

**Long-Term Care and
Services Information
Focus Group Findings**

**What Do You Need
and
How Do You Want It?**

Pennsylvania Department of Health
Pennsylvania Department of Aging
Pennsylvania Intra-Governmental Council on
Long-Term Care

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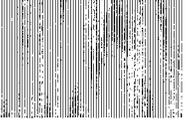
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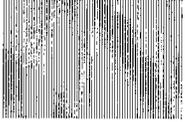
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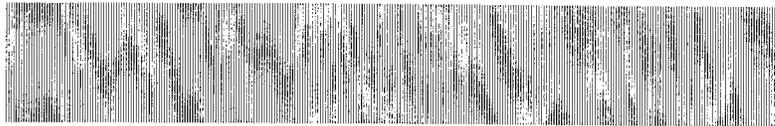
EXECUTIVE SUMMARY



The Pennsylvania Department of Health, the Pennsylvania Department of Aging (the Departments), and the Pennsylvania Intra-Governmental Council on Long-Term Care (the Council) recently undertook an initiative to garner feedback and input from consumers of and professionals working in long-term care across the Commonwealth. Ten focus groups were conducted as a part of this effort. The purpose of this Executive Summary is to summarize the findings of those focus groups, with additional detail and context provided in the remainder of the report.

The Council and the Departments have recently begun a comprehensive effort to provide better information related to long-term care and services to consumers and others. This effort has four primary components:

1. Provide useful information to consumers on long-term care options, including performance profiles for providers, by enhancing existing agency websites, adding new ones, and improving traditional written materials, so that more informed decisions can be made.
2. Make information on long-term care available in a single location by creating a clearinghouse of long-term care information and establishing a toll-free telephone number.
3. Educate and inform professionals, especially those who provide information to



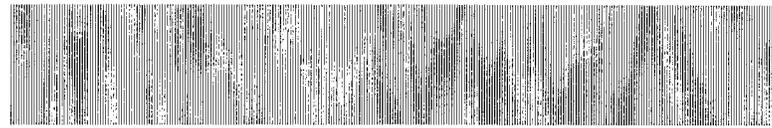
consumers and families and influence their decision making, on the availability of services and how to access information on them.

4. Implement a statewide media effort to inform consumers and families about the availability of long-term care services and how to access information on them.

Additionally, the Department of Health is working to identify the best ways to help consumers measure quality. While in past focus group efforts (see *Assisted Living Long-Term Care and Services Discussion Session Findings* published by the Council in February 1999) consumers clearly said that quality must be driven and determined by consumers. The Council and the Departments wanted to determine, from this round of focus groups, what information consumers would find helpful in making that determination and in what format.

When it comes to the issue of quality of care, it was interesting to note how little attention consumers and professionals paid to the issue. In fact, at times, they preferred to talk about other issues such as availability of services and the challenges of recruiting long-term care staff, as opposed to issues of quality and information needs.

Clearly, when it comes to quality there are many perspectives. There is a high level of ownership on the part of many providers, agen-



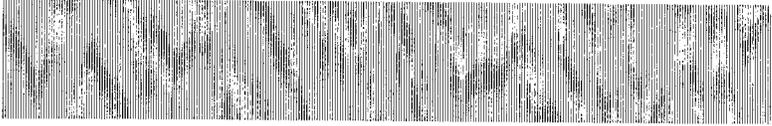
cies, and other organizations as to what constitutes an accurate measure of quality. It is critical according to the focus groups, however, that consumers drive this issue, with quality being viewed from two perspectives. Public standards for *quality of care* should be developed based on minimum guidelines, and provided in a comparative format. Care must be taken in establishing these minimum guidelines to minimize subjectivity, and to not create an ambiguous or difficult to use “rating system.” Then, and just as importantly, the issue of *quality of life* must be determined...and that can only be done by the consumer based on his or her individual and personal preferences.

The focus group participants were adamant that the Commonwealth must make the development of specific definitions of services a top priority. Consumers and professionals both continue to be frustrated and confused by a lack of clear definitions. Following the development of specific definitions of services, a significant public education initiative should be undertaken to educate the citizens of the Commonwealth regarding these definitions. Such an effort should broadly encompass all age groups and encourage planning for future services needs.

A high level of frustration was evident on the part of the participants when discussing how to locate information from which to make long-term care and services decisions. According to them, a consumer-centered standardized process should be developed to assist consum-

Every Group Strongly Believes

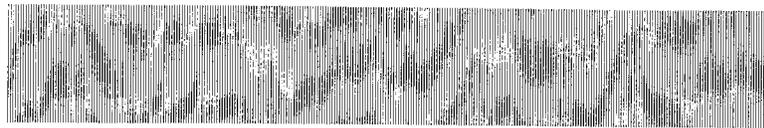
- u There is a need for a single source of information for consumers to eliminate frustration and confusion.
- u There must be an easily navigated, step-by-step process to making long-term care and services decisions.
- u There is a need for clear definitions of services.
- u Information provided to consumers should be clear, “non-technical,” and easy to follow.
- u When in a crisis situation, it is paramount that consumers have a person to speak with, rather than a recording or some other form of information.



ers in making decisions about long-term care and services options and individual providers. This process must be user-friendly and interactive and serve as a “decision tree” that can accept consumer-specific information and then provide appropriate options to assist in decision-making.

Furthermore, many participants told of having no idea where to turn for information when faced with a long-term care and services decision. Many spoke of being confused and unclear regarding where to locate information and being referred to myriad sources, often with less than effective results. The need for a single source of such information was paramount according to the participants.

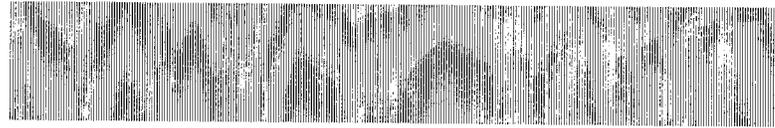
In discussing the proposed toll-free telephone line with the participants, which will provide the single source consumers and professionals have been asking for, several thoughts were expressed by the participants. The telephone line should be staffed with adequate numbers of knowledgeable individuals, with extended hours for consumer convenience. In order to ensure that the line is implemented in a truly consumer-centered fashion, follow-up measures and goals to determine the effectiveness of information provided should be developed and implemented. Consideration should be given to testing the toll free line in a limited geographic area to make any necessary adjustments before committing the significant resources needed to implement such a service statewide.



