents. These included the risk that insurers might take advantage of opportunities to maximize profits at expense of policyholders, concerns about the long term viability of companies, and aggressive sales tactics employed by agents.

My biggest fear when I bought it was whether the carrier would be around to actually pay the policy. I still have the policy and I got my first rate increase this year because the way the policy was set up...it went up from \$1,000 a year to \$1,700, I still think I got a steal....That's my biggest fear, will they be here to pay the bills when I need them to? I truly believe that either they will still be here or someone will have bought that contract.

c. Policies too complex to evaluate

Some participants expressed feeling frustrated or overwhelmed by the complexity of policies and the extensive variability across products.

It takes a long time to understand what you are really getting for your money. It took us 3 visits from an insurance person to explain it to me on the Partnership.

d. Not suitable candidate for insurance

Another reason provided for the decision not to buy insurance was related to the targeting of policies to individuals with appropriate income and assets. Participants described their understanding of suitable candidates, indicating that people with either substantial or few assets should not consider purchasing long-term care insurance. Being found ineligible as a result of medical conditions was mentioned as well.

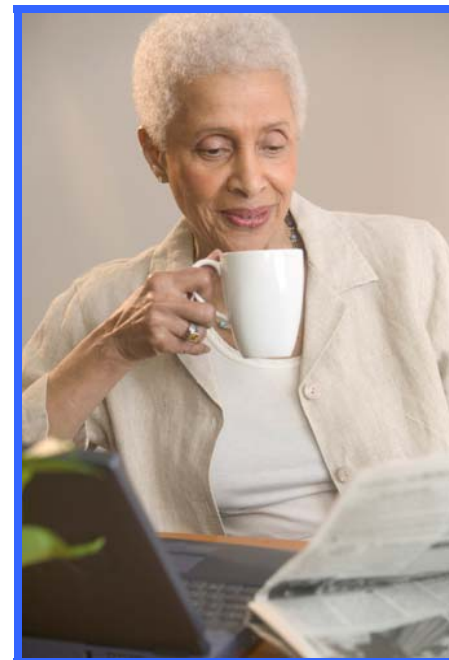
I believe in Consumer Reports. Most of what they have to say is very well put so they are a really good source of information about long-term care insurance. They essentially bracketed people by saying if your total assets are under \$100,000 you probably shouldn't buy long-term care insurance and if they are a couple of million dollars and up, you don't need it. Some people buy, but they're buying it really to protect an estate for kids or for somebody else. It's the midrange that's vulnerable, but that's a big mid range from \$100,000 up to a million.

4. Specific policy or tax incentives that might encourage purchase of insurance

Participants brainstormed about a number of types of government incentives or policy design features that might stimulate interest in purchasing long-term care insurance. These included tax-based incentives, innovative and flexible policy benefits, and most importantly, strategies for enhancing accessibility and affordability of policies.

a. Tax incentives

It would seem to me, one thing that the state and the federal government are doing well for us is giving incentives to people to sign up for this stuff earlier and when I mean earlier I mean 30's and 40's, as in tax breaks. I don't know whether insurance companies like that very much, I think they probably would and it's rather important that they get the word out. I am not asking the state to do advertising for the insurance companies but it would be wise, in my explanation, to let people know that you don't have to be 65 and over to end up needing LTC.



b. Innovative and flexible benefits

One recurrent theme was the nature of the policies being dynamic, requiring ongoing assessment to determine whether the policy would meet changing needs and was of reasonable quality.

I searched out a person who could help me and at the time which was 10 or 11 years ago, I bought what I could afford and I bought a good policy. I had nursing home care and at home care, with an inflation rider and all this kind of stuff. I don't think anybody should not have it if you can afford it. I mean some people can't afford it and some people wait until, they wait until they are 60 or 70 years old and then they can't afford the premium. So mine may have limitations because it is old and if I were to buy it today it would probably cost me double.

The state wouldn't be interested in this, but I would hope some insurance company would sell not a long-term care policy but what I call a 'goodies' policy. So that if you exhaust your assets and go into a nursing home and you are impoverished at that point, that policy would then pay for the other things in life that would make living in a nursing home tolerable. It's a different way to approach it. It would be for extras...[other respondent] like going to a hair dresser appointment or for your bubble gum.

c. Accessibility and affordability

There were extensive discussions about the need to make policies more accessible and affordable. Suggestions regarding accessibility focused on the potential role of employers in raising awareness about long-term care insurance and in providing group offerings as part of benefits packages. Suggestions for making policies more affordable addressed aspects of the policy design, such as extending the waiting period or refining some of the elements of policies that are perceived to drive up cost (such as inflation protection). Participants varied in terms of their views on the critical importance of the inflation protection feature in particular.

