

The Issues

Consumer Choice

Defining Assisted
Living

Aging in Place

Shared or
Negotiated Risk

Regulation and
Quality of Care

Funding

ASSISTED LIVING Long-Term Care and Services Discussion Session Findings

February 1999

PENNSYLVANIA
Intra-Governmental

COUNCIL ON LONG-TERM CARE

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SESSION SPONSORS

The Pennsylvania Intra-Governmental Council on Long-Term Care wants to extend our sincere thanks to the many organizations which came together to make it financially possible for us to conduct the discussion groups and to develop this report. Without their support this initiative would not have been possible.

Pennsylvania Department of Public Welfare

Pennsylvania State Independent Living Council

Pennsylvania Association of Non-Profit Homes for
the Aging

Pennsylvania Department of Health

Pennsylvania Health Care Association

Pennsylvania Association of Home Health Agencies

Alzheimer's Association (Southeastern, Southcentral,
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Pennsylvania Coalition of Citizens with Disabilities

Pennsylvania Council on Aging

Pennsylvania Association of Area Agencies on Aging

County Commissioners Association of Pennsylvania

Southwestern Pennsylvania Partnership on Aging

Pennsylvania Department of Aging

And Many Thanks Go Out To...

The Council would like to take this opportunity to acknowledge and thank the following organizations and facilities for their assistance in providing the discussion session venues, greatly contributing to the success of the assisted living structured discussion groups.

Barclay Friends, West
Chester

Berks County Senior Citizens
Council, Reading

Blair Senior Services, Inc.,
Altoona

City of Philadelphia, Municipal
Services, Philadelphia

Community Center for
Crawford County, Meadville

Country Meadows, Hershey

HealthSouth Rehab Hospital,
Pleasant Gap

Jewish Association on Aging,
Pittsburgh

Kelly Apartments, Lewisburg

Sunnyview Home, Butler

Valley Crest, Wilkes-Barre

Westmoreland County
Community College

TO THE READER...

This report is the culmination of a three month initiative centering around 12 discussion groups designed to identify assisted living needs and to garner opinions on specific issues.

The report highlights the key messages and issues which the volunteer citizens shared during the structured, facilitated sessions.

The Council would like to thank those citizens who volunteered their time to share their thoughts, concerns and ideas about assisted living.

The Council also wants to extend its sincere thanks to the many organizations that came together to make it financially possible for us to conduct the discussion groups and to develop this report. Also, thanks is due to Dostalick ET AL Management Consultants for doing an excellent job of getting people to share their views, listening, and carefully recording what they had to say.

Any comments, questions, or other feedback should be directed to Dale Laninga, Council Executive Director, at the address and telephone or facsimile number listed below.

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Discussion groups are increasingly being used to obtain qualitative data regarding what individuals are thinking about specific issues. While this report does not constitute a "statistical sampling," it is an accurate reflection of the consistent thoughts, comments, and ideas of a cross-section of Pennsylvanians.

EXECUTIVE SUMMARY

Pennsylvania, like so many other states, is struggling with assisted living. Struggling in terms of defining it, providing it, and ensuring its quality. At the same time, consumers are calling for more options, more alternatives, more choices. While assisted living is just one component of the long-term care continuum, the Pennsylvania Intra-Governmental Council on Long-Term Care (Council) realizes the sense of urgency surrounding both long-term care and specifically, the issue of assisted living.

The Council's number one recommendation—reach out and involve citizens in long-term care issues—made to the Governor in 1996 guided the design of this initiative. The Council's goal for this initiative was to go out to persons across the state, especially consumers, caregivers, and others involved in long-term care and services, to talk about issues associated with assisted living. These relatively new services in the long-term care continuum continue to grow and require clear definition in Pennsylvania from a variety of aspects.

The Council contracted with a professional facilitator to conduct 12 structured discussion groups across the state. They wanted to listen to what the people had to say about the issues associated with assisted living and to get a sense of what they felt; the Council has done that. Based on the consistency of messages heard, they believe this report is an accurate portrayal of what a cross-section of people across Pennsylvania think and want with regard to assisted living.

Why Long-Term Care and Services Is An Issue

- ◆ Between the years 2000 and 2020, Pennsylvania is expected to experience a 31.9% increase in individuals age 60 and over.
- ◆ Between 1986 and 1997, spending in Pennsylvania for long-term care and services increased by 450% from \$600 million to \$2.7 billion.
- ◆ In 1997, Pennsylvania spent \$2.7 billion on long-term care and services.
- ◆ Approximately 81% of Pennsylvania's long-term care and services funding in 1997 was allocated to nursing home care, with the remaining 19% allocated to home and community-based care.

Council's Assisted Living Philosophy

- ◆ Encourages and supports individuals to live independently.
- ◆ Provides individuals privacy and dignity.
- ◆ Maximizes consumer choice to promote and support an individual's changing needs and preferences.
- ◆ Supports living in the residential environment of the consumer's choice.
- ◆ Promotes integration and mainstreaming.

The purpose of this Executive Summary is to summarize the findings of those discussions and to provide all Council members, key policy makers, department decision-makers, and legislators with direct feedback from those who are interested in and impacted by the development of assisted living in Pennsylvania.

The Issues

In exploring assisted living with the discussion group participants, the Council's assisted living philosophy and definitions were shared with the groups. There was a sense of frustration on the part of many participants that to date, assisted living has not been defined in Pennsylvania; by far, they found the most compelling aspect of the Council's definitions the concept of choice.

It was clear from the discussions that consumers of long-term care and services are growing more demanding and vocal. This is not a phenomenon unique to this industry; consumer-driven philosophies are driving much of business today, with long-term care and services being no exception. Furthermore, it is important to point out that "demanding" does not equate to unreasonable or unrealistic. Consumers' needs continue to become more complex because their lives are more complicated. This is an important message for the Council to consider as it moves forward with assisted living.

Additionally, individuals clearly do not want to see assisted living follow a nursing facility model in terms of funding, quality of care, or regulation. They want a consumer-oriented system that puts the needs of the

users in the forefront when the system is planned and designed. And in their opinion, this is not the nursing facility model.

The following are the six issues around which the participants' key messages were centered:

- Consumer choice
- Defining assisted living
- Aging in place
- Shared or negotiated risk
- Regulation and quality of care
- Funding

Consumer Choice *(page 20 for more details)*

In almost all cases, the philosophy of consumer choice drove the participants' responses. Time and time again, the aspect of consumers having control, making decisions for themselves, and taking responsibility for the consequences rose to the surface. In fact, for many participants the appeal of assisted living was based on the aspect of having choices, particularly when the Council's definitions of assisted living services and assisted living residence, which incorporate choice, were shared with the participants.

Defining Assisted Living *(page 21 for more details)*

While individuals had a difficult time defining assisted living, they did want it to be available as an alternative to them. The key commonalities in their definitions of assisted living were that it is the provision of any services necessary to maximize independent living. In other words, services very much tailored to the individual consumer. The primary difference in their definitions revolved around where these services would be provided. Some

The Council's assisted living definitions highlighted below were discussed at each of the 12 discussion group sessions.

Council's Definition of Assisted Living Services

- ◆ A combination of supportive services and personalized assistance services designed to respond to individual needs of those who need assistance with activities of daily living (ADLs) and instrumental activities of daily living (IADLs).

Council's Definition of Assisted Living Residence

- ◆ Residential setting that offers, provides, and/or coordinates a combination of personal care services, 24-hour supervision, and assistance (scheduled and unscheduled) activities, and/or health related services.
- ◆ Has a service program and physical environment designed to minimize the need for tenants to move within or from the setting to accommodate changing needs and preferences.
- ◆ Has an organizational mission, service programs, and a physical environment designed to maximize residents' dignity, autonomy, privacy, and independence.
- ◆ Encourages family and community involvement.
- ◆ Will disclose services offered, provided, and/or coordinated and the costs thereof.

participants thought of assisted living as being provided in a facility setting while others thought of it as being provided in their home.

The Council was very interested in what participants thought an assisted living residence should look like. Knowing that potential public funding will only go so far, the groups were asked what accommodations they would wish to see in an assisted living residence. The participants said a private room, bath, and locked door were important. However, if they could have just one of those, the overwhelming majority chose a private room over a locked door or private bath.

