

A Project of the
Nursing Home
Community Coalition
of New York State
and the Coalition of
Institutionalized
Aged and Disabled
in association with
The Independent
Production Fund

Viewing and Resource Guide

RESIDENTS HAVE THE ANSWERS

*Improving
Quality of Life
in Long-term
Care*



RESIDENTS HAVE THE ANSWERS: Improving Quality of Life in Long-term Care is a project of the Coalition of Institutionalized Aged and Disabled (CIAD) and the Nursing Home Community Coalition of New York State (NHCC) in association with the Independent Production Fund, documentary producers located in New York City. It was developed with funding from The Fan Fox and Leslie R. Samuels Foundation, Inc.

CIAD was established in 1973 to bring pride, purpose, and self-determination to those who find themselves in long-term care institutions. CIAD is an organization run by and for nursing home and adult home residents. It seeks to empower residents to advocate for themselves, to protect and promote their rights, and to improve the quality of their life and care.

NHCC is a New York State-wide coalition of 30 consumer, professional, and civic organizations that is dedicated to improving the quality of care and life in long-term care facilities.

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RESIDENTS HAVE THE ANSWERS

Quality assurance has long been a part of nursing home management, but most measurement has focused on the quality of care being provided rather than on the quality of life being experienced. In part, this is true because performance indicators exist in many clinical areas but have not yet been fully developed in quality of life areas. Also, clinical data tends to be quantitative and seem easier to obtain than quality of life data. Consider the difference between trying to ascertain the frequency and severity of falls or the number of residents with decubiti, for example, versus trying to determine if your residents feel respected or if they are satisfied that the choices presented to them each day provide for their individual interests and needs.

The Nursing Home Reform section of the 1987 Omnibus Budget Reconciliation Act (OBRA '87) requires surveyors to assess quality of life issues but many facilities are unsure how to define quality of life and they lack performance indicators to measure it.



This project has developed and tested a process to do both.

- This process is important for managers because it can lead to higher customer satisfaction.
- It is important for resident care staff because a more complete understanding of resident needs can lead to greater job satisfaction.

The Process

Step 1. Conduct focus groups



Step 2. Customize a questionnaire for one domain



Step 3. Conduct resident interviews

Sample Questionnaire
Residents Have the Answer:
Improving Quality of Life in Long-term Care

Part 1. Demographic Information

A. Resident Name _____ B. How do you prefer to be addressed? _____
C. Gender _____ D. Age _____

E. How long have you lived in this facility? _____
F. How long have you lived in this community? _____

G. How long have you lived in this country? _____
H. How long have you lived in this state? _____

I. How long have you lived in this neighborhood? _____
J. How long have you lived in this building? _____

K. How long have you lived in this room? _____
L. How long have you lived in this bed? _____

M. How long have you lived in this facility? _____
N. How long have you lived in this community? _____
O. How long have you lived in this country? _____
P. How long have you lived in this state? _____
Q. How long have you lived in this neighborhood? _____
R. How long have you lived in this building? _____
S. How long have you lived in this room? _____
T. How long have you lived in this bed? _____

Step 4. Analyze interview data



What the Package Contains

This package contains a complete training program for the implementation of this process. This Guide is divided into two parts. The Video Guide enables you to facilitate a discussion of the video with staff members. The Resource Guide provides a detailed description of how to replicate this process in your facility, including a questionnaire template and sample items for six quality of life domains. Six domain-specific templates also are provided on a computer diskette in MS-Word format for PCs to facilitate their customization and duplication.

How to Use the Package

The overall purpose of this process is to achieve a better quality of life in your facility. This video/print package can be used both to train staff how to plan, manage, and implement a formal quality of life measurement program and to introduce the program to all those who will be affected by it.

Obtaining buy-in from all levels of staff, residents, and families is vital to the success of this program. No one wants to feel that others are collecting data about their performance that they will have no opportunity to discuss. You certainly do not want resident care staff to feel that you are going behind their backs to collect this data. If they are involved in the process and understand its overall purpose, many hurt feelings can be avoided. Residents also must have a clear understanding of the purpose and process and believe something positive will result. Their initial buy-in will help ensure their full and frank participation.

The video also can be used informally to provide all staff with an understanding of residents' feelings, positive models of how to communicate with residents, and an understanding of the degree to which residents *can* communicate their needs and feelings if given the opportunity to do so. In particular, it can sensitize staff to the different ways that people say things, and teach them to listen with a "third ear" — i.e., to listen not only to the words residents say but to their meaning.

Finally, in addition to being used to determine the quality of life residents experience, the focus group model shown can be applied to other areas. You might use it in staff orientation meetings or with a representative group of family members, for example, to ascertain areas they perceive as problematic, or with resident care staff, to get their input on how their quality of life can be improved.

Key Elements of the Process

- The project has adapted two long-proven techniques of market research to the nursing home setting — focus groups and targeted interviews — and developed a structured process that both identifies quality of life areas that are of concern to residents and helps you develop an action plan to improve the situation. The process is facility specific and relates to the problem identification and information gathering stages of a typical quality assurance investigation.

- It looks to the residents themselves for information. Research has shown that many nursing home residents can and do communicate clearly and eloquently about what they need to experience a more satisfying quality of life.