The intent of this is to have a consumer-centered outcome, while ensuring efficient use of resources.

In developing new information sources, it must be remembered that the information is typically accessed in one of two situations: when a consumer perceives he or she is in “crisis” or when a consumer is in a planning situation. These two scenarios will call for significantly different content and formats as detailed within this report. It was clearly the opinion of the participants that at this time, consumers who find themselves in the position of needing to make quick decisions are affected by a lack of easily accessible, user-friendly information.

When providing information to consumers, it is critical that the specific needs and characteristics of the population being served are kept in mind. A significant percentage of Pennsylvanians who utilize long-term care and services are elderly. Eyesight may be failing, there may be a potential lack of knowledge regarding technology, and they may be more easily overwhelmed by large amounts of information. Too often the format of information does not take this into account, with something as basic as producing materials with a larger typeface being overlooked. Asking a pilot group of consumers to review any new information that is developed before it is widely distributed would be an effective way to determine if consumer needs are being met.



Thought should also be given to designing information that is attractive and specific to the communications needs of those who are the future consumers as they are assisting others with choices today, and may be planning for their own futures. This may result in increased use of web-based information, etc. The new website should be developed with the input and feedback of long-term care and services consumers and professionals. This group should provide input to ensure the effectiveness of the website based on established goals.

According to the focus group participants, several specific areas must be further explored to determine whether there are information gaps or whether a perceived gap is actually the result of information that is not being shared. Depending on the determination made, the situation should then be appropriately addressed. These areas identified by consumers include medical assistance, community-based care, services for those with brain injuries, and legal issues.

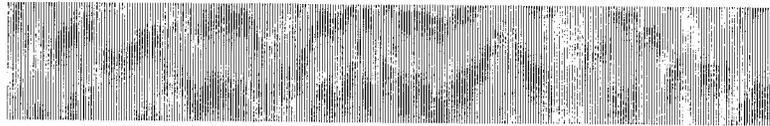
Further detail and context to these summarized findings is provided in the following pages of this report.

INTRODUCTION & PURPOSE

Dostalick ET AL Management Consultants, an independent consultant, was retained to conduct ten focus groups. The purpose of the focus groups was to learn what information is most important to consumers as well as to those who have the ability to influence consumers. Specific attention was paid to gaining information on how consumers define “quality” and what information they need to determine the quality of a particular long-term care option. The goal of the Council and the Departments was to listen to consumers and others *before* moving forward and crafting additional information sources regarding long-term care and services, so that the needs of Pennsylvania’s citizens remain in the forefront of any decisions made.

Specifically, the focus groups were designed to determine:

- What information and/or criteria is most valuable to consumers and their families when they are selecting a long-term care option.
- How consumers and their families want to “see” information packaged in terms of overall concept and format.
- What providers of information (e.g., hospital discharge officials; Area Agency on Aging representatives; facility officials; etc.) believe consumers want to know and what is



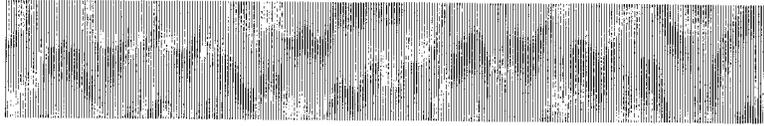
their current role in assisting consumers in the decision-making process.

Also of great importance was information gleaned in earlier focus group efforts conducted by the Council. Throughout this report reference may be made to information gained in the two earlier focus groups (1997 and 1998), as it is pertinent. This is done to provide additional context. Of particular relevance were the key values that consumers identified in 1997 and validated in 1998. Specifically, these values are the three things that consumers 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.

The three values are:

1. Remain as independent and live at home as long as possible.
2. Respect and dignity for the individual.
3. Consumer choice.

While all three values were kept in mind throughout the “just completed discussions,” the consumer choice value was particularly prominent. Clearly, while consumer choice is viewed as a positive, choice brings with it the responsibility to make *informed* choices. It was in this context that the discussions occurred;



the focus groups set out to determine what information must be made available to ensure that consumers have the ability to make informed choices.

METHODOLOGY

People Needing Long-Term Care and Services

| | | |
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| u | Elderly | 57% |
| u | Working Age Adults | 40% |
| u | Children | 3% |

The 10 focus groups were held between April 17, 2000 and May 1, 2000, and included 134 participants. The participants of the focus groups were chosen based on nominations submitted by members of the Council.

The focus groups were approximately two and half-hours in length and were conducted at five sites around the Commonwealth with two sessions held at each site. The Council sent invitation letters to potential participants, and thank you letters to all participants who attended the focus groups.

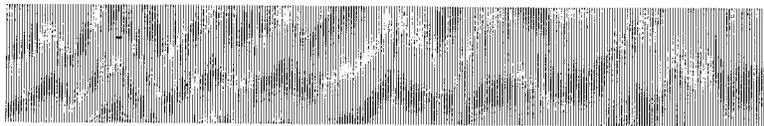
The two sessions were based on the perspective participants brought to the table:

Group 1—Consumers (including family members, informal caregivers, etc.)

Group 2—Professionals (those who have the ability to influence consumers)

Two representatives from Dostalick ET AL attended each of the focus group sessions, one to facilitate the session and the other to take notes. At least one Representative from the Council, and/or the Departments attended every session. While these individuals did not participate, they were able to provide subject matter expertise on technical issues, when such issues arose.

The groups ranged in size from 7 to 19, with an average size of 13 participants. The focus groups were designed and facilitated to



ensure that each individual had numerous opportunities to share thoughts and perceptions. The focus groups were facilitated as informal conversations, and each participant was assured anonymity with regard to specific comments being used in this report.

To set the stage, each session began with a very short introductory discussion on the definition of long-term care, which was to be used during the focus groups (see sidebar). The values mentioned on page 8 were also shared with the focus groups as a foundation for the conversation. Additionally, a set of “ground rules” was discussed. These were designed to ensure productive discussions, allow for participation by everyone, and reduce monopolizing of the conversation by any one or a few participants.

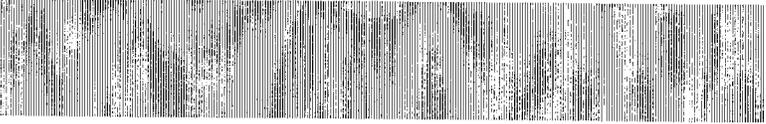
To facilitate meaningful discussions, each group was asked a series of questions. Group 1 (consumers)—comprised of those who would most likely be *needing* information—was asked the following questions:

1. Where do you/did you/will you first turn to get information on long-term care and services?
2. What specific information on long-term care and services are you looking for?
3. What is most frustrating for you when you try to *find* information?