Aging in Place (page 22 for more details)

A significant majority of participants felt that aging in place, or not having to relocate to obtain the services they need, was extremely important. It was intriguing to note how most of the participants defined home. They continually referred to home as their current residence as opposed to any facility or assisted living residence in which they might reside in the future.

Many also spoke to the issue of dignity and allowing people to remain where they wished, even when conditions dictated the need for assistance. The disruption caused by moving—at a time when individuals may be least comfortable with such change—was undesirable to most participants.

Shared or Negotiated Risk

(page 26 for more details)

The concept of shared or negotiated risk was described as one in which individuals negotiate a contract with an assisted living services provider regarding how they live—within

given parameters of safety for themselves and particularly other residents.

The majority of participants felt it was a good idea, although several concerns about the concept were raised. These concerns particularly related to family members not honoring the contract and others (providers) defining what “risk” is for the consumer.

Regulation & Quality of Care

(page 24 for more details)

The majority of participants believed that quality is best handled by a combination of consumers and government, with minimum regulation serving as a starting point and guiding, not dictating, quality of care. They believed that while this base of practical regulation is important, it is the consumers’ feedback that should be the defining factor. There was overwhelming agreement that the nursing facility model for quality is not working, due to the experiences participants had with what they perceived as less than appropriate quality.

Funding *(page 27 for more details)*

Participants of the discussion groups resoundingly felt that there must be a reallocation of funds from the nursing facilities to community-based services. However, they also felt that mere reallocation would not be enough; there must be additional funding sources developed. Furthermore, the participants felt that the funding streams should be based on consumers’ needs and should “follow” the consumer, with proper education provided. There are too many examples of individuals using services that they do not really need because that is the only funded service available to them; the participants do not want to see this happen with assisted living.

Key Issues

- ◆ Consumer choice
- ◆ Defining assisted living
- ◆ Aging in place
- ◆ Shared or negotiated risk
- ◆ Regulation and quality of care
- ◆ Funding

Overall Observations

The current system and doctrines that guide it have become seen as the “norm.” This appears to have left many participants with the belief that what currently exists is the *only* possibility, with little or no chance of meaningful improvements being made based on consumer needs and expectations.

Discussion group participants believed it was inevitable that government would be unable to think in terms of guidance versus regulations; to think in terms of consumer versus benefit recipient; to think in terms of partner versus provider; to think in terms of flexibility versus procedures; to think in terms of serving versus mandating.

Keep in mind that one of the strongest messages heard from the participants was that they want to see some action taken by the Council and policy makers. Consumers, in particular, are frustrated and have grown weary of a long-term care system that is difficult to access and navigate. Above all else, they do not want assisted living to be engulfed by this cumbersome system. And, they are looking to the Council to take action to ensure that doesn't occur.

Participant Expectations, Hopes, and Desires

Ironically, while the sessions were introduced as forums for the participants to think and provide feedback as consumers, the vast majority of individuals brought a mentality of “what is” rather than “what might be.”

It was surprising how the participants’ exposure to, and experiences with, the current long-term care system had conditioned their thinking, limited their perceptions about what “might be,” and influenced their ability to think like a consumer.

However, after some discussion, they did begin to think like consumers and articulate a combination of needs, expectations and desires.

For the most part the participants said they expect:

1. Not “Cadillac” services, but a certain level of quality services based on an established baseline.
2. Funding that is directed to those long-term care services they need and want, rather than to those services that have traditionally received the lion’s share of the funds.
3. An extensive public education and information initiative about all aspects of the long-term continuum.
4. The consumer—not government—should assume the lead role in setting the standard for quality of care and services, although there should be minimum guide-

Participant Expectations

- ◆ Consumers will receive quality services based on an established baseline.
- ◆ Funding will be directed to those long-term care services that consumers need and want.
- ◆ An extensive public education initiative should be implemented.
- ◆ The consumer should assume the lead role in setting quality of care.

Participant Hopes and Desires

- ◆ Government must view the citizen and receiver of benefits and services as a consumer.
- ◆ Government must view regulations as one methodology to be judiciously used.
- ◆ The needs and expectations of the consumer must drive change.
- ◆ Assisted living must not go the way of nursing facilities.

lines. The outcome should be an industry that is responsible, but not over-regulated.

There was also another set of messages that surfaced as an indirect outcome of the structured discussion groups. These messages would best be categorized as hopes and desires. They cannot be called expectations because the participants believe that, while these messages are the key to re-engineering the current, long-term care continuum, the “powers that be” may not want to heed them.

- Government must shift to becoming truly interested in viewing the citizen and receiver of benefits and services as a consumer.
- Regulations are necessary to guide the quality of care and services; however, government, bureaucrats, and policy makers must not view regulations as a panacea, but instead as one methodology that should be judiciously used. The key to regulations is that less is more; they should be based on people’s needs, not government’s.
- Existing bureaucracies, turfs, inherent beliefs, institutional memory, and comfort levels must not be the drivers of how change is defined and executed. It must be the needs and expectations of the consumer.
- Assisted living, which must be defined and managed, should not go the way of nursing facilities.

We hope their expectations, hopes, and desires will be given the same level of careful thought that the participants gave to the structured discussion group questions.

THE SESSIONS

In 1996, the Pennsylvania Intra-Governmental Council on Long-Term Care (the Council)—through their Assisted Living Work Group—began working in earnest on the issue of assisted living. The Council’s Work Group began by developing an assisted living philosophy and definitions (see sidebars on pages 2 & 3) and then began tackling the development of recommendations related to regulatory, funding, and quality assurance issues.

The Council quickly realized that stakeholder input, and particularly consumer feedback, were critical to understanding the complexity of this rapidly growing component of the long-term care continuum. As such, the Council decided to talk to individuals throughout the state about long-term care and services, and more specifically, assisted living.

Why Structured Discussion Groups?

The Council decided to use structured discussion groups to solicit feedback from consumers and others who are personally involved with assisted living and long-term care. These sessions support the Council’s commitment to reach out to consumers and others, which was initiated with the first series of structured discussion groups held in 1997 (see “Then and Now” on page 14). They chose discussion groups because other methods of obtaining feedback such as surveys, telephone interviews, and questionnaires are not as effective

Who Is the Council?

- ◆ Established by Act 185 in 1988.
- ◆ Dedicated to providing recommendations for a long-term care and services system that addresses the need of Pennsylvanians into the 21st Century.
- ◆ 37 members who represent the diverse interests of the long-term care and services consumers, providers, and purchasers.

in addressing in-depth topics, controversial and/or complex subjects, or issues that engender emotion or strongly held beliefs. All of these characteristics are associated with the issue of assisted living. Qualitative methods of obtaining information, such as discussion groups, are very effective in these circumstances. This is primarily because they allow facilitators to probe to get to the emotion of an issue or to identify the real issue which might be difficult, if not impossible, to uncover through other feedback methods.

The Council's decision to once again involve stakeholders in a direct way puts them in good company. In fact, according to the American Management Association, the use of focus groups or structured discussion groups and an increased emphasis on qualitative research in planning processes has been dramatically rising: 91% since 1990. In fact, *The Boston Business Journal* notes the use of structured discussion groups has exploded to a \$1 billion a year industry as public and private entities realize the success of these groups in identifying key issues and trends. Volumes of data are no longer looked upon as a prerequisite to solid decision-making. Today's rapidly changing environment calls for quick and agile decision-making; calculated risk-taking—based on experience—is leading many planning efforts, with “number crunching” assuming a supporting role. And nowhere is this rapidly changing environment more prevalent than in the long-term care and services arena in which change is an almost daily occurrence.

In summary, it is recognized that structured discussion groups allow for:

- Educating regarding the specific topic being discussed;
- Obtaining feedback on key issues;
- Gauging emotional intensity; and
- Leaving participants with a sense of being listened to.

Structured Discussion Group Trends

The Council incorporated a number of current trends into the design of this initiative. For example, while once the thinking was that discussion groups should have well over a dozen participants in each session, the trend is now toward smaller focus groups. *The average size of the Council's structured discussion groups was 11 participants.* Two facilitators were used to ensure the analysis of group dynamics was maximized and that all participant messages were clearly detailed. Having two facilitators to ensure that all comments, thoughts, and ideas were captured was critical to the sessions' effectiveness. This made the participants feel more comfortable, as evidenced by the animated conversation and the tendency for participants to remain after the session was officially concluded to continue discussing the issues.

