Transcript of the Proceedings
of the April 3rd, 2008
Creating Home in the Nursing Home:
A National Symposium on Culture Change
and the Environment Requirements

Symposium Proceedings include:

- **Speaker Presentations**
- **National Stakeholder Responses**
- **All Public Comments Made**
- **Recommendations resulting from the April 4th Invitational Workshop**

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This document consists of the transcript of all the proceedings of the Creating Home national symposium which took place on April 3rd, 2008 in Washington D.C. It includes the presentations made by expert speakers, national stakeholder group responses and all public comments made in two public comment periods. It also includes the recommendations that resulted from the April 4th Invitational Workshop attended by culture change experts and national stakeholder representatives. It is part of contract number HHSM-500-2005-00076P between the Centers for Medicare & Medicaid Services and Edu-Catering, LLP and Carmen Bowman. The content of this document does not necessarily reflect the views or policies of the Centers for Medicare and Medicaid Services. For more information, contact Carmen Bowman at 303-981-7228 or carmen@edu-catering.com.

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Introduction

On April 3rd, 2008 a once in a lifetime event occurred entitled *Creating Home in the Nursing Home: A National Symposium on Culture Change and the Environment Requirements*. The event was co-sponsored by the Centers for Medicare & Medicaid Services (CMS) and Pioneer Network also a first, hopefully of many more.

The symposium focused on changes to the physical environment of nursing homes being made by innovators and how these changes relate to Federal and State regulations and the Life Safety Code.

The Symposium featured national expert presentations on private rooms, household and residential models, lighting and glare, issues and ideas regarding "creating home," a presentation on the Life Safety Code by the National Fire Protection Association, State success stories, national stakeholder response panels to each topic, and public commentary through open microphone sessions.

An invitational workshop for stakeholder organization leaders, culture change experts and researchers, and regulators occurred on April 4, 2008 and developed recommendations regarding:

- Research needed concerning resident outcomes, costs, and the feasibility of making various changes to the physical environment of nursing homes.
- State-level issues that could be led by State culture change coalitions concerning potential changes to state regulations and codes.
- Federal requirements - what potential changes are needed within the regulations as well as interpretive guidance, surveyor training and protocols.
- Life Safety Code – problems it is presenting and making recommended changes to meet new models of care.
- What groups (committees, task forces, study groups) should be formed to consider these issues and on what schedule should they convene?

A document summarizing all of the recommendations made by any speaker, public commenter or workgroup are available at the Pioneer Network's website www.pioneernetwork.net. Additionally the papers and presentations made by the speakers are available there as well as the background paper written to set the stage for the symposium and lay out the issues regarding changes within the culture change movement and issues with involved State, Federal and Life Safety Code regulations written by myself also under contract with CMS Division of Nursing Homes.

Please join CMS, the Pioneer Network and your State's culture change initiative in promoting changed cultures for persons living and working in nursing homes. For particular volunteer opportunities and to share your ideas please contact the Pioneer Network at 585-271-7570.

Chapter 1:
Opening Comments

Thomas Hamilton, Director, CMS Survey and Certification Group:

Welcome to Washington D.C. If you don't think environment can make a difference, take a walk around the grounds, go down and see the cherry blossoms. You've picked a fantastic time of year to join us here in D.C. So welcome to the national symposium on culture change entitled Creating Home in the Nursing Home.

I'm Thomas Hamilton. I'm the Director of the Survey and Certification Group in the Centers for Medicare and Medicaid Services otherwise affectionately known as CMS. Acting Administrator Kerry Weems sends his personal regards and best wishes for the day. Kerry Weems thinks highly of this work and, in fact, made this conference one of the highlighted items in his testimony in front before the Senate Aging Committee in November. We at CMS applaud the goals of the culture change movement to bring about a new way of providing care to our nation's nursing home residents, fostering a greater quality of life for all. Such goals are entirely consistent with federal legislation embodied in OBRA '1987 - the Nursing Home Reform Act - and CMS regulations; both of which give high prominence to both quality of care and quality of life.

We at CMS have been pleased to play a small role in supporting the culture change movement over the past few years such as the projects as the 2002 national broadcast in concert with the Pioneer Network that first introduced the culture change movement to our surveyors; participation in the St. Louis Accord in 2005; the four part culture change broadcast that took place in 2006 and 2007 called "From Institutional Care to Individualized Care" together with Barbara Frank and the QIOs; and two culture change audio conferences for all state survey agencies just this past year.

Now this conference is one that we've been particularly looking forward to. I was tracking a lot of the emails that were flying back and forth when people were considering whether or not we all ought to team up to do this conference, and my favorite was actually an email from Brian Kaser who was cautioning his Pioneer colleagues who said, "We might hear the music of culture change, but since CMS will be in charge, we may only hear military music." Well hopefully that may be partly true but not entirely true. And a number of individuals have worked very hard to make sure that we have a good balanced symposium today. And many people worked to bring this conference to fruition and I'd like to thank just a few individuals with the time available this morning.

First, Larry Minnix and the AAHSA board for working with us and allowing us to piggyback this conference on their national conference. Secondly, Carmen Bowman who authored that excellent background paper that is in your packet. Carmen will be moderating today's session and at the end of the conference, after the conference will be creating a synopsis of the proceedings for us all to benefit from, as well as individuals who could not be here today, and Carmen is off to your left. Thirdly, Karen Schoeneman from the Survey and Certification group at CMS who has carried the culture change agenda since the very beginning at CMS and has done a wonderful job and will speak momentarily. And not the least of which who I should thank is the Pioneer Network itself.

I will confide in you that thirty years ago when I was first working in the long term care field, I gave up on nursing homes. I despaired of the possibility that nursing homes could ever offer the quality of care and quality of life that our elders could truly endorse. For the next twenty years, I devoted myself to developing and running programs that were alternatives to nursing homes. Helping hundreds of thousands of individuals avoid the need to go to nursing homes, to leave nursing homes in favor of environments that we thought could better realize the possibility of true individualized, person-centered care.

I did note with gratification, however that before I left Wisconsin, the Pioneer Network, the nascent Pioneer Network back in 1998 met in Oshkosh, Wisconsin and formulated a mission and vision statement that closely aligned nursing home care with quality of life as a goal. Now with the Green House model, there is a possibility that culture change in nursing homes can be a vehicle that does indeed bring person-centered care to the forefront. Individualized, person-centered care, in my opinion, is where the best long term care and the best medical care, for that matter, is to be found. Whether you're called the Pioneer Network, Green House or culture change aficionado, what you're doing is very important. And can also be very frustrating because it is pioneering work with all of the disappointments, the hopes, sometimes the confusion that learning unavoidably involves.

So as I get ready to turn the microphone over to Bonnie Kantor, Executive Director of the Pioneer Network, let me simply suggest that we take some inspiration from the Pioneer Network name and as we find ourselves throughout the day struggling perhaps to find direction and answers, we might remember the experience of another set of pioneers a long time ago, Louis and Clark, as they set out to map the western territories of what is now the western part of the United States. In 1805 despite, or even with, some of the best guides from the Nez Perce tribes, the Louis and Clark Expedition became hopelessly lost in a blinding blizzard in the Bitterroot Mountains. William Clark later wrote in his diary that in a moment of deep despair he remembered some fortifying words that his friend Daniel Boone had told him years earlier. Boone had said, "Pioneers are never lost but occasionally bewildered." Let us wander in the "bewilderness" for a while today as we find our direction and way. Thank you very much.

Bonnie Kantor, Executive Director of the Pioneer Network:

Good morning everyone. And thank you Thomas. Thomas just talked about military music. For those of you who don't know me well, even actually those who do know me well, might not know that I have studied belly dancing for quite a while. And so, Thomas on one hand talks about military music I will talk on the other hand about belly dancing music. And in between is probably truth and where we need to be. So I think that we will indeed today find our middle ground.

I am, as Thomas said, Bonnie Kantor, the Executive Director of the Pioneer Network, and on behalf of our Board of Directors and our President, Charlene Boyd, I'd like to welcome you today to our symposium. I say "our" very purposely. This symposium belongs to all of us and many others who are not able to be here today. None of us, and I mean that so sincerely, would be here today without the years of hard work, energy and commitment of those around the country who advocate for and care so deeply for our elders. Chances are, you are one of them. And the chances are great as well that the person sitting to your left or to your right is one of those champions too. So, thanks each and every one

of you for everything you have done to get us to this important and impressive point in our history and future of long term care.

And I would like to take just a moment and give special thanks to those individuals and organizations who provided direct support for the Pioneer Network's participation in this event and who have pledged their support for continuing activities following today.

As many of you know, this symposium is a joint project of the Centers for Medicare and Medicaid Services and the Pioneer Network, and we are grateful, very grateful, that we were able to develop this event in cooperation with Larry Minnix and all the wonderful folk at the American Association of Homes and Services for the Aging.

In addition, The Pioneer Network's participation in this event is generously supported by the Commonwealth Fund, its President Karen Davis, and most directly, Dr. Mary Jane Koren and the Frail Elders Program.

The following organizations have provided the Pioneer Network with valuable additional support for this event and, in most cases, the activities that will follow. We want to express our deep appreciation and gratitude to the American Health Care Association, the Maurice and Hulda Rothschild Foundation, Dorsky, Hodgon, Parrish and Yue Architects, the SEIU, the Quality Care Committee, the Continuing Care Leadership Coalition, and the Green House Project and NCB Capital Impact.