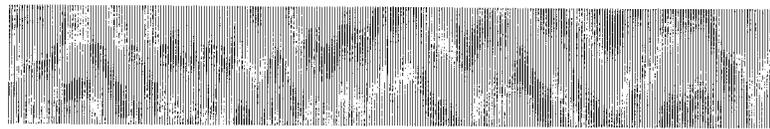
Long-term care and services is a wide range of assistance, services, or devices designed to meet medical, personal, and social needs of persons in a variety of settings or locations.

Focus Group Ground Rules

1. We want to hear from everyone.
2. We want YOUR point of view.
3. All ideas and opinions count.
4. Keep emotions in check.
5. There is no need to “sell” or “market” your idea.
6. Give everyone an opportunity to speak.
7. ENJOY.

- 
4. What is most frustrating for you when you try *to use* information?
 5. What communication formats are or would be most helpful to you in making decisions about long-term care and services?
 6. In the case of information that you need to make a decision about long-term care and services, what would “user-friendly” look and/or sound like?
 7. When receiving information from which to make a decision, how important are the following? (asked to select “top 3”)
 - Information must be current.
 - Information must be from a trusted source.
 - Information must be easy to obtain.
 - Information must be easy to follow.
 - Information must be brief.
 - Information must be very detailed.
 8. From whom should information you need to make a decision come from and why?
 9. How do you judge whether the long-term care and services you receive are “good enough”? How do you measure quality?
 10. Should more information be available on the Internet? What kind of information?

To allow for the varying perspectives of those who *provide* information to consumers,



Group 2 (professionals) was asked the following questions:

1. What specific information do you most often find yourself needing for consumers? Do you have the right information to provide?
2. What would make your job easier as an information provider?
3. Who do you trust to provide you with information for passing on to consumers?
4. When receiving information from which to make a decision, how important are the following to consumers? (asked to select "top 3")
 - Information must be current.
 - Information must be from a trusted source.
 - Information must be easy to obtain.
 - Information must be easy to follow.
 - Information must be brief.
 - Information must be very detailed.
5. What communication formats do you think are or would be most helpful to consumers in making decisions about long-term care and services?
6. What communication formats are most helpful to you?
7. How do consumers' needs for information

Participant Feedback

Listed below are the percentage of participants who gave a "good" or "great" response to the following questions.

To what extent:

- u Did you feel the session was a good use of your time? 93%
- u Did you feel comfortable participating? 92%
- u Did you feel able to speak freely and honestly? 93%
- u Did you feel attentively listened to? 100%

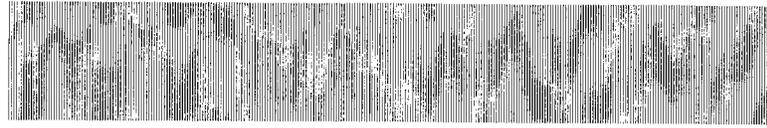


change when they are in a crisis versus planning situation?

8. Should more information be available on the Internet? What kind of information?
9. How should information be presented or provided to consumers so that they can measure quality? What are the key components they need to know about in making long-term care and services decisions?
10. What do you most often get frustrated about with regard to locating information on long-term care and services?
11. What do you most often get frustrated about with regard to using information on long-term care and services?

The discussions resulted in hundreds of thoughts, comments, concerns, and ideas. At the end of each session, the participants were also asked if they had any additional comments, thoughts, or concerns they wanted brought to the attention of the Council and the Departments. This allowed them to share any additional points they thought warranted attention.

Additionally, as part of the consumer-centered focus of the sessions, the Council and the Departments also wanted to obtain participants' feedback so that changes could immediately be made to improve subsequent



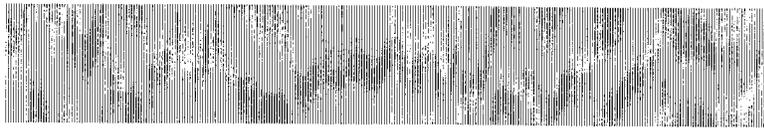
focus groups. When asked to complete a session evaluation, 93% of the participants felt the session they attended was a productive use of their time.

FOCUS GROUP REPRESENTATION

In selecting individuals for the focus groups, members of the Council were asked to submit nominations to the consultant. The nominees were to be diverse consisting of consumers (includes family members, informal caregivers, and volunteers) and professionals who have the ability to influence consumers (includes Area Agency on Aging staff, Centers for Independent Living staff, hospital discharge staff, and other providers) and were individuals who would bring value to the specific conversations. Both consumer and professional perspectives were equally represented, even though the actual number of consumers and professionals who attended were not equivalent. This is because many times professionals may also be caregivers for a member of their family, friend, etc. In that case, they bring two perspectives to the table: professional *and* consumer.

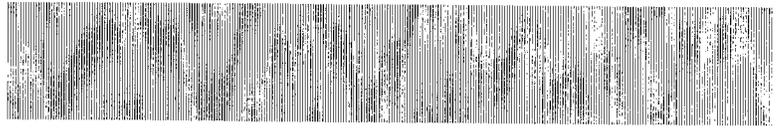
The five focus group sites provided a geographic cross-section that included urban, suburban, and rural environments. Focus groups were held in State College, Erie, Pittsburgh, Philadelphia, and Nanticoke, Pennsylvania. The various locations provided an opportunity to determine if geography would influence points of view. Additionally, from a more practical standpoint, the multiple locations provided easier access for those who attended. Each site was fully accessible to those persons with disabilities.

A total of 76% of the participants were female; the participants ranged in age from 24

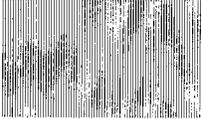


to 79 years. Clearly, 134 participants make up a small percentage of the Commonwealth's constituents, and certainly do not comprise a statistically valid sample. While some individuals may be reluctant to accept qualitative research because it lacks numerical data, according to Dunn and Bradstreet, when focus groups are done well and findings are consistent, additional research is typically not necessary. A good rule of thumb is validate, through quantitative means, anything that doesn't make sense or appears to be an anomalous message.

