

Oklahoma State Health Department  
“Best Practices Medical Directors Subcommittee”  
Inaugural Meeting  
February 20, 2008 2:30 PM

**PRELIMINARY AGENDA**

1. Call to order. (Chair)
2. Opening Remarks. (Chair)
3. Introductions.
4. Subcommittee membership. (Chair) - see attachment
5. Overview of quality initiatives in the LTC continuum.
  - a. National
    1. CMS Nursing Home Quality Initiative, “Nursing Home Compare”
    2. Advancing Excellence in America’s Nursing Homes.
    3. National Commission for Quality Long-Term Care.
  - b. Oklahoma Perspective
    1. Oklahoma Foundation for Medical Quality (Lisa Bewley)
    2. Focus on Excellence
  - c. Stakeholders.
6. Where we are in Oklahoma. (open discussion)
7. Where we want to be. (open discussion)
8. Brainstorming Session. (open discussion)
9. Establish subcommittee goals and objectives
10. Schedule next meeting. (approximately every 4 months)
11. Adjournment at 4:30 PM.

Name
Bewley, Lisa
Brinkley, Mary
Clark, Gene
Cox MD, Douglas
Cranmer MD, Kerry
Crawley, Theo
Hambric, Diane
Hartman MD, Richard (Tent)
Houser, Esther
Lawson, Cassell
Magness, Mich
Moore, Becki
O'Connor DO, John T
Qayyum MD, Qaisar
Root DO, Jean (co-chair)
Taaca MD, Perry
Timmons, H. F.
Wilsie, Gara
Winn MD, Peter (Chair)

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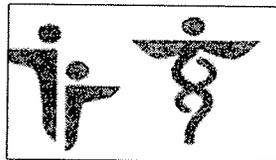
FFB 08 2008

Protective Health Services

***Opportunities for Living Life***  
**Focus on Excellence**  
***Nursing Facility Providers***

Primary Care Health Policy Division  
Department of Family & Preventive Medicine  
University of Oklahoma Health Sciences Center  
Oklahoma City, OK

October 5, 2007



# Opportunities for Living Life Focus on Excellence

## *Nursing Facility Providers* Executive Summary

**Purpose:** The purpose of this study was to assess Oklahoma nursing facility owner's opinions on how the quality-based reimbursement system is working in the early implementation stage. This was accomplished by focusing on three areas: 1) six (6) of the resident-centered quality of care measures, 2) nursing facility interaction with My InnerView, and 3) continued education and outreach about the program through development and distribution of education and survey material for nursing facility providers.

As authorized by House Bill 2842, Oklahoma has implemented a quality-based reimbursement program for Nursing Facilities called Focus on Excellence. Implementation of this program is being accomplished primarily through a contract with a Wisconsin based consulting firm, My InnerView.

Faculty and staff in the Primary Care Health Policy Division, Department of Family & Preventive Medicine (DFPM) at the University of Oklahoma Health Sciences Center (OUHSC) were asked to assist the Oklahoma Health Care Authority (OHCA) with monitoring the current status of this program.

**Background:** "Public dollars subsidize health care at every turn."<sup>1</sup> This statement, from a 2006 editorial in the Des Moines Register, resonates in the long-term care and nursing home arena, where costs can be substantial. Medicaid pays for 44% of the \$193 billion spent annually for long-term care in the U.S. In fact, more than one-third (35%) of Medicaid's \$215 billion

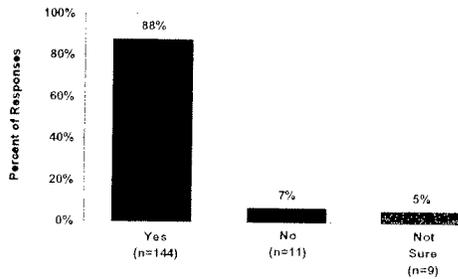
budget is spent on long term care. Medicaid is the nation's major source of financing for long-term care. Most of those dollars are spent in nursing facilities.<sup>2</sup>

Medicaid and Medicare outlays have been increasing steadily over the past 10 years. A recent update by the Congressional Budget Office (CBO) stated that the long-term fiscal outlook for the U.S., which ran a deficit of \$248 billion last year, "continues to depend primarily on the future course of health care costs."<sup>4</sup> Medicare/Medicaid spending totaled 4.6% of the gross domestic product (GDP) in 2006 and could consume 5.9% of GDP by 2017.

Because Medicaid is a state-federal collaboration, states bear a portion of the fiscal responsibility for long-term care expenditures. But with pressure to contain costs and the baby boom generation approaching retirement age,<sup>5</sup> states will have to be increasingly innovative in order to balance fiscal responsibility with access and quality in long-term care. Pay-for-performance, through the Focus on Excellence program, is a financing mechanism Oklahoma is implementing that could increase both quality and access.

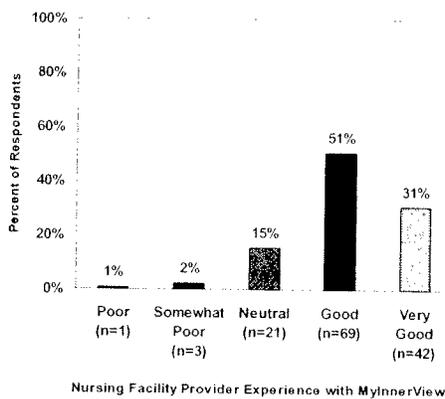
The experiences of nursing facility residents and/or the family members of residents are crucial in measuring the quality of care in nursing facilities. It is important that there is congruence between what residents or family members think is important and what nursing facility providers perceive is important to their residents. This report describes nursing facility

**Figure 2. Percent of Nursing Facility Provider Respondents Participating in My InnerView Study (n=164)**



Eighty-two percent (n=111) of the 136 providers responding to this questions felt the experience with My InnerView was either “Good” (51%, n=69) or “Very Good” (31%, n=42) (Figure 3).

**Figure 3. Nursing Facility Provider Respondents Experience Working with My InnerView (n=136)**



Raw survey data and all comments from the respondents are attached (Appendix C). Researchers credentials are attached (Appendix D).

**Findings:**

1. Analysis of six quality of care measures showed no statistically significant differences between demographic sub-groups (i.e., size and location of facility, percent of beds funded by SoonerCare).
2. Respondents ranked all six quality of care measures as “very important.”
3. Eighty-eight percent (88%, n=144) of nursing facility providers in our sample said they were involved in the My InnerView research process (Figure 2).
4. 136 of 144 respondents answered the question about their experience with My InnerView. Eighty-two percent (n=111) of the 136 providers responding to this question felt the experience with My InnerView was either “Good” (51%, n=69) or “Very Good” (31%, n=42) (Figure 3). This indicates a successful program implementation to date.

**Recommendations:**

1. Continue with the current implementation strategy.
2. Continue longitudinal measurements of indices of success. These results may be used to enhance the continuous-quality improvement aspects of the Focus on Excellence program.
3. Continue education process.

17. High Level of Resident and/or Family Satisfaction Compared by Number of SoonerCare Beds  
(n=164) .....12

18. Quality of Interaction with My InnerView by Location (n=133).....14

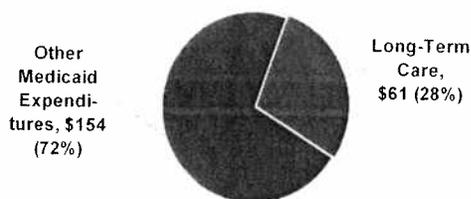
19. Nursing Facility Providers' Opinion of How Important Six (6) Quality of Care Measures are to  
Residents and/or Family Members .....15

families and staff and, at the same time, achieve financial success.”\*

## Background

“Public dollars subsidize health care at every turn.”<sup>1</sup> This statement, from a recent editorial, resonates especially in the long-term care and nursing facility arena, where costs can be substantial, resulting in severe financial losses for families as well as for public and private payers. Nationally, Medicaid pays for 44% of the \$193 billion spent annually for long-term care in the U. S. In fact, more than one-third (35%) of Medicaid’s \$215 billion budget is spent on long term care. Medicaid is the nation’s major source of financing for long-term care.<sup>3</sup> Most of those dollars are spent in nursing facilities.<sup>2</sup>

**Figure 4. Portion of National Medicaid Budget for Long-Term Care Services (\$B)<sup>3</sup>**

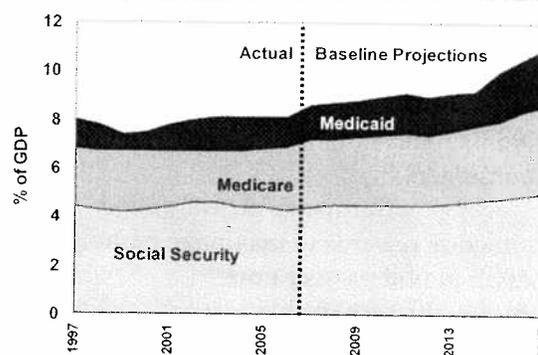


Medicaid and Medicare outlays have been increasing steadily over the past 10 years. A recent update by the Congressional Budget Office (CBO) stated that the long-term fiscal outlook for the U.S., which ran a deficit of \$248 billion last year, “continues to depend primarily on the future course of health care costs.”<sup>4</sup> Medicare/Medicaid spending totaled 4.6% of the gross domestic product (GDP) in 2006 and is expected to consume 5.9% of GDP by 2017 if left unchecked (Figure 5). In addition, “[O]ver

\*<http://www.myinnerview.com/index.php>

the past 4 decades, costs per beneficiary under Medicaid and Medicare “have increased about 2.5 percentage points faster per year than has per capita GDP.”<sup>4</sup> If costs continue to increase at the current rate, both programs could consume “about 20 percent [of the GDP] by 2050.”<sup>4</sup>

**Figure 5. Congressional Budget Office Actual and Projected Medicare and Medicaid Spending as a Percent of GDP: 1997 to 2017<sup>4</sup>**



Because Medicaid is a joint state-federal collaboration, states bear a portion of the fiscal responsibility for long-term care expenditures. With pressure to contain cost and the baby boom generation approaching retirement age, state programs will have to be increasingly innovative as they seek the means to balance fiscal responsibility with access and quality in long-term care.<sup>5</sup>

One method for utilizing reimbursement as a mechanism to improve access and quality in long-term care is to tie specific and measurable quality measures to a tiered-reimbursement system that rewards quality.<sup>10</sup> This type of system, also called “pay-for-performance,” has also been suggested as a way to control costs and improve care in hospitals and for Medicare.<sup>11-15</sup>

According to a recent Institute of Medicine report, pay-for-performance should address specific and measurable outcomes (Figure 6).<sup>12</sup>

# Methods

This study utilized a survey instrument (and accompanying education material) to gather feedback on OHCA's quality-based, tiered-reimbursement system for nursing facilities regarding specific quality measures. DFPM faculty and staff assisted OHCA in developing the feedback instrument and educational material, and performed data analysis using methods similar to those described for several previous studies.<sup>6,16-22</sup>

## Subjects

The target population for this study included nursing facility administrators and nursing managers/directors statewide. OHCA distributed surveys once via postal mail to all 317 nursing facilities in Oklahoma that receive SoonerCare (Medicaid) reimbursement.

## Survey Instrument and Materials

Program faculty and staff assisted OHCA in the development of a survey instrument to gather nursing facility feedback that may be correlated with a similar survey to be distributed to nursing facility residents or their family members. Performance measured by these criteria will be used to reward facilities that meet or exceed criteria guidelines, in a pay-for-performance reimbursement system. The quality measures studied on this survey and on the similar survey to be sent to residents/family members are patient-based measures.

A copy of the survey is attached (Appendix A). In addition, program staff assisted with the development of an educational document to accompany the survey (Appendix B). A total of

317 surveys and the accompanying educational document were distributed by OHCA on June 22, 2007; 164 surveys were returned, a 51.7% response rate. This is a high response rate compared to previous surveys.

Questions on the survey (Appendix A) included:

1. Demographic questions,
2. Opinion, Likert scale questions, and
3. Narrative comments.

## Data Analysis

All survey responses were entered into an Excel spreadsheet. Data entry was subjected to random testing to ensure accuracy. Surveys were checked at designated intervals (every 3<sup>rd</sup> to 4<sup>th</sup>) against the original survey by Division staff members not involved in the data entry process to reduce errors. Columnar data were visually checked for accuracy as well. The raw data from the survey are available (Appendix C).

Numerical data were analyzed using Microsoft Excel. Frequency, mean, median, mode, standard deviation, and standard error of the mean were calculated, where appropriate. All graphical representations of the results were generated in Excel.

In addition to standard descriptive analysis, survey questions were reviewed to determine which would lend themselves to comparisons that might yield valuable information for OHCA. Statistical measures of association and analytical tests were calculated using SPSS V.11 statistical software.

# Results



*“Making our homes better is a great goal for all of us. Keep up the hard work and concerns you have for the elderly!”*

**Note:** Not all respondents completed every survey question. Therefore, the number of responses for each individual question may vary and are included for each question.

### Abbreviations used in this analysis:

SEM = standard error of the mean

p-value<sup>\*</sup> = The p value used to determine significance for this study was  $p \leq 0.05$ .

**Metro** = metropolitan, >90,000 population

**Urban** = urban/suburban, 25,000-90,000 population

**Rural** = <25,000 population

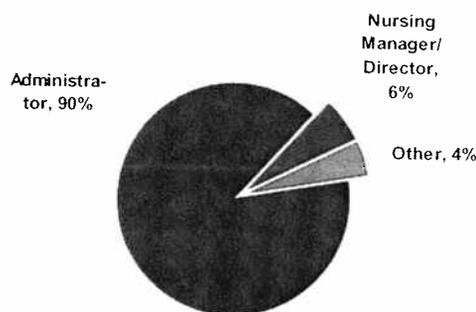
### Survey Results by Question

A total of 317 nursing facilities were sent surveys on June 22, 2007 by OHCA; 164 (51.7%) completed surveys were received and analyzed. A previous survey of this same group of nursing facility providers, conducted in August, 2006, achieved a 41% response rate (130 out of 319).<sup>24</sup> Survey results are presented in order as they appear on the survey instrument (Appendix A).