Now as I said at the beginning, this symposium belongs to all of us and we each have a role to play. And I just briefly want to talk about what that role is. Please know that all comments made -- large and small -- will be heard and will be considered. The brochure describing this event stated, "The federal government is listening." And, as you can see here today, from Thomas' comments and from the many folks here from CMS, the federal government certainly is listening. But I would like everyone to know, as well, that the Pioneer Network is listening as well. Based on what we hear today—both formally in prepared comments and comments in the public sessions and also comments that are given informally over coffee and tea - will all be considered, and a plan is going to be developed that will facilitate progress and action over the next year. I want to make sure everyone knows that this symposium is not a stand-alone event. It is part of a larger agenda, and we will at the end of this session be talking about that which will follow in the year ahead. But I'll just give you just a little hint, and that is that following this symposium there will be a group representing national stakeholders that are going to meet to review the day and are going to provide us with a series of recommendations for action. And again we will talk more about those at the end of the day. The Pioneer Network's role is to facilitate the recommendations at both the federal and a state level.

As I close, I am reminded of the words spoken centuries ago – Thomas took us back to the 1800's, I'm going to take us back even further – to the words spoken by the Roman Emperor and philosopher Marcus Aurelius. "Everything," he said, "is the result of a change." And none of us know yet what will result from the changes and recommendations that are made here today. However, I think I can say with confidence that they will be good changes, they will be timely changes, and they will be changes that will prove to be the culmination of the hard work and dedication to culture change that we all associate with our next speaker. It goes without saying that none of us would be here today without the extraordinary commitment of CMS over the years and the tireless efforts of our colleague and champion,

Karen Schoeneman of the CMS Division of Nursing Homes. Please join me in showing our appreciation for both CMS and Karen as she approaches the podium.

Karen Schoeneman, CMS Division of Nursing Homes:

[Applause] Wow. Thank you so much. I love getting a standing ovation, I haven't said anything yet. I'm going to be very brief. Those of you who know me, know I can speak on for hours. I just have just one little job here. I want to tell you a little bit about why you are here.
I work for the CMS Division of Nursing Homes as Thomas said. And my specialty there is quality of life. I was privileged, very privileged, to be a part of that original gathering in 1997 in Rochester in a blizzard that led to the formation of the Pioneer Network. I have been a very enthusiastic supporter of the principles of culture change ever since, because they make a lot of sense. And they are something I've always hoped for, something I always hoped would happen in my previous career before I got to CMS as a nursing home social worker.

Today's get-together was my idea, and I'd like to tell you that seeing you all here is actually a dream come true for me; something I've been thinking about and trying to work toward for years. Here's why I proposed this symposium. I've given many talks at national conferences over the past several years, mostly on culture change and compliance with the federal regulations. At each talk I'd take some questions from someone who wanted to bring up an issue on the physical environment. Sometimes I could provide the answer, especially if they had misunderstood the interpretive guidelines or just weren't sure what it meant or what the surveyors were going to do with that information or misunderstood what was in that regulation. But sometimes I would have to say to them that there is no federal regulation that says you can't do that or you have to do this. It must be something your state has, or maybe even something your locality, your city has - it's not federal. Then in other cases the issue was in the Life Safety Code, and I would say to them that's not CMS - we don't write the code but we adopt it. It actually comes from the National Fire Protection Association and not from CMS, which was usually greeted by the audience going, "really, I didn't know that." So I felt stumped that there was such a disconnect, and it seemed to me like things were getting stuck as providers wanted to try new designs and do new things especially with the environment and they weren't able to figure their way through these levels of regulation.

So I decided that conversations like this that I was hearing must be going on all over the country with no resolution, since the issue is so complicated, and there are so many regulatory players involved. It seemed to me as an old social worker that when there is a complex situation like this with differences of opinion or interpretation, that the best way to move forward would be to get everybody in a room together to start a dialog, to listen, to learn from each other, to get a chance for "the government" to listen while the interested public got a chance to speak their piece into the record.

I'd like to thank my managers, Thomas Hamilton, whom you've met, and Cindy Graunke and Joan Simmons for buying into this idea. Cindy had the idea of CMS collaborating with the Pioneer Network to do this together. CMS awarded a contract to a noted culture change and regulations expert, Carmen Bowman, whom I'll introduce in a minute as your moderator today. That was sort of a hyperbole, it will be a few minutes. We formed a team, Carmen and me with Bonnie Kantor and Rose Marie Fagan of the

Pioneer Network, and we worked on this for many months. I thank my three partners for all their hard work and brilliant ideas. Let's give a hand to them as well.

The brochure for this event says that "the government is listening." Perhaps that attracted your attention [when] you saw this brochure. So I want to actually let you know who is here from the government, both federal and state. Government folks, pay attention now as I call your name; I want you to please stand up momentarily and let the audience see you. I want you to know that the regulators like me have a red stripe on their badge that matches our conference colors. So if you see one of them at break time, you can say hello to a regulator and know who they are.
Alright, the following group are all from CMS headquarters in Baltimore.

First of all I already spoke, I'm in the count now, and I want you to let you know I'm going to introduce 32 people - at least by my math.

First, Thomas Hamilton, Director of the Survey and Certification group.

Cindy Graunke, Director of the Division of Nursing Homes.

Joan Simmons, Deputy Director of the Division of Nursing Homes and my direct boss who has been a great support to me in putting this together.

Dr. Crystal Simpson, our Medical Officer for the Survey and Certification group.

James Merrill who is the Life Safety Code lead for the nation for nursing homes out of the Division of Nursing Homes.

Marsha Newton, Acting Director of the Division on Institutional Quality Standards, and Trish Brooks and Diane Korning from that division. This is the division in CMS that is responsible for actually writing and revising the actual federal regulation language itself, while the Division of Nursing Homes has responsibility for the interpretive guidelines and surveyor training. We work together, the two of us different divisions.

Mary Pratt, Mary and I co-led the CMS Quality of Life research contract and she and I did the first formative work toward the Artifacts of Culture Change tool. She works for and is the Division Director up in our Office of Clinical Standards of Quality. The division that has responsibility for the upcoming MDS 3.0, perhaps you've heard of that. Mary has brought one of her staff members, Traci Archibald.

Next Sheila Lambowitz who is the Director of the Division of Institutional Post Acute Care. Her division, pay attention now, writes the payment regulations. Hear that?

We have Mary Kahn from the CMS Press Office here in D.C.

The following people are from our CMS Regional Offices:

Steven Chickering, the Consortium Survey and Certification Officer from our San Francisco office. He'll be one of the people speaking on our state success Stories panel later this afternoon.

Alfreda Walker, is a manager of the survey branch in our Atlanta office.

Gary Georges, Safety Engineer from our Philadelphia office.

And that's our CMS attendees.

In addition we have two other federal attendees who are not from CMS.

We have Sue Nonemaker, from the Office of the Inspector General. She's the Director of their Division of Evaluation Planning and Support. If her name sounds familiar, she was a part of the CMS Division of Nursing Homes for a long time and is responsible for the MDS 1.0 and 2.0. And now she works for the OIG, they're the people that evaluate CMS. We get inspected too.

We have Sarah Imhof from the Government Accountability Office or the GAO, and these are the federal attendees. In addition I'd like to tell you who is here from state survey agencies.

First is, not from a state survey agency but above them at the secretarial level is Cathy Greenlee, Secretary of Aging for Kansas. Wow. Madame Secretary - thank you for coming.

Now from the state survey agencies. Most of these people are directors. I'll tell you if there are some of their staff too.

Ray Rusin from Rhode Island Department of Health. He is also the President of the Association of Health Facility Survey Agencies. Actually all the state survey directors have their own group and conferences together and he is the current president of them. He'll be speaking later today.

Mary Gear, Oregon Department of Human Services and People with Disabilities. She's one of our speakers later on.

Carol Shockley from the Arkansas Office of Long Term Care. She'll be a speaker later today.

We have Vera VanBruggen from the Kansas Department of Aging. I see her at every culture change meeting I go to.

From the South Carolina Department of Health and Environmental Control we have Pam Dukes, Mary Maertens, Ken Moore, Randy Clark, and Kevin Ridenour. A gang from South Carolina.

We have Kimberly Smoak and Skip Gregory, Florida Agency for Health Care Administration.

We have the Maryland Office of Health Care Quality gang here – Pete Sansone, Wendy Kronmiller and Linda Taylor.

If there are any other regulators I've missed I apologize. There may be some few others. It's hard to tell from our registration because the ombudsmen are here, they're also marked federal and we have a lot from our sister agency the VA, from its headquarters and from VA facilities as well.

All the regulators only have these red ribbons like me. Really say hello to us at some point.
Now it is my great pleasure to do one more thing, and then I will promise I will be quiet and sit down. It's my pleasure to introduce your moderator for today Carmen Bowman. Carmen Bowman is nationally recognized as a culture change expert as well as an expert in the long term care regulations, and of course my good friend as well. Here's just a little you should know about her.

Carmen started out as an activity director in nursing homes. She spent nine years as a state surveyor in Colorado. The first certified activity director to be a state surveyor in the entire nation. She founded the Colorado Culture Change Coalition. She also worked for a short while with me in the Division of Nursing Homes collaborating with me on surveyor training especially in quality of life. Carmen has now her own culture change company called Edu-Catering.
She is constantly sought as a speaker at national conferences and has made many keynote presentations. She has served on several culture change advisory committees and has provided culture change consulting to several nursing homes. With that busy schedule as well as a very active three year old, Ellie, Carmen has also found the time to author or co-author five culture change books. And now her latest writing endeavor is in your conference folder, her terrific and detailed background report to this symposium. Carmen. Thank you.

Carmen Bowman, Edu-Catering, Symposium Facilitator:

Welcome to this exciting and historic event everyone. We are so honored you chose to be a part of it. Thank you to the Pioneer Network for co-sponsoring the symposium, to the Commonwealth Fund for funding the Pioneer Network, and to all our other underwriters already mentioned. I think I probably speak for all of us as we would especially like to thank CMS for their willingness to co-sponsor this event - an event where the government is listening, truly cutting-edge and very appreciated.

Actually, this symposium is the second ever of its kind - the first having been held by CMS and facilitated by Karen Schoeneman in July of 1996. It was called the Quality of Life symposium and had a format very similar to today's.