The other thing that is needed to change in long-term care insurance is a much longer waiting period. So instead of waiting 90 days before the policy kicks in, maybe have a policy where you have a 3 year waiting period or 2 year waiting period or 1. A lot of people could afford to pay for some longer period of nursing home care out of their personnel assets; it's the more catastrophic losses they can't tolerate. If they are at home for 3 or 4 years that exhausts many, many people's assets but in terms of how you price insurance, from a price standpoint, the first loss, the only loss, is most expensive loss, a lot of the high premiums are required in order to pay for that loss. If you could have people doing more self-insuring on the front end, I think you could reduce the cost of LTC insurance to a point where it would have a growing market.

Factors influencing individual financial planning for long-term care

A number of factors were identified by participants as influencing their planning efforts, including affordability of long-term care insurance (addressed above), their own individual planning style, psychosocial factors, family and peers, considerations regarding Medicaid quality of care, and individual preferences for a care setting.

1. Planning style or approach

Some participants described a generally passive approach to long-term care planning, reporting that they have not made efforts to gather information about options, or have not carefully reviewed materials in hand. In some instances people candidly admitted simply not wanting to think about the possibility they may require long-term care. In other cases, participants expressed being overwhelmed and confused by information. Others talked about a more proactive style, seeking out information from a variety of sources and considering wide range of options in depth. These individuals typically spoke with confidence about their ability to make an informed choice that was best for their own circumstances.

I have been thinking about LTC insurance. I met with an independent agent and he was talking to me really as if I had this opportunity to take advantage of the insurance companies. I found the price of the thing was very affordable. It was \$200 a month and I was about to pull the trigger on it and go with it. But I feel as though I need to do more research, because it just sounded too good to be true the way the agent was speaking. I wasn't very sophisticated about that, so I checked with an attorney who has a friend who sells it and we are kind of looking into it further. But a few hundred dollars a month, I think it sounds to be a very reasonable thing for a person in his fifties.

2. Psychosocial factors

Prior research on long-term care financial planning suggests that psychosocial factors play an important role in the decision-making process[20]. These factors include fear of becoming dependent or impoverished, denial or avoidance of long-term care issue, anticipation of needing long-term care, feeling conflicted about planning decisions, and tensions regarding the balance between government and private responsibility.

a. Fear

Participants were surprisingly candid in sharing their fears regarding long-term care. Concerns about becoming dependent on others were expressed, both in terms of not wanting to burden children, as well as a strong preference not to be cared for in an institutional setting such as a nursing home.

My dad ended up paralyzed when I was little and he spent 13 years in a nursing home...it was awful. I had this dread, this god-awful dread of getting old and ending up in a nursing home because of how he ended up. He was in a state institution, a state hospital because we didn't have any funds and because he was paralyzed for so many years we ended up on Welfare... I had a major dread of long-term care because of that. I'm afraid.

b. Denial or avoidance of long-term care issue

Tendencies to deny or avoid thinking about long-term care were also described. Some participants characterized their behavior as procrastination. They viewed long-term care planning as an important activity, yet for a variety of reasons had not focused attention on it. Others were more dismissive of the value of or need for planning ahead. Some felt they had few real choices available to them. Others recounted family histories (parents or grandparents died young without needing long-term care) and felt they would be healthy far into the future. Still others simply put off or avoided making the decision. There was remarkably candid discussion about the fact that some individuals simply did not want to think about long-term care planning.

I have been putting things off. I did have one meeting with a [x company] representative and found at the time it was too expensive with the other expenses I had at that point and I haven't done anything since then. It's probably a year ago, so what I would like to be able to do is to talk to somebody who is unaffiliated with any programs with any insurance plans, with any homes and somebody who is really impartial about the whole situation. Not a financial advisor but someone who would be able to advise me about the options.

c. Anticipation of needing long-term care

In contrast to those who expressed avoiding thinking about risk of needing care, others were explicit in their consideration of future dependence. In contemplating the possibility of requiring long-term care, they also perceived potential financial implications.

My concern has been that sometimes this stuff can be very debilitating, and one can be debilitated for a month, two months, three months or perhaps even more so....Would my financial assets that I currently have be diminished by this cost for the care? Consequently, when either myself or my wife goes back to our usual physical condition, would we then be in a much reduced financial position?

d. Conflicted about planning process and goals

Despite earnest efforts to understand the full range of planning options and to make the 'right' decision, some participants described feeling conflicted or uncertain.

I just know that what is supposed to be a way for me to feel secure in the future and give me a sense of peace has been this very complicated, very emotionally charged, a source of doubt. I don't have a lot of money and I am sacrificing to pay for these premiums. So anyway, you can see that this has not been an easy journey for me. Maybe I am neurotic and it seems like a lot of people just make the decision that's it and they live with it and they are happy with it, but it hasn't been that way for me.

e. Tension regarding personal and government responsibilities

Tensions as to the respective roles of government programs and private planning were freely discussed among focus group participants. These exchanges revealed unresolved issues regarding how much individuals and families should be required to contribute to paying for their long-term care, as compared to 'the government.' One participant made the observation that government programs are funded by individual taxpayers, suggesting that the dichotomy between public and private is not useful.