According to the American Management Association, the use of focus groups and placing more of an emphasis on qualitative research in planning processes has been dramatically increasing—91% since 1990. In fact, *The Boston Business Journal* notes the use of focus groups has exploded to a \$1 billion a year industry as organizations realize the success of focus 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. Additionally, focus groups are being used to heighten the awareness of specific entities and become more, in this case, constituent-driven, meeting the needs of Pennsylvania's citizens.



Interestingly enough, with few exceptions, the key messages heard in the focus groups did not vary significantly among the ten groups. A detailed discussion of these key messages follows.



SPECIFIC FINDINGS



The focus group participants were attentive and provided myriad thoughts and ideas on the need for information. It was interesting to note that, while each focus group had thoughts and ideas unique to them, there was significant agreement among the groups with regard to their need for specific information and how those needs are or are not being met by the Commonwealth, providers, and what they termed “the system.” In fact, with all the groups, the following issues surfaced as being extremely important.

Making Long-Term Care Decisions

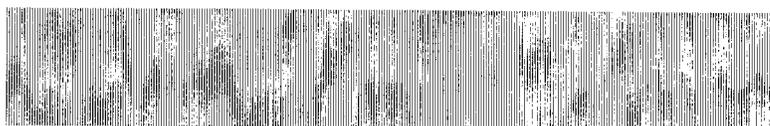
Participants indicated there are four steps—in an ideal situation—to making a long-term care decision.

1. Conduct an assessment to determine the level of care and specific services that can meet that need.
2. Provide a listing of providers who offer those options.
3. Provide some broad information about quality related to the specific options to further narrow down the choice.
4. Act on the consumer’s personal preferences, relying on visits, interviews, and their instincts to determine what specific option and/or provider meets their needs.

Unfortunately, while this is the process participants believed should occur, they also stated this is not the current reality.

Where Do Consumers Go for Information?

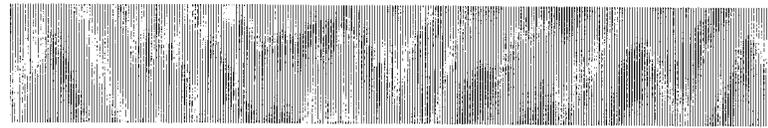
- u Providers
- u Pennsylvania Department of Aging
- u Area Agency on Aging
- u Physician
- u Medical Assistance office
- u Center for Independent Living
- u Veterans Administration
- u Social worker
- u Internet
- u CARIE
- u Clergy
- u Friends
- u Family



Where to Turn for Information

There is no *one* source that people think of when it comes to obtaining information—and they wish there were. Many times, they have no idea where to turn, which leaves them frustrated, a situation only to be further exacerbated by a fragmented network of services and difficult to understand financial structure. The fragmentation of Pennsylvania's long-term care and services system was clearly demonstrated when participants were asked where they turn for information to make long-term care and services decisions. The answers were as varied as the participants themselves. They ranged from "my friends," "my doctor," "a facility I was interested in," "the Area Agency on Aging," "the Department of Aging," and "someone I know who recently was taking care of their mother-in-law" (additional comments are provided in the sidebar).

While not all participants were aware of the Area Agencies on Aging, those who were considered them to be a reliable source of information. Providers of long-term care and services were looked upon less favorably as a source of information; the participants overall felt that they may be biased and direct consumers to services they provide. While physicians are highly trusted by consumers, the vast majority of participants found that physicians, as a group, are woefully lacking in knowledge about long-term care and services options. A suggestion to develop an educational partnership with professional groups was offered as a way to improve this situation.



Regardless of where individuals turn for information, participants wanted action as a result of each contact made. In other words, individuals don't want to spend a lot of time calling a variety of places trying to find out who they need to talk to; instead each conversation should result in an action being taken on their behalf.

Professionals primarily turn to a network of colleagues and peers for information. They also rely to a great extent on institutional memory, which is lost or diminished as experienced individuals leave the field.

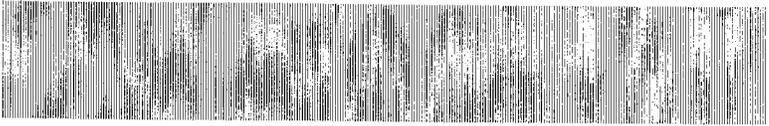
Information to Be Provided

When asked what was most critical with regard to the information received, three answers continually surfaced:

1. Information must be current.
2. Information must be easy to obtain.
3. Information must be easy to understand.

When asked what was meant by "current," the vast majority of participants said they meant that the information must be accurate at whatever point in time they request it. Professionals said that it is challenging to keep current in the constantly shifting environment. New programs are introduced regularly, eligibility requirements change, and guidelines always seem to be in flux.

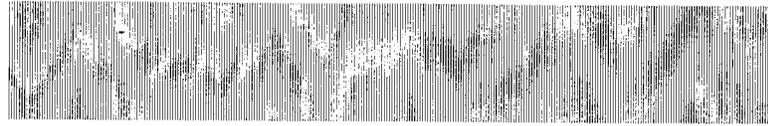
Interestingly, participants didn't rank information coming from a trusted source to be



as important. In fact, it was somewhat surprising how little the issue of trust impacted the conversation. From the professionals' standpoint, this issue manifested itself in their desire to have everything in writing. When questioned further, they replied that the written copy gave them something to hold someone accountable to if what was stated wasn't actually the case.

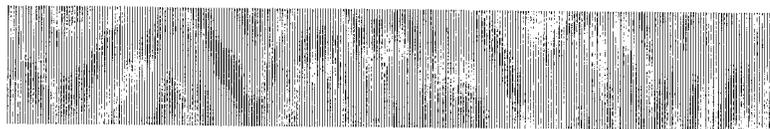
Participants lamented the fact that they often get differing opinions from various sources or in some cases, from different people within the same agency. Professionals further reported that the inconsistency in information provided from county to county is particularly troubling. Participants want consistent information no matter who they speak to and a "one-stop information clearinghouse" may help in this regard. Inconsistency of information results in the need to check and double-check information or risk a less than favorable outcome. This was described as grossly inefficient when you are trying to quickly make decisions.

There was significant disparity among the participants as to whether they would prefer information to be brief or in-depth and detailed. This was not unexpected as individual preferences, as well as function-related differences, would naturally impact this issue. Generally speaking, the professionals wanted to have more detail than the consumers. The result is that information has to be available both ways. This is further described in the *Creating a Consumer-Focused Website, Website Format* section of this report.