Of the six research experts who presented in 1996, one is in the audience today, Dr. Rosalie Kane of the University of Minnesota, a researcher whose name is synonymous with quality of life. Dr. Kane is someone many of us discovered while conducting research of our own during our work as students in this field of long term care. Dr. Kane was also on the Institute of Medicine's Blue Ribbon Panel of experts which developed the basis of the Nursing Home Reform Act of OBRA '87. Dr. Kane where are you? [Dr. Kane stands briefly.]

Out of the Quality of Life symposium, came recommendations such as:

- discovering the costs and benefits of encouraging private rooms in new construction, something which has been researched since then, that you will be hearing about today from Dr. Margaret Calkins,

- "attaching nursing staff to residents, not to units" now known as consistent staffing or permanent assignments which has been brought to life by the culture change movement and which the Advancing Excellence Campaign has made one of its 8 goals,
- Full automation of the MDS was suggested then and now exists, and
- Lastly, something suggested back in 1996 but still an issue today is residents wanting more control over their environment, namely their schedule; wanting an individual instead of facility-determined routine. Thanks to early pioneers and the Pioneer Network, this issue is receiving much more attention but, we have much more work to do to make this a reality for all persons living in nursing homes.

Just as many good ideas came out of that previous gathering sponsored by CMS, today's opportunity - that CMS and the Pioneer Network have created - is a chance for us all to move even further forward in creating the best quality of life for people who live in nursing homes. And what is so exciting is that what may come from this historic day is still before us.

As facilitator for this event, let me outline the flow of our day together. We have invited nationally recognized experts on what we are considering to be the "hot" topics of the day regarding the physical environment of nursing homes. Each speaker will make a short presentation on a topic of interest concerning the physical environment, culture change, and any regulatory issues. After each presentation we have invited responses by national stakeholder organizations.

Another feature of today's national symposium is that there will be two open microphone public comment periods: one before lunch and one at the end of the day. This is an opportunity for your comments, not questions - the speakers are not coming back up - but for your ideas and your comments. We also have available in your folders a comment page. If you don't get a chance to come to a microphone, we invite you to give comment on your comment page instead, and you can hand them please to the people at the microphones. If you do make comment at a microphone, we need you to please still use the comment page to give us your name and affiliation so we have it for the record and hand it in when you come to the microphone. We have three microphones, one in each aisle. We are recording the entire day and I'll be preparing a symposium summary paper that includes your public comments made as well as any written remarks turned in.

Please turn your cell phones off if you haven't already and blackberries either off or to vibrate.

Lunch is on your own from 12 to 1:30. In your folders you will find a list of nearby restaurants. Coffee is on both sides of our beautiful big ballroom.

Today's symposium is packed full of information and we are on a tight schedule in order to get it all in. We will be holding speakers and responders to their set time frames and we will start and end at the times indicated on your agenda. Please be prompt returning from our two breaks and lunch. We know none of us want to miss anything here today.

We have tried to "go green" as much as possible today but also wanted you to have a bound version of the background paper. Hopefully you have read it already in preparation. It was a privilege to write this paper under contract with CMS to provide all of us with some history as well as the current status of the environmental side of the culture change movement, and to identify barriers and potential solutions to

furthering innovation. Each speaker's Power Point presentation and a few other resources referred to today, will be available after the symposium on the Pioneer Network website.

Besides saving some trees, we wanted to go "paperless" as much as possible to move us into a "change of conference culture" and a dimension of engagement we rarely get to experience. We invite you to engage yourself, all of yourself, with all that transpires here today. Please be thinking about how the information shared might impact you, your organization, your state and the status of nursing homes nationally. Allow yourself to think, and ponder and don't worry about getting every single thing written down each speaker says right now but instead allow yourself to be fully present.

The purpose of today is to collect ideas, issues, information, and recommendations. As part of my contract with CMS, I will be capturing the results of today and a subsequent workshop that Bonnie mentioned into a post-symposium summary which will also be made available on the Pioneer Network website. So, be watching the Pioneer Network website - always be watching the PN website.

So let's begin. How many of us are looking forward to sharing a room with a stranger when we need nursing home care? In talking to a nursing home resident recently, she referred to her side of a shared room as a "compartment." I hate to say it, but that is perhaps one of the best definitions I've ever heard. How many of us would much prefer a private room all to ourselves? I think we all know that a private room is probably most people's preference and we have evidence from the CMS contracted Quality of Life study conducted by the University of Minnesota that people living in nursing homes do prefer private rooms. It seems that the market is responding to this desire evidenced by a trend of newly constructed and renovating nursing homes offering more and more private rooms. It does seem with the advent of an aging Baby Boomer population private rooms will be the room configuration of choice and you get to hear today some fascinating, evidence-based research that shows cost advantages to building private rooms instead of shared.

Chapter 2:
Private Rooms

Introductory Remarks - Carmen Bowman, Symposium Facilitator:

Speaking of which, I would like to introduce our first speaker, Dr. Margaret Calkins.

Dr. Calkins is an architectural researcher who is nationally recognized as a leader in the field of environments for older adults. She is President of IDEAS which stands for Innovative Designs in Environments for an Aging Society, a consulting firm dedicated to exploring the therapeutic potential of the environment as it relates to frail and impaired older adults. Dr. Calkins is also Chair of the Board of IDEAS Institute, which focuses on research and education in these areas and she is the Immediate Past President of SAGE- the Society for the Advancement of Gerontological Environments. Dr. Calkins has published extensively, and her book Design for Dementia: Planning Environments for the Elderly and the Confused was the first design guide for special care units. Her latest book Creating Successful Dementia Care Settings, a four volume series, addresses the care setting in a holistic manner, combining physical, social and organizational issues into one comprehensive text.

Welcome Dr. Calkins

Dr. Margaret Calkins Presentation - "Private vs. Shared Bedrooms in Nursing Homes"

I am honored to be here and to be the first speaker. I want to thank CMS, Pioneer Network, AAHSA, AHCA all of the supporters of this conference. I think that this is a thrilling event and I expect 10 and 15 years from now those of us who are still in the field will look back and say this was the turning point. This is when things really started to change. So I am delighted to be here. The project I'm going to be talking about today draws on years of experience and draws upon resources from lots of other people, - Rosalie Kane certainly her work was involved - but I certainly want to thank specifically the Commonwealth Fund who provided some funding for this research project. A copy of the paper that this report is based on is available for download at www.ideasinstitute.org.

When we talk about private rooms and Carmen alluded to this, this morning, at one side it's just common sense we all want it. Nobody raised their hand when Carmen asked, "Who wants to share a room with a stranger?" I watched, nobody raised their hand. It just makes sense. On the other hand, we still hear comments like there are some people who do better with a roommate, they like having someone to socialize with, they get lonely living alone. Sometimes there are couples who want to continue to live together. So the question whether every room needs to be a private room I think is open for some debate. We've moved a long way. This is what we used to have. [Picture on screen of ten people in one ward/room.] This was considered quality care. When we moved out of that model we moved into 6-bed, 4-bed, 2-bed rooms with what I call the ubiquitous "privacy curtain."

In the paper, if you download the paper, I provide some definitions of privacy. If you look at the definitions of privacy they talk about control over information or space or territory. And then you look

up the definition of semi-private and it talks about sharing a room in a hospital. Now if privacy doesn't have anything to do with being in a hospital why does semi-private have to with the sharing of a room in a hospital? So we really need to think about what the definitions of the terms are that we use. There are lots of different beautiful ways of creating private rooms that allow a person to express their individuality to continue to be surrounded by the things they have that are important to them, that have meaning, that have value, that tell others about them. I particularly like this room that has a door. It has a direct door outside. We don't get enough outside time. Betsy's going to talk about lighting, and I'm sure she'll cover outside exposure as well but we need to be thinking about these kinds of elements that lead to quality of life. When we talk about bedrooms, we talk about private and we talk about shared rooms. When, in fact, shared rooms come in a wide variety of designs. There's the traditional shared room, and there are several different kinds of enhanced shared [rooms] where each person has a little bit more separation of territory, but there is a shared bathroom.

So this is our traditional shared hospital layout side by side - one person gets the window, one person gets the bathroom. For the person with the window to get to his/her space they always have to transport through the space or territory of the other person. Lots of negatives are associated with that in terms of lack of control, lack of privacy, infringement on feelings of territory and safety. So we've seen a generation of new kinds of shared rooms that we call generally "privacy enhanced shared rooms". In this version, side by side each person has their own space, their own territory, they don't have to cross each other's territory, and they have their own window. It has a shared bathroom with two doors which often is a problem. We don't yet have a very good system for how you deal with shared room doors.

And it still is separated only by that piece of fabric. I generally refuse to call it a privacy curtain. I don't think it does that. There are newer designs where you have a solid wall between the beds but again it still has the privacy curtain so you don't have olfactory privacy, you don't have auditory privacy, you can't meet HIPPA requirements for having any kind of health care conversation in there and if you're really taking HIPPA seriously the roommate will always know something about the medical care about their roommate because the staff are coming in, they're talking about it, they hear the care that's being given. You cannot do HIPPA regulations in a room where there's only a piece of fabric between two people. It doesn't have to be just a solid wall; you can have pieces of furniture to divide them, but again you can still see that piece of fabric separating each other. There are some newer designs coming out. I particularly like this design where each person has their own very clearly defined space (slide 13). This is a public hallway space so that you're not imposing on the other person's territory. The bathroom is still shared, but it only has a single door. This is a facility that after they opened up, some of the people in it wanted a little more privacy (slide 14). It was designed so that in fact each bedroom wall could have a door put on it, not just a piece of fabric. They have now gone back and retrofitted it, and I believe every room now has a door [instead of a fabric curtain].

Here is another version where each person has their own door from the hallway, their own private space but again a shared bathroom (slide 15). So there are lots of different kinds of ways of doing a shared room that give each person their own privacy their own territory, acoustic privacy. We need to be exploring those. They are not looked at in the research nearly enough.