The framework is that we are taught to make provisions for ourselves in some way, based on an unknown. We don't know what the future will hold. Somehow within that framework we need to probably make some kind of contribution earlier on. With Social Security we don't have a lot of choice in that. Mostly it is taken out of our paycheck because it is an expectation in the country. Maybe long-term care has to be part of that expectation early on.

3. Family and peers

The influence of family and peers on plans to pay for long-term care was woven throughout discussions. First, participants described interdependence between spouses in a number of ways. Second, the long-term care needs and experiences of family and peers was described in relation to individual planning. Third, broader influences of family dynamics and circumstances were described. Fourth, the importance of leaving an estate for one's heirs was discussed as a motivation for certain planning behaviors.

a. Interdependence between spouses

The presence of a spouse is relevant to decisions about LTC financing in several ways, both concretely in literally how decisions are made and by whom for the couple, and also why decisions are made, taking into consideration conditions and characteristics of the individual and the spouse together. There were a number of ways in which an individual's decision regarding insurance purchase was influenced by one's spouse, including the fact that one spouse is primarily or solely responsible for financial decisions, the couple makes decisions jointly, one spouse failed to qualify for insurance due to illness or chooses not to purchase because of younger age and the view it is not currently necessary. One motivation for purchasing insurance was to ensure the spouse will be provided for if respondent needs LTC. Interestingly, there were several references to the perception that women need long-term care insurance, while men do not because they do not survive for long once they move into a nursing home. One participant described a circumstance in which she would have preferred to purchase long-term care insurance, yet her spouse became uninsurable and she felt forced to self insure.

To be honest, we were torn as to whether or not we would simply pay out of pocket or if we would have an insurance policy. When it looked like everything was going to be about \$2,500 per year, I would rather have paid for the policy. After this [change in spouse's health], they said if he is insurable, his would probably go to about \$7,000 a year. So at that point we would probably take a chance and pay out of pocket. We haven't really made that total decision yet.

b. Knowledge of others' long-term care experiences

Participants described being influenced by long-term care experiences of parents and others, their health problems, quality of life, and the individual's own role in providing and financing LTC for these others. They also considered the consequences of others' lack of financial planning for long-term care, or lack of resources. Finally, they considered peers' or parents' long-term care planning choices, such as insurance, self-funding, Medicaid estate planning, reverse mortgages. There were consistently expressed preferences to avoid burdening others, and to avoid the kinds of difficulties others have encountered.

I have an 83-year old step mother who's been in an Alzheimer's home for seven years now and she's depleted all the money my father left her and a good deal of my sister, brothers, and my inheritance from our dad. I came to learn a fair amount about what the law is in Pennsylvania because that's where she is and I just started getting interested in what's going on here and it's a huge thing. I don't have it [long-term care insurance] myself but I wish I had bought when I was much younger. I am looking at policies now and they are pretty steep. But if all I can afford is a year, I'll take it.

c. Leaving an estate

Planning to leave an estate for one's heirs is a central consideration in planning as it relates both to the purchase of long-term care insurance and Medicaid estate planning. The relationship between the desire to leave an estate and the decision to purchase long-term care insurance is complex. Some individuals who want to leave a legacy decide not to buy insurance to save that

premium money for their heirs. Others who want to preserve assets for heirs do buy the insurance in order to preserve other assets. For those who don't care about leaving a legacy, the same is true. Some buy it so as not to burden the kids (even though they don't want to leave them anything) and others don't buy it on the theory they'll enjoy what they have as long as they can. In each case, although the decision may differ, people seem to be making the same type of tradeoff analysis as described previously, weighing factors on both sides of the issue and incorporating their understanding of risk.

Right now I could live to be 92. I mean I want to live to be 92 and at that point I will be broke. My kids won't have anything left over; they won't expect anything from me but I don't expect to dump on them either and that's my purpose for LTC policy, I don't want to be at their doorstep.

Another perspective asserted that if you want to leave assets to your children, it is wiser to purchase a life insurance policy rather than long-term care insurance.

I don't think you have to leave enormous amounts of money to your kids, you have a life insurance policy, that's what you should leave to them and spend the money that you have. Have a life insurance so you know exactly what you are going to give them and that's it and then spend it and enjoy.

Participants talked about asset transfers from parents to children (from both perspectives) in two distinct but related contexts: to avoid estate taxes, and as part of Medicaid estate planning. They talked about risk of losing control of the assets (house), or the alternative of selling the house to one's children. Some people described a family history of generations of passing assets to children, while asset transfer is not a realistic or desirable goal for others.