- The process relies on sampling — selecting a diverse but representative part of the population to pro-

vide data that can be generalized to the whole. While most of the residents you involve in the process will be relatively cognitively intact, such individuals are often uniquely conscious of how less cognitively able residents are treated, perhaps fearing that they will be treated similarly as their cognitive level decreases. Thus they often speak both for themselves and for those who cannot speak for themselves.

- The process can be managed by a wide variety of departments, from activities to social services to nursing to senior management.

- The process can be used repeatedly. Each time the cycle is repeated, the process identifies and focuses on a single quality of life area. Thus you will want to repeat the cycle both to measure different quality of life areas and to measure change over time in any single quality of life area.

VIDEO GUIDE

Background

The video was taped at two nursing homes: St. Cabrini Nursing Home in Dobbs Ferry, New York, and Cobble Hill Nursing Home in Brooklyn, New York. Unless otherwise identified, all of the residents you see are actual residents of these facilities. Staff members and consultants were trained by the project directors to facilitate focus groups and conduct interviews and then managed the process in much the same way you would in your facility.

Video Synopsis

This video runs approximately 33 minutes and is divided into five discrete segments. Ideally, your group would spend at least two hours viewing the video and discussing it. This would provide time for a brief discussion prior to watching the video (see *Suggested Activities Before Viewing* later in this section). You could then view the entire video once through, have a general discussion about the process, and return to individual segments for more concentrated study and discussion (see *Recommended Followup Activities and Discussion*). If it is not possible to meet for a two-hour session, determine in advance which portions of the video you will show at each session and which discussion questions you will use.



Segment 1: Introduction

(Length: 2:15)

This section differentiates the measurement of quality of care issues from quality of life issues, places the assessment of quality of life issues firmly in the overall responsibility of the quality assessment department, discusses some of the challenges involved in assessing quality of life, and provides a rationale for looking at three key questions:

- What quality of life domains are most important to your residents?
- What quality of life domains in your facility are working well?
- What quality of life domains in your facility need improvement?

It then introduces the four-step process that is at the heart of the video:

- Step 1.* Conduct focus groups
- Step 2.* Customize a questionnaire for one domain
- Step 3.* Conduct resident interviews
- Step 4.* Analyze interview data

Segment 2: Conduct focus groups

(Length: 7:15)

This section establishes the purpose of the focus group — to determine what quality of life domain or issue is most important to your residents — and discusses why a focus group is a good way to obtain this information.

Viewers then see portions of an actual focus group and observe some of the techniques used by the facilitator to make people comfortable, validate their comments, and overcome such barriers to communication as residents who fear retaliation, have low expectations of what life in a nursing home should be, or who are so loyal to the facility that they are uncomfortable expressing any negative comments.

Segment 3. Customize a questionnaire for one domain

(Length: 5:30)

This segment shows how the staff analyzes their notes from the focus group to select a single quality of life domain that seems most important to the residents at this time. They then examine a template with existing questionnaire items for that domain to see whether the items are applicable to their facility, and create new questionnaire items that reflect the specific concerns that emerged in the focus group. In this way, they customize the questionnaire template that is on the computer diskette in this package for their own facility and situation.

Segment 4. Conduct resident interviews

(Length: 12:15)

This section illustrates the process of using the customized questionnaire to interview residents. Each interview is in two parts. The first part presents a series of multiple choice questions that determine the importance of specific indicators to a resident and the frequency with which those actions occur in the facility. The second part probes for more detail on selected questions. The video segment also includes a discussion of how to select residents to interview and how to probe in ways that encourage residents to provide useful information.

Segment 5. Analyze interview data

(Length: 5:45)

The data from the multiple choice portion of the questionnaire are tallied and the information gathered during the discussion portion of the interview is analyzed to determine whether a problem exists and what has been learned about it. Finally, the staff begin to develop a plan of action to address the problem identified — which in this video case concerns a different quality of life experience between days, when the regular staff is in attendance, and nights and weekends, when agency and other per diem workers provide care.

Suggested Activities Before Viewing

1. Before showing this video to your assembled group, ask: "How would you define a good quality of life for a nursing home resident?" Keep track of people's comments on an easel pad. Request each member of the group to add to or refine the definition further. When all members who desire to speak have done so, review the definitions and point out that what the group has generated is a *staff or facility*

view of what quality of life means to residents. Explain that the process shown in this video concerns how to get residents to tell you what quality of life means to them.

2. Ask members of your group to predict difficulties they might expect to encounter in asking residents to talk about their quality of life.

3. If your group is seeing this video for a second time, assign each member to pay particular attention to some part of the process (e.g., the probes used in the focus group, differences in techniques used by the different interviews, the role of the recorder, responses of individual residents, etc.). This will enable you to build a much fuller discussion of the video following viewing.

Recommended Followup Discussion and Activities

1. What criteria would you use to select eight to ten representative residents to participate in a focus group?

2. Although the focus group members will determine which quality of life issue the process will measure, you will want to do some thinking ahead about those issues that might come up. This will help you think about probes in advance. What issues would you expect to emerge in your facility?

3. See how many different probes your group can recall from the video. Then generate a new focus group question and develop specific probes for it.