When we talk about the value of a private room, it's privacy for conversations. I talked about HIPPA, but it's also privacy for being able to talk with families, having a private conversation about your will or something else going on with your health care condition or just private family conversation. You don't

always want everybody to know what's going on in your family. Control over lifestyle and environment is incredibly important. It's all of these things about when you get up and when you go to bed, who likes the lights on or the windows should be open or the curtains closed, or the door to the hallway open that cause friction between people being forced to be an unwilling observer of others. I was in one facility where I was doing interviews with residents, and one resident was tired so she wanted to do it in her room. Her roommate was also in the room. In the middle of our interview her roommate got up and used the commode right next to her toilet right next to her bed without pulling the curtain. The person I was interviewing said, "That's what I don't like about a shared room. I have to watch her do that." Well, you know, I didn't think it was a very pleasant experience either.

In response to the comment I put up earlier that some people just like having a roommate, they like being with someone else, there was some very interesting research done where people were moving from a traditional shared nursing home with shared rooms into a new building with all private rooms. They asked the individuals how they thought they were going to feel about having a private room. This study actually took place in Japan. As you can see about 40% were not sure they wanted a private room. They liked the shared room experience. A month after they had moved in that had gone down to about 10%, and after 9 months, 100% of the people were 100% happy with having a private room. So it may be that, you know, if you have to live in a shared room you make the best of it and you say, "It's not so bad." But if you've had the experience of living in a private room people say, "I'd never go back."

There is very good research, and I'm not going to go into all of the details that privacy relates to different kinds of behaviors. I think its privacy, it's territoriality, there are lots of subtle issues in this - we need to do some more research to get into. I'm not going to read all of these quotes but the immediate difference that moving into a private room can have on how someone responds and reacts and therefore how they respond and react to the staff who are trying to provide support for them makes a huge difference. End of life issues are also critical. It's very hard for families to come in and to gather to be there, to be supportive at the end of life when they are intruding on somebody else's space. The roommate feels like they're an imposition to the family. It's just always a very difficult situation.

Beyond those psychosocial factors, there's a whole host of clinical factors where we know there are more positive outcomes associated with having greater privacy and greater separation from people. There are lots of studies, particularly around nosocomial infections. Again these are all detailed in the research paper that you can download, I won't go into them. We could significantly reduce transfers into hospitals by reducing nosocomial infection in nursing homes and save, one study estimated, 8 billion dollars.

This sleep research…. Unfortunately it's remarkable to me how much sleep research is conducted that doesn't bother to ask if you are in a private or shared room. It doesn't keep track of that. So, they talk about staff coming in and waking you up, but they never talk about staff coming in and waking up your roommate and what that does to your sleep pattern. We need to have more research on that. Certainly in the focus groups that I did, the staff all said and the residents said, "Yes, everybody wakes up when the staff come in and do night time checks or have to take someone to the bathroom or check some vitals." That's just part of life in a shared room.

There are a lot of operational factors that affect ongoing operational costs. None of the facilities that I did focus groups in had an empty bed in a private room. All their private beds were full. If they had an

empty bed, it was in a shared room. So there are marketing issues. It is harder to fill a shared room. You have to deal with gender. You have to deal with compatibility. There is a lot of time spent managing roommate conflict. Some staff said it's not that much, other staff said it's almost all of my time. I'm almost always dealing with residents who are upset because of something their roommate has done. There is one research project that has not yet been published that shows that staff turnover is lower on units that have a higher percentage of private rooms. And staff turnover costs are huge. It can cost as much as $16,000 to replace one CNA. And if you have 50 or 80 or 100% turnover, that's a lot of money that you are spending that isn't going towards quality care. Also with roommate disruptions and roommate conflict, if you can't resolve it and you have to relocate somebody, there are lots of costs associated with that. You need to clean the room and get some different kind of cleaning. There are isogenetic consequences of that in terms of having to move somebody to a new unit. There are new staff who aren't familiar with them and there is often a cascading effect. If you've got a fairly high census, and you need to move one person, you may not just have the right room to move them into. The facilities told me they sometimes move 2 or 3 or 4 other people who are happy where they are or at least content with where they are. If you've got to go to families and say, "I'm sorry your mother has to move and she's happy but we need to move her" now how does that support quality of life for anybody?

There are building costs, both initial construction costs and energy use. And this was the most interesting part of the study. I looked at 189 bedroom plans, all different types. I did a very detailed analysis on them and put together some cost assumptions for both low end construction and a higher end construction. We did it literally element of building by element. We measured the exterior wall. We knew whether it had angles in it, whether it had corners, how big the windows were and all of those factors were taken into account. Not surprisingly the traditional shared room square foot per person is the smallest - 135. This is the average. It goes up to 214 for private rooms. So, private rooms have more square feet per person. Therefore they cost more to build. If you look at this what you've got is $41,000 to build a shared room for two people. It's $36,000 to build one private room. So it's $73,000 to build two private rooms. So if you're going to replace the shared room you have to build two private rooms. That cost differential is $32,000. That includes debt service assuming 7% interest for a 30 year mortgage. $32,000 is a lot of money but when you start looking at it, looking at life cycle costs there are other ways of doing it.

The Genworth Company did a survey of costs of private and shared rooms in nursing homes. It found that the difference on average is $23.00. A shared room is about $167.00 and a private room is $190.00. Those were 2005 figures. So at $23.00 a day, you're charging $23.00 a day more for your private room, it will take you less than two years to recoup the costs of constructing two private rooms versus one shared room. Meaning for 28 years of that mortgage you are losing money from having built one shared room. That assumes that the beds are occupied. But if you happen to have an opening in your shared room because your private rooms are always filled, you're not losing $23.00 you're losing $167.00 a day. And at $167.00 a day, it takes you less than 6 1/2 months to have built two private rooms for the cost of having built one shared room. So you need to look at these kinds of costs. The paper goes into some other analyses.

Michigan did a waiver program where they did a $5.00 a day per diem increase if you were building private rooms for Medicaid residents. And at $5.00 a day, it takes about 9 years to recoup that cost difference so you're still making more money when building two private rooms over the life cycle of that mortgage. We're not even talking the life cycle of the building I'm just talking life cycle of the

mortgage. If you want to narrow it down to a no cost equation, it's about $1.25 a day. So if you can charge $1.25 more per person you can build all private rooms and still come out ahead financially.

So, my recommendations. I think we need to prohibit of the traditional side-by-side shared rooms. (Applause)

The regulations still permit 4-bed rooms so I think we need to get rid of 4-bed rooms.

I think we need to write the regulations so that you do not have a piece of fabric between two beds. If you're going to do a shared room, you need to provide solid acoustic privacy.

There are some people who do prefer to share a room, couples, there are some people. Ideally, everyone always gets their choice. Nobody should have to move into a shared room without that being what their choice is. Operationally, it's always going to be difficult because you're going to have one person move out and you're not going to have the right space. It still has some operational indications, but if the shared rooms are designed so that each person has their own space, their own territory or maybe it's a sliding door between the two rooms that could be opened as you see in hotel rooms. I'm working with a couple clients now who are doing that. I think we make that work so that each person gets their own space and own territory.

I think we need to increase basic square footage allotted to 125 per person regardless of whether it's a private or shared room.

We need to do research to study the impact of shared rooms and privacy-enhanced shared rooms. There isn't enough research that tells us how people respond to them, staff as well as the residents as well as the families. I think facilities don't understand these cost implications.

We need to develop some analytic tools that tie in some of your MDS data so that you can easily track whether or not people in the private rooms have a lower infection rate. Are they less likely to be sent to the hospital? Whether you've got some units with more private rooms and your staff is more stable there. We don't have the tools to make it easy for facilities to understand the implications of their different bedroom designs.

I think we need to look at the Medicare and Medicaid funding stream. To take a lifecycle cost that if it is true that private rooms significantly reduce hospitalizations, the cost savings to the healthcare system are substantial. The nursing home itself isn't saving money because the nursing home doesn't pay for the hospital cost. Medicare pays for the hospital cost. If it's a person receiving Medicaid, it's not impacting the bottom line for the facility. So we need to take a different approach in looking at the costs of the whole system.

Culture change coalitions need to learn how to educate state regulators as it is often the state regulations that are restricting how much square footage can be built in each room. We need to teach the regulators and the surveyors to more deeply assess resident satisfaction with roommate kind of issues. We need to use the research and provide it to [people] who supervise the codes.

Thank you very much.

Carmen Bowman, Symposium Facilitator:

Thank you Dr. Calkins.

Maggie referred to her paper everyone. All of our speakers have written a paper that has been shared with the responders. So that's what the Responders will now be responding to. You'll hear more about the future of their papers from Bonnie later.

Now we have our first set of Responders:

Representing the American Association of Homes and Service for the Aging also known as AAHSA, is Larry Minnix, President and CEO of AAHSA.

Representing SAGE, the Society for the Advancement of Gerontological Environments is Amy Carpenter, the current Vice President of SAGE.

Representing the National Association of State Ombudsman Programs is Joani Latimer, State Long-Term Care Ombudsman of Virginia.

Larry Minnix, AAHSA:

We're all convinced, but how do we get from the current concrete situation into a new era? Management guru Peter Senge says that, "Systems deliver what they are perfectly designed to deliver." And if you don't like the outcome of what you have today you can't simply go back in and simply change symptoms you've got to rethink your system. Our current nursing home delivery system is based on a model driven by capital, by episodes of illness and an extension of a hospital. And there are thousands of these places built today like that. So, a lot of people in this audience today would say close them down. Easy to say. Hard to do. Needs still need to be met.