There was significant agreement among both consumers and professionals as to what information would be most helpful in making long-term care and services decisions. While some of the information discussed relates only to the facility or community-based setting, other information is more universal in nature. However, in general, the following information would be helpful to consumers in making long-term care and services decisions:

- ☑ Guidelines for assessing the current situation relative to needs to help determine the best option for care
- ☑ Financial eligibility information
- ☑ Definition of the services available
- ☑ Clear information on the financial aspects of the options (e.g., what happens when the money runs out?)
- ☑ List of others (with their permission) who have gone through the decision-making process to contact for assistance
- ☑ Information to help families understand what the consumer is experiencing
- ☑ Step-by-step instructions for consumer in navigating the system
- ☑ Directory of services with contact telephone numbers by geographic region
- ☑ Level of care available in different settings
- ☑ Cost of services
- ☑ Availability of services (e.g., accurate information on waiting lists)



- Availability of transportation
- A set of questions to ask providers

It should be noted that information listed here is *in addition* to the quality information listed in the next section and should be provided in a comparative manner according to the participants.

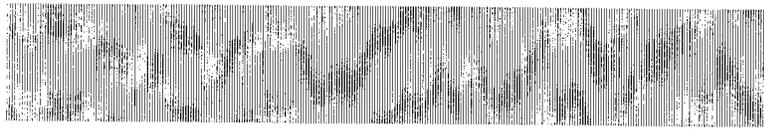
A unique message heard in the urban settings, particularly Philadelphia, was to make information about the ethnic diversity of the staff available to consumers.

It was interesting to note that while the majority of consumers thought this information was not available, the majority of professionals said that much of it is available. According to the professionals, consumers are just not aware of what is available and therefore, they don't ask for it.

Measuring/Defining Quality

The focus group discussions very much validated the findings of focus groups conducted by the Council in both 1997 and late 1998. Specifically, participants stated that in determining what makes for "quality" care in a long-term care and services setting is primarily related to individual consumer preferences.

They also said that there must be basic measures of quality that can help them narrow down their choices, after which it is up to individuals to make their decisions based on

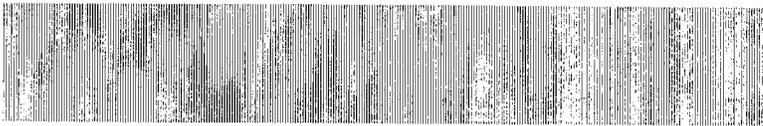


what is important to them personally. These two “steps” represent the need to determine both *quality of care* and *quality of life* when determining overall quality.

When asked what broad basic measures should be provided, the participants had difficulty responding, as it was hard for them to determine what would be most important for them to know. Professionals, or those who provide information to consumers, were hesitant to respond at first, primarily because of their concern about making any specific recommendation to consumers. This is a clear demonstration of how isolated consumers may feel in making what can be very difficult decisions.

It was interesting to note the degree to which the participants lamented about how little attention is paid to the quality of long-term care and services when a decision is being made. However, there was not a great deal of conversation on the subject by the participants themselves.

The participants also made it clear that many times quality becomes almost irrelevant as a consumer is most frequently in a crisis situation, with availability of services being the determining factor. Further comments on the issue of decision-making in a crisis situation are provided in the section, *Making Long-Term Care Decisions, Planning Versus Crisis Situations*.

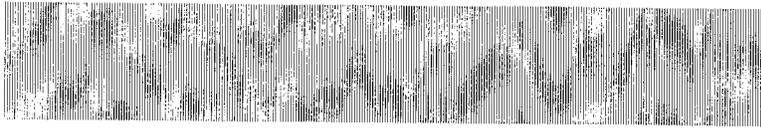


The indicators of quality of care most frequently mentioned for consumers who are considering *facility-based care* included:

- Survey data/results
- Accreditation information (e.g., JCAHO)
- Staffing ratios
- Training provided to staff
- Staff turnover
- Activities
- The ability to meet an individual's changing needs
- Food quality
- Cleanliness/odors
- Consumer control over decisions, particularly with regard to schedules for activities of daily living
- Presence of consumer complaint resolution process

The indicators of quality of care most frequently mentioned for consumers who are considering *community-based care* options included:

- Staffing ratios
- Training provided to staff
- Staff turnover
- Reliability of caregiver
- Consumer control over decisions, particularly with regard to scheduling
- Presence of complaint resolution process
- Bonded and screened personnel



- ☑ Availability of care manager for each client who wants one

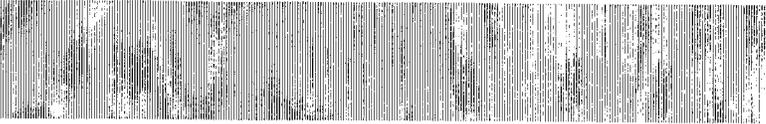
It was easier for both consumers and professionals to provide items for facility-based versus community-based settings. This appeared to be because of the broad spectrum of services offered in the community-based settings, making definitive quality-related indicators or measures much more difficult to identify on a universal basis.

The participants felt that such information should be provided in a format that allows for comparisons among the various service providers. However, concern was expressed regarding the need to maintain objectivity. The key, according to the participants, was to provide information in a comparative fashion, but not create an ambiguous or difficult to use “rating system.”

A number of participants spoke of the importance of having consumer satisfaction data available that individuals could refer to when making long-term care decisions. However, there was a great deal of concern over how to make such a satisfaction survey process work. The majority of participants agreed that individuals, regardless of the setting in which they receive care and services, would be hesitant to complete any type of consumer satisfaction survey for fear of retaliation of some sort which would disrupt the services they rely on. The idea is brought up here, however, as there was agreement that the consumer should be driv-

Information Needs When in Crisis

- u Very specific
- u Quick turn-around time
- u Assistance with needs assessment
- u Immediate financial eligibility determination
- u Focused on availability of services
- u One-on-one conversation with a person
- u Abbreviated questions to ask providers



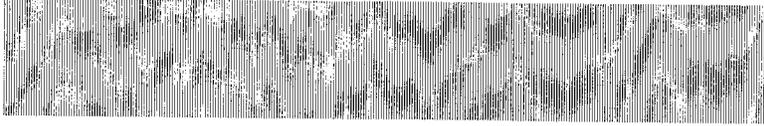
ing quality. In short, the answer is here; the challenge is now bringing that answer to fruition.