You know I am just going to tell you this story about doing that with your assets. I know some woman who did that to avoid taxes and to have care- went on Medicaid. Gave it to her daughter and then her husband, her son-in-law divorced the daughter and was able to claim ½ of that as part of their marriage.

4. Medicaid as source of financing care

The role of Medicaid as a source of financing care was discussed at length. One recurrent issue involved concerns about the quality of care provided to individuals on Medicaid, as well as constraints in accessing care in specific settings. A second theme was the stigma, or shame associated with receiving benefits from a welfare program. Finally, participants discussed the impact of program eligibility requirements on the beneficiary's spouse.

a. Concerns about quality and access

Participants expressed diverse views about whether individuals whose care was being paid for through Medicaid had limited access to good quality care. While some observed that the payment source did not influence the quality of care given, others felt there were negative consequences both in terms of access to certain care settings as well as the quality of care received within a particular setting such as a nursing home.

I think that the only way to get good care is to have a whole lot of money, because when it comes time to go into a nursing home, for one thing you get into the right nursing home. A lot of nursing homes of course you have to have so many Title 19 people and so many private pays and if you are not a private pay, your chances of getting into a nursing home are slimmer than they would be if you had a big bundle of money.

b. Stigma, shame of welfare

The issue of stigma associated with receiving benefits through a welfare program was raised in each group. Participants shared poignant and candid worries about the impact of needing to rely upon a public program for long-term care.

Why do you have to put people through that? I mean Medicare is not means tested. Can't we do something so that it's not means tested and the rest of us, it's a terrible situation to be in, I think. I find it so demeaning personally - I hope I am never forced to do that. I hope my life doesn't get to that. I suppose any of us could be pushed to that point if we have unbelievable health problems.



c. Eligibility requirements (spousal impoverishment)

Participants discussed the effect of Medicaid eligibility requirements on the spouse. The degree of knowledge as to specific criterion for determining spousal protection allowances was limited. However, there were general concerns about the spouse's financial well being in the event one partner needed to enroll in Medicaid in order to have access to long-term care.

What happens with a married couple is they divide everything in half and of course half gets used up and the other person has the other of whatever is saved by the people. If me and my spouse got sick, we would use up half of our assets and I would be left with the half that's left over. That's great but you know what, the half that's left over, if you take any married couple and you divide their assets in half, that's quite a shock in reality.

5. Preferences for home and community based care

One last factor that emerged as playing an important role in people's long-term care planning efforts was the clear and consistently expressed preference for home and community based care.

What I would personally like to do is think that you could hire someone to live with you and leave your house to them. My parent stayed home with 4 different shifts. It did cost them out of their pocket plus their LTC insurance but they stayed home. The care you get at home is obviously far different.

Information on long-term care financing

Finally, and perhaps most importantly, participants identified a number of issues related to information about the full range of long-term care financing alternatives. First, sources of information are quite limited or are unknown to the general public. Second, many available informational sources lack credibility for potential consumers. The one exception to this was the Partnership for Long-term care, which participants uniformly perceived as neutral and unbiased. Third, information that is available is frequently confusing and overwhelming.

1. Sources of information

Participants identified a wide range of information sources ranging from highly trained professionals to informal contacts with varied expertise (Table 4). People described having long-standing trusted relationships with financial planners and attorneys, while others complained of misinformed advisors, getting misinformation from neighbors/social network. People feel bewildered and don't know where to turn for impartial information.

You know, oh my neighbor told me reverse mortgages are really a bad idea. They don't go to experts to find it and they make decisions based on other people's opinions. The average person really doesn't know where to go, what to do and who to trust.

Table 4: Information sources

Informal sources	Friends, neighbors, word of mouth
Professional sources	Financial planners, attorneys, independent insurance agents
Employers	employer-sponsored insurance fairs representing a variety of insurance companies, and sessions run by representatives of individual insurance companies
Non-profit associations, foundations or organizations	AARP, AAA, Consumer Reports
State and local government	Partnership for Long-term care (office, volunteers and regional forums), town agencies, adult education
Insurance companies	Specific long-term care insurance carriers (individual contacts, or public seminars)
Other media	Mailings, Internet, TV, radio

2. Credibility/objectivity

One recurrent message was the view that the information source should be unbiased and neutral. Participants described concerns and skepticism about the neutrality of insurance agents who don't disclose big commissions and give a sales pitch that sounds too good to be true.

It has to do with credibility and what I am kind of hearing said in a different way is there has got to be a more credible source, unbiased, not prejudiced, not in somebody's back pocket. You like to think that might be, might be, a government office, committed, dedicated to serve the citizens of the state.

Government agencies were perceived as highly credible information sources. The Partnership for Long-term Care and Housing and Urban Development authority were mentioned.