So, as we move to a system that is consumer driven and quality of life driven, therein lies the next ten years of major capital changes that have to occur. That means we need to move from a compliance philosophy with regulation to a quality improvement philosophy of management and regulation. We need to begin to define quality of life. Environment communicates what we expect out of people doesn't it, it is a truism. So if you expect sickness, you get sickness and we train staff to deal with people when they get sick. As opposed to what Pioneer, Eden Alternative, Wellspring, the Green Houses, how do we change the whole paradigm? Now while we're changing the capital, which will take time, and I've been in lots of places where our members are proud of the 5 million dollars they just invested in new curtains and wall paper. If you're an architect out there, do not tell people that they can do that and say that they're going to stand the test of time. Do not march us boldly from the 50's to the 70's in design. (Applause). A little advice for the architects.

At the same time, a lot of us have to be creative. And creativity comes from people. So we have to begin to think of the staff as our culture change partners as well as partners in care. I've been in a lot of

nursing homes where you see fat dogs and bird cages. That doesn't necessarily mean there's a healthy culture, does it? Healthy cultures come from very hard teamwork which you know all too well.

We're in a, what I would predict, a 5 year era of thinking through what the new nursing home [looks like]. Nursing and home. We need to put the nursing back in nursing home and home back in nursing home if it was ever there to begin with, right? It's just that complex and just that simple. We're going to need some help with the capital side of it. We're going to need some patience on the regulatory side of it. We're going to need to help staff to create the kind of atmosphere [with] well-trained and developed staff to make the best of the bad capital situation so something new can be built, you know that. So how do we get people through this next era? And I think that's our challenge. That means the government, providers, consumers, researchers and supportive people like architects are going to have to work better and differently together than we ever have. So I hope this conference will be one of many where we come in here and share progress as well as frustrations. It can be done. I've been in lots of places in which you want to live in if you're severely impaired, have no family, have no other alternatives and some will tell you it's the best quality of life they've had in years because they've put attention to staff relationships first, attention to the environment to the extent they can change it and they've had the cooperation from surveyors and others to say let's give this a try within the confines of regulations that are fundamental and basic that we all have to be. If we work together we can get through it.

Amy Carpenter, SAGE:

I completely agree with Dr. Calkins' position paper and her recommendations. I agree that the side by side shared bedroom arrangement should be prohibited. As Dr. Calkins stated, the notion that a piece of fabric creates sufficient privacy to maintain resident dignity is a fallacy. Visual privacy alone is not nearly enough to truly fulfill the intent of OBRA 1987.

I would take Maggie's recommendations one step further and suggest the following revisions to the Federal Regulations:

1. Regarding Tag F457, as Maggie said, unless we go to all private rooms, change the maximum number of residents in a room from four to two. Given the current research, it is unconscionable to have that many people share a room. There is no way that they have adequate control over their environment or adequate privacy.

2. Further, change this tag, F457, to read "Shared bedrooms shall be arranged such that each resident shall have equal space, equal access and equal amenities." Residents in Shared rooms should not have to pass through another resident's space to access their bed/living area. They must each have equal, unobtrusive access to both the bathroom and the unit entry door and common spaces. They must both be able to look out of the window from their bed! They must both have the same amount of living space, equal storage space, space for personal belongings and the like. They must both have enough space to accommodate visitors, to accommodate flexible furniture arrangements, to accommodate their favorite chair from home. Even if it is avocado green and held together with duct tape! That's their choice and should be their right.

3. Lastly, I question why Tag F460 requires ceiling suspended curtains extending around the bed in shared rooms? If shared rooms are adequately designed to maintain visual privacy (as Maggie described the "enhanced shared rooms"), curtains should not be required or, at least, privacy should be allowed to be achieved by other means. As Carmen so aptly described in her background paper, this "tent-like experience" is less than ideal and should be avoided whenever possible.

I was horrified to read in Carmen's background paper that Florida, until recently, required resident beds to be positioned perpendicular to the head-wall with space on both sides for staff access. Other states have similar regulations. While this may be fine criteria for ensuring that a resident room is designed to be large enough for this arrangement, regulations should not prevent residents from moving their furniture to another arrangement that better suits their needs. Many residents enjoy the shelter of the side of the bed pushed up against the wall. Many do not need staff to attend to them as if they are in a hospital. This is a perfect example of how well intended regulations can be completely at odds with what is best for the individual resident. This also points to the larger picture, beyond the Federal Regulations, where each State sets their own rules. I argue that the basic needs of an elder in one state are not different than the basic needs of an elder in another state. My dream is that someday, we will have one unified set of regulations, separate and distinct from hospital/acute care regulations, are adopted by all states nationwide and enforced uniformly.

We have come so far in our quest to make Long Term Care more like home. We need to now take this next step to improve resident dignity, resident choice and resident control over their environment.

Joani Latimer, National Association of State Ombudsman Programs:

Well, I don't know that I can add a whole lot more to the deliveries here. I thought the paper was outstanding. I think we talk about culture change being a journey so I'm going to tell you a little about my journey. I'd say it's a very rare exception. When Carmen initially came to me and our association the National Association of State Ombudsmen Programs to address the particular topic of private rooms, I think I was frankly wishing I'd been assigned to the topic of home and homelike. That seems such an unequivocal goal that any ombudsman could fully commit to. I was sending out feelers even in my own environment and got "Yeah but the cost." So it seemed a little bit more challenging than what seems so absolutely clear - the home and homelike ideal.

At about the same time, I was having coffee with a colleague and expressing a little about my concern with the challenge of this issue in terms of the private room being the absolute. I was saying that I was not sure that it was quite as centrally rooted in my passion about culture change. Well about a half an hour later after my colleague peeled herself off of the seatback of the booth in which she was sitting in response to pushing more deeply into it from my emotional, albeit caffeinated monologue, she ventured, "I think you feel a little bit more strongly about this issue than you realize." And it was true and that was part of my journey in coming here today. Suddenly I was vehement about having stumbled into essentially the realization of just how absolutely critical the fact of private space is to this whole notion of culture change. The fact that it is absolutely central and in many ways the heart of the issue, the more I thought and explored my feelings about it. I know we have limited time.

When I talk about private space, I'm not sure that it [should] be the absolute requirement that every room be a private room. I think that the ombudsman perspective on that would be that the ideal is that the option should always be there. As the research would indicate, many would choose a private room. The option that's so critical to our ability to define the quality of our life. We have only to look through the glossy magazine pages on the newsstands today to get some sense of just how critically important privacy and personal space is in our culture. How much we value it and even define ourselves by it. The very idea of having to be literally exposed in some of the most intimate and personal functions of daily life in the presence of someone you hardly know or possibly would not choose is really unthinkable to most of us. I had to think about what if as many of us came to the hotel last night we found that we had been assigned to share a room with a randomly assigned roommate. Someone who maybe screamed through the night who couldn't make it to the bathroom, who rummaged through our luggage all night long looking for something, she couldn't quite remember what. It would be intolerable to us for one night. To think what if by some luck of the draw our final years or months were to be defined by that set of circumstances, not a one of us would be able to tolerate that.

So I think the cost issue obviously is something we have to consider. We do somehow find that those very central parts of the care that we're all committed to provide, things that are costly -items like medication, cost of salaries to pay the staff to care for our residents, somehow we make the equation work there. We understand that these things are absolutely essential to the physical health and well-being. But I think we then have to say if we are really committed to resident-centered care, resident-directed care, what do residents want? What do they think is important in the course of daily life? For sure, study after study indicates that residents would say that it's independence, it's autonomy, it's dignity, it's some sense of control over this environment at a time of life when much has been lost and there really is frankly little left that one can control. If we as people who are dedicated to change, if we deliver safety and provide for good clinical outcomes but neglect the parts and elements that define the quality of each day for our residents, it's all for naught, frankly. Unless we provide living space in which the mental, and emotional and spiritual well-being of our residents is afforded, unless we provide a safe haven where residents can cherish a private moment and communicate intimate feelings with loved ones, a space in which they have some sense of control and that very sense of autonomy that gives us a sense of dignity, we've really missed the boat. We will have preserved bodies at the expense and at the neglect of the selves which we derive from meaning and value of life. Thank you to all of CMS and Pioneer for making this possible.

Carmen Bowman, Symposium Facilitator:

Thank you to our first set of Responders.

Chapter 3:
Household and Residential Models

Introductory Remarks – Carmen Bowman, Symposium Moderator:

Recent research conducted by Drs. Rosalie Kane and Lois Cutler of the first Green Houses in Tupelo, Mississippi show improved quality of life. Anecdotal evidence shows greater satisfaction by both residents and staff for the household model as well. I know personally after spending a week in a household at Perham Memorial Home in Perham, Minnesota studying the household model, that life in a household is just plain "good living" and "good working." Both the residential and household models do just that, give 'home' back. And as might be expected, these very new ways of providing nursing home care have bumped into regulations that were written before these new ideas were ever thought about. Cooking food in these new home settings and outside of what we've come to know as the 'main' kitchen for example, is presenting new challenges with regards to current regulations and codes but certainly not ones that cannot be overcome.

With that, I would like to introduce our second speaker Gaius Nelson.

Gaius Nelson is president of Nelson•Tremain Partnership, an architectural and consulting practice in Minneapolis, MN, dedicated to serving the design needs of older people. In 1987 Mr. Nelson pioneered the first household/neighborhood concept within a skilled nursing setting at Evergreen Retirement Center in Oshgosh, WI. Since then he has worked diligently to promote relationship-enabling, resident-focused environments for living through design, education, and policy advocacy.
He is a steering committee member of SAGE and serves on the American Institute of Architects' Revision Task Force of the Guidelines for the Design and Construction of Health Care Facilities.
Mr. Nelson has been instrumental in working towards change in building and design codes that are inappropriately applied to facilities for older people, testifying before legislative committees and spearheading successful state rule modifications.
Please welcome Gaius Nelson

Gaius Nelson Presentation - "Household Models for Nursing Home Environments"

Good morning. I too believe this really is becoming a watershed moment in terms of designing environments for living for residents within facilities. I came to D.C. Tuesday for an Access Board meeting - just kind of part of this watershed. The Access Board and the ADA are finally realizing that the current standards don't meet the needs of seniors. They actually convened a task force, not an official task force, they wanted to get some input from architects, designers, facility operators, human factors, ergonomics experts and we're really going to start looking at providing environments within the ADA that can provide the types of facilities that would help elders and the caregivers within those facilities. So this really is starting to be a watershed moment.