<sup>\*</sup>A measure of probability that a difference between groups happened by chance. For example, a p-value of .01 ( $p=.01$ ) means that there is a 1 in 100 chance the result occurred by chance. The lower the p-value, the more likely it is that the difference between groups is real.

**1. What is your position in the nursing facility?** Ninety percent (90%,  $n=145$ ) of those responding to the survey were administrators of the nursing facility. The remaining respondents were nursing managers or directors (6%,  $n=10$ ), or individuals who categorized themselves as “Other” (4%,  $n=7$ ). Five of the seven who checked the “Other” category indicated they were office managers, owners, executive directors, and administrative assistants, all of whom could be described as administrative as opposed to direct care providers. Two respondents were social workers. If multiple positions were indicated, it was counted once in the “Other” category (Figure 7).

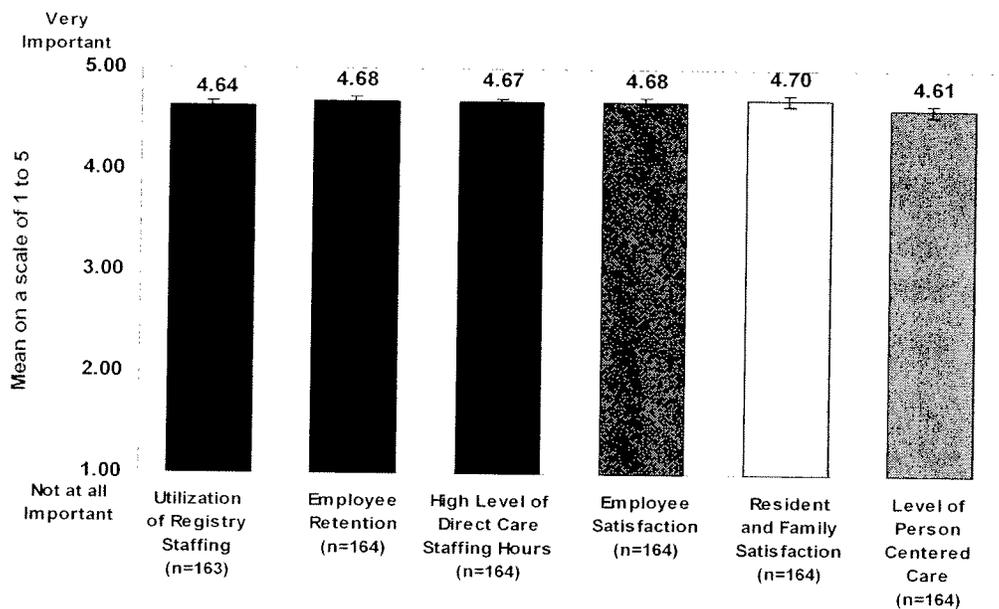
**Figure 7. Distribution of Respondents by Job Position (n=162)**



**Table 1. Survey Questions 5 through 10:  
Potential, Resident-Oriented Quality Measures**

Survey Question #	Question
5	How important is it to your residents and/or family members to have a special relationship with a caregiver they see frequently (utilization of registry staffing)?
6	How important is it to your residents and/or their family members to see mostly familiar faces among the staff at the facility (employee retention)?
7	How important is it to your residents and/or family members that a knowledgeable staff member is readily available to answer questions or meet their health care needs (high level of direct care staffing hours)?
8	How important is it to your residents and/or family members that the staff are friendly and helpful, and appear to enjoy their jobs (employee satisfaction)?
9	How important is it to your residents and/or family members that the facility have a family-friendly environment (resident and family satisfaction)?
10	How important is it to your residents and/or family members that the facility encourages a comfortable, home-like living space where residents can have personal items, chairs, photographs, etc. (level of person-centered care)?

**Figure 11. Nursing Facility Providers' Opinion of How Important Six (6) Quality of Care Measures are to Residents and/or Family Members**



***“My Innerview program is very good. It also requires a lot of time.”***

**13. Please list any other thoughts you have for a reward-based reimbursement system for nursing facilities.** Most comments, such as the following, applauded the creation of a quality-based reimbursement system.

- *A reward based system would make all facilities strive towards excellence since it would affect the payment amount.*
- *I think it is important to reward good performance.*
- *It may be a good system. We are way over regulated and way underpaid. People are not attracted to this industry-it will grind you to a pulp.*
- *That would be great to be rewarded for good care -- we reward our staff for good care.*
- *I think it is a fair system. It also assists greatly with your facility QA.*

**Other comments addressed inequities or potential problems with a rewards system.**

- *It has been my experience that people with complaints will do a survey more than people who are happy.*
- *For facilities that have extra resources and funds to accomplish these changes will probably benefit more, but for those who do not it will be a burden on them to achieve the changes that may be required. So how can an equitable payment system occur?*

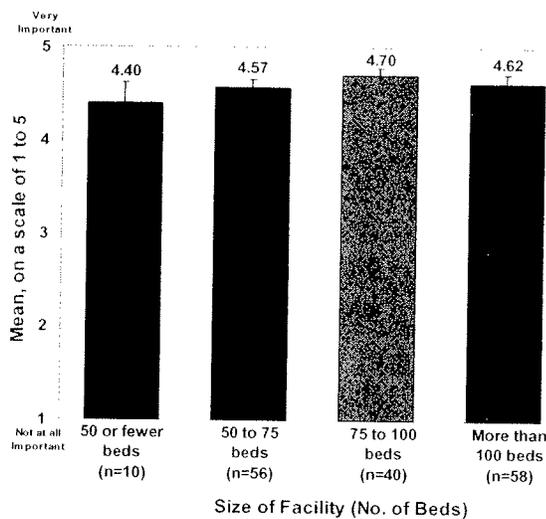
**Still others offered suggestions for potential quality measures or administration of the program.**

- *Higher number of staff hours does not ensure knowledgeable [staff] to answer questions (thanks for asking) Some of the questions will vary results due to facility locations, rural-populations leaving to go to big city.*
- *Better care should be better reimbursed--more assistance with compliance rather than just more rules to comply with.*
- *Reward based reimbursement has merit but may not take into consideration two points. One is that some residents and/or families are never satisfied and two the inability to hire quality staff in rural areas.*
- *Should not be survey based--different surveyors survey differently. Consider % of satisfaction-study or pick a number that is reasonable, ex 80% then have a challenge of 90%.*

**Comparison 3. Level of Person-Centered Care Compared by Size of Facility (Number of Beds).** Person-centered care in assisted living, nursing, and other long-term care facilities has become an important component of quality care.<sup>29</sup> The goal of person-centered care is to allow the resident to maintain their individuality and to give them the flexibility to choose lifestyles that suit them. To determine whether size of facility predicts importance of person-centered care, we analyzed person-centered care (survey question 10) compared with facility size (survey question 3) (Figure 16).

Although smaller facilities (fewer than 50 beds) considered person-centered care to be somewhat less important to their residents than larger facilities, all facilities in this study considered person-centered care to be “Very Important.” The slight differences in mean are not statistically significant.

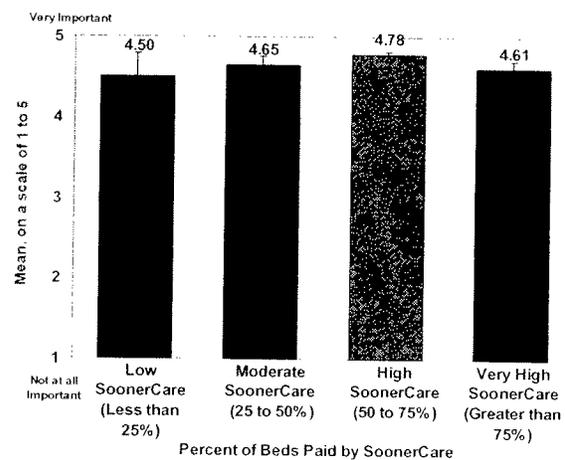
**Figure 16. Importance of High Level of Person-Centered Care Compared by Facility Size (No. of Beds) (n=164)**



*“For rural areas [a quality based reimbursement system] is hard due to lack of staff, licensed personnel, etc.”*

**Comparison 4. Importance of Resident and/or Family Satisfaction by Number of SoonerCare Beds.** In facilities with a higher number of beds paid by SoonerCare, it might be hypothesized that personal service and resident satisfaction might be less important than in facilities with fewer SoonerCare beds. We asked providers to rate how important level of resident and/or family satisfaction might be to their residents then cross-analyzed the result with the percentage of SoonerCare Beds (Figure 17).

**Figure 17. High Level of Resident and/or Family Satisfaction Compared by Number of SoonerCare Beds (n=164)**



Facilities with fewer SoonerCare beds were somewhat less likely to consider resident and/or family member satisfaction to be important. The differences, however, were small and not statistically significant. All facilities considered resident and/or family member satisfaction to be “Very Important.”

**Comparison 5. Perception of Nursing Facility Providers of Interaction with My InnerView Compared by Location of Facility.** The final comparative analysis performed examined the quality of nursing facility providers’ interaction with the My InnerView, crossed by facility location. Most facilities (82%, n=111) responding to the question indicated that their experience with My InnerView was positive.

**Table 2. Survey Results-At-A-Glance**

Survey Question		Results	Interpretation
1.	What is your position in the nursing facility?	Administrator-90% Nursing Manager-6% Other-4%	Nursing facility administrators completed most of the surveys
2.	Where is your facility located?	Large metro-18% Suburban area-20% Town or rural area-62%	Most respondents were located in rural areas.
3.	About how large is your facility (number of beds)?	Fewer than 50 beds-6% 50 to 75 beds-34% 75 to 100 beds-24% Over 100 beds-35%	94% of facilities had more than 50 beds.
4.	Please estimate the average percentage of beds paid for by SoonerCare (Medicaid).	Less than 25%-3% 25 to 50%-13% 50 to 75%-56% More than 75%-29%	85% of facilities had more than 50% of their beds paid for by SoonerCare
5.	How important is it to have a special relationship with a caregiver they see frequently (utilization of registry staffing)?	Mean=4.64 SEM=0.05	Utilization of agency staffing was considered "very important"
6.	How important is it to see mostly familiar faces (employee retention)?	Mean=4.68 SEM=0.04	Employee retention was considered "very important"
7.	How important is it that a knowledgeable staff member is readily available (high direct care staff hours)?	Mean=4.67 SEM=0.04	High direct care staffing hours was considered "very important"
8.	How important is it that staff are friendly and helpful, and appear to enjoy their jobs (employee satisfaction)?	Mean=4.68 SEM=0.04	Employee satisfaction was considered "very important"
9.	How important is it that the facility have a family-friendly environment (resident and family satisfaction)?	Mean=4.70 SEM=0.04	Resident & family satisfaction was considered "very important"
10.	How important is it that the facility encourages a comfortable, home-like environment (level of person-centered care)?	Mean=4.61 SEM=0.05	Level of person-centered care was considered "very important"
11.	Is your facility involved in My InnerView?	Yes=144 (88%) No=11 (7%) Not Sure=9 (5%)	Nearly all respondent facilities were involved in the My InnerView study.
12.	Overall, how would you rate the quality of your experience with My InnerView?	Mean=4.09 SEM=0.07	Overall, facility providers rated their experiences with My InnerView as "Very positive"
13.	Please list any other thoughts you have on a reward-based reimbursement system for nursing facilities.	Narrative	See Appendix C.

\*SEM=Standard Error of the Mean

study on rating the criteria from the perspective of their clients.

A survey with the same quality and performance questions will be sent to approximately 2,000 nursing facility residents and/or family members or guardians. That study will be reported in the Spring of 2008.

# References

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2. Summer L. Medicaid and long-term care. Fact sheet. Georgetown: Health Policy Institute, Georgetown University; May, 2003, pp. 2.
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## Appendix A. Nursing Facility Provider Survey

1. What is your position in the nursing facility?

- Administrator  
 Nursing manager/director  
 Other (describe): \_\_\_\_\_

2. Where is your facility located?

- Large metropolitan area (~90,000+ population or greater, e.g., Oklahoma City, Tulsa, Norman, Lawton)  
 Urban, suburban, or small city (25,000-90,000 population, e.g., Broken Arrow, Enid, Midwest City, Stillwater, Shawnee)  
 Town or rural area (less than 25,000 population, e.g., Watonga, Gotebo, Paul's Valley)

3. How large (number of licensed beds) is your facility?

- Fewer than 50 beds     50-75 beds     75-100 beds  
 Greater than 100 beds (number): \_\_\_\_\_

4. Please estimate the average percentage of beds paid for by SoonerCare (Medicaid).

- Less than 25%     25-50%     50-75%  
 Greater than 75% (indicate percent): \_\_\_\_\_

The remaining questions deal with issues that may be important to your residents and/or their family members.

5. How important is it to your residents and/or family members to have a special relationship with a caregiver they see frequently (utilization of registry staffing)?

Not at all					Very
Important	Unimportant	Neutral	Important		Important
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>

6. How important is it to your residents and/or their family members to see mostly familiar faces among the staff at the facility (employee retention)?

Not at all					Very
Important	Unimportant	Neutral	Important		Important
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>

7. How important is it to your residents and/or family members that a knowledgeable staff member is readily available to answer questions or meet their health care needs (high level of direct care staffing hours)?