4. Make a list of specific ways in which you think residents at your facility might discuss the issue of dignity and respect. What examples might they give of being treated with dignity and respect? Brainstorm as long a list as possible and see what, if any, categories or common themes emerge from the discussion.

5. Make a list of things you liked about each interviewer and things you would have done differently.

6. Discuss how you think the residents seen in the video compare to those in your facility?

7. What are some barriers to getting good information from residents and how might you overcome these? Among those barriers noted in the video are loyalty, low expectations, and fear of reprisals.

8. To help staff think about what it means to listen with a "third ear," present the following statements and ask them to analyze what they think residents mean by what they are saying: "A sandwich for dinner is not enough for a person like me." "I missed the taxi to visit my friend because no one helped me get ready in time." "I don't want to wear the clothes the aide put out for me."

9. The residents interviewed gave very different kinds of responses. Which are most useful and why? What probes might you have used to try to get more information?

10. What did you learn about dignity and respect in the facility pictured in the video? How would you make these findings known to your colleagues? What (if any) action would you recommend as a result of what has been learned?

In Step 3 of the process, staff members interview individual residents using a customized facility-specific questionnaire.



Review of Key Concepts

All of these concepts are discussed in greater detail in the Resource Guide that follows.

- Nursing home surveyors are required to assess quality of life as well as quality of care. While numerous objective indicators exist for measuring quality of care (e.g., number of decubiti, rate of weight loss, frequency and severity of falls), fewer agreed-upon indicators exist for quality of life issues. Further, those quality of life indicators that do exist tend to be subjective and thus harder to measure.

- You can identify the nature and extent of quality of life issues by speaking directly to your residents through focus groups and one-on-one interviews. This process produces facility-specific data that administrators can use with confidence to determine areas that are working well and plan improvements in those areas that are problematic.

- Focus groups obtain data from a sample of the population, which is then generalized to the whole. The process developed by NHCC and CIAD contains several points at which data is analyzed to ensure that it is valid.

- The purpose of the focus group is to identify the quality of life domain or issue of greatest concern to the residents. The video demonstrates this process with a group that decides that its most important area of concern is ensuring that residents are treated with dignity and respect. Other focus groups might have selected a different domain, e.g., food, autonomy, staff interactions, activities, and so forth.

- Each focus group contains eight to ten residents, a facilitator, and a note taker. Several focus groups might be scheduled in larger facilities. The facilitator sets the tone for the group, presents the ground rules, and keeps the meeting's agenda. Focus groups begin the research process.

- After the focus group, the staff analyze the examples and anecdotes given by the residents to determine which quality of life area is of most concern to residents at this particular time.

- The next part of the process uses resident interviews to obtain additional information on the nature and extent of the problem. The specificity of this information will help facilities develop a plan of action to improve quality of life. All interviewers use the same two-part questionnaire — a series of eight to ten multiple choice questions that are related to the

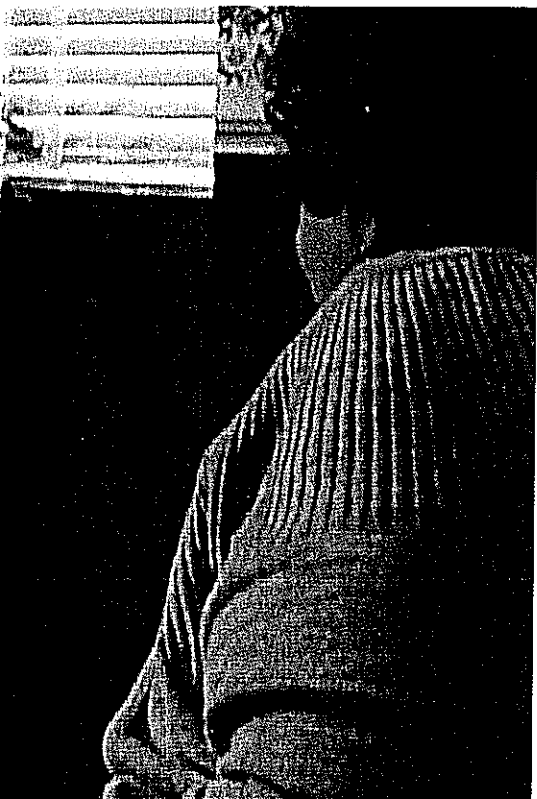
domain established by the focus group and a more focused discussion of selected items from the first part of the questionnaire. Each interview takes about 30 minutes.

- Interviewers need to listen with a third ear to what residents mean as well as what they say. A resident may repeatedly say, for example, that they know the staff is very busy. What they may mean, however, is that they would like more attention.

- Barriers to candid communication include residents' fear of retaliation if they identify problems, low expectations of what life in a nursing home should be, and a feeling of loyalty to one's home that precludes speaking ill of it. Individual personalities may also be such that they are uncomfortable voicing negative thoughts.

- To overcome barriers to communication, interviewers need to help give the resident confidence that they really want to hear what they have to say and that the resident's remarks will not be interpreted as criticism but will be used (along with others) to help improve the facility.

- Interview data needs to be analyzed to differentiate concerns that relate to the facility as a whole from those which are individual situations.