OBRA '87 - 21 years ago. That's a long time. The final rules that went out for public comment didn't happen until 1989. So that took two years. It's a slow motion process that we're going through. So 21 years, 23 years, but it's happening. Quality of life - that's a term that has always struck me as something

difficult to define especially when it comes to the physical environment. When we look at the State Operations Manual from CMS there's some tags, there's 240 through 258 or so that talk about quality of life issues. And the kind of guidance they give designers, architects, people building facilities are things like "you'll have an uncluttered and sanitary environment." Well, that tells me a lot about how to design a building. "You'll have adequate heat." "Adequate lighting." Just some very basic things of that sort.

And so when it comes to the idea of quality of life, I did a little bit of research and I came across this concept of flow from a psychologist out of Chicago. Mihaly Csyikszentmihalyi. I don't know if anyone of you heard of the concept of flow. It's a concept where he looks at what people do during the day. He looks at how we feel about it and who we're doing it with. And one of the important things that I found in his studies is that it really makes a difference, not the individual but also the relationships that happen between people. And that's part of what creates the flow experience. Now when it comes to flow, flow is when you're involved in a task and you just become one with the task. You know, everybody has their own personal things that they like doing. You're involved in something, it's challenging enough, it's something that you really get into. And think about it, you're not happy while you're doing it, you've really just become one with the task but after you're done you finish and you reflect on it, that's when the happiness comes. You really think, boy that was something important in my life.

So trying to bring some of these qualities together got me thinking about quality of life. As part of the studies from Csyikszentmihalyi,he actually studied every day activities that people were participating in. And he tried to break it down into activities that created how people felt about it: happiness, motivation, concentration and flow. There were a number of activities that were the opposite of flow but the flow activities really broke down into some particular types of things. Working. Surprisingly people can get into a flow sense while they're working. Hobbies. Sports. Talking. Socializing with people. I like the one Driving. I've tried to figure out how you can get the experience of driving. We've all driven. You're driving down the road and five minutes will go by and you wonder, you got perfectly well to where you were going, but somehow you were just into it and you didn't really know that you were driving. Having Sex - that's a whole different seminar I won't get involved in. But these are everyday activities that I think we can take a look at and try to integrate within the life of residents. This was something out of the Chicago Tribune. They're using the Wii game console. This really struck me, this picture (slide 6). There are three different activities going on here. Hobbies, sports, socializing. It's in a retirement facility and I think there are ways I think we can look at providing this type of flow experience. Activity directors. I started thinking about some new terms. How about a Life Engagement Coach? How about something like a Flow Facilitator? And what I took from the Csyikszentmihalyi studies is that flow is something that we should try to change our lives around in order to be able to maximize the types of activities we participate in, where that type of flow experience can occur.

Now another thing, I heard this on NPR News. I'm listening to National Public Radio all the time. It's all I have on my radio on my car. And the Walden School in Vermont came up and they talk about relationships too. What's my relationship to myself? What's my relationship to culture? And what's my relationship to the natural environment? I think that these are three very important pieces to bring into the concept. Both of these ideas talk about individual issues. Everyone is different when it comes to what brings them flow, what types of relationships are meaningful to them. Unfortunately, when it comes to the design of facilities like nursing homes you come up with something I call "form follows regulation." The regulations really start to dictate what facilities look like. They lock you into the existing models. They make it really hard to innovate. It really makes it so that you read a regulation,

something like “bedrooms are required to open to corridors.” Well, you automatically have corridors. There’s no way around it. You have to have visual control of the corridor from a nurse station. Well, that assumes you have to have a nurse’s station to begin with. So you have a nurse station at the middle of intersection of corridors and you get the type of facilities we see all over the country.

Another concept that is missed so often in the design of facilities is the hierarchy of spaces. This is a diagram from Sandra Howell, her Patterns and Use book from 1980. And it talks about four different zones of space within facilities. Her study happened to be for senior housing projects. I’ve put some words below these different zones (slide 10). The Private Zone - I call that the bedroom in a nursing home. The Semi-private Zone - which would be a household. A Semi-public Zone - that’s where you have some potential interaction with other public people that are not part of your household and the Public Zone. So having a facility that works through the progression of the hierarchy of spaces and the appropriate direction from public to private is important. Unfortunately, most nursing homes today, or the ones in existence for the last 20-30 years, get the hierarchy completely wrong. It’s so often you’ll walk through the front door and the first thing you do is walk down a private corridor with bedrooms in it before you get down to any public spaces. Now in 1978, Joe Koncelik tried to reevaluate this hierarchy a little bit. And he took what used to be the day room in a facility and distributed it between the hallway, the corridor and the bedrooms in order to create a semi-private zone for the residents and their bedroom (slide 11). Give them a nice little buffer to that freeway that crosses in front of their front door of the bedrooms. And this was a first step in trying to get that hierarchy correct. But it still wasn’t quite there.

It really takes rethinking things completely. This is a diagram (slide 12). I credit myself on it while I was working at KKE Architects. 1987. Just a coincidence that it was OBRA 1987, the same year. But somehow intuitively the idea of the household - a small scale environment discreet clusters with decentralized services - came into being in taking a look at this facility at Evergreen Retirement Community. There was no grand idea when this came about. The facility at that point in time had another facility open up down the street that had all private rooms. They had a lot of semi-private rooms and their goal was we can’t compete without private rooms. But in the process this household developed. It really started going down the process of creating home in the nursing home. The keys that I’ve found in designing facilities is that in order to get a good scale household you need to reduce the scale of the people. Usually it takes an environment of 8-12 people when you’re looking at a smaller scale environment. You need understandable and identifiable spaces. People know what to do at a dining room table off of a country kitchen. It’s just a natural environment. You need to get that hierarchy I talked about correct. You need to make it easy for people to move around the facility and you need to get that important component of having access to nature. In so many facilities so many residents don’t have the opportunity to go outside, feel the sun on their face, and just be one with nature.

1987 the first diagram was drawn. It took until 1997 for the building to be realized. So the household was developed in a skilled nursing setting with some very helpful regulators in the state of Wisconsin. They worked through this. And interestingly enough they identified about 100 different waivers or issues at the start that they needed to deal with. In the end, it did not take any waivers at all but this was working through the process. Unfortunately, that doesn’t happen in every state.

But again small scale environment, easy access. What can be easier to get to the dining room than if the dining room is just across the hall? You see in this diagram (slide 13) 11 residents clustered around

living spaces, a variety of living spaces. All the activities of daily living located in one small environment. Very easy for the residents to get to. Nobody's more than about 40 feet away from any of the activities required. Normal living rooms, country kitchens, dining rooms, access to the outdoors. The doors are not locked in this facility (slide 16). An interesting thing, if you look closely, the fences in this facility in the home are only 42 inches tall. They aren't trying to create six foot fences because the environment is so natural that it's a home. You have to create a home. People want to be in a home. It's when you're not in a home, people want to go somewhere else.

Trying to take the aspects of living and working in a facility and deinstitutionalize them, make them as homelike as possible. Well, make them a home. The bathing room, the spa on the right (slide 17), we needed some supplemental heat. What do we do? Put in a fireplace. It's much more natural than some sort of a blower on the wall that typically happens. The nurse areas. You still need places for nurses, for resident assistants to do the work they need to do but try to make it as unobtrusive as possible. This is a med cart on the left (slide 17). You see there is a cabinet, it's right next to the dining room. All the meds are stored in there. There's a wash area for people to clean their hands. All the aspects you need in a nurse med room are there but its natural, its out in the open, it's a cabinet and a space. You can deinstitutionalize these aspects of the environment.

The Green House (slide 18). Everyone's heard of the Green House. This is another household but they've taken it to the culmination where each house is separately designed, independent from another, has the opportunity to look like a residential house on the street. The idea is that all the cooking occurs right in the facility. All of the support functions occur within a household of ten residents. Very similar concepts. You have a hearth room. You have the living room/hearth room opens up to the dining area. Opens up to the kitchen where cooking can occur and all the aspects, again, of daily living occur. And it looks like a house in a neighborhood. The whole idea is that it can become a house in a community. In this case, the site plan shows the original Green House at Traceway in Tupelo, Mississippi. The four yellow houses on the top of the plan, those are the original Green House model facilities. And they're nearby the original nursing home. But in this way they were able to take an incremental step and take a look at how can we create a different environment that really is household, resident-centered.
Now, in talking about community, that's another aspect within the nursing home that often is neglected. You have your semi-private room which has no privacy, we hear. But then all you have is a social area is a large dining room, a large activity room where maybe 60 people get together at a time and there is really nothing in between. The household provides you that in between.

Other parts of community though are how do you get together with people in other households? What types of larger activities can you participate in? Are there religious services where you might gather together with a group of like-minded people for certain functions? So trying to integrate community within the nursing home is something that often is left out and people really struggle to get the community into the nursing home, especially the outside community. In this case at Evergreen, four households share a neighborhood center. That is what I call the semi-public space. So you have the private rooms, the semi-private household but then you can go to the semi-public neighborhood square in this case they call it Neighborhood Place (slides 21 and 22) . It provides a variety of activities. There's a kids play area, a fireplace, a library, Internet access, for residents to go and participate in other types of activities. Remember these pictures. There are a couple of things I'm going to talk about later. Display cases on the left, and the room the Neighborhood Place, there's no corridor or very little semblance of a corridor especially through Neighborhood Place.