There is also a real movement toward encouraging interaction among structured discussion group members to elicit more points of view. In fact, *Qualitative Health Research* highly recommends interactive group discussion to better reflect the thinking of the represented community. The Council's structured

Who Did We Hear From?

- ◆ Consumers
- ◆ Family Members
- ◆ Volunteers
- ◆ Informal Caregivers
- ◆ Providers
- ◆ Advocates

Participant Feedback

Listed below are the percentage of participants who gave either a "good" or "great" response to the following questions. To what extent:

- ◆ Did you feel the session was a good use of your time? 98%
- ◆ Did you feel comfortable participating? 99%
- ◆ Did you feel able to speak freely and honestly? 99%
- ◆ Did you feel the important issues were brought forth? 97%
- ◆ Did you feel attentively listened to? 100%

discussion groups' dynamics were clearly interactive. The groups were encouraged to learn from each other and ask each other questions and seemed to appreciate the chance to hear other perspectives.

According to Dunn and Bradstreet, when structured discussion groups are done well and findings are consistent, additional research or validation is typically not necessary. A good rule of thumb is to validate, through quantitative means, anything that doesn't make sense or appears to be an anomalous message. Interestingly, the issues raised by the structured discussion groups were extremely consistent, distilling to six key issues, as detailed beginning on page 20.

Who Participated?

The 12 structured discussion groups were conducted between November 19 and December 11, 1998, involved 137 participants, and lasted two and a half hours each. Participants were nominated by Council members and randomly selected by Dostalick ET AL based on specific criteria. Letters were sent inviting individuals to participate, and again thanking them following the sessions. The participants included a cross-section of individuals including long-term care and services consumers, providers, family caregivers, volunteers, and advocates. Many of the participants brought multiple perspectives; in all cases, they were asked to come from their personal perspective as a current or potential user of services.

Geographically, the structured discussion groups were held in 12 locations designated by the Council. This was done to determine if geography would influence points of view or

concerns. This was not found to be the case with this initiative. Additionally, from a practical standpoint, the multiple locations provided easy access for those who attended.

The Structured Discussion Group Sessions

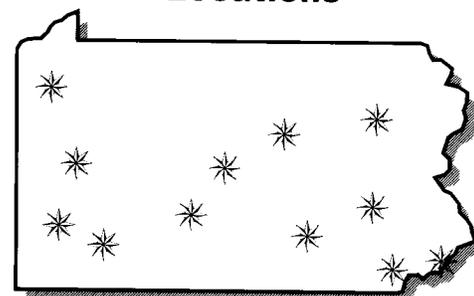
The sessions were designed to be casual and comfortable while still focusing on the rather complex topic of assisted living. To that end, the facilitators spent time in conversation with the participants prior to the beginning of each session to help put the participants at ease. This was very helpful in assisting participants with assuming the proper mindset: a willingness to share their perceptions and points of view with the facilitators and actively participate in the dialogue. Both of these are critical to the effectiveness of the sessions.

The purpose of the sessions was three-fold:

1. Review the long-term care and services values developed by the 1997 structured discussion groups (see "Then and Now," page 16);
2. Provide general education on long-term care and services and more specifically, assisted living; and
3. Obtain feedback on several key issues associated with assisted living.

Following a discussion regarding the 1997 values, the sessions turned to providing "facts and figures" to the participants related to long-term care and services in general. These were reviewed in order to provide context for the assisted living discussion to follow.

Discussion Group Locations



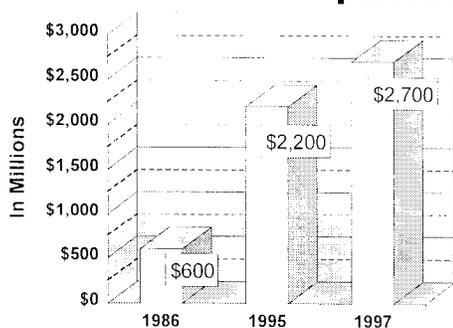
Session Ground Rules

- ◆ We want to hear from everyone.
- ◆ There is no need to "sell" your ideas.
- ◆ It is alright to disagree.
- ◆ Come from your personal perspective.
- ◆ Do not engage in "side" conversations.
- ◆ If your intent is not understood, let us know.
- ◆ There is no right or wrong response.
- ◆ Do not monopolize the conversation.
- ◆ Have fun.

What Did The Council Ask?

- ◆ How important is aging in place?
- ◆ How should quality of care be assured with assisted living?
- ◆ Is shared or negotiated risk a viable alternative?
- ◆ How should assisted living be funded?
- ◆ Should funds be diverted from nursing facilities to assisted living?
- ◆ Should assisted living be provided for those who cannot afford it?
- ◆ Should those who can afford assisted living have to pay?
- ◆ How important is a private room, private bath, locked door, and kitchen to you?

Growth in PA's Long-Term Care & Services Spending



This includes Medicaid, Lottery funds, Social Services, York Grant, Human Services Development Fund, the state supplement to SSI and the Veterans Homes.

Source: PA Department of Aging and PA Department of Welfare, May 1998.

Long-term care and services continues to be an issue of growing concern in Pennsylvania. Not only is spending rising at an alarming rate, but the accompanying current and projected population growth makes this an issue of potentially crisis proportions. And while this issue often seems to focus on our elderly population, statistics clearly show that individuals with disabilities also comprise a significant population in need of long-term care and services. It was for this reason that the Council made certain to have representation of both individuals with disabilities and those familiar with the concerns of our aging population.

With government currently being the primary payer of services, concern about needs outpacing resources is also growing rapidly. Furthermore, those resources are not being appropriately funneled into areas that consumers have said they want, namely home and community-based services. Assisted living was discussed with the participants as an option that is more home and community-based rather than facility-based in the traditional sense.

To facilitate meaningful discussions, each group was asked a series of questions:

1. How important is the idea of aging in place and why? What challenges do you see associated with allowing individuals to age in place?
2. How should quality of care for assisted living be assured?
3. Do you think the concept of shared or negotiated risk is a viable alternative to bal-

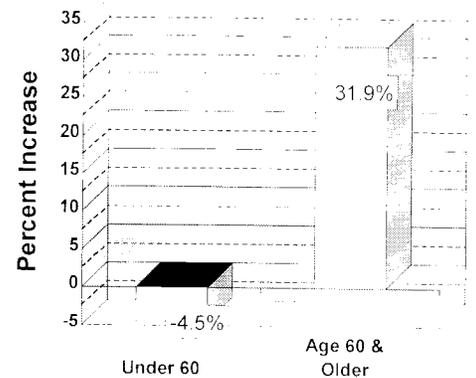
ancing consumer choice and public protection? What are other ways we can achieve that balance?

4. How should assisted living services be funded?
5. Should assisted living services be provided for those who do not have the resources to pay for them? Should those who can afford assisted living services have to pay for some or all of the services they utilize?
6. Should funds be diverted from nursing facilities to assisted living?
7. How important would the following be if you were looking for an assisted living residence: private room, private bath, locked door, and/or food preparation area? If cost were an issue, which single one would you require?

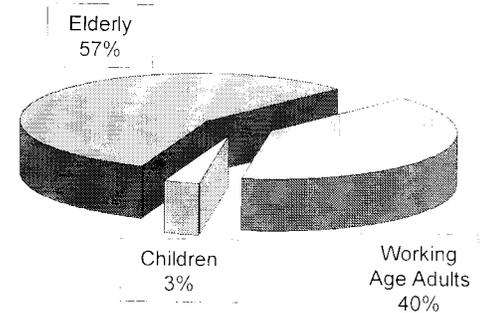
The discussions were animated and stimulating, resulting in hundreds of comments, ideas, issues, and concerns from the participants regarding assisted living. At the end of each session the groups were also asked if they had any additional comments, thoughts, or concerns to share with the Council. This allowed them to surface additional points they thought warranted the Council's attention.

As part of the consumer-driven focus of these sessions, the Council also wanted to obtain attendees' feedback so that changes could immediately be made to improve subsequent structured discussion groups. Of the 137 participants who responded to the session evaluation, 98% of them felt that the session was a productive use of their time.