Not at all					Very
Important	Unimportant	Neutral	Important		Important
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>		<input type="checkbox"/>

8. How important is it to your residents and/or family members that the staff are friendly and helpful, and appear to enjoy their jobs (employee satisfaction)?

Not at all					Very
Important	Somewhat	Unimportant	Neutral	Important	Important
<input type="checkbox"/>					

9. How important is it to your residents and/or family members that the facility have a family-friendly environment (resident and family satisfaction)?

Not at all					Very
Important	Somewhat	Unimportant	Neutral	Important	Important
<input type="checkbox"/>					

10. How important is it to your residents and/or family members that the facility encourages a comfortable, home-like living space where residents can have personal items, chairs, photographs, etc. (level of person-centered care)?

Not at all					Very
Important	Somewhat	Unimportant	Neutral	Important	Important
<input type="checkbox"/>					

11. Is your facility involved in MyInnerView (the firm contracted with OHCA to evaluate quality)?

Yes		No		Not Sure
<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>

12. Overall, (if you are involved with MyInnerView) what has been the quality of your interactions?

Poor		Somewhat		Neutral		Good		Very
<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>		<input type="checkbox"/>

13. Please list any other thoughts you have a reward-based reimbursement system for nursing facilities.

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This survey may be returned in the self-addressed postage-paid envelope provided or faxed to Sarah Hyden at 405-271-8800. Thank you for participating in this important study.

## Appendix C. Raw Data and Comments

Survey #	Q1. Position in facility?	Q1. Other, please describe	Q2. Facility Location	Q3. Size of facility (#beds)	Q4. % beds paid by Sooner Care.	Q4. % if >75%	Q5. use of registry staffing	Q6. employee retention	Q7. high level of direct care staffing hours	Q8. employee satisfaction	Q9. resident and family satisfaction	Q10. level of person-centered care	Q11. Participation with My InnerView	Q12. Satisfaction with My InnerView	Q13. Other thoughts	Comments
1	2		3	3	2		5	5	5	5	5	5	2			
2	1		3	4	119		5	4	3	5	5	2				
3	1		3	2	2		5	5	5	5	5	5	1	4		4
4	1		1	1	4	95%	4	4	4	5	5	5	1	4		4
5	1		3	3	3		4	4	4	5	4	5	1	3		3
6	1		3	2	4	80%	4	4	4	4	4	4	1	3		3
7	1		2	2	3		5	5	5	5	5	5	1	4		4
8	1		3	2			4	4	4	5	4	2	2			2
9	1		3	2	4	92%	4	4	4	5	4	4	1	4		4
10	1		3	1	2	85%	4	5	4	4	4	4	1	4		4
11	1		3	2	3		4	4	4	4	4	4	1	3		3
12	1		3	2	3		5	5	5	5	5	5	1	4		4
13	1		2	4	120		5	5	5	5	5	5	1	5		5
14	1		3	4	114		5	5	5	5	5	5	1	3		3
15	1		3	1	4	87%	5	5	5	5	5	5	1	4		4
16	1		3	2	3		5	5	5	5	5	5	1	4		4
17	1		2	2	4		4	4	4	5	5	5	1	4		4
18	1		3	4	4		4	4	4	4	4	4	1	2		2
19	1		3	2	4		5	5	5	5	5	5	1	5		5
20	2		3	2	3		4	4	4	4	4	4	1	4		4
21	1		3	4	125		5	5	5	5	5	5	1	4		4
22	1		3	3	3		5	5	5	5	5	5	1	4		4

Making our homes better is a great goal for all of us. Keep up the hard work and concerns you have for the elderly.

A reward based system would make all facilities strive towards excellence since it would affect the payment amount. Less regulations that are overly strict would allow more money to implement culture changes.

For rural areas this is hard due to lack of staff, licensed personnel, etc. great

We are just beginning the MyInnerView

## Appendix C. Raw Data and Comments

50	1	4	133	4	85%	4	4	5	5	5	1	4	Depending upon your staff and their rating my depend upon your reward even though it reflects them
51	1	2		5		5	5	5	5	5	1	5	
52	1	3		5		5	5	5	5	4	1	5	
53	1	2	160	4	98%	5	5	4	4	4	2	5	
54	1	2	3	4		4	4	4	4	4	1	4	
55	1	4	148	4	90%	5	5	5	5	5	1	4	we haven't gotten any results from the survey yet
56	1	1	275	3		5	5	5	5	5	1	4	just because a home spends more does not mean they should get more which is how it is now!
57	1	3	2	2		5	5	4	4	5	1	4	
58	1	1	4	3		5	5	4	5	5	1	4	
59	1	2	3	3		4	4	5	4	3	1	4	
60	1	3	2	3		5	5	4	5	5	2	4	I think it is ok --but that was supposed to be the goal of the MDS when it started even for non-skilled facilities. I think that's the better way to pay facilities. our innerview has just gotten started
61	1	3		3		5	5	5	5	5	1	4	
62	1	1	4	4		5	5	5	5	5	1	4	
63	1	3		3		4	4	4	5	4	1	3	
64	1	1	105	4	98%	4	4	5	4	4	1	4	
65	1	2	2	4	80%	5	5	5	5	5	1	5	
66	1	3	1	4		5	5	5	5	5	1	4	
67	1	3	4	3		5	5	5	5	4	1	3	
68	1	3	4	2		5	5	5	5	5	1	5	I feel reimbursement should not be reward based system. I feel it should be across the board--anyone in the business has a right to be paid. I do not think it should be 5???
69	1	3	2	3		5	5	5	5	5	1	4	excellent idea
70	1	2	2	4	98%	4	4	4	4	4	2	4	a good survey should count for a good reimbursement
71	1	3	1	4	83%	4	5	3	4	3	3	4	I'm cautiously optimistic
72	1	2	4	3		5	5	5	5	5	1	4	
73	1	3	3	3		4	5	5	5	5	3	5	1. number of complaints /yr. 2. survey 3. census
74	1	3	4	4		5	5	5	5	5	1	2	my innerview program is very good. It also requires a lot of time
75	1	3	3	3		4	4	5	5	5	1	5	turnover ratio is always going to be higher than we want in the urban area--no matter what we do
76	1	3	2	2		5	5	5	5	5	1	5	
77	1	1	4	117		5	5	5	5	5	1	4	

## Appendix C. Raw Data and Comments

106	1	1	3	1	5	5	4	4	4	4	3
107	1	2	3	3	4	5	5	4	5	5	4
108	1	2	3	2	5	5	4	5	5	5	5
109	1	3	4	4	5	5	5	5	5	5	5
110	2	3	3	3	4	4	5	5	4	4	3
111	1	3	2	3	5	5	5	5	5	5	3
112	1	3	1	3	4	4	4	4	4	4	2
113	1	3	3	4	4	4	4	4	4	4	5
114	1	2	4	213	5	5	5	5	5	5	5
115	1	3	3	4	5	5	5	5	5	5	5
116	1	1	4	2	5	5	5	5	5	5	5
117	1	3	4	110	5	5	5	5	5	4	4
118	2	2	4	104	5	5	5	5	5	5	3
119	1	1	2	4	4	4	4	4	4	4	4
120			2	4	5	5	5	5	5	5	4
121	1	3	3	4	5	5	5	5	5	5	5
122	1	3	3	3	5	5	5	5	5	5	4
123	1	3	2	3	4	4	4	4	4	4	3
124	1	2	4	3	5	5	5	5	5	4	4
125	1	2	2	2	4	4	4	4	4	4	4
126	1	1	3	4	5	5	5	5	5	5	5
127	1	3	1	3	5	5	5	5	5	4	2
128	1	3	3	3	4	4	4	5	4	5	3
129	1	3	4	118	5	5	5	5	5	5	4
130	1	3	3	1	4	4	5	3	4	4	5
131	1	3	4	120	4	4	4	4	4	4	4
132	1	3	4	3	4	4	4	4	4	5	1

Better care should be better reimbursed-more assistance with compliance rather than just more rules to comply with

reward based reimbursement has merit but reimbursement into consideration two, both. One is flat some residents and/or families are never satisfied and two the inability to hire quality staff in rural areas

Customer service is key to resident outcomes. Medical director actively involved in care is critical.

I think staffing numbers of call-ins etc. not sure why it is needed-time consuming for all this info.

I think it is a fair system. It also assists greatly with your facility QA. #121 was not here at the beginning of my interview am not sure if there are any other equipment participants- Interim-Penn. Dirkey- Interim-Memorial Nursing Center. Frederick, OK

**Appendix C.  
Raw Data and Comments**

158	1	2	4	142	4	90%	5	5	5	5	5	1	4
159	1	3	4	180	3		5	5	5	5	5	1	5
160	2	3	2		1	90-100%	5	5	5	5	5	3	5
161	1	3	1		4		4	4	4	4	5	1	4
162	1	3	2		2		5	5	5	5	4	3	
163		3	2		3		5	5	5	5	5	3	
164	1	2	4	130	3		4	4	5	5	5	1	4

not sure on # 5. we believe in treating our residents like family.

nurses aide's need more money even if they love their work

## **Appendix D.**

### **Biographical Sketches of Project Faculty and Staff**

#### ***Sarah D. Hyden***

##### ***Health Policy Research Coordinator, Primary Care Health Policy Division***

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Sarah Hyden joined the University of Oklahoma Health Sciences Center (OUHSC), Department of Family and Preventive Medicine, Primary Care Health Policy Division as Project Coordinator in May of 2003. She holds a Bachelor of Science degree from Southern Nazarene University. Prior to joining OUHSC, she spent six years in healthcare sales and marketing field, with a focus on outreach and contact management, specifically with physicians and other health practitioners. Sarah Hyden is responsible for supervision of projects within the Primary Care Health Policy Division. Additionally, she ensures all work requirements and time deadlines are met; establishes protocol for completion of grants, contracts and/or Division research and analysis projects. Ms. Hyden conducts research projects including presentations, survey administration and data collection to targeted populations throughout Oklahoma and serves as liaison between the Department, the Division and various government and university agencies. She has participated in the design and conduct of numerous successful research projects for the Oklahoma Health Care Authority. She is currently the health policy research coordinator for the division.

#### ***Andréa L. Adams, MPH***

##### ***Health Policy Analyst, Primary Care Health Policy Division***

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Andréa Adams is the health policy analyst for the division. Mrs. Adams joined the department in August of 2004 after working as a research associate in health policy research at the Oklahoma State Health Sciences Center in Tulsa for two years. She has also served as an independent statistical consultant for various non-profit agencies in Oklahoma. Mrs. Adams earned her bachelor's degree from the University of Nebraska in Lincoln in 2000 and completed her Masters of Public Health degree at the University of Oklahoma Health Sciences Center in 2002. Her primary responsibilities for the division are data analysis and statistical reporting. She has experience using statistical tools such as SPSS and MS-Excel and has published several articles on health policy research prior to joining the division.

#### ***Denise M. Brown, PHR***

##### ***Senior Administrative Manager, Primary Care Health Policy Division***

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Denise Brown has been in the healthcare field since 1974. Ms. Brown has been with the University of Oklahoma Health Sciences Center (OUHSC) since 1984 and joined the Department of Family and Preventive Medicine in 1989. Ms. Brown holds a Bachelor of Science degree in Social Work and is a certified Professional in Human Resources. She has an extensive background in human resource, administrative and hospital based management; including patient and employee relations. As senior administrative manager, she works closely with the projects coordinator.

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# NATIONAL COMMISSION FOR QUALITY LONG-TERM CARE

FEB 08 2008

Protective Health **Services**

## Final Report

December 3, 2007

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Writer/Editor

The Commission would like to acknowledge the work of Geralyn Graf Magan, whose writing and editorial assistance has enabled the Commission to summarize its work and express its members' diverse opinions in a single, comprehensive document.

\*The views expressed by Judith Salerno are her own and do not necessarily represent the views of the National Institutes of Health, the U.S. Department of Health and Human Services, or the United States Government.

**NATIONAL COMMISSION FOR  
QUALITY LONG-TERM CARE**

AN INDEPENDENT COMMISSION AT THE NEW SCHOOL [www.newschool.edu](http://www.newschool.edu)

# FINAL REPORT

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FROM ISOLATION TO INTEGRATION:  
Recommendations to Improve Quality in Long-Term Care

DECEMBER 3, 2007

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QUALITY LONG-TERM CARE  
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## OVERVIEW

The population of the United States is heading toward a dramatic and unprecedented demographic shift. Well into this century, the number of older Americans will grow substantially with each passing decade as the average person lives longer than we ever imagined possible. As a result, the nation will experience an unprecedented demand for high-quality long-term care services provided in a wide variety of settings, including private homes, assisted living facilities and nursing homes. Unless we take action in the near future to prepare for these changes, our nation will not be ready and, inevitably, many of our citizens will suffer.

The National Commission for Quality Long-Term Care calls for a bold, national discussion about how the United States can create a new and better long-term care system that will help older people and people with disabilities remain independent for as long as possible. The Commission calls on the Congress of the United States to hold hearings during 2008 that will investigate and recommend workable strategies to design and implement that system. The Commission also urges the next President of the United States to provide the leadership necessary to launch a multifaceted transformation of long-term care so that it:

- Places the needs and preferences of consumers at the heart of every care setting and fosters the right of those consumers to make care and lifestyle decisions for themselves.
- Provides adequate supports for family caregivers, without whom the nation could not care adequately for its aging citizens and citizens with disabilities.
- Ensures that long-term care workers receive the training, compensation and respect they need to provide compassionate, high-quality care.
- Adopts emerging technologies that will help maximize the independence of older consumers and make care provision more efficient.
- Institutes a financing system that utilizes public and private resources to ensure that every American who needs quality long-term care will have access to those services.

solution to the health care crisis without a complementary solution to the long-term care crisis, and vice versa. Neither crisis can be addressed in isolation.