You have to go to HUD for their OK to allow you to do this [reverse mortgage]. You are not just getting some hustler, you're getting a federal program and they have to follow certain guidelines and regulations and you needn't worry quite as much as you would otherwise.

Within the last couple of years, I started going to a seminar. I went to one that dealt with the CT Partnership. That seemed to me, without doing a broader research effort on it, to be one of the better plans because it is quasi government sponsored anyhow as opposed to being entirely private and commercial. I also went to some financial planning seminars.

3. Clarity/ease of understanding

An issue that was identified in each group and discussed extensively was the lack of clarity of information regarding financing tools such as long-term care insurance and reverse mortgages. Participants expressed feeling unprepared to ask appropriate questions in gathering information. Those who had investigated long-term care insurance described the application process as both complicated and overwhelming.

The problem we have right now is that nobody understands it. Everybody just thinks it just there and then you can get pumped into in so many years.

4. Educate younger people

The importance of targeting educational efforts toward younger adults was noted. Participants discussed overall trends in savings and debt among younger adults, with implications for lack of retirement and long-term care financial planning as well.

I just wanted to say I think one of the long term answers is that we have to do a better job of educating our youth about the need to save money. What was it last year - negative 1% savings? You know, two things aren't taught in school: how to raise kids and how to save money. We have to teach kids about the personal responsibility in saving our money, if we save 10% and we are smart about it, then we don't need socialized medicine, because I don't think that is the way to go...I want to keep the government out of most everything I can, and, if you let me, keep my money and my taxes and you me invest. I know I can take care of myself.



Recommendations

1. Continue and enhance multiple efforts to educate the public about the full range of long-term care financial planning alternatives

The 2007 Connecticut Long-term care Needs Assessment concluded that education for state residents about many aspects of long-term care financing must be a key priority for state policymakers [3]. This study explored the views of residents who were somewhat more financially sophisticated than the general population and found that the need for education persists, even among this group. One of the strongest themes from the discussions was the critical need for objective, clear, accessible information about the full range of long-term care financing options. Even many of the most active planners in this study, who concede the need for making informed decisions about long-term care financing, expressed confusion and frustration about their options.

Study group participants also differed from the general population in that none were currently using long-term care services for themselves, although many had witnessed the need in family members or others. All were in the stage of planning for a potential future need rather than a current reality, and most expressed awareness of only the most publicized financing techniques, such as long-term care insurance and reverse mortgages. Many newer and less well-known financing techniques, such as hybrid life insurance or annuity policies, were never mentioned.

The content of educational programming should be comprehensive in providing information about the full range of long-term care financing options to both people in the planning stages, such as the study participants, and people confronting an immediate need for services who may not have done adequate planning. To the greatest extent feasible, the information should use clear, direct language readily understood by the general public. A comprehensive planning tool setting forth a clear and concise review of the entire menu of options, including information about potential sources of neutral, objective information is strongly recommended.

In addition, participants expressed strong preferences for receiving care in the home or community, yet knew little about these alternatives. Educational campaigns should seek to dispel the view that long-term care is primarily medical in nature and provided in institutional settings. They should address how individuals choosing to live at home may employ some combination of paid and unpaid services using different financing sources, and how their options may change depending on the degree of need. Formats should include written material available in central, accessible community-based locations, web-based tools and community-based educational forums similar to those already run by the Connecticut Partnership for Long-term care. Finally, particular attention should be directed at developing innovative approaches to reaching out to young adults to educate them about financial responsibility generally, as well as in the context of retirement planning and long-term care planning.

As indicated in the recommendations from the Long-term care Needs Assessment, Connecticut should continue to pursue the joint federal-state Own Your Future long-term care Awareness Campaign designed to increase consumer awareness about, and planning ahead for, long-term care needs. Other models of public education campaigns include Connect-Ability which addresses employment for people with disabilities and the Able Lives series produced by Connecticut Public Television.

2. Review current long-term care insurance agent training to identify potential areas of improvement

Insurance companies and their agents who sell long-term care insurance are already subject to various licensing, training, and client suitability requirements. Many financial planners and other advisors also hold a variety of industry designations that require minimum amounts of training and continuing education in their fields. What is clear from this study, however, is that some professionals advising clients on long-term care financing issues do not consistently provide current, comprehensive and objective information. Regulations of advisors and insurers should be reviewed and modified as needed in order to keep pace with developments in this relatively new field. Other states should be surveyed to determine whether there are best practices that Connecticut might adopt.