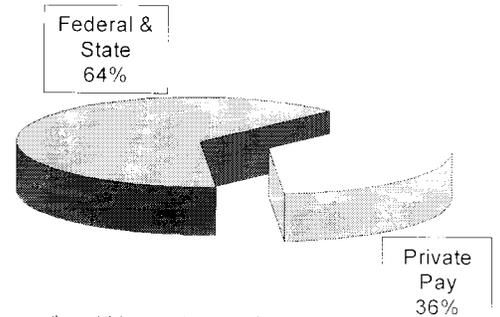
Projected PA Population Growth 2000 - 2020



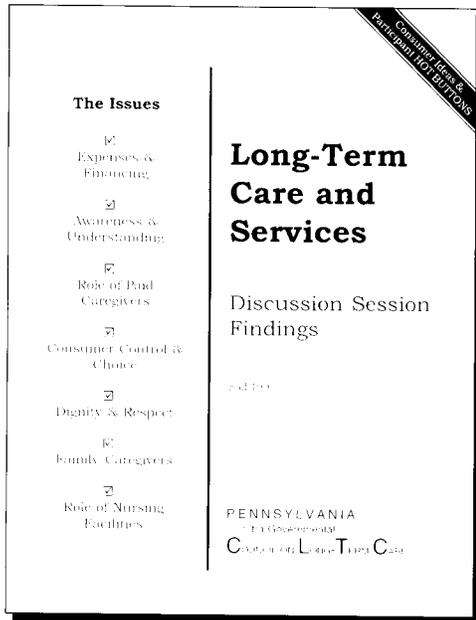
People Needing Long-Term Care & Services



Who Pays for Long-Term Care & Services in the US?



THEN AND NOW



In May 1997, the Council held 12 structured discussion groups on the topic of long-term care and services. The purpose of these structured discussion groups, as with the sessions recently completed in December 1998, was to reach out to consumers and others who are personally involved with long-term care and services in Pennsylvania.

Values

One of the most important aspects or purposes of the 1997 discussions was the development of values with regard to long-term care and services. A value was described to participants as “the one thing they most wanted the Council and others to keep in mind as they set about making recommendations and setting policy for the long-term care and services system in the Commonwealth of Pennsylvania.”

As a result, the 12 groups developed 3 common values as shown in the sidebar. Each and every one of the 148 participants in 1997 felt it was critical that these three values be reflected as long-term care and services policy was formed in Pennsylvania.

These values were revisited during the 1998 sessions. Rather than ask participants to develop new values for long-term care and services, the facilitators asked instead:

1. Should the Council continue basing its decision-making process on these values,

1997 Consumer Values Reaffirmed

- ◆ Remain as independent and live at home as long as possible
- ◆ Respect and dignity for the individual
- ◆ Consumer choice

2. Should these values continue to figure prominently in every conversation conducted by the Council, and
3. Did the 1998 participants unequivocally agree with the importance of these values?

Overwhelmingly, the groups upheld the 1997 values. They sent a resounding “stay the course” message to the Council, encouraging—if not demanding—the continued prominent consideration of these values as long-term care and services policies are shaped in the Commonwealth.

Common Themes

In addition to reaffirming the values, it was interesting to note the similarities, in terms of several key messages, between the participants in 1997 and those in 1998. While the topics discussed by the participants were markedly different in 1997 and 1998, several common themes emerged although the facilitators did not specifically bring them up. It is important that the Council know that issues raised in 1997 are still very much on the minds of citizens today.

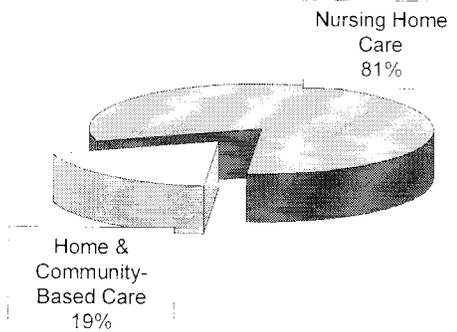
Nursing Facilities

The message was clear: there is a definite place and role for nursing facilities. However, the more telling message was that while there is a place for nursing facilities, no one really wants to live in one. The participants also found it extremely frustrating that nursing facilities are often the only choice.

Common Themes 1997-1998

- ◆ There is a place for nursing facilities, but they shouldn't be the only choice.
- ◆ The role of the professional caregiver must be elevated.
- ◆ There must be a shift in funding from facility-based to community-based services.
- ◆ Public education is critical.
- ◆ Regulations determining where funds are directed must be re-evaluated and overhauled.

1997 PA Medicaid Expenditures



Source: PA Department of Aging

Role of the Professional Caregiver

As was discussed in the 1997 sessions, the sentiment is that until professional caregivers are held in higher esteem and treated accordingly (e.g., salary and respect), attracting qualified, caring individuals to this profession will remain extremely difficult, causing great turmoil in the long-term care and services field. The enduring message from participants is that there must be a dramatic change with regard to how these individuals are viewed. Otherwise, Pennsylvania will never be able to provide the quality and level of care necessary to afford consumers the respect, choice, and dignity they deserve.

Funding Shift

The issue of a necessary shift in funding continues to underlie all of the messages heard. Again, the role of nursing facilities is fully recognized, but consumer choice emphasizes that services be provided in the community to a much greater extent than is currently done. Participants felt that the funding system needs to be re-evaluated and, in their opinion, completely overhauled. They believed that the system dictates that consumers be directed to facilities, when community-based services are what they truly want. It is consumers' needs and wants, not the current policy- and procedure-driven system, that should determine where the funding goes.

The System Is Broken

The participants continue to feel the long-term care and services system in Pennsylvania is broken to the point where mere adjustments and refinements will not be enough. This is from the aspect of funding, public education, delivery of services, and access to the

system. In short, a complete overhaul of the system is needed if it is to be truly consumer-driven.

Public Education

As in 1997, one of the most plaintive calls from discussion group participants was on the subject of public education. By this they meant education related to both the issues of long-term care and services and the logistics associated with accessing services. At times it seems nearly impossible for consumers to access the system. They say they need clearer direction as to what services are available from whom. They also want any new long-term care option, such as assisted living, to be consumer-friendly. Additionally, participants continued to believe that, in general, consumers should be educated about aging issues on an ongoing basis, perhaps beginning as early as school age.

The following section provides a discussion of the common concerns and issues among the 12 assisted living discussion sessions conducted in November and December 1998.

KEY MESSAGES

The messages heard in the 12 structured discussion groups were very consistent and very much centered around the concept of consumer choice. Clearly, consumer-driven philosophies are driving much of business today, with long-term care and services being no exception. This is an important message for the Council to consider as it moves forward with assisted living.

The following are the six issues around which the key messages heard from the participants center:

- Consumer choice
- Defining assisted living
- Aging in place
- Regulation and quality of care
- Shared or negotiated risk
- Funding

These issues are presented here in no particular order of importance. It is hoped that the participants' messages provide the reader with a "dose of reality" from the perspective of those to whom future decisions regarding assisted living will have great impact. They are concerned and anxiously awaiting action.

Consumer Choice

In almost all cases, the philosophy of consumer choice drove the participants' responses. Time and time again, the aspect of consumers having control, making decisions for themselves, and taking responsibility for the consequences rose to the surface. In fact,

Key Messages Consumer Choice

- ◆ Want control over their lives
- ◆ Want to make their own decisions
- ◆ Want to take responsibility
- ◆ Find assisted living appealing due to choice

for many participants the appeal of assisted living was based on the aspect of having choices, particularly when the Council's definitions of assisted living services and assisted living residence, which incorporate choice, were shared with the participants (see sidebar on page 3). In short, the participants do not want someone making decisions for them; they want to make their own decisions. In the words of one participant from Youngwood, "I don't want someone making decisions about me when it's a job for them and a life for me."

What was intriguing, however, was that while individuals wanted choice for themselves, they didn't have the same confidence in the ability of others to make effective choices. This was particularly evident when discussing issues such as negotiated risk (see page 26).

Defining Assisted Living

Interestingly, when asked to define the term assisted living, participant comments were all over the board as shown in the sidebar. Assisted living was looked at by several participants as "for the rich only" based on the lack of public funding (see discussion on page 27), and more than a few individuals saw assisted living as a "marketing term" used by providers to attract more residents into what are actually Personal Care Homes. Assisted living was also described as the "last stop" before a nursing facility, again pointing to the desire for options. Many providers expressed confusion regarding the lack of regulation and staffing and a concern over the quality of care.

While individuals had a difficult time defining assisted living, they wanted it to be available as an alternative to them. The concepts

Key Messages What is Assisted Living?