Like the nation's health care system, the long-term care system begs for transformation. Demographic changes over the next 20-30 years will pose entirely new challenges to long-term care, and meeting those challenges will require new approaches to serving long-term care consumers. Thirty years may seem like a long time to get ready to face these challenges, and we may be tempted to adopt a wait-and-see attitude concerning the impact that a growing aging population will have on long-term care. That attitude would be dangerous. True long-term care transformation will take time if it is going to be effective and sustainable. To ensure success, we must start work *now*.

With this report, the National Commission for Quality Long-Term Care calls for a national discussion about how we can create a new and better long-term care system. The Commission calls on the Congress of the United States to hold hearings during 2008 that will investigate and recommend workable strategies to design and implement that system. The Commission also urges the next President of the United States to provide the leadership necessary to launch a multifaceted transformation of the long-term care system so that it will be able to serve consumers for decades to come. This transformation cannot take place only at the local or state levels; instead, we need *national* solutions to the long-term care crisis so that all Americans, no matter where they live, can benefit from the system's reform. That reform must ensure that long-term care:

- Places the needs and preferences of consumers at the heart of every care setting and fosters the right of those consumers to make care and lifestyle decisions for themselves.
- Provides adequate supports for family caregivers, without whom the nation could not care adequately for its aging citizens and citizens with disabilities.
- Ensures that long-term care workers receive the training, compensation and respect they need to provide compassionate, high-quality care.

assisted living facilities and nursing homes, these Americans require assistance with such private activities as bathing, eating, dressing or using the toilet — and such essential daily tasks as shopping for groceries, preparing their meals, managing their medications or keeping their homes clean.

We all know at least one of these Americans. He or she may be a young cousin born with cerebral palsy or an adult brother or sister coping with multiple sclerosis. But most likely, the long-term care consumers we know best are our own mothers, fathers, aunts and uncles: people who enjoyed full independence until a stroke, hip fracture, the onset of dementia or another disease associated with aging compromised their health or brought on disability and frailty.

About two-thirds of long-term care consumers are 65 years or older, a sobering statistic for the oldest members of the Baby Boomer generation, who will begin to reach this age in a matter of years. While few of these Baby Boomers will need long-term care services for at least a decade after they turn 65, the fact that so many members of this large generation will need care at the same time has provided the nation with an important “wake-up” call. Clearly, it’s time to begin planning ahead for the impact these aging Americans will eventually have on the long-term care system. Especially sobering for the future is the fact that half of all Americans 85 years and older find themselves in need of long-term care services. The 85+ population is projected to increase from 4.2 million in 2000 to 6.1 million in 2010 and then to 7.3 million in 2020.<sup>3</sup> It is prudent to assume that as the number of very old people increases, so will their demand for high-quality long-term care services.

Media outlets interested in the sociological effects of an aging population are helping to make average Americans generally aware of what this predicted population growth will mean, on so many levels, for our country. But it remains the challenging work of care providers, policy makers, researchers and aging advocates to develop and champion a national strategy to ensure that the long-term care system will be capable of serving this

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<sup>3</sup> Administration on Aging. 2006. *A Profile of Older Americans: 2006*. Available at <http://www.aoa.gov/prof/statistics/profile/2006/2006profile.pdf>.

- ***Government agencies are under pressure.*** Understaffed agencies, charged with measuring and ensuring the quality of long-term care services, struggle to enforce regulations that are sometimes poorly designed and that often allow mediocre providers to survive while failing to reward innovative ones. State Medicaid agencies, which fund long-term care services in partnership with the federal government, must stretch their limited budgets among competing interests, including acute care and long-term care provided in institutions and home settings. For their part, state and federal policy makers also face competing pressures to keep taxes low while providing adequate funding for a host of government services, including health and long-term care.

### **Encouraging Signs**

Over time, these pressures have served to undermine the long-term care system and to compromise its ability to provide quality of care and quality of life to the oldest and frailest of our citizens. Yet, we're now seeing some hopeful signs that the development of comprehensive strategies to improve quality is becoming a new priority for a growing number of long-term care consumers, providers, and government regulators, funders and policy makers. In recent years, these stakeholders have renewed their efforts to regain the public's trust by taking steps that could lead to a complete transformation of the very culture of long-term care. That transformation, if successful, will mean that quality improvement, consumer direction and a collaborative spirit will eventually become the focal point of every care setting.

In 2002, three major provider organizations in the long-term care industry — the Alliance for Quality Nursing Home Care, the American Association of Homes and Services for the Aging and the American Health Care Association — adopted a voluntary initiative called “Quality First” to improve the care their members provide. In a fitting complement to this provider initiative, the U.S. Department of Health and Human Services (HHS) launched the Nursing Home Quality Initiative and the Home Health Quality Initiative that same year. Both of these HHS initiatives focus on developing strategies to promote quality in long-term care settings and to make quality information available to the public.

environments. Those environments respect the wisdom and worth of every person who lives there. They also ensure, each and every day, that the lives of long-term care consumers are characterized by security, fulfillment, enjoyment, dignity and self-direction. To us, seeing what is possible has meant believing that we can make a difference.

Over the past 12 months, members of the National Commission for Quality Long-Term Care have chosen to focus our attention, not on the flaws that we know exist in long-term care, but on the quality environments that have given us hope. We have examined policies and practices that have encouraged long-term care providers to design and implement the kind of high-quality services that we ourselves would purchase for our mothers and fathers, and for ourselves when the time comes. We place our hope in these emerging models of care, oversight and financing, many of which are described in these pages. We urge the nation to take actions that will cultivate these and other effective models so they can be adapted and adopted by care settings and policy makers throughout the country.

### **Purpose and Structure of This Report**

The National Commission for Quality Long-Term Care has translated its discoveries and analyses over the past 12 months into a set of recommendations that address three specific aspects of long-term care delivery: quality, workforce and technology. These recommendations are contained in the first three chapters of this report. In Chapter 4, the Commission presents a framework and general principles that address the important area of financing long-term care. Commission members believe that these recommendations and principles can serve to move the nation forward in its efforts to reform long-term care:

- **Quality:** We can reform long-term care by transforming its culture through organizational and caregiving innovations that focus on improving both individuals' quality of life and their quality of care. In addition, we can better support the millions of informal caregivers by providing them with respite care, information and assistance, and assessments of their own needs.

- *Essential but Not Sufficient: Information Technology in Long-Term Care as an Enabler of Consumer Independence and Quality Improvement*, presented by Ross D. Martin, MD, MHA, David Brantley, and Darcy Dangler, BearingPoint, Inc., in September 2007.

## **An Integrated Approach to Reform**

The Commission believes strongly that action in the areas of quality, workforce, technology and finance is required if the level of quality in long-term settings is to increase measurably. We recommend that policy makers, providers and other stakeholders focus their attention equally on all four issue areas. Because these areas are interconnected on a variety of levels, our successes or failures in one area will affect every other area. For example:

Our nation's success at improving quality of care and service in long-term care will depend on our ability to develop and enforce quality care standards ... *and* our ability to recruit, train and retain quality staff people to provide that care ... *and* our ability to use technology to provide accurate data that are essential to quality assessments.

Our nation's success at developing an adequate supply of caregivers will depend on our ability to invest additional money in staff salaries, benefits and training for formal caregivers ... *and* our support for informal family caregivers who provide the vast majority of direct care to people with disabilities ... *and* our ability to use new technology to ensure that staff members work more efficiently and effectively ... *and* our ability to create quality care settings where professionals and direct care workers will want to work.

Our success at incorporating technology into both home care and institutional care will depend on our ability to bring new dollars into long-term care settings ... *and* our ability to let quality-driven principles such as consumer independence, autonomy, privacy and choice guide our technical efforts ... *and* our ability to train staff at multiple levels of long-term care organizations to make the best use of the technology at their disposal.

## CHAPTER 1: QUALITY<sup>4</sup>

Gather a group of 20-30-year-olds at a party or other social function, the old story goes, and inevitably these young adults will begin chatting about a variety of topics, including their respective careers and their growing families. Gather a group of 40-, 50-, or 60-year-olds together at a similar function, on the other hand, and the conversation will inevitably turn to the one emotion-packed topic that affects nearly everyone in the room: their aging parents and the multilayered challenges involved in accompanying those parents on their journey through the aging process. Inevitably, the conversation will also turn to the aging processes, disabilities and conditions that these Baby Boomers and their friends are experiencing, as well as some expressions of their own care preferences should they find themselves in need of assistance in the future.

The journey into old age can be fulfilling and especially meaningful for older people who remain actively engaged in their communities and families. But when illness or disability interferes, the journey can often become a painful and emotional one for parent and child alike. For older persons, frailty can bring with it difficult and life-changing decisions about housing and lifestyle, the need for courageous determination to live fully in spite of physical or mental limitations and, ultimately, the very-real fear of dependence and irrelevance. For middle-aged Baby Boomers, seeing once-strong parents experience physical and mental declines can bring sadness and worry over an older parent's well-being and safety, as well as fatigue and stress, brought on by the rigors of providing direct care.

For both parent and child, the aging process may also eventually bring with it the need for assistance with routine daily tasks. Initially, caring family members will typically provide most, if not all, of the long-term care services that an aging relative requires. However, older

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<sup>4</sup> Unless otherwise noted, the information presented in his overview is taken from *Strategies for Improving the Quality of Long-Term Care*, a paper presented to the Commission by Joshua M. Wiener, Ph.D., Marc Freiman, Ph.D., and David Brown, M.A., RTI International, in April 2007.

Unfortunately, that last challenge — feeling confident about quality — is often the hardest one to master. And no wonder. Providers, regulators and policy makers have struggled for years to ensure that consistent high-quality of care is provided in a variety of settings. In the process, those stakeholders have asked critical questions, over and over again, about what quality means and what specific features are present in high-quality long-term care programs and services. More broadly, they have sought to discover how the nation can go about ensuring that all long-term care consumers experience high-quality care and enjoy the highest possible quality of life no matter how many long-term care services they receive or where they receive them. These questions bear repeating today, with new urgency. As the United States gears up for an unprecedented increase in the number of its older citizens, the need to define and ensure high-quality care and services is great.

### **Measuring Quality of Care and Quality of Life**

Over the years, the most piercing questions from regulators and policy makers about long-term care quality have been spurred by scandal. In the 1980s, for example, the Institute of Medicine identified widespread concerns about quality in nursing homes, and Congress subsequently enacted the landmark Omnibus Budget Reconciliation Act of 1987 (OBRA), which raised quality-of-care standards and strengthened federal and state oversight of nursing homes participating in Medicare and Medicaid. Since then, the level of quality in nursing homes has been measured in a number of very specific and objective ways. For example, nursing homes literally count the number of residents who are *not* receiving good quality care because these residents are, for example, being restrained physically or chemically, have pressure sores or dehydration, or are using urinary catheters. Decreases in these and other troubling practices and incidents have been among the nation's best and most concrete indicators that nursing home residents are receiving more attention and better care as a result of OBRA.

As might be expected, however, OBRA did not turn out to be the “magic pill” that would cure all the quality concerns that ailed nursing homes. Many facilities continued to operate with serious deficiencies after 1987 and the new system didn't always succeed in forcing

evaluated objectively and translated into recommendations for friends and family. A diner, for example, can report on the apparent freshness of a restaurant's food or on the promptness of its service. A traveler can examine the firmness of the hotel mattress or the cleanliness of the bathroom. And the reader can objectively assess the technical expertise of the writer when deciding what grade to give a particular book.

These largely objective assessments can help consumers draw certain conclusions about the quality of their individual experience. But those conclusions won't be completely accurate unless consumers include that vague, but no less valuable, sense of how the product or experience made them *feel*. Did the meal give the diner pleasure? Did hotel staff make the traveler feel welcome and at home? Did the book entertain or inspire?

The same multilayered evaluation process can and should be applied to long-term care. Up until now, some suggest, long-term care regulators have placed too much emphasis on measuring the firmness of that hotel bed, so to speak. By focusing only on *quality of care*, these regulators have been evaluating only those practices that can be measured by counting restrained residents or cataloging bad outcomes, among other quality indicators. While these are important measures that can't be ignored, they also don't tell the entire story about quality.

Granted, long-term care has definite *medical* aspects that need to be measured in objective ways. But because long-term care also provides *social* aspects of care — care with which older people must live 24 hours a day for long periods of time — a critical component of quality provision and evaluation must also include attention to the resident's *quality of life*. Like the diner, traveler and reader, consumers of long-term care can tell us how their care makes them *feel*, and if that care is provided in a way that is consistent with the kind of life the consumer wants to live.

Measuring quality of life means asking essential questions about the lives of long-term care consumers — questions that aren't typically found on a surveyor's checklist. They include:

delivery and to increase the amount of support available to family caregivers, who provide the bulk of long-term care services that older people receive in their own homes.

To ensure that dignity and autonomy don't disappear when older consumers leave home, some providers of facility-based long-term care services are working hard to transform the entire culture of their organizations — including their physical settings — so that those facilities feel more like “home” in every sense of the word. These providers have made a commitment to preserve the privacy, dignity, autonomy and choice of their residents. They deliberately deemphasize the hierarchical, medical and bureaucratic features — the provider-centered features — that have dominated long-term care settings for so many years. They give renewed attention to making sure that every aspect of facility design and operation reinforces the organization's goal to place the consumer — and his or her preferences and desires — at the heart of every care decision.