RESOURCE GUIDE

Step One. Conduct focus group



What is a Focus Group?

A focus group is a meeting of a selected group of people who come together for a fixed period of time to respond to pre-determined questions

about a particular topic. Think of a focus group as a group interview in which each person responds to the same set of questions. Focus groups are a qualitative form of research used often in the social sciences and are led by a facilitator.

Choosing a Facilitator

The facilitator has several responsibilities: to make members of the group feel comfortable, to present a series of ground rules and make sure they are followed, to engage residents in discussion, and to follow an agreed-upon focus group protocol. The facilitator should be skilled in running groups, objective, friendly, and a good listener. This individual may be part of the staff of the facility, or you may want to engage a professional facilitator from outside the facility. Each choice has advantages and disadvantages. If the facilitator is a staff member, residents may be reluctant to speak about problems, fearing retribution. Staff facilitators will need to make clear that their role in the group is different from that of their regular job and that for the purposes of the group, their job is primarily to gather information to improve the facility. If the facilitator is a consultant, residents may need reassurance about the usefulness of the process and that an outsider can produce change. In either case, it is important to provide time for the members of the focus group to become comfortable with the facilitator.

Choosing a Recorder

Each session also should have a recorder (someone who keeps notes on a easel pad of what is being said). The recorder should have clear handwriting and try to note the residents' actual words. If it is possible to tape record the session as well, you will have both a detailed record of what was said and an outline to help you see the big picture. Do not tape record the session without the agreement of the participants, however. If participants feel uncomfortable about the procedure, they will have more difficulty speaking forthrightly.

Scheduling and Locating the Focus Group Meetings

The length of each meeting will depend a lot on the strength and tolerance of the group members. Plan on 90 minutes but be prepared to stop early or to keep going if the discussion remains fruitful. Select a time that does not interfere with the residents' medication regimens or activities that are important to them. Look for a location within the facility where you can set up chairs in a circle so everyone can see each other and interact without distractions. This configuration best accommodates those in wheel chairs as well. You also want a room that protects the residents' confidentiality. If focus group participants think they can be seen or heard, they will be less likely to speak openly.

Selecting and Inviting Members of the Group

You want to involve approximately 10 percent of your resident population in the focus group process. In a facility of 100 residents, for example, this will mean coordinating a single focus group of eight to ten residents. Larger facilities may want to schedule additional focus groups to ensure that they are really sampling a diversity of opinion.

In each focus group, your goal is to maximize participation. You do not want the group so small that dis-

cussion is limited, nor do you want it so big that people get lost in the group. It is probably a good idea to invite 10 residents to each focus group so that if some cannot come on the day of the meeting, you will still have a good-sized group. Among the factors to consider are different units, cognitive ability, physical limitations, ethnic backgrounds, gender, stamina, and levels of independence. A written invitation might say:

Please join us on _____ at _____ for an important discussion about the quality of life at _____. The meeting will last about an hour and a half. Your comments will be kept confidential. Your participation will help us improve life here for everyone.

Be sure to invite each person individually and in person. Take time to explain the process and the amount of time you are asking the resident to commit. Also be sure residents understand the overall purpose of the process.

Developing the Focus Group Protocol

This is basically a series of questions and probes, along with time cues to ensure that the meeting will end on time. Typically, a focus group protocol has two parts:

Introductions (10-20 minutes)

- Set the tone. Present the purpose of the discussion and tell what you hope to accomplish.
- Stress that the purpose of these meetings is to improve everyone's quality of life and that in order to do that it is important to find out what issues are important to people.
- Let the group know how long you expect the session to run (most groups will run 60-90 minutes) and determine whether group members would like a break in the middle of the meeting.
- Make sure everyone is introduced unless they already know each other. Be sure to introduce the recorder.

Review the ground rules:

- One person speaks at a time.
- Everyone is respectful of each other's remarks.
- Everyone will get a chance to speak.
- There is no such thing as a wrong answer or a bad idea.
- All comments are confidential. Ask group members not to discuss things that are said in the meeting with anyone outside of the group.

Leading the Discussion (45-60 minutes)

This is where the key questions are asked. The questions should be clear and direct. Start with general questions while the group members are getting comfortable, and move to more probing questions as the trust level develops. Here are some ways you might begin:

- What do you like about this home? (It is always a good idea to begin with a positive question.)
- What would you change if you could?
- What could be improved?
- What would the ideal home look like?
- Would you recommend this home to others?
- Why or why not?

Notice that these are all ways of getting at the same information. One question may elicit information from one resident, and another may elicit information from someone else. Thus, facilitators need to prepare not only the primary questions they will ask, but also the probes that will help jog residents' memories and prompt them to move beyond the general to the specific.

The goal of the focus group is to determine a quality of life issue of general concern to the group. You will do this by listening carefully and checking the recorder's notes often to see if consensus is emerging around a common theme. It is important to listen to resident's concerns with a "third ear." The specific anecdote a resident relates may initially seem to be about something rather simple, for example, about the type of food served. Upon probing, however, a more sophisticated framework may suggest that what the resident means is that he or she wants more independence and to be offered choices.