3. Address affordability of long-term care insurance at multiple levels

If the state is seeking to encourage the purchase of long-term care insurance among suitable candidates, perceived affordability persists as a major impediment to attracting purchasers. This study revealed the complexity of the primary stated reason for non-purchase: it is too costly. In fact, consumers weigh a number of financial, personal and family-related factors when assessing whether a long-

term care insurance policy is worth it. The affordability barrier can be addressed from three directions. First, insurers (and the state, through the Connecticut Partnership for Long-term care) can continue to refine policy features to achieve the difficult balance between high quality policy benefits and premiums that consumers are willing to bear. Spreading the risk over a substantially larger population should make pricing more reliable and reduce concerns about adverse selection. Second, efforts to reach out to and engage purchasers at younger ages must be enhanced; this requires continued engagement of public and private sector employers across the state. Finally, the factors underlying consumer views that a policy is too costly must be considered more closely to determine whether there are possible interventions to address these concerns in the design and/or marketing of long-term care insurance products. Such factors include perceptions of risk of needing long-term care, the role of family in caregiving and desire for asset protection, psychosocial factors such as fear of becoming dependent on caregivers.

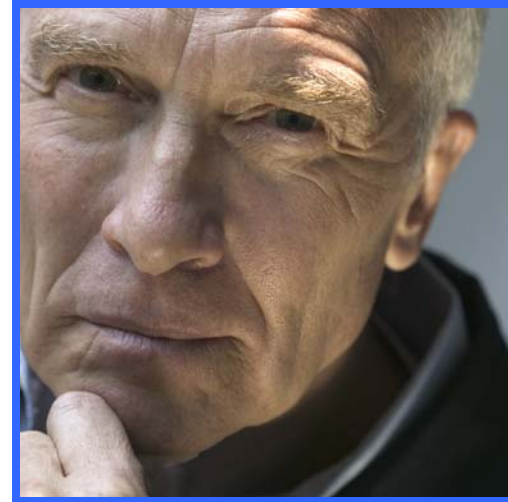
4. Consider recommendations made by study participants

Participants were eager to offer their views on a wide range of potential financing alternatives, as well as modifications to existing options such as long-term care insurance. Alternative programs focused on supporting care in home and community-based settings through sharing one's home with a caregiver who provides care in lieu of rent, or leaving one's home as payment to the caregiver. Suggestions related to long-term care insurance included the concept of a 'goodie' policy which covered 'luxury' items for those in a nursing home, redesign of policy features to address affordability (such as longer waiting periods) and greater flexibility in services covered by the policy, such as paying family to provide care. In particular, tax incentives were discussed as an effective means of making long-term care insurance attractive to potential purchasers.

There were also extensive comments about the need for fundamental reforms of the long-term care financing system, such as including long-term care as a benefit under the Medicare program, imposing mandatory tax such as Social Security to provide government long-term care benefits, and calls for universal health care including long-term care. A number of participants suggested careful review of models of long-term care in other countries, including Germany. Selected quotations are presented in order to illustrate the diversity in participant views about the broader question of public and private responsibility in paying for long-term care.

I think it would be interesting to look at other countries' plans, whether it's socialized medicine or it's democratic or capitalistic. It brings up the issue of care. How much do we really care? In America a nurse's aide is being paid \$11 an hour or whatever the going rate is. It brings up kind of pay for quality. You get what you pay for.

I am 46 years old and I have about a 0% chance of seeing any of that [Social Security] unless there is a dramatic change in the process. I think what you are asking today is, are we expecting the same dramatic change from some type of long-term care program. To me if there is going to be change in Social Security, they should add this to the picture. To me that's the exact spot that should be taken care of, but on the same token we need to make sure we are funding it correctly. We are setting up for the long term, and someone has got to actually go out and figure out what So why couldn't the state, when you take the State income tax, why couldn't we pay in this state for long-term care. You pay into it from when you started working, just like everything else. It is a built up insurance policy within the state.



The suggestions of study participants and other interested members of the general public should be considered in a public forum such as a regular meeting of the CT Long-Term Care Advisory Council or the CT Long-Term Care Planning Committee.

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Appendix A

LTC Planning Focus Group Discussion Guide

Thank you for joining us today. We appreciate you taking the time to talk with us about your views and experiences regarding planning for long-term care. My name is....I am from the University of Connecticut Health Center. Assisting me is.... This project is being done as part of the Statewide Long-term Care Needs Assessment mandated by the Connecticut Legislature.

I want to go through a few details to help our time together go smoothly.

1. This session will be one hour long, so we'll be done by XXX. If you need to use the restroom, please feel free to get up and do so, and return as quickly as you can. (Tell where restrooms are located).
2. No full names or identifying information will be used anywhere. We'll only use first names for our discussion. No information will be released that would allow anyone to identify you.
3. You can decide not to answer a particular question, and you can also leave the group at any time.
4. We will be tape recording as well as taking notes in case the recorder breaks.
5. A few tips that will make our discussion go better:
 - a) There are no wrong answers, only different points of view.
 - b) Please speak one at a time, repeating your first name each time, so the recorder can pick up each voice.
 - c) Remember we have a lot to talk about during our time today, so (moderator) be moving us along.
 - d) Please respect other people's privacy by not discussing the comments you hear today with anyone else.