Notable examples of these transformative models can be found throughout the country, and include the Eden Alternative, the “Green House” movement, and the Wellspring Model. Together, these models are breathing new life into long-term care facilities by strengthening the ties between residents and the greater community; by creating smaller facilities or smaller units within large facilities that present a truly homelike environment where residents make their own decisions about how they will spend their time; by training direct care workers so they feel both competent and valued; by using long-term staffing assignments to encourage those workers to develop long-term relationships with residents; and by empowering staff members to work with residents to make care decisions. To date, the results of this consumer-centered approach to long-term care have been encouraging, with documented evidence of more satisfied and empowered residents, better care outcomes, better quality scores on regulatory surveys, reduced staff turnover and, in some cases, reduced costs. Long-term care consumers and the quality of long-term care services seem likely to benefit from more widespread adoption of these basic quality-of-life principles in all settings.

OBRA quality standards appeared to have done their job in this regard. After studying data from state inspectors and surveyors, the GAO concluded that there had been a significant decrease in the proportion of nursing homes with serious quality problems in the prior six years, from about 29 percent in 1999 to about 16 percent in January 2005.<sup>5</sup>

This decrease in serious quality problems is a good sign and a step in the right direction. But it is not the end of this story. The GAO findings also mean that serious quality problems are still leaving residents in 16 percent of nursing homes at risk. This situation is clearly unacceptable and requires that regulators take rapid, aggressive steps to enforce standards more effectively.

The GAO has noted nursing home quality enforcement problems for several years. For example, its 2005 investigation found inconsistencies in how state surveyors were conducting their nursing home inspections, and raised concerns that surveyors were understating the serious deficiencies they found. In addition, delays in the reporting and investigation of serious complaints, and an inadequate system to ensure that identified deficiencies were addressed and corrected, created doubts about whether the carefully crafted survey process was fulfilling its mission in all circumstances. A follow-up study released by the GAO in March 2007 indicated that enforcement policies at the Centers for Medicare and Medicaid Services (CMS) allow some homes with the worst compliance histories to escape immediate sanctions designed to punish them for putting residents at risk.<sup>6</sup> Given this poor record, it is not surprising that in 2005 the Administration on Aging's (AoA) national long-term care ombudsman reporting system reflected more than 230,000 consumer complaints in the prior 12 months concerning quality of care and quality of life.<sup>7</sup>

<sup>5</sup> U.S. Government Accountability Office. 2005. *Despite Increased Oversight, Challenges Remain in Ensuring High-Quality Care and Resident Safety* (GAO-06-117). Washington, DC: U.S. Government Accountability Office.

<sup>6</sup> U.S. Government Accountability Office. 2007. *NURSING HOMES: Efforts to Strengthen Federal Enforcement Have Not Deterred Some Homes from Repeatedly Harming Residents* (GAO-07-241). Washington, DC: U.S. Government Accountability Office.

<sup>7</sup> Administration on Aging. 2005 national ombudsman reporting system data tables. [www.aoa.gov/prof/aoaprof/elder\\_rights/LTCombudsman/National\\_and\\_State\\_Data/2005nors/2005nors.asp](http://www.aoa.gov/prof/aoaprof/elder_rights/LTCombudsman/National_and_State_Data/2005nors/2005nors.asp).

invaluable sense of independence, autonomy and control. People who use home care typically *do* report high levels of satisfaction, and the Commission believes strongly that consumers and their caregivers are usually the ones who can best evaluate the quality of the services and support they receive. However, some regulatory interventions may be needed to set standards and guidelines regarding what constitutes good quality in home and community-based settings. These standards can guide both providers and consumers in designing and evaluating services.

Regulating home care carries its own practical challenges, since that care is provided in diverse settings. In addition, the recent emphasis on consumer-directed care will also require that regulators ask new and probing questions about how and to what extent HCBS quality should be measured, and if a consumer's power to hire, schedule, direct, monitor and fire care workers will, in and of itself, improve quality in the home-care marketplace. Some answers to those questions can be found in the Cash and Counseling initiative, a concept developed with funds from the Robert Wood Johnson Foundation, which allows consumers to hire, schedule, direct, monitor and fire care workers. Research on the program has found that participants report a higher quality of life and fewer unmet needs.

Older people who are fully capable of exercising their power in the marketplace may be able to guarantee quality care for themselves. However, regulators and policy makers may need to step in to protect consumers who have serious illnesses or disabilities, have cognitive impairments or dementia, or are making care decisions in the midst of a crisis or without families to help them. Policy makers will also need to weigh the benefits of regulating home-based care against the risks of stifling innovation, imposing a medical model, raising costs and limiting choice.

### **Empowering Consumers**

Older consumers and their families can play a central role in fostering improved quality in long-term care settings. However, in order to fill that role, consumers need to be well-informed about standards of quality in long-term care; they also need to know what questions to ask about a provider's quality record and how to best use their power in the

or are even aware of these Web sites.<sup>9</sup> In addition, consumers without Internet access may have trouble accessing data that is only available in electronic form.

- Second, and far more serious, the quality data currently being disseminated for consumer use may not be accurate. In 2002, the House Committee on Government Reform charged that the Nursing Home Compare Web site had major flaws that could mislead families seeking to find a good nursing home. The investigators concluded that Nursing Home Compare “does not include tens of thousands of recent violations of federal health standards, including nearly 60 percent of the violations involving death or serious injury. Many nursing homes with documented violations of federal health standards are incorrectly portrayed on ‘Nursing Home Compare’ as complying with federal standards.”<sup>10</sup>

### **The Role of Providers**

Providers in all segments of the long-term care field have a critical role to play in the transformation of long-term care — by transforming their own long-term care settings and by working with other providers to ensure that they understand the concept of transformation and the steps necessary to achieve it.

Providers are currently participating in voluntary programs to improve care and institute new practices at the facility and agency level. One notable example is Quality First, a program sponsored by the Alliance for Quality Long-Term Care, the American Association of Homes and Services for the Aging, and the American Health Care Association. Quality First offers technical assistance and resources to help providers systematically study the care and services they provide, and then engage staff, board members, consumers and other stakeholders in an effort to make improvements. Expanding these voluntary efforts and encouraging more providers to participate in them could be an important element of a multipronged effort to

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<sup>9</sup> Stevenson, D.G. 2006. “Is a Public Reporting Approach Appropriate for Nursing Home Care?” *Journal of Health Politics, Policy and Law*, 31(4), 773-810.

<sup>10</sup> Minority Staff, Special Investigations Division, Committee on Government Reform, U.S. House of Representatives. 2002. *HHS “Nursing Home Compare” Website Has Major Flaws*. Report prepared for Rep. Henry A. Waxman and Sen. Charles E. Grassley, February 21.

through which AoA helps states, local communities and tribal organizations provide a continuum of caregiver services. While the program has successfully assisted millions of caregivers — far exceeding AoA expectations — it has addressed only a fraction of the need. Additional legislation to support caregivers has been considered over the past few years, including the Lifespan Respite Care Act, signed into law in December 2006, which created a yet-unfunded program to help states offer caregivers needed and periodic breaks (“respite”) from their caregiving responsibilities. These programs represent important, albeit small, steps to reach out to caregivers in a meaningful way that assesses and addresses their needs for support before they or the people in their care experience any adverse effects.<sup>13</sup> However, additional steps are needed to adequately support the family caregivers who still provide the bulk of long-term care in this country.

### **End-of-Life Care**

It has been said that the truest test of any society is the way it treats its most vulnerable members. In much the same way, the true test of a long-term care setting — that is, whether that setting is truly person-centered — is how it treats older people at their most vulnerable stage, as they face the end of their lives. Consumer-centered, end-of life care will incorporate several elements, outlined by the Center for Gerontology and Health Care Research at the Brown University School of Medicine:<sup>14</sup>

- The dying person’s physical and emotional discomfort is recognized and he/she receives his/her desired level of comfort.
- Health care providers communicate and negotiate with the person regarding goals of care and formulate plans, including contingency plans, so that the person’s preferences are honored.

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<sup>13</sup> AARP. 2006. *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support*. Washington, DC: AARP.

<sup>14</sup> Teno, J.M., Okun, S.N., Casey, V., and Rochon, T. 2001. *Toolkit of Instruments to Measure End of Life Care (TIME) Resource Guide: Achieving Quality of Care at Life’s End*. Available at: <http://www.chcr.brown.edu/pcoc/toolkit.htm>.

end of life to avoid accusations of patient neglect. In addition, long-term care providers may not spend enough time working with patients to develop clear advanced directives so that all caregivers truly understand the wishes of the dying person. Financial issues may also affect the availability of palliative care. For example, *The New York Times* reports that consumers aren't choosing hospice in greater numbers because many insurance programs — including Medicare — will only pay for hospice care if the patient gives up all life-prolonging medical treatment and any hope of recovery.<sup>16</sup> These insurance restrictions have, essentially, taken away from older persons the most important choice of their lives — the choice about how they will die. A better, “open access” approach, which is currently available through a handful of private insurance providers, would improve older patients' quality of life by allowing them to benefit from hospice care and, at the same time, continue making their own decisions about ongoing medical treatment.

Long-term care providers have an important role to play in helping many older residents approach death. By developing a philosophy of a “good death,” by communicating that philosophy to staff and residents, and by developing programs that support that philosophy, these providers can allow residents to die with dignity. Adopting such an approach to end-of-life care may very well be the most valuable gift that long-term care providers can offer to the people they serve.

## Next Steps

Older consumers with disabilities seek out long-term care because they are in need of intensely personal services that include help with such basic activities as bathing, dressing and using the bathroom. Meeting those needs with high-quality care requires a deeply personal response to each consumer. As noted here, some progress has been made in the quest to ensure quality in the long-term care environment. But, as the following recommendations illustrate, much remains to be done.

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<sup>16</sup> Abelson, Reed. 2007. “A Chance to Pick Hospice, and Still Hope to Live,” *The New York Times*, February 10, 2007.

4. The cornerstones of culture transformation in long-term care are: (1) person-centered care; (2) a physical environment that is residential and home-like; and (3) the empowerment of the caregivers who work most closely with older consumers. Long-term care consumers, including those living in both institutional and non-institutional settings, must be allowed to make choices in meaningful ways, as should their direct caregivers.

## II. QUALITY MEASUREMENT AND DATA

5. A common set of measures for quality of long-term care should be developed that is standardized, comprehensive and clear. Systems should be designed to identify gradations of quality. In addition, it is important that excellence be recognized at the same time that poor performance is identified and corrected. Core measures of quality should cover both quality of care and quality of life and should be common across all long-term care settings so that outcomes can be compared across settings.
6. Quality measures should be designed to minimize the burden associated with collecting the data. Since many measures will likely involve self-reporting by providers, data need to be easily verifiable.
7. Individual and family satisfaction and experience with care are critical dimensions of quality. Satisfaction should be uniformly measured and reported consistently across all settings and services in a way that meets consumer needs.
8. Collection of quality measures must be sufficient to provide adequate and current assessments of all services and providers. Inadequacies in existing data collection need to be remedied. For example, while 80 percent of Medicare skilled nursing facility residents receive physical therapy, assessment of outcomes is not possible since assessment data are not collected and reported at discharge.

homes and assisted living facilities) and should employ broad-based outreach methods, in addition to the Internet, to promote the widest possible awareness of long-term care quality.

14. Comprehensive survey results should be made available to the public in print and electronic formats that are easy for consumers to understand. This information should include the results of complaint investigations and other information related to quality, such as staffing levels and staff turnover.

#### IV. OVERSIGHT

15. Standards for certification or licensure are critical and must ensure acceptable performance for services provided in all settings. These standards should be comprehensive and efficient. They should reflect all important quality dimensions, especially person-centered care, within a minimum number of standards. Finally, standards should be clear so that they can be applied consistently.
16. Standards and inspections should be transformed so that they no longer focus only on the detection of deficiencies, but also assess relative performance and identify excellence. Poor and unacceptable performance should still be identified, scrutinized and effectively addressed. Appropriate due process procedures need to be in place for resolution of disputed survey findings. Providers' performance scores should be publicly available. Summary measures of performance with respect to certification and licensure standards should be developed.
17. Sufficient resources need to be invested to assure thorough and consistent oversight. It is necessary to train an adequate number of surveyors and provide sufficient oversight of and support of their work. Alternative methods of timing for surveys should be explored so that surveys will be less predictable. For example, surveys could be triggered by complaints, by changes in top leadership at the long-term care setting, or by random selection using a table of random numbers; they could also occur at different times of

22. Technical assistance efforts must be clearly separated from monitoring and enforcement functions.

## VII. END-OF-LIFE CARE

23. Long-term care providers have a special obligation to identify and address the physical, palliative, psychosocial and spiritual needs of individuals who are in the final phases of life, especially individuals who are using residential long-term care services.
24. Increased flexibility is needed when defining eligibility for hospice, provided at home or in the nursing home, and palliative care services under the Medicare program. Policy makers should consider how Medicare can best be structured to support those with terminal illnesses through the provision of palliative care and hospice services.
25. Because movement between settings is typical of those requiring long-term care, mechanisms or processes must be developed that keep individuals' vital clinical information with them as they move between care settings. These mechanisms and processes must be designed in a manner that protects the privacy and security of consumer information.
26. Steps should be taken to: (1) help long-term care consumers avoid preventable hospitalizations when possible; (2) improve those transitions to acute care when they are necessary; and (3) involve individuals and family caregivers in all phases of care transitions.

having problems accessing services and, in some cases, their safety, quality of care and quality of life are being compromised in the process. Unfortunately, the problem will only get worse unless effective steps are taken to develop the workforce needed to meet future demand for services.