- ◆ It's a marketing term.
- ◆ I stay in my home, receiving the services I need to live independently.
- ◆ I don't know if it means in my home or in a facility.
- ◆ It's for rich people.
- ◆ It's confusing.
- ◆ It's supervised living.
- ◆ It's the step before a nursing home.
- ◆ Allows me to live as independently as possible.
- ◆ It's temporary assistance.
- ◆ Tailored services depending on my needs.
- ◆ Socialization of the individuals versus being isolated.

The Council's assisted living definitions highlighted on page 3 were discussed at each discussion group.

Key Messages Assisted Living Residence Needs/Desires

Listed below are the percentages of participants who said that the respective component was "important" to them in selecting an assisted living residence using public funds:

Private Room	83%
Private Bath	79%
Locked Door	70%
Kitchen	40%

Listed below are the percentages of participants who said the *single* component was *critical* to them:

Private Room	60%
Locked Door	20%
Private Bath	16%
Kitchen	3%

Home

"Home" is wherever you choose to live, whether it is a facility, a private residence in a neighborhood, or anything in between.

—As defined by the Council

behind assisted living, namely independence, choice, and tailored services as presented in the Council's assisted living philosophy and definitions (see pages 2 & 3) were compelling to the participants.

One of the topics discussed during the sessions related to what assisted living residences should look like, particularly if public funding were involved. To determine what amenities would be important when selecting an assisted living residence, four options were offered to participants. They listed a private room, bath, and locked door as important and a food preparation area significantly less important.

When asked what single condition was most important, more than three times the number of participants selected a private room over a locked door or private bath. The food preparation area was ranked as least important by a significant margin.

Aging in Place

The concept of aging in place was discussed with great interest and animation. A significant majority of participants felt that aging in place, or not having to move to obtain the services they need, was extremely important. It was intriguing to note how most of the participants defined home. The definition of home used by the Council for the sessions is shown in the accompanying sidebar. However, participants continually referred to home as their current residence as opposed to any facility or assisted living residence in which they might reside in the future.

The concept of aging in place was the one issue where participants' ages made a difference in their responses. Younger individuals did not feel that aging in place was as important as it was to older participants. In the minds of younger individuals, their home was wherever they were. As one woman said in West Chester, "I take my roots with me when I go." Additionally, for those who were less emphatic about aging in place, it was often because they didn't want to inconvenience family members.

"I take my roots with me when I go." As one spouse of an Alzheimer patient in Altoona said, "I told my kids, if I get like your father, don't try to keep me at home; take me to a nursing facility."

But participants were fair about the challenges associated with aging in place including issues of safety, uniform quality of care, unavailability of services, isolation concerns, and affordability. Specifically, there was great concern over the availability of community-based services and, in particular, the lack of transportation services.

However, by an overwhelming majority, consumers want to age in place and more often than not felt that place was their home. Individuals thought aging in place was important in degrees ranging from "paramount" to "critical" to "critically paramount." Many also spoke to the issue of dignity and allowing people to remain where they wished, even when conditions dictated the need for assistance. The disruption caused by moving—at a time when individuals may be least comfortable with such change—was undesirable to most participants. In the words of one participant from Philadel-

Key Messages Aging in Place

- ◆ Consumers do not want to move to receive the services they need.
- ◆ "Home" was seen primarily as their own residence and is very important to most.
- ◆ This issue was not as important to younger participants.
- ◆ Availability of community-based services is critical to making this a reality.

Aging in Place

Providing services in a manner so as to minimize the need for individuals to move from their desired residence or home to accommodate their changing needs.

—As defined by the Council

phia, "When people move, they give up." And as one caregiver in Altoona characterized her visits with several older residents of an assisted living facility, "I sit for hours listening to them talk about the homes and gardens they left behind." The message came through loud and clear: "When people move, they give up." staying at home mattered to the participants.

Key Messages Regulation and Quality of Care

- ◆ Regulation by itself cannot ensure quality.
- ◆ Quality should be driven by the consumer, with minimal practical regulation serving as a starting point.
- ◆ Direct consumer feedback on care and services is critical.
- ◆ The nursing facility model for quality is a failure and assisted living should not follow that path.

Regulation and Quality of Care

For the most part, the structured discussion group participants felt that while quality of care and services is incredibly important, regulation by itself is not the vehicle by which to ensure that quality. It was agreed that regulations should not be Band-Aids[®] for system-related problems as the participants felt has happened in the past with nursing facilities. Instead, the root cause of quality issues must be identified and dealt with, without immediately defaulting to a regulatory reaction. Time and time again the groups called for one umbrella of regulation, not a conglomeration of separate regulations for all the different types of care.

The participants felt that quality is best handled by a combination of consumers and government, with minimum regulation serving as a starting point and guiding, not dictating, quality of care. In their opinion, consumers must be actively involved in determining quality of care. Some ideas of how to do that included: involving consumers in the definition of quality for assisted living; mandating a quality assurance system that incorporates consumers' thoughts; and above all, asking the consumer to evaluate the service they receive. However, the key to this effort is that the consumer must be an *educated* consumer.

There was overwhelming agreement that the nursing facility model for quality is not working. As an example of this, there was some concern expressed that if the consumer was responsible for driving quality, he or she may be afraid to complain in the current system, fearing some sort of retaliation by the provider.

Participants believed that regulation should provide a practical and sensible baseline from which consumer input and satisfaction feedback would then drive the level of quality. Consumers need to be educated and trained in how to manage their caregivers; too many are scared to complain because they think that, as a result, they won't get the services they need.

Several participants also discussed the rising levels of acuity and the reality that assisted living may take on more and more consumers who have greater health needs. Because assisted living could become accessible to more consumers if public funding were provided, overburdening of the system may occur, potentially resulting in poor care.

Participants also linked elevating the role of the professional caregiver to quality of care. The connection to be explored here is between employee satisfaction and consumer satisfaction in that if the professional caregiver feels that he or she is treated well, they will tend to do a better job in working with the consumer.

In short, the overwhelming majority of participants strongly believed that the consumer should be driving the issue of quality in assisted living. While a base of practical regulation is important, it is the consumers' feedback that should be the defining factor.

Involve Consumers In Determining Quality By...

- ◆ Involving consumers in the definition of quality for assisted living.
- ◆ Mandating a quality assurance system that incorporates consumers' thoughts.
- ◆ Asking the consumer to evaluate the service they received.
- ◆ Competition among services providers driven by consumers.
- ◆ Consumer councils.

them should a mishap occur. As one provider from Pleasant Gap said, “This idea is the only thing I lose sleep over.”

More than a few participants also felt some hesitation at having people other than the consumer deciding what constituted risk to the individual. In their opinion, perceived risk is often much greater than actual risk, and such decisions should unequivocally belong to the consumer.

Interestingly, the concept of negotiated risk was one that most participants felt made sense for them. When thinking about other consumers, however, the participants were not as sure. It was as though they doubted the decision-making ability of others but not their own ability in this regard.

Funding

The key messages associated with the funding issue related to:

- Reallocation of funds from nursing facilities to community-based services.
- The need for more funding in addition to this reallocation.
- The need for individuals to prepare for future long-term care and services needs early in their lives.
- The funding stream should be based on consumers’ needs and should follow the consumer with proper education provided.
- Public funding is needed for those who cannot afford assisted living while those who can should pay.

Shared or Negotiated Risk As Defined by the Council

- ◆ Contractual agreement between provider and consumer.
- ◆ Provides for greater independence and autonomy for consumer.
- ◆ Only if there is a legislative or regulatory basis will negotiated risk provide reduced liability for providers.
- ◆ Assumes full mental capacity of those negotiating.
- ◆ Assumes basic safety, particularly for others.
- ◆ Renegotiated on a regular basis and whenever there is a change in conditions.

Key Messages Funding Ideas

- ◆ Tax credits.
- ◆ Taxes on various items from cigarettes, to gasoline, to liquor, to consumer items.
- ◆ Rid the Medicare system of fraud and use the “found” funds for assisted living.
- ◆ Have Commonwealth take over gambling concerns and operate like the current state lottery.
- ◆ Cap the lottery at \$10M and use excess as funding for assisted living.

Key Messages Funding Concepts

- ◆ Direct funds from nursing facility to community-based services.
- ◆ Need more dollars than such reallocation will provide.
- ◆ Individuals need to “prepare” early.
- ◆ Funding streams should be based on consumer needs.
- ◆ Public funding should be available for assisted living.