Opening question (3-5 mins)

1. We'll go around the table and please tell us just your first name, and something you enjoy doing when you have free time.

Introductory question (5-8 mins)

We are interested in learning about your opinions about long-term care. Long-term care includes services and supports that a person may need to manage a chronic condition or to help compensate for certain kinds of disability. Most people associate long-term care with nursing homes, but it also can be provided at home or in a variety of places in the community.

2. Please tell us whether you or anyone you know has ever used long-term care services, either at home or in a nursing home.
3. How might that experience have influenced your views on planning to pay for long-term care?



Key questions (35 mins)

General knowledge of long-term care planning

We want to start by hearing more about your general knowledge about long-term care and how it is paid for.

4. How would you describe your general knowledge about long-term care?
5. Let's hear about how you have learned about long-term care. Where do you get information? How useful has it been for you?
6. If you have done any long-term care financial planning, such as considering long-term care insurance or consulting a financial planner, please talk a little about that decision and process.

Perceptions of public/private responsibility

7. Imagine that you might need long-term care in the future. How do you think you might pay for it?
8. Now let's hear your thoughts about what you hope to do with your assets including your home, when you die. Have you considered how you would plan for that (depends on prior responses)?
9. Do you think it might be helpful to get advice from an expert such as a financial planner or elder law attorney? Have you done this? Would you tell me a little about that experience?

MEP

Now I would like to talk a little bit about Medicaid, which is the major public program that pays for long-term care. As you might know, in order to be eligible for Medicaid you need to have very small assets – less than 2,000 in your savings account, and your house may be recovered from your estate to pay back the program after you pass away.

10. Were you aware of these rules about Medicaid?

As you may know, Congress recently made it harder for people to transfer assets in order to qualify for Medicaid. The new rules say that any transfers that are made within 5 years before applying for Medicaid can disqualify you.

11. Do you think you would be inclined to transfer your assets so far in advance of the time when you might possibly need long-term care?
12. What do you think of this policy? How do you think the government might be able to enforce it? For example, do you keep records of financial transactions, including large purchases, charitable gifts, health care expenses, dating back 5 years?



Appendix B

LTC Planning Telephone Interview Guide

Hi, I am.... and am calling from the University of Connecticut Health Center in follow up to a letter you received recently about a long-term care needs assessment being done for the state. Thank you very much for completing a survey for us, and for sending back a card saying you would be willing to be contacted again. We are selecting a small group of people to participate in telephone interviews. The interview takes about 15 minutes to complete. Questions include your opinions about how long-term care should be paid for, and your plans to pay for long-term care if you should need it in the future.

Please be assured that any information you give will be kept confidential. Only researchers from the University of Connecticut Health Center will see your responses, and they will be kept in a locked file. Completing an interview is voluntary, and you may decline if you want to. Completing an interview implies your consent to participate. You can also skip any question you are not comfortable answering. I would like to audiotape the interview with your permission. If you would prefer not to be taped please let me know and I will keep the recorder turned off.

Would you be willing to help us with this? Is this a convenient time, or would you like to set up another time to talk?

If ready....

We are interested in learning about your opinions about long-term care. Long-term care includes services and supports that a person may need to manage a chronic condition or to help compensate for certain kinds of disability. Most people associate long-term care with nursing homes, but it also can be provided at home or in a variety of places in the community.

Knowledge

1. Have you thought about the possibility that you or a family member might need long-term care sometime in the future? What kinds of things have you thought about?
2. Can you tell me what kinds of things you have done to plan for that possibility? (information gathering, financial planning, home adaptation, others)

Perceptions of public/private responsibility

3. Please try to imagine that you might need long-term care in the future. How do you think you might pay for it?
4. Would it be your goal to protect your assets including your home to pass on to your children or to charity when you die? If so, have you considered how you would you do that? Probe: annuities...
5. Do you think it might be helpful to get advice from an expert such as a financial planner or elder law attorney? Have you done this? Would you tell me a little about that experience?

Insurance purchasing decision

Now I would like to talk a little bit about long-term care insurance that may pay for part or all of long-term care needs, depending on the policy.

6. Have you heard about long-term care insurance, and if so, please describe where you learned about it.
7. Have you considered long-term care insurance or consulting a financial planner, can you please tell me a little about that.

MEP

Now I would like to talk a little bit about Medicaid, which is the major public program that pays for long-term care. As you might know, in order to be eligible for Medicaid you need to have very small assets – less than 2,000 in your savings account, and your house may be recovered from your estate to pay back the program after you pass away.

8. Were you aware of these rules about Medicaid?

As you may know, Congress recently made it harder for people to transfer assets in order to qualify for Medicaid. The new rules say that any transfers that are made within 5 years before applying for Medicaid can disqualify you.