Planning Versus Crisis Situations

As is so often the case when discussing long-term care and services, the majority of focus group members lamented that individuals do not *plan* for long-term care by educating themselves as to the options, financial information, etc. before a need arises. As one individual said, "People spend more time investigating a car they are going to buy than they do on choosing a place where they will likely spend the rest of their lives."

We would be remiss if we did not emphasize the point that was brought up time and time again by focus group participants: there must be an ongoing educational initiative that encourages citizens to plan ahead for the need of long-term care and services. This effort must be integrated, far-reaching, and ongoing rather than an isolated effort. It is critical that, as part of the effort, individuals begin to view aging differently and in a more positive light. According to participants, if that is done, people will be more willing to look ahead, think about long-term care needs sooner, and plan.

However, there was also the recognition that it was not realistic to assume a significant societal shift to planning for long-term care will occur in the near future. Instead, because there is such a lack of planning, in-



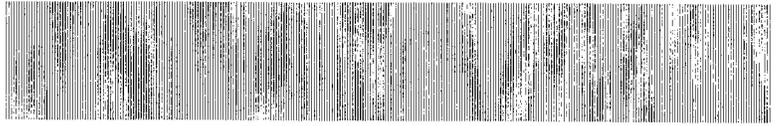
formation must be directed towards what could be termed “crisis communications.” This was not to suggest that information should not be provided to those who do plan, but just that there must be the realization that many people do not plan. Consequently, information must be provided to them differently.

According to focus group participants, the vast majority of individuals accessing information about long-term care and services are in a crisis situation. For example, they are being discharged from the hospital in three days and need either a place to go or services provided to them and have no idea where to start. The focus group participants were concerned that information currently provided is appropriate if you have time to plan, but it is not conducive to assisting consumers who are making decisions in a crisis mode. In particular, in a crisis situation the participants felt it was critical that individuals be able to talk to a person, not simply have pamphlets thrust at them. As a participant in Erie said, “ A warm body is important because it is a highly emotional time.”

As mentioned in the *Measuring/Defining Quality* section of this report, during times of crisis, availability of services becomes the key factor versus any determinations about quality. As such, participants felt it was critical that consumers and their families know that their decision is not carved in stone and can be changed once their situation stabilizes. The participants were very concerned that hasty

Information Needs When Planning

- u Broad and general information
- u Educational focus
- u Insurance information
- u Presenting a variety of scenarios
- u Assistance with financing options
- u List of documentation needed



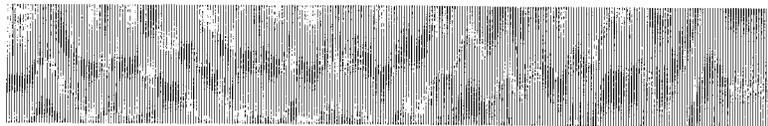
decisions are being made about issues that have significant quality of life ramifications, and that crisis situations do not allow individuals to fully explore their options.

Effective Packaging of Information

The way in which information is presented or “packaged” is often critical to how or if it will be used and how helpful it is. As such, the participants were asked specific questions related to preferred formats for information and for suggestions of how to make information “user friendly.”

Again, participants thought there were two objectives to keep in mind when it came to providing information: broad educational efforts geared toward promoting planning; and very specific “crisis communications” geared to assisting consumers with making very quick decisions. It was clearly the opinion of the participants that at this time, those consumers who find themselves in the position of needing to make very quick decisions are affected by a lack of easily accessible, user-friendly, information.

They also agreed that people who find themselves in a crisis situation must *always* have access to an individual who can guide them in the decision-making process. This is the same regardless of whether it is the consumer making the decision or family members or others who are stepping in to assist them.



Information Formats

It was agreed that information could be provided in a variety of formats including written material, audiotapes, videos, Internet-based information, and personal (e.g., meeting with someone or over the telephone). According to the participants, the format to use very much depends on the information one is trying to communicate. For example, videos may lend themselves well to those trying to select a long-term care facility; through watching it, a consumer can get an idea of the services provided and see the environment, etc. Likewise, a concise set of pamphlets, each one defining and discussing an individual service would be helpful.

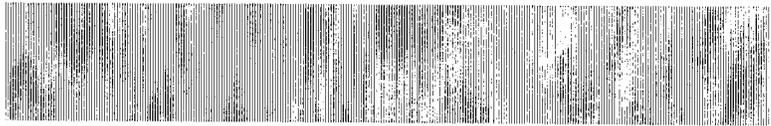
A significant number of participants noted that many individuals who need long-term care and services get their information from the “popular media” formats of TV, radio, and newspapers. As such, particularly from an educational standpoint, participants felt that public service announcements and educational pieces on these outlets would be extremely helpful to consumers.

When asked what should be kept in mind when providing information in different formats, participants gave the following ideas.

1. Any traditional written materials should be available in large print, have clear contrast in colors, and be printed on heavy weight paper.

Effective Information Tools

- u “Just Say No” public service announcements
- u AARP materials
- u Alzheimer Association materials
- u Presbyterian Guide to Living Options (Pittsburgh area)
- u Home Safety Checklist, Sewickley Hospital (Pittsburgh area)



Effective Venues for Providing Information

- u Physicians' offices
- u Townhall meetings
- u Hospital waiting rooms
- u Social security mailings
- u Bingo parlors
- u Grocery stores
- u Churches
- u Jury duty waiting room
- u Libraries
- u Bowling alleys

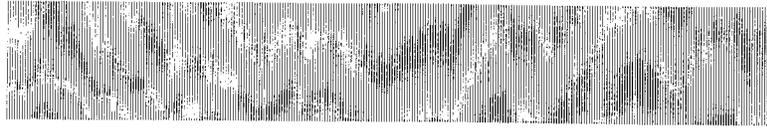
2. All information, including a website, must be accessible to those in the disability community.
3. All information should be available in alternative languages and formats.
4. Contact names and telephone numbers should be prominent.
5. Information should be presented in a "question and answer" format.
6. All information should be dated.
7. Information should be presented as comparative grids whenever possible.

User-Friendly

Regardless of the specific format selected, it is crucial that the information be user-friendly in nature. When asked what user-friendly was when it came to long-term care and services information, most participants' thoughts mirrored one State College consumer's comment, "I've never seen it."

To the participants, user-friendly means:

Keep it simple. Many consumers, as well as professionals, were overwhelmed by the volume and complexity of information provided and want to see the information streamlined. For example, a participant in Pittsburgh stated, "I compare gathering information to taking a drink from a fire hydrant. There is so much information coming at you so quickly that it is difficult to ferret through it." And another professional said, "I frequently retype the information to make it more user-friendly before distributing it to consumers."