## Direct Care Workers

Direct care workers — the paraprofessionals who help older people carry out the basic activities of daily living — are both at the heart of the long-term care workforce and at the heart of its labor shortage. The harsh reality is that this workforce is in danger of buckling under the pressure of simple arithmetic. A report presented to the Commission by the Institute for the Future of Aging Services (IFAS) suggests that between now and 2015, the population aged 85 years and older — the age at which most people begin to require long-term care — will increase by 40 percent. However, the native-born population aged 24 to 54 — the age of most paid and informal caregivers — will not increase at all.

One doesn't need a calculator to realize that, in less than a decade, the pool of available long-term care professionals and direct care workers will be much smaller than needed. And the need for more and better qualified caregivers will become even more critical as the years pass. Even if we set the somewhat conservative goal to maintain the current ratio of paid long-term care workers to the current population of 85-year-olds, the long-term care workforce would have to grow by two-percent a year — to the tune of 4 million new workers — by 2050.<sup>20</sup> To make matters worse, family caregivers, who now care for three-quarters of adults with disabilities, can't be counted on to fill the care gap, as they do now. When Baby Boomers turn 85, they will not have as many children to care for them as do today's 85-year-olds.

Clearly, the demographics of the future aging population will present long-term care recruiters with a huge challenge for many years to come. But demographics are not the only

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<sup>20</sup> Friedland, L., Newman S., Gray, L. and Kolb, K. 2004. *The State of the States in Family Caregiving Support: A 50 State Study*. San Francisco, California: Family Caregiver Alliance, National Center on Caregiving.

in an enormous staffing shortfall in community-based adult day care, respite, specialized Alzheimer's, case management and other programs that fill a wide range of consumer and caregiver needs.

- While the nursing profession has aggressively sought to attract students to its educational programs, it now finds itself in the position of turning away qualified applicants, according the American Association of Colleges of Nursing (AACN). A 2004 AACN survey determined that 32,797 qualified applications to baccalaureate, master's, and doctoral nursing programs were not accepted; an insufficient number of faculty was cited by 47.8 percent of responding schools as the major reason for not accepting all qualified applicants.<sup>21</sup>

For a number of years, the John A. Hartford Foundation and other philanthropic organizations have attempted to bolster the number of geriatricians, geriatric nurses and geriatric social workers by supporting the development of faculty scholars in schools of medicine, nursing and social work. These scholars have two goals: to teach aging-related courses and to attract students into each of these professions. This is an important initiative and similar initiatives should be encouraged.

Improving and maintaining quality in long-term care will also require that nursing home, assisted living and community-based service providers ask important questions about the role that professionals can and should play in long-term care. Providers need to find ways to attract more of these professionals to the long-term care field, but they also must ensure that these professionals are properly trained and educated, and that long-term care settings take full advantage of the expertise and experience they have to offer.

Take physicians, for example. Since 1990, nursing homes reimbursed by Medicare or Medicaid have been required to employ a physician medical director who is responsible for implementing medical care policies and coordinating medical care. Nursing homes have met

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<sup>21</sup> American Association of Colleges of Nursing. 2005. *Faculty Shortages in Baccalaureate and Graduate Nursing Programs: Scope of the Problem and Strategies for Expanding the Supply*. Washington, DC: AACN. Available at: <http://www.aacn.nche.edu/Publications/pdf/05facShortage.pdf>.

that RNs have the lowest job satisfaction of all professionals<sup>23</sup> — the implications for quality will be alarming unless positive action is taken to increase job satisfaction among these important long-term care professionals. As mentioned in the previous section, and as noted on Table 1, turnover rates are even higher among direct care staff. This turnover also affects quality.

## Workforce Issues

Solving the long-term care workforce crisis won't be easy or simple. It will require innovative strategies and decisive action to improve many aspects of the long-term care work environment, including improvements to training, compensation, job safety and working conditions. It will involve educating prospective employees about the aging process and the evolving face of long-term care. And, it will require a significant effort to answer big questions about how long-term care should be designed, delivered and financed to meet the future demand for its services. The answers to these big questions will have a significant impact on workforce issues because those answers will determine how many people will be needed in the long-term care workforce; how they will be recruited, compensated and trained; what duties they will perform; and in which settings they will work. Other issues, including the use of technology in long-term care settings and the degree to which long-term care providers will adopt consumer-directed care approaches, will also have a tremendous impact on what long-term care workers do and how they interact with consumers.

We don't yet know the answers to many of these questions. Yet, despite these unknowns, we can be sure that certain core workforce issues won't go away or solve themselves in the next decades. Even a cursory glance at Table 1 (page 49), which presents a profile of the long-term care workforce, underscores the importance of three issue areas, which the Commission believes are at the heart of the workforce crisis and require the nation's

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<sup>23</sup> Spratley, E., Johnson, A., Sochalski, J., Fritz, M. and Spencer, W. 2001. *The Registered Nurse Population, March 2000: Findings from the National Sample Survey of Registered Nurses*. Rockville, MD: U.S. Department of Health and Human Services, Bureau of Health Professions. Cited in Institute for the Future of Aging Services. 2007. *The Long-Term Care Workforce: Can the Crisis be Fixed?* Washington, DC: AAHSA and IFAS.

directly passed through to frontline workers in the form of higher wages or benefits. According to IFAS, research evaluating the impact of these wage “pass-throughs” has been mixed, and experts are suggesting that better accountability mechanisms are needed to ensure that the earmarked funds actually make it into workers’ paychecks.

### **Inadequate Preparation and Training**

As noted earlier, many individuals working in long-term care — including physicians, nurses, administrators and direct care workers — could play a greater role in providing quality care if they were better prepared for their jobs. For example, physicians and nurse practitioners, who bring valuable medical services and expertise to long-term care settings, would benefit from more training in geriatrics. The same is true for administrators and registered nurses, who perform the majority of administrative duties within long-term care settings. The federal government requires states to license nursing home administrators. However, the federal government also allows those states to decide for themselves whether and how to credential other long-term care administrators, including those that oversee the operations of assisted living facilities and home health agencies. RNs receive several years of education, but their training often includes little information about long-term care and little training in the specific skills they need to carry out their growing supervisory duties.

Of greatest concern is the fact that most states require little or no training for direct care workers, the frontline workers who provide the bulk of hands-on care in long-term care settings. While all states require training for Certified Nursing Assistants (CNAs) who work in nursing homes, training requirements are generally lower for direct care staff working in assisted living facilities. Paid caregivers who work independently for individual consumers frequently have little to no formal training. As a result, many of these caregivers often feel unprepared for the jobs they are asked to do, and overwhelmed enough to leave those jobs within the first few months.

Adequately training workers is not without its challenges. States and individual providers struggle with ways to encourage direct care staff to enroll in and stick with training programs when those workers may be inexperienced and uncomfortable with classroom learning, and when family and work responsibilities keep them from attending class. An inventive program in North Carolina seems to overcome these barriers by bringing a 33-hour curriculum to direct care workers in the state's nursing homes as a way to improve their clinical and interpersonal skills. The key to the success of WIN A STEP UP is that classes are offered on site during the regular workday, and are tailored to individuals' education levels and learning styles. To encourage participation, those who successfully complete the program receive a pay raise or bonus in return for a commitment to stay in their jobs for at least three months. Evaluations of the program conducted by the University of North Carolina found that the on-site training initiative has made workers more confident in their jobs, increased their job satisfaction, added to their knowledge and improved their ability to work in teams.

At the federal level, the President's High Growth Job Training Initiative, administered by the Employment and Training Administration in the U.S. Department of Labor, has targeted \$3 million dollars to encourage regional approaches to meeting long-term care workforce challenges. Through the grant program, six organizations have received \$500,000 each to prepare workers for careers in long-term care. Grant-supported initiatives will create CNA career tracks, deliver on-the-job talent development programs, and develop credential and certification programs to prepare community college students to advance up the nursing career ladder. The High Growth initiative is a good example of what can be accomplished when public- and private-sector partners come together to implement education programs. These and other programs like it promise to help create a pipeline of qualified workers to meet the needs of the future long-term care consumer.

### **Working Conditions**

Long-term care workers have typically characterized their work settings as being organized in a hierarchal way and marred by a culture that doesn't provide adequate supervision, doesn't respect the knowledge and skills that nurses and aides bring to their work, and doesn't

**Provider coalitions.** A coalition of Wisconsin providers was responsible for developing the revolutionary Wellspring model, which has been replicated in several states. Wellspring was developed by an alliance of 11 freestanding, not-for-profit nursing homes that came together in 1998 to improve the quality of their care and work environments through such strategies as collaborative training programs, sharing of resident data, and the use of multidisciplinary teams to implement care-improvement interventions. A recent evaluation funded by the Commonwealth Fund credited Wellspring with lowering the rate of staff turnover in member facilities, improving the performance of those facilities on federal surveys and helping staff take a more proactive approach to resident care.<sup>29</sup>

Any effort to improve working conditions for long-term care workers must include aggressive action to make the work environment safer. This is a challenging task, since long-term care settings have extremely high accident and injury rates. Alison Trinkoff and her colleagues report in a 2005 paper that the rate of worker injuries within nursing and personal care facilities is second among all industries, with nursing homes placing among the top 10 industries for musculoskeletal problems, the major cause of worker absenteeism, workers' compensation claims, and worker injury and illness.<sup>30</sup> The very nature of long-term care jobs explains the high injury rates to a certain extent: caring for frail older people literally requires heavy lifting and working in awkward positions. In addition, out-of-date equipment, inefficient job designs and low staffing levels exacerbate the risks of injury that workers encounter each day at work. These risks and dangers must be addressed before long-term care settings can become places where skilled and caring individuals will want to work — and will be able to work—over the long term.

## Taking a Holistic Approach

<sup>29</sup> Stone, R.I., Reinhard, S., Bowers, B., Zimmerman, D., Phillips, C., Hawes, C., Fielding, J., and Jacobson, N. 2002. *Evaluation of the Wellspring Model for Improving Nursing Home Quality*. New York: The Commonwealth Fund.

<sup>30</sup> Trinkoff, A., Johantgen, M., Muntaner, C., Rong, L. 2005. "Staffing and Worker Injury in Nursing Homes." *Am J Public Health* 95(7):1220-1225.

- **Competitive compensation.** When the first Green Houses opened in 2003, shahbazim were paid \$11 an hour, a rate that was \$4 more than was paid to CNAs who continued to work in Methodist Senior Services' traditional nursing home units.
- **Sufficient training.** Shahbazim who are not CNAs when they are hired must undergo training and become state certified. Once hired, they receive 120 hours of additional training: 40 hours with Green House staff to learn about the project's philosophy, policy and procedures; and 80 hours with outside professionals who teach classes on first aid, CPR, culinary skills, food safety and home repairs.

These investments have shown good results, according to an evaluation of the Tupelo Green Houses conducted by Rosalie Kane of the University of Minnesota. Kane's evaluation shows that turnover rates among nursing assistants dropped to nearly zero after the Green House project began and that Green House staff have high levels of job satisfaction.<sup>32</sup> In addition, according to a 2006 article in *The Gerontologist*, transfer-related injuries among staff have dropped dramatically; none were reported during the evaluation period. The article attributed this improvement to higher levels of staff empowerment, which encourages staff members to demonstrate "increased skills, self-esteem, problem-solving and self-possession."<sup>33</sup>

## Next Steps

All of these workforce initiatives are encouraging, both because they exist at all and because they are showing positive outcomes in recruiting, training and retaining a qualified long-term care workforce. Now it's time to establish similar initiatives in every long-term care setting. This goal is achievable, but it will require hard work. The Commission believes that the following recommendations will help, in the words of Dr. Konrad, set us forward "on our way."

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<sup>32</sup> National Clearinghouse on the Direct Care Workforce. Green House Project. Accessed at: [http://www.directcareclearinghouse.org/practices/r\\_pp\\_det.jsp?res\\_id=187910](http://www.directcareclearinghouse.org/practices/r_pp_det.jsp?res_id=187910)

<sup>33</sup> Rabig, J., Thomas, W., Kane, R., Cutler, L., and McAlilly, S. 2006. "Radical Redesign of Nursing Homes: Applying the Green House Concept in Tupelo, Miss." *The Gerontologist* 46(4):533-39.

2. Develop and support the implementation of a leadership training initiative to improve the supervisory and leadership skills of long-term care managers.

The leadership training initiative could be organized, sponsored, funded and staffed by the major long-term care provider associations and coalitions representing for-profit and not-for-profit nursing homes, assisted living facilities, home care agencies and home health agencies. The following entities should be involved in developing and implementing the initiative: long-term care employers; representatives of professional associations; state boards of nursing and relevant state boards for other professions; long-term care workers; consumers; education institutions; and experts in geriatrics, adult learning, knowledge transfer and cultural diversity. Philanthropic organizations could be called upon to supplement the initiative's funding and staffing levels; to assist in planning, implementing and evaluating the initiative; and to provide ongoing support for replication and wide-scale diffusion.

### III. WAGES AND BENEFITS

3. Develop strategies to raise wages and improve benefits for long-term care professionals and direct care workers.

A working group made up of the American Association of Homes and Services for the Aging, the American Health Care Association, the Alliance for Quality Nursing Home Care, the National Association of Home Care, the National Governors Association, the National Conference of State Legislatures, long-term care workers, consumers, and other national and state groups could be charged with developing proposals to leverage current federal and state long-term care funding streams to improve compensation for long-term care professionals and direct care workers. The work group could address such issues as "pay for performance" proposals tied to wage and benefit enhancements and could develop strategies for improving the effectiveness of "Medicaid wage pass-throughs" in increasing wages and benefits. The working group itself would not require new funding;

in long-term care settings. States that participate in the demonstration program would be required to meet strict benchmarks regarding the quality of resident/client care. Planning for the demonstration should be a cooperative venture between the federal government and the states.

time, the long-term care consumer will likely undergo a fair number of laboratory tests and screenings, may visit the emergency room occasionally and will probably experience multiple hospital admissions.