The participants called for a diversion and reallocation of public funding from nursing facilities to assisted living and other community-based services. A few individuals were concerned that the diversion of funds may take necessary support away from nursing facilities. However, the majority felt that if the funding were reallocated, many individuals who are currently in nursing facilities because public funding subsidizes them would be able to avail themselves of community-based services. As an individual in Wilkes-Barre said, “Current laws result in folks being stripped of what they own so that they can get the services they need. They’re at the mercy of society.” In the words of another participant from Butler, shifting the funding would keep society from “... putting consumers through agonizing situations they don’t need to go through.”

Persons with disabilities who participated in the sessions also pointed out that the current funding mechanisms have contributed to 75% unemployment in the disabled community because they lose their benefits if they earn too much. As one participant from Lewisburg put it, “...if we changed the system we could have the best of both worlds [minimal spending and employment]; now we have the worst of both worlds [greater spending and unemployment].”

Participants felt that reallocation was a “win-win” with the taxpayer benefiting from more cost-effective provision of services in the community and the consumer having more choices and control. There was some disagreement as to whether home-based services were, in fact, more cost effective. Participants cited

differing studies as well as opinions formed by personal experience. One participant in Reading said, “We spent \$32,000 for the last year of my sister-in-law’s life...so keeping her at home was not a way to save money.”

While it was agreed a shift in funding was in order, it was also agreed that mere reallocation wasn’t enough; it is critical that additional funding streams be created or tapped. The most accepted ideas are in the accompanying sidebar; additional thoughts are included in the individual session descriptions (pages 32 through 43) as they apply. The most often mentioned idea was tax credits for long-term care insurance or other consumer long-term care savings plans. The idea of “luxury taxes” was also discussed and while seen as favorable by some individuals, more than a few participants expressed concern that such taxes would result in “black markets” or ill feelings toward assisted living consumers because of the additional cost.

The majority of participants felt that funding provided for assisted living (and long-term

“Current laws result in folks being stripped of what they own so that they can get the services they need.”

care and services in general) should “follow the consumer,” with the consumer controlling the funds they receive.

The current system requires them to jump through a convoluted series of hoops in order to receive funding. A more efficient system would distribute funds directly to the consumer for use as he or she sees fit, rather than the consumer accepting services that may not apply but are reimbursable. They fear the cur-

Long-Term Care Insurance Feedback

- ◆ Too expensive
- ◆ Not for the poor
- ◆ Too complicated
- ◆ Many don't qualify
- ◆ Should consider premiums based on sliding scale
- ◆ Concern over whether it "fits" persons with disabilities

rent ineffective long-term care and services funding system will become the model for an assisted living funding system of the future.

This concept of funds following the consumer also directly tied into the dignity of the consumer, which is consistent with the intent of the Council's definition of assisted living, as well as the consumer values developed in 1997 (page 16). As one consumer in Pittsburgh said, "I like to have the opportunity to hand the check to the services provider so they know who they answer to." Participants felt that in addition to providing consumers with the dignity they deserve, such a system also helps ensure quality of service, as the provider must answer directly to the consumer, not a third party payer.

However, there were concerns that funds going directly to the consumer could be used inappropriately. For example, unscrupulous relatives or others in the home could utilize the dollars for something other than the services for which they were intended. In short, participants agreed that extensive counseling, oversight, and education efforts would be paramount to giving consumers direct control over the dollars.

The structured discussion group participants also felt that it isn't equitable or appropriate that assisted living is currently for the wealthy alone. It was unanimously agreed that individuals who cannot afford assisted living services should receive public assistance so they can obtain at least the minimum services they need. However, most felt that current long-term care funding programs need to be reviewed and revised—if not completely over-

hauled. The feeling was that there is a great deal of redundancy in the current system and a more seamless program would result in a bigger “bang for the buck” for the government. They also were quick to point out that a distinction must be drawn between *need* and *want* when using public funds. In the words of one participant from West Chester, “Cadillac services can’t be funded.”

They also felt that those who can afford services should pay for at least some, if not all, of the services they receive. More than a few participants, however, felt strongly that someone may appear to have more resources than they truly do. It is important that any kind of sliding scale analysis take into consideration an individual’s total expenses.

Long-term care insurance was often discussed as a means to pay for services. The overwhelming consensus was that such insurance is confusing and the buyer should beware because of the many exceptions and fine print. Participants shared story after story of benefits being denied because consumers did not have a clear understanding of what the policy did or did not cover. Overall, the majority of the participants expressed a general distrust of the insurance industry.

“I like to have the opportunity to hand the check to the services provider so they know who they answer to.”

While there was a high level of consistency in the messages received from the 12 structured discussion groups, the following sections provide some insight into the individual groups and some of their unique thoughts and comments.

GROUP 1

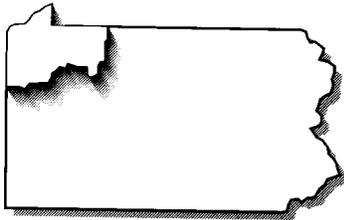
This group strongly advocated having the money follow the consumer. In the words of one participant, "Just tell me how much money I have and let me decide how to spend it."

The group raised interesting ideas for diverting funds from nursing facilities to community-based services. They felt some funds could be diverted from nursing facilities by reducing the survey process, in turn paring costs. The group did not think there should be a flat cutting of funds to nursing facilities; often, projections of need are inadequate and short term and "we may be shooting ourselves in the foot" regarding future need. Furthermore, the higher acuity in nursing facilities results in higher cost.

Any cuts must be well planned and balanced by increased efficiencies and/or cost savings.

In terms of additional sources of funding, the group suggested that taxpayers be able to check a box on their income tax forms if they would like a dollar or two of their refund to go to an assisted living fund. Additionally, special taxes on everything from new automobiles to gambling were discussed as revenue sources.

With regard to ensuring quality, participants suggested that a pilot assisted living residence project be initiated by the government with substantially less regulation and significantly more consumer control. The idea would be to demonstrate whether consumer-driven quality in assisted living would be more effective than the more traditional approach of regulation.



Counties:

Crawford
Erie
Forest
Mercer
Venango
Warren

Discussion held in: Meadville

Intriguing Thought

—Initiate a pilot project to demonstrate the impact of consumer-driven quality versus quality driven by regulation.

"I would pay a tax on anything as long as I know it's going for long-term care and services."

GROUP 2

This group put a different twist than the other groups on the rationale for providing assisted living services for those who cannot afford them. They believe that assisted living services can help keep people out of more expensive publicly-funded nursing facilities. Their rationale was if individuals are given a little assistance now, it will keep their needs from becoming more significant and more costly.

The group also came up with a unique idea to raise funds for assisted living. They talked about using a school tax model based on the percentage of individuals in need in a given area. This group was also one of the few who thought that an increase in income tax should be considered to raise funds for assisted living.

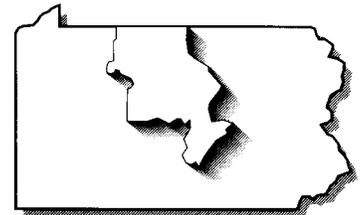
In this group, the topic of negotiated risk was particularly key for the participants with disabilities who were very much in favor of the concept. In

“Even if I have only one day a month when I know where I am, I want to be where I want to be.”

the words of one gentleman, “My whole life is negotiated, beginning with my family.” His point was that just because you are receiving long-term care and services, your freedom to make decisions and live your life in the manner you choose should not be taken away.

The group discussed cracking down on Medicare fraud and using the money saved to help fund assisted living. An 85-year-old consumer made the point when she told of her doctor charging her \$29 for a regular procedure and then charging the system over \$100. She has reported him on more than one occasion, but to date, nothing has been done. In her words, “It would be nice if that money were doing someone some good.”

This group was particularly adamant about aging in place and felt that it should be a priority in any assisted living program designed for Pennsylvania. As one participant said, “Even if I have only one day a month when I know where I am, I want to be where I want to be.”



Counties:

Cameron
Centre
Clearfield
Clinton
Elk
Juniata
McKean
Mifflin
Potter

Discussion held in: Pleasant Gap

Intriguing Thought

—Develop a school tax model to raise additional funding for assisted living.

GROUP 3



Counties:

Bradford
Columbia
Lycoming
Montour
Northumberland
Snyder
Sullivan
Tioga
Union

Discussion held in: Lewisburg

Intriguing Thought

—Consider taxing waste that enters the Commonwealth from other states and use the funds for assisted living.