Focus group facilitators should avoid the temptation to try to fix problems that are identified or to become overly involved in the feelings of the group members as they report difficult situations. This will take them away from the main goal of the meeting — which is to determine a quality of life issue of general concern to the group. The facilitator needs to remain undefensive and a neutral party in order for all members of the group to feel safe enough to share information. If a specific problem emerges that you feel must be followed up because of its immediacy or severity, obtain permission from the group member who brought it up to look into it further after the group is over. Make sure you understand any limitations the resident wants to impose on how you discuss the issue with the administration or other staff.

In closing, remember to thank the participants for their time and restate that the overall goal of the process is to improve everyone's quality of life.

Facilitation Techniques

It is important to limit the number of staff members in the room to the facilitator and the recorder, but to have one additional staff member on call if a resident needs to leave the group and requires assistance to do so. You want to reduce as many barriers to honest communication as possible and additional staff members may be perceived as intimidating.

If your facility is large, the group that you bring together may not know each other. Spend the first ten minutes of your time together introducing residents to each other and giving residents a chance to become comfortable with you.

Some tips:

- Engage everyone in the discussion quickly by going around the room in an informal way, making sure everyone has a chance to respond to the first question.
- Be comfortable with pauses and silence. Give residents a chance to gather their thoughts.
- Repeat phrases from resident's replies to validate what the group member has said, to ensure that other members of the group have heard it, and to give the recorder a chance to note the comment.
- Follow up on residents' comments to probe for more specific information. Asking for examples often

produces the level of specificity that will help you understand the underlying issue.

- Keep the discussion positive. Ask "How would you like it to be?"
- Repeat, summarize, or clarify each comment and watch residents' body language to ensure that you actually heard what they said. Be objective and neutral.

Bear in mind that many things may make it difficult for residents to communicate clearly about problem areas, e.g.:

They may be afraid, fearing retribution if they are frank.

Assure participants that their responses will be kept confidential.

They may not have high expectations and may not see problems. They never expected life in a nursing home to be wonderful.

Ask residents about how they would like it to be in an ideal world.

They may lack confidence or be deferential.

Remind them that they are the experts when it comes to what life is like in the home.

They may refuse to talk about problems because it may seem disloyal to the home.

Remind them that working to improve the home for everyone is, in fact, a very loyal act.

In all cases, be reassuring and encouraging. If residents answer with phrases like "Everything is fine," or "Everyone is nice," ask for examples. Try to communicate that their input will not be viewed as a complaint. It is information that will help the facility improve conditions for everyone.

Bear in mind that sometimes when people have difficulty being specific or repeatedly give monosyllabic but positive responses, they may be people with very sunny personalities who invariably see the glass as at least half-full. While you will want to keep probing to see if you can get more specific responses, you do not want to leave the impression that positive responses are unacceptable. Oftentimes, residents will answer a question positively because they are truly comfortable with the area under discussion.

Step Two: Customize the questionnaire



This part of the process has two goals: to identify which quality of life issue best reflects the focus group's concerns and to customize a quality of life questionnaire. A

questionnaire template is included in this package (see pages 14-17 and the enclosed computer diskette) along with sample items from which you might select those that are most pertinent to your facility (see page 12).

Determining the Domain that Best Reflects the Focus Group's Concerns

Content analysis is a critical step in making the focus group discussion a meaningful and productive process. By studying the focus group discussion, you will be able to get an understanding of the particular topic discussed, clearly identify residents' concerns, and establish specific priorities.

1. Look at the recorder's notes and listen to the tape recording, if any.

2. List the major points made by the residents. Look for the key or essential underlying issues of a seemingly surface issue. In the video, for example, Antoinette talks about having her lights turned off before she wants to go to bed. Frank talks about being dressed "like a bum" and being served a dinner that is too small for his appetite. When the staff analyze these statements, they determine that they are more about the larger issue of dignity and respect than about food and clothing.

3. Determine the dominant domain to be studied.

It is likely that your residents will touch on many domains during the focus group. Also, it can be challenging to determine from a particular anecdote what domain a resident is really addressing. If a resident talks about the size of food portions, for example, is this a food issue or is it an autonomy issue? Bear in mind that this is a process that you can repeat on a regular basis, so seek out one issue that seems most important at this time for study.

The staff of the facility shown in the video determined that the key issue for their residents at this time is being treated with dignity and respect. While residents related anecdotes that certainly touched on other domains, when these stories were analyzed beyond their surface facts, staff often found that at

the root of the problem was a concern for whether the resident was being infantilized, not treated as an individual, treated discourteously, and so forth. In truth, the staff might have found that several domains were important to their residents at this time. It is important to understand that no issues are necessarily discarded in the effort to select one on which to focus for this exercise. The process can be repeated as many times as seem necessary, with each round focusing on a different domain. Facilities undertaking this research might also find that additional domains or slightly different formulations of these domains emerge from their focus groups.

The domain statements on page 12 are designed to help you start the process of customizing your questionnaire.