All of the health professionals whom the older person encounters will have observed their “patient” or “client;” many professionals will make copious notes or record valuable data that describe the consumer’s well-being. Almost every health professional will recommend something for the care recipient, whether it is a medication, an exercise regimen, a diet or an ongoing therapy. Indeed, by the time the average American reaches 75, he or she will have amassed a plethora of medical records, created by a variety of health professionals, which will document everything from ingrown toenails and eye problems to strokes, cancer and diabetes. Unfortunately, even the most meticulously constructed health record could have limited usefulness because, like the health care system itself, it is likely to be fragmented; that is, scattered across multiple care settings with no user-friendly mechanism for bringing an individual’s health information together in a comprehensive and informative package.

The fragmentation of health records may have several serious consequences for the quality of care that long-term care consumers receive. First, it interferes with the ability of individual consumers to make their own health and long-term care decisions. When a consumer’s health information is scattered across many care settings, the consumer, or a surrogate decision maker acting on the consumer’s behalf, is forced to make informed decisions based on incomplete information. Consumer direction and autonomy suffer in the process, as do quality of care and quality of life.

Secondly, fragmentation wastes time and money. When each care setting is forced to create its own health record for the long-term care consumer, duplicative laboratory tests and, in extreme cases, duplicative procedures can result.

Most disconcerting is the possibility that health professionals who attempt to care for the consumer in an information vacuum will commit serious errors because they lack a complete knowledge of the patient’s medical history. Imagine, for example, a scenario in which one

information and expertise can be shared, new technologies developed and existing technologies adapted to long-term care settings, including a person's private home, in a way that preserves the dignity and safeguards the privacy of older consumers.

***Electronic Health Records.*** Electronic Health Records (EHRs) — computerized records of an individual's lifetime health status and health care — are being introduced slowly into hospital and other clinical settings, and even more slowly into long-term care settings. Once established within a computer network, these records could potentially be shared with any number of health care providers who have been approved by the consumer. In addition to reviewing the consumer's medical history, health professionals could also update that history by documenting the care that they have provided and making those updates immediately available to other health professionals on the consumer's multisite care team.

The Veterans Health Administration within the Department of Veterans Affairs (VA) has developed a comprehensive EHR system which, combined with an innovative quality management approach, has contributed to a higher quality of care for those who receive care from the VA.<sup>35</sup> The VA's work in health information technology (IT) goes back several decades and is a study in how sophisticated EHR systems can be built one step at a time. The agency first created the Decentralized Hospital Computer Program (DHCP), one of the first automated health information systems to support multiple sites and cover the full range of health care settings. The VA followed this innovation with the Veterans Health Information Systems and Technology Architecture (VistA®), a suite of more than 100 applications that support the VA's day-to-day clinical, financial and administrative functions. Most recently, the VA developed the Computerized Patient Record System (CPRS) to provide a graphical user interface to the information captured in VistA®.

VistA® and CPRS have been implemented in about 1,400 VA medical centers and at VA outpatient clinics, long-term care facilities and domiciliaries. As of December 2005, VistA®

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<sup>35</sup> Asch, S.M., McGlynn, E.A., Hogan, M.M., Hayward, R.A., Sketelle, P., Rubenstein, L., Keeseey, J., Adams, J., Kerr, E. 2004. "Comparison of Quality of Care for Patients in the Veterans Health Administration and Patients in a National Sample." *Annals of Internal Medicine* 141(12): 938-945.

***Personal Health Records.*** The HHS framework also supports development of another technology-related initiative: a Personal Health Record (PHR) that a consumer could use to manage personal health information and make decisions about his or her own care.

Consumers would actually own this health record, which is an electronic, Web-based file that would include the types of information that some health care recipients are probably already collecting, in paper form, from all of their health care providers. The PHR could also include information from the consumer's Electronic Health Record, as well as any anecdotal information the consumer wanted to add: details about weight, blood pressure, glucose levels or an exercise regimen, for example.

PHRs provide particular benefits for long-term care consumers who move from one care setting to another: the records are specially designed to travel with the consumer and to ease his or her transition to new care settings and new sets of providers. In addition, consumers could share the record not only with their health care professionals, but also with loved ones and trusted friends who are often intimately involved in their care. Finally, the PHR would play an important role in reinforcing the person-centered, consumer-directed approach to care that is now being advocated by several of the new long-term care models identified in the Quality section of this report. By placing vital and comprehensive medical information in the hands of consumers, PHRs enhance consumer autonomy and control over quality of care and quality of life. As mentioned earlier, developing appropriate privacy and security protections will be critical to ensuring widespread consumer use of PHRs.

PHR technology is already available and being used by several long-term care providers, including Erikson Retirement Communities, a Maryland-based, multifacility organization that has already helped nearly 18,000 of its residents establish such records. The organization, which operates 19 continuing care retirements communities in 10 states, credits its PHRs with saving lives because they enhance communication between physicians and patients. The organization uses a very specific example to illustrate this claim: in 2004, when the Food and Drug Administration recalled the arthritis drug Vioxx after it had been linked with heart attacks and cardiovascular damage, physicians treating Erikson residents were

medication history before writing a new prescription. This critical step in the prescribing process could help patients avoid potentially harmful drug interactions.

All 50 states now allow physicians to “write” e-prescriptions. Next, health care providers, insurance companies and government agencies must take steps to ensure that physicians and their pharmacies can actually make use of this technology. E-prescribing software and hardware must be developed that are user-friendly and compatible with health IT networks across care settings; these tools must be made widely available to physicians and pharmacies; and standards must be developed to ensure the secure electronic transmission of prescription and patient medical histories between prescribers and pharmacies.

Public-private partnerships in many states are beginning to make progress toward meeting at least some of these e-prescribing goals. For example, every physician in New Hampshire will soon receive free access to e-prescribing software, a free pocket computer and a discounted wireless telecommunication plan through a new program launched by Anthem Blue Cross and Blue Shield and the New Hampshire Citizens Health Initiative. Physicians using the system will be able to prescribe medication for every patient, even those who are not Anthem members. They will also be able to check the medication history of each patient through a built-in EHR system.

Progress toward e-prescribing is also being made at the federal level. In addition to creating the Medicare prescription drug benefit (“Medicare Part D”), the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 has helped to advance the implementation of electronic prescribing in long-term care settings by mandating the progressive development and adoption of e-prescribing standards. This process must continue so that Medicare beneficiaries can benefit from this promising new technology.

***Telemedicine.*** Collecting, evaluating and sharing “real-time” information about long-term care consumers is one of the goals of telemedicine, an emerging set of technologies that promises to make it easier for older people to remain independent, often in their own homes, while receiving the care and services they need. Taking advantage of computer

settings. That data, about the care provided to long-term care consumers, can be used to measure outcomes, identify problem areas, and help providers take concrete steps to improve quality. In addition to supporting internal quality assessments, health IT systems can also provide regulators with detailed reports, and can give researchers access to data that they can use to evaluate long-term progress. Most important, health IT systems can collect these data in a more efficient way than paper-based reporting systems, and without imposing undo burdens on already overwhelmed staff members.

### **Provider Networks**

Remote monitoring and other telemedicine innovations are still new concepts in long-term care, in part because providers often lack the expertise to launch technological programs. This lack of expertise could be alleviated by establishing networks and partnerships through which providers could cooperate on technology initiatives and through which more experienced providers could mentor those who have less familiarity or experience with these issues. For example, the VA, which is among the nation's most technologically savvy health care systems, has a wealth of knowledge to share with its peers. The agency currently provides in-home services to more than 5,000 veterans and has one of the largest remote monitoring programs in the nation, according to a U.S. Department of Commerce (DOC) report to the 2005 White House Conference on Aging. The VA system, through which nurses can monitor 150 patients at a time using "relatively inexpensive technology products," could provide a valuable model for other long-term care providers.<sup>11</sup>

### **Remaining Challenges and Barriers**

In the process of developing and implementing health IT in long-term care settings, providers and other stakeholders will need to face important issues, including the following.

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<sup>11</sup> Office of Technology Policy, U.S. Department of Commerce Technology Administration. 2005. *Technology and Innovation in an Emerging Senior/Boomer Marketplace*. Prepared for 2005 White House Conference on Aging.

**Funding.** Long-term care providers spend less than three percent of their total operating budgets on information technology. The money these providers do spend usually goes to support administrative functions like billing and scheduling, rather than care-related functions like EHRs and remote monitoring. Most long-term care facilities report that they have steered away from health IT because the capital resources needed to start such a system are too great, or because they lack the evidence that such technology will improve quality or provide a return on investment. Clearly, the financial costs associated with health IT, and the human effort it takes to establish and maintain a health IT system, represent two obstacles to widespread adoption. Adequate funding of the costs for establishing EHRs and telemedicine systems — including grants, subsidized loans and bonuses to help providers, especially small providers and those in underserved communities, establish EHRs — is essential if these high-tech tools are to become an integral part of the day-to-day care offered by long-term care and other providers. A new pilot program, announced in November 2007 by HHS Secretary Mike Leavitt, will encourage small- to medium-sized physician practices to adopt EHRs. Conducted by the Centers for Medicare and Medicaid Services (CMS), the five-year demonstration will provide financial incentives to 1,200 physician groups that are using certified EHRs to meet certain clinical quality measures. A bonus will be provided each year based on a physician group's score on a standardized survey that assesses the specific EHR functions a group employs to support the delivery of care.

In the area of telemedicine, the Medicare-funded Health Buddy Program represents an important first step toward more flexible reimbursement policies for health technologies. The pilot program, based in Washington and Oregon, has distributed free, lunchbox-size computers to 2,000 Medicare patients who have diabetes, congestive heart failure or chronic obstructive pulmonary disease. Patients use the Healthy Buddy appliance at home to conduct a daily dialogue with their physicians and other health providers. During the course of each dialogue, the patient answers questions about his or her condition, receives coaching and information about preventive behaviors, and transmits his or her vital signs through a secure Web site. Health Hero Network of Redwood City, California, which developed the Health Buddy, claims that the technology reduces hospitalizations because it allows

about standards to ensure interoperability and widespread access to aging-services technologies. All of these activities are sorely needed.<sup>43</sup>

## Next Steps

Ever since IBM introduced its first personal computer in 1981, Americans have had a complicated relationship with technology. For some, that relationship has been a love affair, based on the conviction that there are few problems that can't be solved with a computer or other electronic gadget. For others, technology — and its potential to challenge us, steal our privacy, and control our lives — has always been something to fear. As we attempt to create a future in which technology will be an integral part of high-quality long-term care provision, we need to remain open to the benefits that this technology can offer us, and cautious about how we use technological tools. The Commission makes the following recommendations to encourage long-term care stakeholders to harness technology as a way to empower long-term care consumers and to improve the quality of care and services they receive.

# TECHNOLOGY RECOMMENDATIONS

## I. USING TECHNOLOGY TO ACHIEVE QUALITY

1. Promote information technology as one way to bring about quality improvement in long-term care.
2. Encourage the adoption and application of consumer-centric, continuous process improvement methodologies in long-term care. Health information technology (IT) can play a critical role in helping long-term care providers collect valuable data about the care they provide and then to use that data to measure, assess and improve the quality of that

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<sup>43</sup> Visit the CAST Web site at [www.agingtech.org](http://www.agingtech.org) to learn about specific long-term care pilots in this area.

technologies that will help the United States prepare for the unprecedented growth of the older population and the impact this demographic shift will have on the nation's health care system. In order to be most effective, the consortium should include representatives from the long-term care community, align itself closely with other government agencies that address health IT issues, receive adequate funding, and be required to collaborate with federal long-term care and research programs.

### III. OPEN COMMUNICATION AND DATA SHARING

8. Promote information flow across care settings as a way to help transform health care. Every segment of health care — including acute care and long-term care — must commit itself to providing consumer-centered, quality care through a single, seamless system. Achieving this goal will require that health and long-term care professionals, technology firms, government researchers, policy makers and other stakeholders step beyond the lines that currently separate their sectors so that information and expertise can be easily shared.
9. Encourage the long-term care community to actively monitor existing and emerging innovations that can be applied to long-term care, and develop that can promote innovation in care.
10. Facilitate more efficient technology transfer between federal government research institutions and the nation's private sector. The long-term care community should promote legislation that would specifically require existing mechanisms to support the transfer of long-term care and aging-related technologies between the public and private sectors.
11. Publicly recognize advances in long-term care technology carried out by academia, technology vendors and others. A “National Medal for Aging and Long-Term Care Technology” could bestow prestige on the recipient while stimulating awareness of the

16. Work with the Drug Enforcement Agency (DEA) and the Food and Drug Administration to find solutions that will permit safe and legally enforceable electronic prescribing of controlled substances, which are effective in relieving the pain associated with many chronic conditions experienced by older people. Considerable progress has been made in modifying archaic state laws and regulations that prohibited the use of electronic prescribing. However, the DEA has yet to create a framework for permitting electronic prescribing of controlled substances. Older consumers are disproportionately affected by this limitation.

## V. ENCOURAGING INNOVATION AND RESEARCH

17. Support the development of longitudinal Personal Health Records (PHR), PHR-related standards and consumer-centric mechanisms for using PHRs to link long-term care providers and other settings. Personal Health Records (PHR) have the potential to become a key means for sharing patient information between different care settings. They can also support older people to remain independent for longer by providing those consumers with personal medical decision support tools. Long-term care settings must be included in the development of future PHR-related use cases.
18. Support the foundational work required to create the standards, tools and infrastructure necessary to support health information exchange and semantic interoperability. The work required is far removed from direct patient care and is slow to yield noticeable returns. However, it is absolutely essential to ensure that the nation can reap future benefits from its investments in health IT. For example, the need for a physical technology infrastructure supporting broadband communications and information exchange is a necessity if many home-based technologies that promise to keep older people independent are to be realized. Other countries have already committed themselves to making wireless broadband a ubiquitous offering. Municipalities in the United States are beginning to do the same, and they should be encouraged to continue this effort.