9. Do you think you would be inclined to transfer your assets so far in advance of the time when you might possibly need long-term care?

10. What do you think of this policy? How do you think the government might be able to enforce it? For example, do you keep records of financial transactions, including large purchases, charitable gifts, health care expenses, dating back 5 years?

Financial profile

Now I would like to get some general information about your financial profile.

13. What category best describes your total monthly household income from all sources before taxes? Include income such as wages, salaries, Social Security, retirement benefits, veteran’s benefits, public assistance, investment income, or any other income.

Less than \$500 each month	\$4,000 - \$4,999
\$500 - \$999	\$5,000 - \$6,999
\$1,000 - \$1,999	\$7,000 - \$8,999
\$2,000 - \$2,999	\$9,000 - \$12,499
\$3,000 - \$3,999	\$12,500 or more

14. How many people are supported by this income (including you)? _____

15. What category best describes the total value of your assets? Do not include your home or your car. Assets include bank accounts, stocks, bonds, investment or business property, and the cash value of any life insurance.

Less than \$5,000	\$75,000 - \$149,999
\$5,000 - \$14,999	\$150,000 - \$249,000
\$15,000 - \$29,999	\$250,000 - 349,999
\$30,000 - \$74,999	\$350,000 or more

16. Do you own your own home or condominium/townhouse?
No Yes

Closing

Thank you very much for your time today. Your participation will help the state in its efforts to develop a comprehensive long-term care plan for Connecticut. Is there anything else we didn’t get to talk about that you wish we had? Any other thoughts about long-term care financing that you would like to offer today?

Appendix C

Interview sample development

The sample was developed purposefully, in order to include individuals who had detailed knowledge or direct experience relevant to long-term care financing decisions (Mays and Pope, 1995). Potential interview participants were chosen from two different sources: a random sample of people who registered for one of three educational forums held by the Connecticut Partnership for Long-Term Care and a random sample from a subset of the Connecticut Long-Term Care Needs Assessment survey responders.

The three Partnership forums used for the sample were held in the fall of 2006, and represented three different parts of the state – Litchfield, Hartford, and New Haven counties. Twenty-five registrants from each of three forums were randomly chosen. Each received a letter of invitation signed by the Director of the Partnership and the principal investigator of the study asking if they would like to participate in an interview to learn more about your views and experiences regarding long-term care planning. Follow-up calls were made to further explain the study and determine if the person were willing to participate (a telephone number could not be located for 22 of the 75 registrants).

Sixty survey responders were also invited to participate in a confidential telephone interview. Each one had completed a statewide Connecticut Long-Term Care Needs Assessment survey in the fall of 2006. In addition, each had indicated on an optional response card sent back with their survey that they were willing to be contacted for future research. Sixty participants were chosen randomly from a subset of survey responders who fit the following self-reported criteria:

- Willing to be contacted for future research
- Age 42 – 75
- Not currently using long-term care services
- Total assets of at least \$30,000 (not including home or car)

Survey respondents who did not speak English and those without a telephone number were excluded from the subset.

A total of 32 telephone interviews were completed – 12 with forum registrants and 20 with survey responders. The sample size was determined by the principle of ‘theoretical saturation.’ This is the point at which no new concepts emerge from reviewing of successive data from a sample that is diverse in pertinent characteristics and experiences (Glaser and Strauss, 1967; Strauss and Corbin, 1998).



Focus groups sample development

Focus group potential participants were chosen using a purposeful sampling technique. All focus group participants had completed a general resident Connecticut Long-Term Care Needs Assessment survey in the fall of 2006. On the optional response card sent back with their survey, all had indicated that they were willing to be contacted for future research. Similar self-reported criteria were used to determine this sample of potential participants:

- Willing to be contacted for future research
- Age 42 – 75 (stratified into two groups: 42-60 and 61-75)
- Not currently using long-term care services
- Total assets of at least \$30,000 (not including home or car)

Survey respondents who did not speak English, those without a telephone number, and the 60 potential interview respondents were excluded from the subset. This resulted in 191 older adult and 143 boomer potential participants. Letters were sent to all potential participants inviting them to participate in a focus group to talk about your views and experiences regarding long-term care planning. This was followed by a telephone call to further explain the focus group and determine if the person were willing to participate. Each respondent was offered \$20.00 for their participation, and refreshments were provided at the group. Each focus group was approximately 60 minutes long. An experienced moderator facilitated the discussion, while an assistant taped the focus group and took notes. Six focus group sites were chosen in three different counties across the state: Hartford, New Haven, and Fairfield. Two focus groups were held at each site: one for older adults and one for boomers. When contacted by telephone, participants were given the flexibility to sign up for the focus group site that was most convenient for them. A total of 22 older adults and 18 Boomers participated in a focus group.



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