**Choosing a specific
domain to study
further can be diffi-
cult. Researchers
studying quality of
life issues have
identified six major
domains that
contribute to a
resident's quality
of life:**

- 1. Activities**
- 2. Autonomy**
- 3. Food**
- 4. Dignity and
Respect**
- 5. Living
Environment**
- 6. Staff Interactions**

Sample Domains and Questionnaire Statements

Activities

1. I am told what activities are available.
2. I have enough opportunities to do personal activities such as reading, watching TV, writing letters, visiting with family, etc.
3. There are enough trips and outings.
4. There is enough variety in activities offered.
5. There are enough activities for me that use my mind.
6. There are enough activities for me on the unit.
7. The activities are offered at the right time for me.

Autonomy

1. I am encouraged to participate in decisions about my care.
2. I decide what I am going to do each day.
3. I feel I can express my feelings and opinions around here.
4. Equipment is available that allows me to be independent.
5. I am free to come and go as I please.
6. I can choose when to have my bath or shower.
7. I feel I have enough freedom to make my own choices.

Dignity and Respect

1. When staff come to my room they explain why they are there.
2. Staff addresses me in the way I like to be addressed.
3. I am dressed in the way I want to be dressed.*
4. Staff knock on my door and wait for me to respond before they come in.*
5. I am able to dine in a way I want to dine.*

Food

1. I get enough different kinds of foods to choose from.
2. I can get the types of foods I like to eat.
3. The taste of the food is o.k.
4. The temperature of the food is o.k.
5. I am given the right amount of food.
6. Food is available when I am hungry.
7. I am given enough time to eat.
8. I get the food I ordered.

Living Environment

1. This is a comfortable place to live.
2. I have enough privacy.
3. My personal belongings are safe here.
4. The home is clean and tidy.
5. My room is how I like it to be.
6. It is noisy around here.
7. This place is in good physical condition.
8. The home smells okay.

Staff Interactions[†]

1. Staff treat me with patience, tenderness, and kindness.
2. Staff ask about my interests and life and tell about their life.
3. Staff listens to what I have to say about how I want care.
4. Staff are well trained to do their job.
5. Staff know what I want and need and try to give it.
6. Staff is cheerful.
7. Staff make me feel comfortable enough to kid around.
8. Staff talk to me in a pleasant and respectful manner.

Unless otherwise noted, these statements are adapted with permission from the "Long Term Care Resident Evaluation Survey" (Version 2, August 2000) developed by the Long Term Care Resident Evaluation Consortium, Ontario, Canada.

*These statements are adapted from U.S. Department of Health and Human Services, Health Care Financing Administration, Guidance to Surveyors — Long Term Care Facilities, Rev. 274, June 1995.

[†]These statements were developed by the project staff.



Customizing the Questionnaire

Once a domain is selected, study the items listed under that domain to determine whether or not they pertain to your own facility. You may then want to develop additional items (up to a maximum of 10 in the full questionnaire) that relate to specific issues raised in the focus group. This process is illustrated in the video and shown on the sample questionnaire that follows, on which the items added by the facility are highlighted in bold face. You will need to review the focus group notes and discuss other topics that emerged, developing such additional items as may be needed to cover the concerns of your residents.

In developing facility-specific items, work to word items in a manner that is very concrete, uses simple language, and focuses on one specific experience. An item that says "My dining experience pleases me" will be easier for residents to answer and for you to analyze than one that says "My food is served on time, is hot, and tastes good." In the first case, if this turned out to be an item that a resident rated negatively, you would have an opportunity to probe in the second part of the interview to learn more about what part of the experience was not pleasing. In the second example, when you went to analyze the data, you would not know which part of the item the resident really responded to.

When customizing the questionnaire with new items that reflect the specific concerns or your residents, use simple wording and ask about only one experience in each statement.

Bear in mind as well that these items should be worded as statements, not questions, and that a good test of whether the item is adequately clear is to test it out on another person to see if it can be answered in the same form as the other questions. Negatively worded items tend to be confusing, for example, when put into the form of the questionnaire. It will be easier for residents to rate the importance of a statement such as "This place smells o.k." than to rate the importance of "This place has bad smells" when the question is asked in the form of "Tell me whether this statement is "Not at all important to you," "Somewhat important to you" or "Very important to you."

The Questionnaire Template

Each resident interview questionnaire has three parts:

1. Demographic information (completed prior to interviewing the resident)
2. Multiple choice questions (about 10 minutes per resident)
3. A focused interview that probes for additional information about selected questions from the multiple-choice part (about 20-30 minutes per resident)

The demographic information lets you look at people's responses and determine if a particular problem affects one group of people more than another, e.g., people in a specific unit, people with specific disabilities, and so forth. You may want to add questions to this part of the questionnaire that make it more specific to your population and facility.

A sample questionnaire follows. It features questions on dignity and respect. A blank template for all three parts of the questionnaire and for all six domains is included in this package on a computer diskette. This template can be customized by your facility with the items you choose to include in your questionnaire.

Sample Questionnaire: Instructions for Administering

Residents Have the Answers: Improving Quality of Life in Long-term Care

Part I. Demographic Information

Complete this section from your own knowledge or facility records prior to meeting with the resident. This will allow you to keep the interview with the resident as brief as possible. To preserve the confidentiality of the process, it is recommended that you use a code rather than resident's real name. You may also wish to add questions that are specific to your facility.