## CHAPTER 4: FINANCE

When it began its work in 2004, the National Commission for Quality Long-Term Care accepted a simple mission: to draw attention to, and further a national discussion about, the current and looming crisis in long-term care and how the nation might respond to it. The Commission has issued this final report in an effort to share important information about that long-term care crisis and to describe a number of strategies that promise to help the nation improve the quality and accessibility of its long-term care services. Those strategies include:

- Transforming the culture of long-term care settings and placing the needs of consumers — not the needs of providers — at the heart of those settings.
- Devising a long-term care system that emphasizes quality of care *and* quality of life.
- Strengthening the long-term care workforce by improving training, upgrading working conditions and increasing compensation.
- Incorporating emerging technologies into home-based settings and long-term care facilities in order to maximize the independence of older consumers and make care provision more efficient.

In the process of exploring these and other strategies over the past three years, the Commission has had a valuable opportunity to hear from a variety of long-term care experts and to hold lively discussions about various approaches to improving long-term care. During each and every discussion, however, two unresolved questions hung in the air and still challenge Commission members. They are:

1. How will the nation cover the cost of researching, choosing, developing and implementing the quality improvement measures that the Commission has recommended?
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cover those costs, policy makers must understand what role each stakeholder currently plays in the long-term care marketplace, what unique challenges they face, and how an equitable long-term care financing system could serve their needs. Those stakeholders include:

***Persons with disabilities.*** Long-term care is a key part of Americans' health and financial security. Virtually all people will have an experience with long-term care, whether that experience involves purchasing long-term care services for themselves, or providing or purchasing such services for a friend or a family member. In addition, most people will come to long-term care after the onset of disability, whether that disability presents itself at birth, after a trauma, or as a result of diseases associated with aging. At the onset of disability, many older people find themselves in the untenable position of having declining income and savings at the same time when disability-related expenses are mounting. This confluence of challenges brings with it a harsh reality: many frail older people simply do not have the financial resources to obtain the services they need, either in the community or in long-term care facilities.

***Family and friends.*** The vast majority of long-term care is provided by "informal" caregivers, including spouses, children and neighbors who make great personal sacrifices in order to provide a range of services to frail older relatives and friends. The nation's need for unpaid caregivers is likely to increase in the future, as federal and state governments adopt "nursing home diversion" and rebalancing programs aimed at shifting long-term care spending from institutions to the community. Additionally, Commission members recognize that because of changes in the composition of the family, geographic mobility and other factors, an increasing number of persons will need care while families will have fewer younger members available to provide informal care. Aware that most consumers prefer to remain in their own homes for as long as possible, the Commission applauds the new interest in home and community-based services. However, Commission members also are aware that such a shift will increase the costs — economic, emotional, physical and social — that caregivers currently pay in order to serve the majority of the nation's frail citizens. In many instances, caregivers who are compelled to constrain their workdays and turn down professional opportunities in the workplace may put their own retirement security at risk.

in long-term care, it must make an investment in long-term care that allows providers to make necessary improvements in their services, adequately train and compensate staff people who provide hands-on care, and incorporate into care settings the kind of technology that could improve quality and efficiency in long-term care settings.

**States.** Every state plays a vital role in overseeing long-term care quality and ensuring access, by the poorest among us, to needed care. Unfortunately, many states carry heavy economic burdens and struggle financially to maintain a wide range of state services in the face of limited resources and rising costs. As a result of these economic pressures, states are increasingly being forced to make difficult tradeoffs as they balance their citizens' competing needs. In some states, these competing interests bring with them resource shifts that can adversely affect long-term care financing levels. These shifts create an unintentional inequity among Americans with disabilities and create disturbing situations in which residents of one state may have adequate access to care when residents of a neighboring state do not. Such inequities impose geography-based burdens on individuals that simply are not fair.

**Federal government.** The Medicare program pays only a small portion of the nation's long-term care expenses, primarily covering limited home health services and a limited amount of skilled nursing care. Other federal programs, such as the Older Americans Act, also provide supports to those needing long-term care and their families. By far, however, the largest share of federal long-term care funds goes to the Medicaid program: the federal government and the states share the costs incurred through that program. Medicaid is the largest public payer of long-term care but it is available only to low-income Americans or those who have impoverished themselves. While many older people receive help from Medicaid dollars to pay for institutional long-term care, the federal government also approves some Medicaid home and community-based services waivers and has taken other steps that allow individuals across the country to remain in their homes and communities while receiving long-term care services. The challenges facing the entire health care system — such as increasing costs — also face the Medicaid program.

*Strategy #2: Expanding the safety net for people with low-to-modest incomes, while expecting those who are able to rely on private financing.* A national floor of protection would be created for some individuals and some of the gaps in the current Medicaid program would be closed. Such an approach could remove some existing state-by-state variations in the Medicaid program. However, this approach would still be a safety net and not the same as insurance. Individuals with more financial resources who did not meet the safety-net eligibility criteria would use private financing, such as savings or private long-term care insurance, to pay for their long-term care. While there would be an expanded public safety net, a large number of individuals would need other financing options.

*Strategy #3: Establishing public catastrophic long-term care insurance, while stimulating complementary private insurance to fill in the gap for those who can afford it and providing a safety net for those who cannot.* Public and private long-term care policies and programs would work together in a way that they often do not today. Under this approach, a public catastrophic program could provide coverage after an individual had already spent a certain dollar amount or length of time receiving benefits under a private long-term care insurance policy. Different models under this approach might vary in how closely they tie the availability of the public catastrophic coverage to the purchase of a private policy.

*Strategy #4: Establishing universal public long-term care insurance, while supplementing that with private financing and a public safety net.* Everyone would receive a basic foundation of coverage on which to build. For example, a public universal long-term care insurance program could provide a basic benefit to all who pay into the program, but would not cover all the services that an individual might need or cover services for as long as an individual might need them. Individuals could purchase private long-term care insurance policies to cover what the base program does not cover and to provide additional financial security against long-term care costs. The public safety net would provide coverage to those who met eligibility criteria and did not have other coverage. The public program could require individual contributions and could encourage innovation in private long-term care insurance policies, as would some of the other approaches.

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consumer direction and autonomy among its central features. Such a consumer-centered approach could mean more choice and control for the consumer.

In one possible scenario, a person's long-term care choices would no longer be limited to a one-size-fits-all set of services, as the current financing system often prescribes. Instead, beneficiaries of a new, consumer-centered financing system could receive financing assistance, in the form of a cash benefit, to purchase services that they — or their surrogate decision makers — determined were most needed. That cash benefit would be triggered when the person reached a predetermined level of disability. This cash benefit could be one of several options available to consumers; consumers could also choose to receive home care services that are coordinated by an agency, or long-term care services that are provided in an institutional setting.

A consumer-centered financing system would respect an individual's ability to make decisions about his or her own care. It would also use public funds more efficiently to purchase those services that addressed a consumer's individual needs. Clearly, such a system would require careful fine-tuning before it was adopted: fine-tuning that might include setting criteria for the level of disability that would trigger benefits, ensuring alternatives for consumers who could not or did not feel capable of making care decisions, and resolving other important issues.

### **Consumer Planning**

Consumer empowerment is a two-way street. As stated earlier, a long-term care financing system should empower consumers to take some responsibility for their long-term care. By the same token, however, that same system needs to encourage consumers to assume a certain level of responsibility for advance planning. That planning would help consumers to anticipate the possibility of disability, to take preventive measures that might help them avoid or decrease the severity of that disability, and to prepare financially for long-term care expenditures. Education and adequate, stable and flexible financing options are critical to encouraging consumers to plan for their long-term care needs.

Consumers also need more public and private financing options to help them plan and pay for their long-term care. However, it must be noted that financial planning alone will not necessarily provide an individual with adequate resources for long-term care.

Consumers also need access to a range of tools — such as tax credits or affordable reverse mortgages — that will enable them to save. In addition, a number of strategies could be pursued at the federal level to harness the “power of compound interest” by encouraging individuals to start saving early for long-term care. Tax incentives could be established to reward personal savings, and could provide younger people with incentives that are meaningful enough to spur them to set aside money today for services that they won’t use for many decades. Tax incentives should be examined to determine who they would assist, if this assistance is efficiently and effectively directed to the people who need it, and the costs and benefits of such incentives.

#### **Pooling and Spreading Risks**

Both trauma-related disability and disability associated with age-related chronic illnesses and frailty are insurable events; that is, by paying a periodic premium, consumers can spread the cost of long-term care among a large pool of individuals, and avoid the risk that long-term care costs will deplete their assets. Under the right circumstances, public and private insurers could be encouraged to create such risk pools, and consumers could be encouraged to participate in them. Such insurance needs to be comprehensive and affordable. The universal public long-term care insurance strategy discussed above (Strategy #4) would be one example of building a large pool and spreading risk. Neither the private nor public sectors alone can provide the range of options needed; both public and private financing roles are important.

The nation currently does employ both public and private financing mechanisms for long-term care but, as noted, there are numerous problems that leave millions at risk. One strategy calls for a systematically enhanced partnership through which private long-term care insurance could be combined with publicly sponsored long-term care insurance and a residual safety-net of public funding for those who might otherwise fall through the cracks. There are several ways in which this enhanced public-private partnership could be developed:

### Safety Net

While individual responsibility should be encouraged, the Commission also recognizes that the occurrence of a disabling condition or the lack of financial resources is often beyond the control of an individual. Disability may still affect individuals who practiced health-prevention strategies throughout their lives. In addition, disability may ensue because, through no fault of their own, individuals were unable to participate in those strategies. Likewise, the Commission recognizes that, due to lifelong financial challenges, some consumers will be unable to prepare economically for the costs of long-term care, either by saving on their own or by participating in other financial-planning activities. Individuals may also lack or have exhausted all of their other financing options.

Therefore the Commission asserts that all financial reform strategies must feature a public safety net that is designed to ensure that a consumer's inability to pay will never be a reason for that consumer's lack of access to needed care and services.

### Demographic Considerations

The options described above, as well as other long-term care strategies, will have different value and applicability to the three distinct segments of the long-term care market:

- The *Silent Generation* (born before 1946): Some members of this generation are already experiencing frailty and disability; others will continue to do so through the next several decades. Those individuals who have not pre-funded their long-term care, either through savings or insurance, are unlikely to do so in their 60s, 70s, or 80s. Therefore, policy makers will need to develop a short-term approach to providing this generation with equitable access to long-term care services. This approach will be different from the approach policy makers will use to provide affordable long-term care access to subsequent generations.
- The *Baby Boom Generation* (born between 1946 and 1964): These individuals are likely to need long-term care services beginning around 2025. Members of this generation, who

Council of Aging Organizations (LCAO), a coalition of national nonprofit organizations concerned with the well-being of America's older population and committed to representing their interests in the policy-making arena. The Commission shares these principles in the same spirit in which LCAO developed them: "to provide a framework for focusing attention, generating discussion and crafting a solution to the problem in the near future." They include the following:

1. ***National Problem, National Solution*** — Recognize that although states, communities, families and individuals have important roles to play, long-term care financing is a national problem that requires a national solution.
2. ***Universality with Limited Opt-Out*** — Create a public program that allows all people, including individuals with disabilities and those near retirement, the opportunity to contribute to and prepare for the costs of long-term care. Make participation as convenient as possible, such as through an automatic payroll deduction, but give people the limited choice to opt out.
3. ***Public-Private Partnership*** — Provide a strong foundation of protection while providing opportunities for personal planning that include a role for private sector options. Government, individuals and the private sector have a shared responsibility.
4. ***Affordability and Risk Pooling*** — Provide for broad pooling of risk and appropriate low-income subsidies to make premiums affordable enough so that all people, regardless of income and health status, can participate.
5. ***Fiscal Responsibility*** — Provide actuarially sound funding, such as through voluntary premiums that build reserves over time sufficient to pay for future needs in a way that is affordable to individuals and to society as a whole.

## NEXT STEPS

Discussions about the best way to improve quality in long-term care didn't begin in 2004 with the inauguration of the National Commission for Quality Long-Term Care, and those discussions must not end with this final report. True transformation of long-term care will require ongoing discussions among many stakeholders.

Providers and policy makers will need to sit down with consumers and their families, *really* listen to their needs and desires, and work hand-in-hand with them to design a better long-term care system. All stakeholders — providers, lawmakers and consumers — will need to make tough decisions and agree to compromises about where money can be invested most wisely in order to create inviting, empowering and high-quality long-term care environments. Regulators, consumer advocates and providers will need to explore together the regulatory issues that the transformation process will inevitably raise. These issues, many of them controversial, will not be resolved overnight, nor will providers, policy makers, regulators, consumers and their families find it easy to reach consensus. However, the Commission believes that the process of building a consumer-centered long-term care system, however difficult, is worth the intense effort that it will require.

Commission members are hopeful that these discussions will continue to take place over the next months and years. In this report, we have called on Congress to hold hearings during 2008 that will investigate and recommend workable strategies to design and implement that system. We have urged the next President of the United States to provide the leadership necessary to launch a multifaceted transformation of long-term care. In addition, we note a provision in the Long-Term Care Quality and Modernization Act, which was recently introduced in the House of Representatives by Representatives Earl Pomeroy of North Dakota, Shelley Moore Capito of West Virginia and Tom Allen of Maine. The provision would establish a new, Long-Term Care Quality Advisory Commission, which would be

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