Connecting to the larger community. Now, the public, how do you get the public into the nursing home? How do you get the community in to understand what nursing homes are? In the case of Evergreen, it was a coincidence and a nice coincidence that the only space they had available on campus to put their fitness center was right between two nursing units. So the front door into the nursing units has to pass you right into the community center with warm water therapy, fitness center, a café, a place where people can hang out (slides 23, 24, 25)). Nursing home residents can come down here on their own. They don't need accompaniment. It's still within the facility and they have the opportunity to have a food sort of environment and situation where family come in, where friends come in, they gather, they meet with staff and they have this opportunity. The fitness center itself offers services to the neighborhood, to the city. It's part of the senior center where membership can be bought and you have access to these facilities … in the nursing home. And people willingly come into the middle of the nursing home in order to participate in these types of activities.

Now, it took 10 years for the first Creekview and it's taken a lot longer than that for other people. You think, well it's able to be done but people run into the same problems over and over and over again. I've outlined some of these (slide 26).

The overlapping regulations of different regulating bodies that you need to get with (slides 27 and 28). You need to deal with the whole alphabet soup of regulators and it makes it very difficult to negotiate what's going on in terms of fire marshal - state fire marshals, local fire marshals - local building officials, state health department, food service regulators. Something I think needs to happen is for state health departments to take control of the process when it comes to nursing homes. They need to say we'll take over the building code reviews, we'll take over the health department reviews, we'll take over the food service sanitation reviews so that the goals of OBRA '87 and the goals of creating the right types of environment can be handled in one location and there's somebody to negotiate with. The designers are stuck in the middle of trying to negotiate with two or three or four different entities that may have totally different agendas.

Fire safety issues (slide 31). Fire places get to be a problem. Food service. Cooking. Cooking is one of the biggest issues when it comes to the small scale Green House type environments. Grease laden fumes in a cooking situation require very expensive commercial vent hoods. Recently I came across a study that was put together by NIST – I believe that's the National Institute on Safety and Technology. They're studying residential fire hazards in kitchens and in that report it said a single [sprinkler] head in a kitchen is probably adequate to deal with fires in kitchens. Wouldn't that be a phenomenal thing? Nursing homes are already fully sprinklered. Why do we need expensive vent hood systems based on the NFPA 96?

Other dangers in the kitchens (slide 32). How do you keep residents away from chemicals and sharp knives and forks and hot surfaces and things like that? Well, some of the anecdotal information that's been found in many of these households is that people understand what a kitchen is. They've lived in and dealt with kitchens their whole lives. They know what a hot stove is. Why do we have to have special things in the facilities in order to keep people away from what intrinsically is knowledge that they already have. Maybe allowing or requiring some locked compartments for chemicals and things like that, that might not be quite as much of an issue. That might be helpful.

Sanitary issues. Six inch sanitary legs [Speaker's added clarification: kitchen cabinets raised 6" off the floor to facilitate ease of cleaning and commercial grade equipment and surfaces but which are excessive in the case of small scale kitchens], all of the NSFI equipment. It's very expensive and not really necessary.

Corridors (slide 33). A big issue. Why do we need corridors? One thing I learned when it comes to fire in a nursing home, there's never been a multi-death fire in the United States ever in a fully sprinklered nursing home. The single-death fires, most of them, a large number have been by residents who were smoking while on oxygen. The corridor is supposed to protect us from that. I don't know that a corridor really serves any function other than circulation. The fully sprinkling solves lots of issues. Handrails. Handrails really don't mean anything when you're across the hall from the place you're trying to get to. I don't think handrails are necessary across every piece of every corridor. There's some regulators that require you to put a fence along spaces like this living room I'm showing (slide 34) to hold a handrail because they say, we'll you can't have more than 12 feet without a handrail when you're walking in a facility. It happens. There are regulators where that is the case. So they're fencing off access to places in order to provide access. Not quite what we're looking at.

Staff supervision. Direct visual control of the environment. What's a nurse station? I don't think nurse stations are needed anymore. (Applause). And, if staff really are caring for residents they're probably in a resident bathroom or bedroom they can't see the corridor anyways.

Accessibility I talked about earlier. We're getting there.

Flammability. Deal with flammability issues. The fire sprinklers again, there's an exception in these codes that allow fire sprinklers to substitute for the special fabrics. And when we're creating fabrics that are causing potential health hazards in other ways, they're PCP related fire retardants that you find in the blood and milk of polar bears. These are issues that are, you know, what risks are we really trying to protect from?

Working towards change. This [the symposium] is a great venue for working towards change. Just a quick plug for SAGE - the Society for the Advancement of Gerontological Environments. This is a group very similar to Pioneer Network in terms of culture change except it focuses specifically on the physical environment. There are six state chapters at this current time around the nation. Most visible is it's [SAGE is] a jury for the DESIGN magazine for Nursing Homes that you see each year, you probably get on your desk. And it's a group that tries to get regulators, designers, clinicians, residents, advocates, operators - the whole group of people together talking, similar to this, in order to really work towards change. Oh, Carmen said we are trying to grow chapters in SAGE. The website www.sagefederation.com will get you there. So if you really are interested in the physical environment, SAGE would be a venue to help do that. And there are a number of regulators I see here who have really grasped SAGE and have used that as a way for them to be able to look at the environment in a different way and say it's a possibility. The dialogue works when you can talk and sit down with the regulators, the operators, the designers, the builders it really makes a difference when everybody can get together in the same room and work towards a common goal and a common vision rather than the opposite approach.

Carmen Bowman, Symposium Facilitator:

Thank you Gaius.

Now we will now hear from the following three Responders:

Representing the American Health Care Association is Chris Mallet who is the Vice- President of Projects with Sprenger Retirement Centers of Ohio and also chairs the Life Safety Code committee with the AHCA.

Representing the American Institute of Architects is Jeffrey Anderzahn, who is the Emeritus Chair of the Design for Aging Knowledge Community and current Chair of the Subcommittee for Post Occupancy Evaluations.

Representing The Green House Project is Robert Jenkens, Director of the Green House Project.

Chris Mallet, AHCA:

I appreciate the opportunity to be here representing the American Health Care Association or AHCA and to comment on Gaius Nelson's thoughtful analysis of household models for nursing home environments.

Mr. Nelson chronicles some of the legislative, regulatory, and social history that has helped shaped how physical plants for skilled nursing care have evolved. While we agree with nearly all of Nelson's recommendations, I think it is useful to focus on three issues this report highlights in particular:

Not part of my written comments, but I would recommend that when the materials are available to read his report it was excellent and very informative.

The codes and standards that regulate the design and construction of nursing homes mirror that of hospitals—so moving from that institutional model toward a more patient-centered, residential model requires change.

To fully embrace culture change and to offer more homelike environments, we need to change more than just the Life Safety Code. We would need to consider building codes, health codes, AIA guidelines, and state licensure requirements, to name a few.

We know that this will not be easy as our colleagues with the Green House Project can attest as their model for care giving has conflicted with codes and long-established pre-conceptions by state regulators.

We also need to prioritize our goals and risks. Is quality of life more important, as important, or less important than fire safety or dietary safety? There's absolutely no reason that the needs for safety and the needs for quality of life cannot co-exist. The long-held philosophy of "a man's home is his castle," presumes that the castle is a single dwelling, so the risks that man may take to enjoy his home would not infringe on another. That philosophy is challenged when the individual's rights must be balanced with others' sharing a community.

So, the first step toward ensuring that a facility can provide a more homelike feel is to insist that all facilities be fully sprinklered. Doing so ensures resident safety for a multiple dwelling and will allow for the trade-offs necessary to move toward residential models like those proposed by Mr. Nelson.

In fact, AHCA has called for full sprinklering of facilities ever since the tragic fires of 2003 took the lives of residents in two facilities in Connecticut and Tennessee. We continue to lead this effort alongside Members of Congress who have introduced bipartisan legislation that would provide loans and grants for retrofitting fire sprinklers in nursing facilities. The *Nursing Home Fire Safety Act of 2007, S.1615,* is co-sponsored by Senators Chris Dodd (D-CT) and Richard Burr (R-NC), and *H.R. 2521*, which was introduced by Representative John Larson (D-CT), is co-sponsored by Representatives Peter King (R-NY), Terry Lee (R-NE), Jim Marshall (D-GA) and Elton Gallegly (R-CA).

We also have worked with Congress on the *Long Term Care Quality & Modernization Act of 2007*, which includes a provision that would encourage facilities to invest in capital improvements such as those we are discussing today.

The final point that I believe Mr. Nelson's paper highlights is the importance of working together—something this symposium is giving us the opportunity to do.

Right now, the building codes for nursing homes do not adequately consider how these facilities function. In other words, we need to be far more mindful of what it's like to care for someone in a nursing home and what it's like to receive long term care.

So, how will we ever understand how to balance building codes, fire safety issues, and the quality of life issues that are at the heart of culture change? If regulators who help to develop these codes and standards don't come to the table with an open mind—one that allows consideration of quality of life concerns and not just whether or not adopting any kind of change is possible—how can these committees make meaningful progress?

And lastly, we must encourage the committees that write the codes, and those that draft the regulations for that matter, to include those who have expertise in providing and receiving care—clinical staff and consumers alike. If not, then I fear that those of us here, who embrace culture change, will never achieve the patient-centered care settings that we want.

It is possible. My colleague on this panel from AIA can attest to it as can the assisted living voice of AHCA – the National Center for Assisted Living or NCAL—both of which have been working closely as AIA has developed building guidelines for assisted living residences. That is a model that we should all consider.

I look forward to working with all of you as we move forward on this exciting journey.

Jeffrey Anderzahn, American Institute of Architects:

I am truly humbled to be in a room with such illustrious people and am particularly humbled to be here with Secretary Greenlee from Kansas and would ask the question why did the other 49 Secretaries stay at home?