Part IIa. Individual Interviews/Multiple Choice Questions

Read each of the statements on the questionnaire to the resident. After each statement, first present the choices relating to importance, then those relating to frequency. Thus, you might say: "I am going to read you a statement and I would like you to tell me whether the statement tells about an activity that is (1) Not at all important to you, (2) Somewhat important to you, or (3) Very important to you." You would then read the statement and repeat the choices. Mark the resident's response on the chart. Then say to the resident: "I am going to reread the same statement. This time I would like you to think about how often this activity occurs in this facility and tell me whether it is occurs (1) Never, (2) Some of the time, or (3) All or most of the time." Reread the statement and the choices and mark the resident's response. Strongly encourage participants to answer the questions as they are phrased. Continue until you have completed all ten questions. The process should take about ten minutes.

If a resident wants to discuss any of the items in more detail during this part of the interview, e.g., to provide you with some anecdotes to explain his or her answer, ask the resident to wait until you have finished with the multiple-choice questions when there will be ample time for discussion.

When the multiple choice portion of the interview is complete, you will need to decide quickly which items

to explore further. Select three items for further discussion by visually scanning the chart while you are with the resident. Ideally, you should select at least one statement to which the resident has responded positively and at least two to which the resident has responded negatively or indicated through words or body language that they would like to talk further. This will enable you to ensure that the resident's positive responses reflect their true feelings and will enable you to gain greater insight into the situations to which the resident responded negatively.

- A **positive item** is one that comes closest to a rating of "very important" (3) and "occurs most of the time" (3).
- A **negative item** is one that the resident rates as "somewhat important" (2) or "very important" (3), but which "never" occurs (1) or occurs only "sometimes" (2).

In other words, you are looking for items where the responses cluster in the middle of the chart, indicating that the statement holds some importance for the resident but does not occur consistently.

Part IIb. Individual Interviews/Discussion of Selected Items

This part of the interview will take about 20–30 minutes per resident. Probe for more information about each of the selected items. For example, you might say, "You mentioned that it is very important to you that the staff take an interest in your individual needs, but that this only happens sometimes. Could you tell me a little more about times when this does not happen to your satisfaction?"

Additional probes:

For positive items: Can you give two or three examples of when this happens?

For negative items: What happens instead? When does it happen? Where does it happen? Are there times when it does happen and other times when it doesn't? Can you tell me about each of those times?

Sample Questionnaire

Residents Have the Answers: *Improving Quality of Life in Long-term Care*

Part I. Demographic Information

1. Resident Code: _____
2. Gender: ____ (A) Female ____ (B) Male
3. How old is the resident?
____ Years ____ Months
4. Resident's Unit or Floor

5. How long has the resident lived at this facility?
____ Years ____ Months
6. Which of the following best describes the resident's stay?
____ (A) Short-term rehabilitation
____ (B) Long-term care
____ (C) Special unit
(please specify): _____
7. Does the resident share a room with another person?
____ (A) No ____ (B) Yes
8. Who visits the resident? (*Check all that apply.*)
____ (A) No one
____ (B) Spouse
____ (C) Children
____ (D) Friends
____ (E) Volunteers
____ (F) Clergy
____ (G) Other
9. How often does the resident have visitors?
____ (A) Daily
____ (B) Weekly
____ (C) Twice a month
____ (D) Monthly
____ (E) Every 2-3 months
____ (F) Once a year
____ (G) Never

Add facility specific items here, if desired.

Sample Questionnaire

Part IIa. Individual Interviews/Multiple Choice Questions

Domain: Dignity and Respect

Resident Code: _____ Date of Interview: _____

Interviewer: _____ Facility: _____

	IMPORTANCE TO RESIDENT			FREQUENCY OF OCCURRENCE		
	Not at all important (1)	Somewhat important (2)	Very important (3)	Never (1)	Some of the time (2)	All/most of the time (3)
1. When staff come to my room, they explain why they are there.						
2. Staff addresses me in the way I like to be addressed.						
3. I am dressed in the way I want to be dressed.						
4. Staff knock on my door and wait for me to respond before they come in.						
5. I am able to dine in a way I want to dine.						
6. Staff offer me a meal that suits my appetite.						
7. Staff ask me rather than tell me what to do.						
8. Staff take an interest in my individual needs.						

Statements 1-2 are adapted with permission from the "Long Term Care Resident Evaluation Survey" (Version 2, August 2000) developed by The Long Term Care Resident Evaluation Consortium, Ontario, Canada. Statements 3-5 are adapted from U.S. Department of Health and Human Services, Health Care Financing Administration, *Guidance to Surveyors — Long Term Care Facilities*, Rev. 274, June 1995. Statements 6-8 were developed by staff at the facility seen in the video to customize the questionnaire to their residents' concerns.

Sample Questionnaire

Part IIb. Individual Interviews/Discussion of Selected Items

Resident Code	Date	Interviewer
Item No.	Positive/Negative	Notes
		Is response here consistent with that given in IIa? Yes No
		Is response here consistent with that given in IIa? Yes No
		Is response here consistent with that given in IIa? Yes No
Other issues picked up on but not related to these items:		

Step 3. Conduct resident interviews



When you have established the questionnaire and selected the interviewers, it is always a good idea to have a rehearsal. Have the interviewers take turns role-playing the interview-

ee and a resident. This will help you determine whether questions need to be worded better (if, for example, when you ask the question, no one knows quite how to answer it) as well as whether your selected interviewers have the patience and skill to establish rapport and probe for useful information. This rehearsal can also provide practice in jotting down brief notes for later expansion and analysis.