Non-technical. Use as little technical language as possible, and where technical language must be used, a definition should be provided. Acronyms should not be used unless the general population universally uses them and even then, they should be spelled out first. As one consumer said, “I don’t need all the details. I just want to know: who is paying and when will I lose my home.”

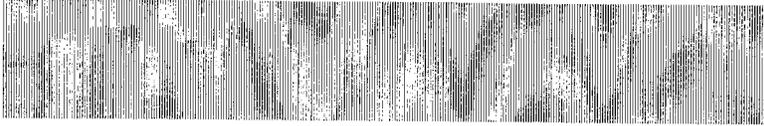
Personal contact. To many, user-friendly meant contact with a person who could answer specific questions. At the very least, all information should provide a contact name and telephone number so that further information can be accessed based on need. Additionally, having “menus” on telephone lines was something most participants abhorred; at the very least, they want the first option on such a menu to allow them to connect directly to an individual or operator.

Single point of contact/clearinghouse. Too often participants find themselves bounced from agency to agency, and office to office, to get questions answered. As such, without exception, all focus groups participants felt a clearinghouse for information was critical. This clearinghouse would be a single stop for answers and additional referrals and would cut down on the amount of “detective work” consumers have to do. Hopefully, this would eliminate situations like the one described by a 90-year-old consumer who got so frustrated during a telephone call that he finally said he didn’t want any help and hung up.



Step by step instructions. It was interesting to note the numbers of individuals who used phrases like “navigating through,” “ferreting through,” and “sifting through,” to describe what it is like to find the information needed. Several individuals suggested that user-friendly would be a decision-tree type process where consumers or those assisting them would answer questions to pinpoint their specific need(s) and determine what options are available to meet those needs.

Cut down on the paperwork. While not directly related to information obtained by consumers, the message came through loud and clear from both consumers and professionals that there is too much paperwork which must be filled out when trying to access long-term care and services. Consumers told of being asked to fill out the same personal information a dozen or more times. This is particularly distressing at such an emotional time. One professional told of how she asks individuals for information once, and then takes care of filling in all the other forms for them; individuals like her, however, are going to be few and far between. And, consumers are not alone in the masses of paperwork they must complete. One professional told the group that she had measured paperwork she received over the past seven months and it was now approaching a stack one foot tall. According to several participants, it is this amount of information that is driving people out of the business. Clearly, some streamlining is in order.

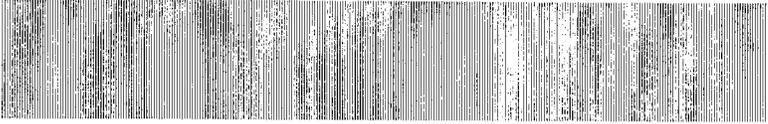


Developing a Consumer-Focused Website

The Council and the Departments are working on developing a website to provide information to consumers. As such, the issue of using the Internet as a source of information for consumers was discussed. With regard to accessing the Internet, approximately 68% of the participants had access to the Internet, with a higher percentage of professionals having access. Regardless of who was asked, most individuals thought there should be more information provided via the Internet. The exception to this was the more rural area (Nanticoke), which displayed less of an interest in this resource from the consumer perspective. One caveat about this: as technology improves with regard to access, a trend has been noted indicating that rural areas will increasingly be using the Internet as a tool to remain “connected” and to stay in touch with others from their more remote locations.

While fewer consumers than professionals currently have access to the Internet, it must be looked at as a tool for the future. The baby boomers of today are very comfortable with technology and Internet access in the home is increasing significantly. Additionally, this is the generation that is currently assisting their parents in making long-term care and services decisions.

The clear message was that more information should be available on any website created by the Council and the Departments.



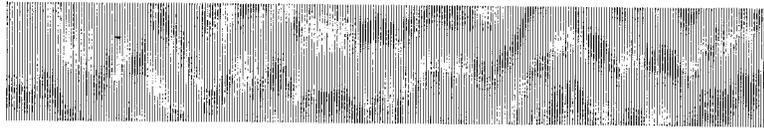
However, it should be remembered that the Internet is only one tool of many for reaching consumers and professionals. The point was also made that the Internet can be an excellent resource for family members who live away from a consumer who needs assistance with long-term care and services decisions.

Website Content

The following suggestions were made by the focus groups as to information that should be put on any new website being developed for consumer use.

1. Include *clear* definitions of the long-term care options available to consumers (e.g., nursing facilities, home care, assisted living).
2. Provide cost information for different long-term care options.
3. Provide comparative quality information on the different options.
4. Provide eligibility requirements for different financial programs and coverage.
5. Consider having the following steps available on the website to help consumers narrow down their long-term care and services options. Note: each step must come with a telephone number to call if the consumer doesn't understand the results.

Step 1: Consumer enters information about him/herself, hits a search button, and is provided with a listing of the options that may be best for them.



Step 2: Another search engine then allows the consumer to locate options that match in their geographic area.

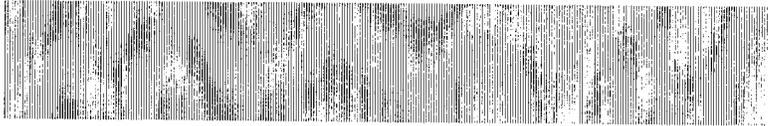
Step 3: Overarching quality information (see *Measuring/Defining Quality Criteria* section) is provided with each of the options listed in their area. Also, include a list of suggested questions for the consumer to ask as they gather more information from providers they decide to further explore.

This suggestion was previously described as a “decision tree” for consumers.

Website Format

The focus group participants also provided several suggestions related specifically to website format.

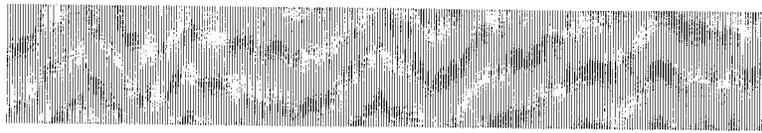
1. The website must be interactive and searchable. As an example, one participant told of a website (shoedog.com) that allows consumers to enter information about their foot size and the types of activities they engage in. It then provides a list of specific shoes that are best suited for the consumer’s needs. The “decision tree” concept described by several participants is also an example of using the Internet in an interactive manner.
2. The website should provide basic information, with links to more in-depth data and information. Consideration should be given to providing two separate “areas” on the site, one for consumers and one for

- 
- professionals with the professional area providing more in-depth and detailed data.
3. Information entered into any website must be truly confidential. The issue of confidentiality was raised as a real concern by many.
 4. Contact names and telephone numbers must be highly visible on the website.
 5. The site should be linked to other related sites that may serve the consumer as additional information sources.