This group was clearly divided along age lines regarding aging in place, with younger individuals saying it really wasn't that important and older individuals taking the opposing view. As one of the older participants explained, "I've grown into my home and I don't want to leave." In contrast, one of the younger participants said, "I'm used to moving around. By the time I retire I will have switched careers and locations perhaps more than three or four times—location just doesn't matter to me."

Several individuals were uneasy with regard to reallocation of funds from nursing facilities to assisted living. While they agreed there needs to be more funding for community-based services, they also thought there

was the potential for a sudden surge of individuals into the assisted living system if

"I've grown into my home and I don't want to leave."

funding became available. These individuals are currently handling their care on their own and the concern was there would not be enough services available for all the individuals who would qualify. Their point was while reallocation should occur, it must be a slow and gradual reallocation until the resulting "user load" is clearly assessed.

The group had some interesting ideas for funding assisted living. These included taking a "harder

"I'm used to moving around. By the time I retire I will have switched careers and locations perhaps more than three or four times—location just doesn't matter to me."

line" on individuals who spend down their savings to qualify for assistance. Another idea set forth was taxation on waste that comes into the Commonwealth from other states. Provision of tax credits for those taking care of

family members at home was also discussed and very much supported by the group.

GROUP 4

Practical regulation was a hot button for this group. One participant remarked that regulations are not the answer for developing a standard of care. In her words, “Look at the nursing facilities—standard of care is not that great and look how regulated they are.” This group wants something different for defining and monitoring quality in assisted living.

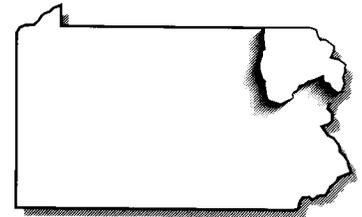
This group, more than other groups, advocated for consumers to plan ahead if they want to stay in their private residence by designing homes with assistive features like shower bars, levers, and ramp-adaptable entrances.

When discussing funding for those who cannot afford assisted living services, the group expressed concern for those individuals who “fall through the cracks”; they aren’t affluent and yet they don’t qualify for a Medicaid waiver. According to the group, these individuals typically end up in a Personal Care Home which is not where they want to be.

“Look at the nursing facilities—standard of care is not that great and look how regulated they are.”

Like most of the groups, participants talked about long-term care insurance. They thought consideration should be given to reversing the current payment process so that individuals pay more into the policy when they’re younger and less when they are older.

The group also very much rallied around volunteerism as a way to help with the shortfall of funding for consumer-based services, although they were concerned that enough volunteers could be recruited.



Counties:

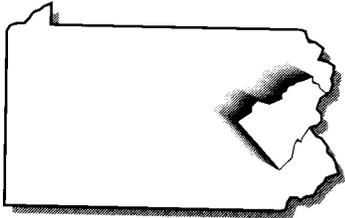
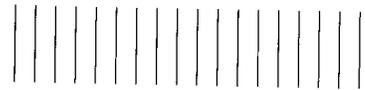
- Lackawanna
- Luzerne
- Pike
- Susquehanna
- Wayne
- Wyoming

Discussion held in: Wilkes-Barre

Intriguing Thought

—Promote volunteerism as a way to gain more community-based services.

GROUP 5



Counties:

- Berks
- Carbon
- Lehigh
- Monroe
- Northampton
- Schuylkill

Discussion held in: Reading

Intriguing Thought

—When dealing with people, a strict definition of assisted living can not be developed; it is, by its very nature, flexible and fluid.

All the structured discussion groups wrestled with the lack of definition for assisted living. However, this group unanimously agreed that there cannot be a strict definition when dealing with people. They cared less about what community-based services were called and more about their availability. There was also some concern that the term “assisted living” has begun taking on a negative connotation. This is because due to a lack of definition, Personal Care Homes and other facilities are calling themselves assisted living facilities.

The group was adamant about the need for funding to follow the consumer. Clearly, the overwhelming majority felt strongly that an individual should receive services from the best provider based on his or her needs, not their finances. However, they all also agreed this will be a very difficult shift

“I have a problem getting consistent help that is acceptable to my mother.”

to make. One interesting reason for this, from a societal standpoint, was that the group felt the public has been conditioned

by the government to see them as our caretakers; a mindset several participants felt would be difficult to alter.

Three other key issues for this group included the difficulty in obtaining home-based services; the quality of life issues based on the concept of it is not *where* you age but *how* you age; and the need for individuals to prepare early for the decisions they will need to make later in life.

GROUP 6

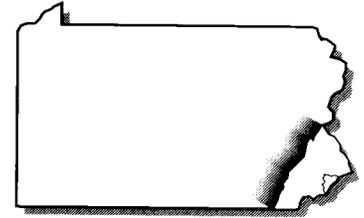
Overall, this group stressed more than any other the need for flexibility and preparedness when discussing aging in place. The emphasis on staying in one place was not as strong as it was with some of the other groups; instead the emphasis was very much on having choices and options, and living the quality of life that one desires. As one participant

“The way it stands now, when the funds expire, mother better expire.”

said, “It’s what I’m doing, not where I am.” And in their opinion, assisted living can play a prominent role in improving their quality of life. In the words of one consumer, “People would enjoy life much more if they would take some assistance.”

The participants of this group were some of the few who were receptive to state and/or federal income tax increases to help fund assisted living. They all agreed that the current funding system should not be the model for assisted living as it is exasperating and certainly not consumer-oriented. In the words of one of the participants, “The way it stands now, when the funds expire, mother better expire.”

The group was adamant that there be more of an emphasis on preventative services to ward off the cost of high-level care. They also stressed the need for education and trying to find ways to force people to plan for the future. They saw great value in creating a sense of awareness about issues of aging early on, whether that be through life management education courses at a young age or recruiting high school students as volunteers for assisted living consumers. And most importantly, they stressed that this education, as well as any information about the system, should be user-friendly in format, language, and intent.



Counties:

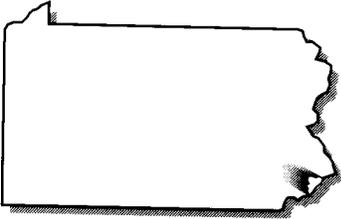
Bucks
Chester
Delaware
Montgomery

Discussion held in: West Chester

Intriguing Thought

—There must be much more of an emphasis on preventative services to ward off the cost of high-level care.

GROUP 7



County:

Philadelphia

Discussion held in: Philadelphia

This group—like the others—saw consumer choice as paramount although they were the most insistent. In every aspect of the discussion, the conversation quickly steered back to the need for consumer choice. In the words of one provider, “I’ve seen the despair of having to usurp someone’s choice.” The group wants assisted living to center around the concept of consumer choice in every aspect.

This group had concerns about individuals who felt that aging in place meant staying in their residence. Given that most of the participants were from Philadelphia, they had observed many people who cut themselves off from services because they don’t feel safe and are afraid to have people come into their homes. They also explained how the urban environment results in a shortage of family members to assist individuals, as many people leave the city for the suburbs and are not, therefore, easily accessible to assist family who remain behind.

The struggle of family caregivers was also discussed in that the system doesn’t recognize the needs of these individuals. One participant shared the story of his mother who was adamant about keeping her spouse at home and was struggling to take care of him alone. It got to the point where her own health was dete-

riorating and she wasn’t taking care of herself. She was found to be taking her

“I’ve seen the despair of having to usurp someone’s choice.”

husband’s nitroglycerine tablets on her own, without seeking any medical advice. She didn’t seek assistance because she was afraid they would make her stop taking care of her husband and he would have to go into a facility. The group agreed that caregivers must be provided with assistance and that the real key to this is access to more community-based services.

Intriguing Thought

—In an urban environment, aging in place may result in individuals cutting themselves off from services due to fear of having people come into their homes; this issue must be addressed.

GROUP 8

When discussing the reallocation of funds from nursing facilities to community-based services, this group focused on consumer choice. They felt that it was ludicrous that the issue of fund reallocation was even being discussed. This was because consumers

“The issue here is trust and good conversation. With enough of both of these, negotiated risk can work.”