You should try to interview at least ten percent of the population of your facility, selecting from among individuals who did not participate in the focus group, but seeking the same kind of demographic balance that you established in inviting individuals to join the focus group. Residents with mild or early dementia can be included among those interviewed but you will want to adapt the techniques slightly — keep the interview short and focused and put notes away if they make the resident anxious.

Each interview will take about 30 minutes. Make sure the interview is at a convenient time for the resident and do not rush through it. The meeting should take place in a private space where residents do not have to worry about being seen or overheard. At the start of the session, review that the purpose of the meeting is to improve quality of life issues for all residents and that individual answers will be kept confidential. Stress that the reason you must take notes is to ensure that you can remember what was learned in each of the interviews you do. Take a minute to develop some rapport

with the resident before getting down to the business at hand. Make sure the resident has whatever aids may be needed for communicating.

Before beginning the interview, review the information on the questionnaire itself and think about the task you will be doing in between the multiple choice section and the discussion, e.g., selecting one positive and two negative areas to discuss in more detail. If you were to try to probe on all ten multiple choice items, the interview would likely run very long and not every probe would be useful. By preselecting those items that are likely to yield the most useful information, you guarantee that you talk about those issues that are most important to the resident.

Bear in mind the strategies for developing probes and overcoming barriers to communication that were discussed earlier. As you probe, you may find that the initial answers residents gave do not seem to fit their real feelings. Once a resident begins to feel comfortable and safe, it is not uncommon for a response that was positive in Part IIa to turn into a negative response in Part IIb. Similarly you may find that a

negative response given in Part IIa really relates to a powerful but isolated incident that would be hard to generalize to the whole facility even though it may need follow up. Also, some residents may seem to give only brief and always positive answers. If you are unsure whether these answers really reflect their experience, ask them to give specific examples. If they can do so, you probably can assume you are obtaining valid data.

Make sure at least 15 minutes is left between interviews to write down information that was too complicated to get down during the interview process and to prepare for the next interview.

**The interview
asks residents
how important
each issue is to
them and how
often it happens.
Interviewers
then probe for
more detail about
particular issues.**

Step 4. Analyze the interview data



To complete this step, meet again to achieve three goals:

1. To tally the interview data
2. To determine the nature and extent of the problem, if any
3. To develop a plan of action

Tally the responses from the multiple choice portion of the questionnaire to see what, if any, patterns develop. It would be noteworthy, for example, if the "positives" and "negatives" were mostly the same for all those interviewed. Be sure to note any answers that changed during the probing part of the interview.

In looking at those items that residents tended to rate negatively, list

the issues raised in the probing part of the interview. Determine what additional information you may need to fully understand the issue. You may need some background, for example, on what the facility's staffing pattern is, or on what directions staff members have been given for handling various situations.

As you look at the raw data and then at the responses to the interview probes, what you are looking for are themes that relate to the domain under study. What is going well and what seems problematic? Review the demographic information for each resident. Are there specific locations where problems tend to occur? Are there specific times where such problems emerge? Are there certain types of residents that seem to be more affected by the problem than others? Are some issues related to gender? To age? To length of time in the facility? This analysis is where the demographic data collected on Part I of the questionnaire will be helpful.

In some situations, you may need to add residents to the sample to gain further insight into the problem.

Once a problem area is understood, staff will need to develop a plan of action to improve the quality of life of residents.

The notes from the second part of the interview are key to the team's thorough analysis of the data. They are used to identify emerging patterns.



In Step 4, all interviewers come together to tally the data; determine the nature and extent of the problem, if any; and develop a plan of action.

Recommended Reading

Cohen-Mansfield, Jiska, Ejaz, Farida K. and Werner, Perla, Editors. *Satisfaction Surveys in Long-Term Care*. New York: Springer Publishing Company, 2000.

Long Term Care Resident Evaluation Consortium. *Long Term Care Resident Evaluation Survey*, Version 2, August 2000. The complete "Long Term Care Resident Evaluation Survey" developed by Peter Norton, Barb van Maris, Liane Soberman, and Michael Murray, is available from: Smaller World Communications, Inc., 8939 Yonge Street, Unit #204, Richmond Hill, Ontario, Canada L4C 6Y3.

Norton, P.G., van Maris, B., Soberman, L. and Murray, M. "Satisfaction of Residents and Families in Long-Term Care: 1. Construction and Application of an Instrument" in *Quality Management in Health Care*, 1996, 4(3), 38-46.

Soberman, L.R., Murray, M., Norton, P.G., van Maris, B., and Tasa, K. "Satisfaction of Residents and Families in Long-Term Care: III. Dissemination of Results," in *Quality Management in Health Care*, 1997, 5(3), 63-71.



This isn't a finite, linear process. It is circular, used with residents to identify concerns and improve quality of life, one issue at a time.

Project Work Group Members

1995-1996

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