Implementing a Toll-Free Number

When focus group participants heard that the Council and the Departments are planning to implement a toll-free telephone number for information, there was a positive reaction. This, however, was tempered with concerns regarding the consumer-friendliness of such of resource. Every focus group brought up the issue of needing an information clearinghouse, or a one-stop resource for information on all long-term care and services options. This was also accompanied by an understanding that one telephone number can't "do it all" and that referrals to others for further information would be necessary. However, having one place to call to get started was seen as a vast improvement over the current "navigation nightmare" many experienced.

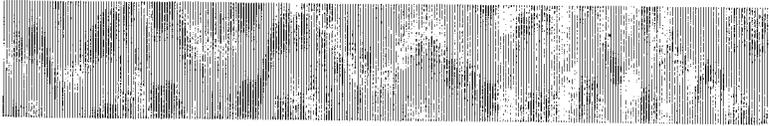
The following suggestions were provided by the focus group participants for the implementation of a toll-free telephone line for consumers.



1. There must be a *knowledgeable* person at the end of the line or an easy way to get to one. Clearly, it will be of no benefit if the individual answering the telephone does not have enough knowledge or experience to answer questions. If that person does not have an answer, he or she must know where consumers can get one. Additionally, if a “menu” is used on the toll-free telephone line, a person must be available as “Option 1” on the menu.
2. The toll-free line must have a *follow-up process* to verify callers were able to get information to meet their needs.
3. The toll-free line must have *adequate staffing* so that consumers do not constantly get either a busy signal nor are they placed on hold for significant periods of time. Should a consumer be placed on hold, they should be advised as to the estimated length of time they may be waiting.
4. The toll-free line must provide consumers with the necessary information about *local resources* in their specific area.
5. The toll-free line must be *accessible outside of regular business hours* for the convenience of consumers.

What is Currently Missing?

As one professional in Philadelphia stated, “This effort will not be successful if a bunch more data is generated. We have tons of data. We have to turn what we have into good information.” To that end, the following areas were described as areas for which there is a lack of information. It is the hope of the participants



that there is data available on these topics from which user-friendly information can be developed.

Definitions of Services

There was significant confusion among participants about the range of services available (e.g., assisted living, personal care homes, independent living), and the difference among them in terms of level of care, services available, etc. An overwhelming majority wants clear definitions of the services. They also want the definitions to be used consistently among providers. This was echoed loudly by both professionals and consumers.

Information on Community-Based Care

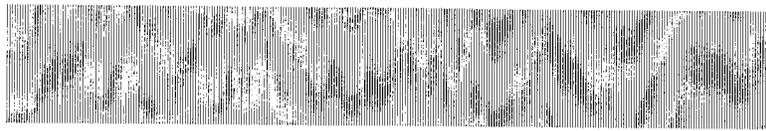
Many participants indicated that the majority of information currently available is related to facility-based care. They would like to see more information on community-based options.

Assistance for Younger Consumers

Several individuals pointed out a lack of information about options available to younger consumers. The examples given were specifically related to consumers with brain injuries.

Medical Assistance

There is a tremendous gap in information available with regard to eligibility requirements and specific coverages for Medicare and Medicaid. This dramatically affects both



consumers and professionals, who report that it is extremely difficult to gain answers to their questions.

Information on Legal Issues

The focus group participants reported a lack of information available about estate recovery, powers of attorney, and living wills. Particularly for planning purposes, the feeling was that it was very important to have such information available.

Training for Professionals

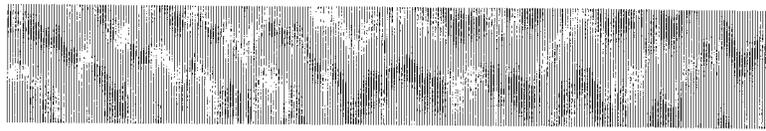
It was the opinion of several professionals that they need additional training. Specifically, they felt that professionals need training to ensure that they listen to consumers and ask the right questions, so that they can then provide the right information. It was also noted that training was needed regarding details on the specific services available.

MESSAGES FOR CONSIDERATION

Interestingly, throughout the 10 focus groups, several additional issues were frequently raised by the participants. These issues were of such significance to the participants that they were, at times, reluctant to discuss the subject of information needs until they shared their thoughts on these issues.

Specifically, while participants were willing to provide input, they clearly believed that providing appropriate information to consumers, while important, is not the most appropriate issue to be focusing on at this time. Instead, what the participants have experienced as a lack of availability of community-based services, financial concerns, and the overall fragmentation of the system were considered much more critical issues. Some of those key messages they brought out, while not related to the scope of this initiative, are provided here for the consideration of the Council and the Departments.

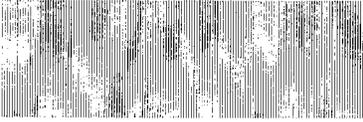
Clearly many of the participants were frustrated by what they see as a lack of progress being made by the Commonwealth with regard to the fragmentation of the long-term care and services system. This fragmentation relates to the provision of services and the funding of services. In the words of one participant, "You can provide all the information you want, but if the services aren't there, it isn't going to matter." There also was significant frustration that funding streams rather than need still dictate to a great extent the services an individual chooses. This was specifically the



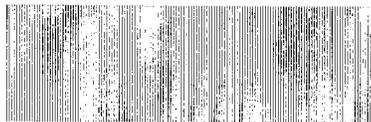
case in the experience of the participants when they or others they know were in a crisis situation and had to make a decision quickly.

The current challenge of recruiting and retaining workers in the long-term care and services industry in Pennsylvania was also forefront in the minds of many. There was concern on the part of professionals and consumers alike that this issue is not receiving enough attention.

The participants found these issues more compelling than the issue of measuring quality and providing appropriate information to consumers. And indeed, the perceived lack of action by Pennsylvania's government on these issues was seen by many as a disregard of consumers and their needs.



APPENDIX



Pennsylvania Intra-Governmental Council on Long-Term Care Members

Focus Group Participant Invitation Letter

Focus Group Participant Confirmation Letter

Focus Group Questions

Focus Group Thank You Letter