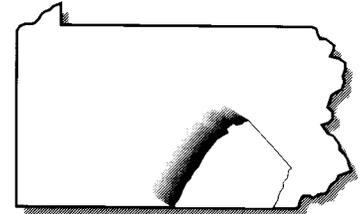
have made it very clear that they do not wish to be in facilities. Without question, the group felt that the majority of funding should be in assisted living and other types of community-based care. Case closed.

This group also felt the business community should take more responsibility for providing employees with ways to plan for the future through benefits such as long-term care insurance. The group was more positive about long-term care insurance than many of the others. They advanced the idea that long-term care insurance premiums be based on a sliding scale so that as individuals get older, they pay lower premiums.

The group was very much in favor of shared or negotiated risk. They likened shared risk to the ability to pay (i.e., the more you pay, the more you get). So with shared risk, the more control you want, the less restrictive setting you get. But you also assume the risk. The participants spent a great deal of time discussing the importance of trust between the provider and consumer if this concept is to be effective. In the words of one consumer, “The issue here is trust and good conversation. With enough of both of these, negotiated risk can work.”

In discussing regulations and quality, the group agreed that regulations alone are not the way to ensure quality. This group wants the consumer appropriately involved in determining quality of care with regard to assisted living.

“You can’t license compassion.”



Counties:

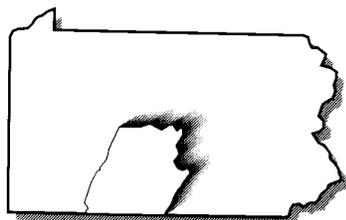
Adams
Cumberland
Dauphin
Franklin
Lancaster
Lebanon
Perry
York

Discussion held in: Hershey

Intriguing Thought

—Long-term care insurance should be based on a sliding scale so that as individuals age, they pay lower premiums.”

GROUP 9



Counties:

Bedford
Blair
Cambria
Fulton
Huntingdon
Somerset

Discussion held in: Altoona

Intriguing Thought

—Many in our society have been conditioned to look to government as our caretaker, making the mindset change to full consumer choice and control difficult for some.

This session included a very interesting conversation about consumer choice as it related to funding following the consumer, perhaps in the form of a voucher. Approximately half the group liked

“I’d rather die, than strip myself of my life and choices.”

the idea, while half the group appeared to be extremely concerned about individual consumers

making inappropriate choices for themselves, potentially squandering the money they received. When pressed, it became clear that they were looking at government as their “keeper” and that from a cultural standpoint, we, as a nation, have been conditioned to expect our government to look after us in their opinion. However, the group did feel that such a system would force competition which would be extremely beneficial, particularly from the aspect of ensuring quality.

The group strongly supported the concept of negotiated risk. One of the most vehement comments came from an older consumer who exclaimed, “I’d rather die than strip myself of my life and choices.” Another consumer told of her father who was a diabetic and took extra insulin so he could have sweets for dessert. On one occasion, this resulted in an adverse reaction, and the family found him unconscious on the floor. But in his daughter’s words, “That was okay; that was his choice and he was more careful next time.” In short, the participants want the ability to make their own choices.

They also felt that funds must be diverted from nursing facilities to assisted living and community-based services. How-

“For me to move would shorten my life.”

ever, they were the only group that said it was important that such diversion be

done incrementally, so as not to dramatically affect the quality of care in nursing facilities.

GROUP 10

This group, more than any other, was very concerned about the impact on family caregivers when making decisions about staying in the home. The discussion centered on the stress caregivers experience and the lack of respite care available for these individuals.

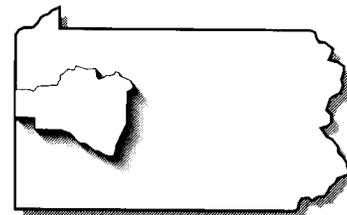
In some cases, as the condition of an individual deteriorates, the abilities of family caregivers also come into question. This adds to the frustration of those who don't want to place their loved one in a facility setting, yet realize they cannot adequately take care of the individual. The group felt that these issues spoke loud and clear to the need for greater availability of community-based services as part of assisted living.

This group very much liked the concept of negotiated risk. In fact, they devised a "three strikes you're out" concept. If an individual had a negotiated contract with their service provider and broke that contract three times through their inability to carry it out, the agreement would then become null and void. For example, an individual enters into a contract that says he didn't need the provider to remind him to take his medication, but then forgot to take it several times, requiring the provider to

*"Leaving my home
would hasten my
demise."*

assist with emergency services. The contract would be broken and no longer valid. Most of the participants thought negotiated risk was a fair way to balance consumer choice with the provider's concerns and liability.

Interestingly, when discussing ways to fund and/or plan for assisted living, the topic of long-term care insurance was raised—with a slight twist. The majority of the participants thought that such insurance should be a state or federal program. The impetus for this was that they believed there is too much waste in the private insurance companies, particularly with high executive salaries.



Counties:

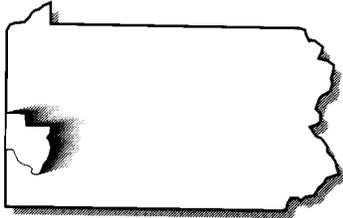
Armstrong
Butler
Clarion
Indiana
Jefferson
Lawrence

Discussion held in: Butler

Intriguing Thought

—The concept of negotiated risk could be further refined with a "three strikes, you're out" addition.

GROUP 11



Counties:

Allegheny

Beaver

Discussion held in: Pittsburgh

Intriguing Thought

—An educated and empowered consumer is critical to developing the services and quality of care that are needed in assisted living.

This group spent a lot of time discussing professional caregivers and the need for training guidelines for those providing assisted living services. Some felt that formal training, particularly in the area of compassion and caring for the individual,

“Whatever you do, please don’t create another department for assisted living.”

was extremely important and should somehow be measured. However, the comments of one gentleman who has a personal care assistant were very interesting. He characterized the necessary relationship and learning curve that must develop between the consumer and the caregiver by saying, “The polish has to be put on the caregiver by the person receiving the care.”

Education of the consumer was also a topic of great interest. Many felt that current consumers have a “Great Depression mentality” when it comes to assisted living and long-term care. It’s as if they feel they must just take what they can get and that anything is better than nothing. In the opinion of the group, an educated and empowered consumer is critical to developing the services and quality of care that are needed in assisted living.

One consumer, in discussing the diversion of funding from nursing facilities to assisted living and community-based services said, “What’s the difference between putting the funds in one box or another? Let the money be where it should be based on consumer need and choice.” Another participant echoed this sentiment, “Whatever you do, please

don’t create another department for assisted living.” The redundancy of the current system has made individuals extremely

“The polish has to be put on the caregiver by the person receiving the care.”

wary of a bureaucratic system engulfing what they perceive to be the consumer-oriented concept of assisted living.

GROUP 12

In discussing funding, the group was the only one that talked about removing “disincentives” from the system. For example, with the current long-term care system, an individual can save all his or her life, paying on a long-term care insurance policy, and then stand by and watch someone else get the

“You give me \$45,000 and you’ll never hear another word from me. But if I have to go into a nursing facility to get the services I need, I’ll be dead in six months.”

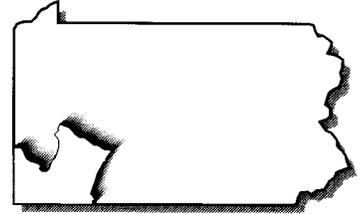
same services for no cost. It makes it difficult to want to do the right thing, according to the participants. The group was very supportive of the idea of funds following consumer need rather than consumers hav-

ing to avail themselves of services based on the funding stream.

One of the consumers, when describing negotiated risk, may have said it best for the group, “I want the opportunity to fail.” Another individual who provides services talked about the risk posed by the concept. She explained that the state may take away her license if all means are not employed to keep an individual alive; she was speaking from recent personal experience and had great impact on the group.

Interestingly, the group was very detailed regarding what should be included in assisted living services. They talked about services such as assistive technology, attendant care, respite care, and transportation, in addition to other services. In their opinion, assisted living should provide any services necessary to allow individuals to live independently.

The participants were adamant that the state should not use the nursing facility model for assisted living when it comes to regulation and funding. They want a user-friendly system and, in their opinion, the nursing facility model is not user-friendly.



Counties:

- Greene
- Fayette
- Washington
- Westmoreland

Discussion held in: Youngwood

Intriguing Thought

—If assisted living is incorporated into the current long-term care “system,” it is critical that disincentives be removed from that system.

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