Without question the nature of design for the elderly has been revolutionized by the 'household' concept over the past decade. More importantly, this concept knits the built environment and program together in a collaborative efficacy of the individual resident, recognizing that resident as an individual who wants to retain choices in life and maintain a continued connection to the larger community. The era has passed when design for long term care follows a prescriptive medical model that focuses on staff efficiency at the expense of resident autonomy and quality of life.

Mr. Nelson's insightful paper and presentation - and I encourage you all when you get a chance to get the paper to read it, it is very good - lays the foundation for the future, for future regulations, the future for CMS. It provides a number of goals that the AIA has regarding the creation of homes as opposed to homelike environments. But we cannot lose sight of the fact that changing regulations may loosen the health and safety of residents that we are charged to protect. Gauis has been a friend of mine and for a number of years, a leader for the household design concept, and perched on the forefront of the person-directed care movement.

He has contributed greatly to the body of design work that has awakened architects and care providers to a new world of care provision and environments that house that care. The movement has been launched and there are many designers throughout the United States and indeed the world who have grasped that banner and moved it forward in the field.

Recognition of the fact that this 'movement' has many faces and many iterations is really nothing more than recognizing the fact that diversity is a critical part of our American culture. Celebrating individual diversity and encouraging this diversity is a critical part of any regulations that CMS may develop. We can no more prescribe a household configuration as equally appropriate for any ethnic, religious or lifestyle group than we can legislate any home or apartment design. The definition of 'home' is different to each of us and is informed by our ethnicity, our beliefs, our lifestyle and our socio-economic situation. To regulate away creativity and sensitivity to these issues is no more or less than to embrace a revised, but modernized, set of existing regulations which stereotype those individuals who live in long term care settings.

In their groundbreaking book "In Pursuit of the Sunbeam," Shields and Norton clearly lay out the intricacies of household creation and the relationships between people, program and place and I recommend that as another area of reading. Within the chapter on environmental transformation, one can discover that to be a successful household, the environment can take a variety of forms, including modification of existing, more traditional facilities. We must approach regulation modification in a manner that embraces all household models and must, in a sustainable society, also embrace the modification of existing building stock in a manner that promotes the household concept. We must also

be open to acceptance of new care models that may profoundly affect the built environment such as apartments for life that cross the boundary between assisted living and nursing care.

The AIA supports regulatory modification and generally supports the modifications put forward by Mr. Nelson. However, these modifications must be drafted in such a manner that they do not hinder creativity in either care programming or design as have past regulations. This is in fact, the very reason we are here today.

Likewise, they need to be based on evidence from a broad variety of resources and not simply based on convenience or past antiquated practices. Regulations need to address the line between program and environment that is continually being blurred. As an example, the AIA, in its post occupancy evaluation initiative found that a universal or modified-universal staff member who is responsible for food preparation, toileting assistance and resident laundry needs to be thoroughly trained in techniques of infection control as well as how the built environment is designed in order to prevent cross contamination. If that staff member remains untrained and if the environmental controls are diminished, the opportunity for the spread of infection will significantly increase.

We as residents of the 21st century are hopefully more humanistic, more empathetic and somewhat more informed than our predecessors. If we modify CMS regulations which simply shift requirements from one paradigm to a more updated paradigm, we have done nothing but moved forward in time when we should move forward toward an enhanced quality of life. We need not simply change regulations for the sake of change, we need to change regulations for allowance of design and care creativity that truly moves the lives of our elderly into a paradigm that is meaningful but recognizes that that paradigm is dynamic.

Robert Jenkens, Green House Project:

From:	Robert Jenkens, Director, THE GREEN HOUSE® Project
Delivered:	April 3, 2008
At:	CMS/Pioneer's: Creating Home in The Nursing Home: A National Symposium on Culture Change and Environment Requirements
In Response to:	*Household Models for Nursing Home Environment*, Gaius Nelson, President, Nelson-Tremain Partnership

I would like to add my thanks to The Centers for Medicare and Medicaid Services (CMS) and The Pioneer Network (Pioneer) for bring us together for these exciting discussions and to begin the important work of forming a strong coalition between like-minded advocates to secure deep and enduring culture change for people living and working in our nation's nursing homes. I also want to thank Gaius for his excellent paper and his hard work throughout the years to improve the physical environment of nursing homes.

Gaius speaks of two approaches to culture change in skilled nursing homes – households and the small house. The Green House Project is one example of a small house model. Each approach, households and small houses, has great potential. They share many policy and regulatory issues and each has distinct areas that require discussion and innovation. I want to speak briefly about

The Green House model in relation to Gaius' descriptions of the models, their benefits, and related regulatory issues. I also want to suggest two additional recommendations to the excellent list at the conclusion of Gaius' paper.

Before I do that, I want to mention two things.

- First, the really good news is that culture change and Green House® homes are succeeding within the current regulations through the commitment and partnership of caring regulators. We have forty-one Green House® homes open across ten states. We are currently developing Green House® homes in an additional twelve states. We have been successful in working with regulators to implement this transformative model in each of these twenty-two states. Our collaboration will only grow stronger and more successful as a result of this CMS/Pioneer effort.

- Second, I want to make a strong endorsement for working together and not fragmenting around individual models of culture change. All of us believe that what we are doing individually is special. This is natural and it is good because it is what propels us. However, all of us also want choices for ourselves and those we care about when long-term care is needed. We are working for culture change to increase choices that fit our individual needs and preferences, not to replace a largely singular institutional model of nursing home care with a single culture change approach. If we are to succeed in creating many good choices, we need to push ourselves to develop our own models as we help others develop theirs.

I raise this second issue because I am beginning to hear arguments over which model is better or best. I am concerned that if we begin to limit the exploration of varied, evidenced-based models, we will become our own greatest obstacles to meaningful change and choice. Multiple creative approaches will incubate a wide range of successful practices, expanding choice and offering tested innovations we can each integrate into our own models. Current and long-term diversity, I believe, is critical to our individual and collective efforts to provide meaningful lives and continuously improve satisfaction for those living and working in long-term care. The strengthening collaboration supported by The Pioneer Network, CMS, states, providers, and consumers will make it possible for our culture change movement to try many ideas and allow on-going research and markets to sort out where we are succeeding and where we can learn from each other. Shutting down this diversity by needing our own model to be the "right" or "best" model will fail to take full advantage of the unusual opportunity before us today.

The Green House Model & Benefits

So what are the benefits of The Green House model's small, detached home with semi-autonomous operations, self-managed staff teams, and self-directed care and why should it be part of this diversity? Four reasons:

1. The Green House home's research results shows significant promise for creating a successful culture change model, including a variety of approaches that can inform continued innovation. Rosalie Kane's research at the original Green House® pilot site found:

"RESULTS: Controlling for baseline characteristics (age, sex, activities of daily living, date of admission, and proxy interview status), statistically significant differences in self-reported dimensions of quality of life favored the GHs over one or both comparison groups. The quality of care in the GHs at least equaled, and for change in functional status exceeded, the comparison nursing homes. CONCLUSION: The GH is a promising model to improve quality of life for nursing home residents, with implications for staff development and medical director roles."
(*Outcomes of Small-House Nursing Homes: A Longitudinal Evaluation of the initial Green House Program*, Journal of The American Geriatrics Society, June, 2007)

2. The Green House home's small size and semi-autonomous operations allow great flexibility in staffing, schedules, and operations to meet the individual needs of the elders and staff in each house. It is a natural laboratory for learning more about the impacts and needs of multiple culture change approaches implemented simultaneously. This is particularly true for staffing flexibility. For any organization with minimum acceptable staffing at or above one certified nursing assistant to ten elders and a commitment to consistent staffing, The Green House model's universal worker and self-scheduling approach and ability to add whole or part-time shifts when and where needed, offers strong tools to support appropriate staffing flexibility.

3. Small, fully detached, and semi-autonomous homes create very strong barriers to a slow slide back into institutional practice that many culture change advocates worry about.

4. And, perhaps most importantly, the same small, fully detached, and semi-autonomous approach provide Green House® homes with a viable structure and operations to create a model of skilled nursing care that is fully integrated into the natural communities where people live – allowing skilled nursing care to truly become a community-based option.

Regulatory Issues

While The Green House Project faces many small and medium regulatory issues as Gaius and Carmen Bowman point out in their excellent papers, including:

- The definition and size of corridors
- The configuration of the fireplace
- The kitchen exhaust and suppression hood
- Allowing personal furnishings

We have found good compromises working in strong and supportive partnerships with local and state officials. These compromises have, generally, strengthened the model rather than eroded it. Within this context, I found each of Gaius' recommendations would provide an expanded foundation, education, and communication for these partnerships and am happy to endorse all of his recommendations. I suggest adding two additional recommendations to Gaius' list:

1. Community-Based Skilled Nursing in Small Homes

Background: One variant of the small home approach that holds great promise to fully deinstitutionalize our approach to skilled nursing care is to move small homes off of campuses and embed them in the real communities where long-term care consumers live. To achieve community integration, a "scattered site" approach of one to two houses at a "site" is required to minimize impact on the existing community and avoid isolation of the homes on a mini-campus. While the homes would have twenty four hour direct care and nursing staff at each site, they would need to share other clinical and administrative to be financially viable. Sharing these services requires that multiple sites would need to operate under a single license.

Recommendation: Form a working group between The Pioneer Network and CMS to identify any federal or state regulatory or program issues related to a defined "scattered-site" strategy for small home nursing homes operating several "sites" under a single license. Create and execute a strategy through the working group for necessary information gathering and policy modifications to support and fund a multiple state pilot for a scattered site small home nursing home model.

2. Well Spouse/Partner

Background: Typically, in traditional nursing homes, few well spouses or partners (spouse) would choose to move into the nursing home with the spouse requiring services. With new, more residential culture change models of nursing care, the desire of well spouses to live with their long-term partner will increase. Continuing to share a life and be actively engaged in the care of an impaired spouse is something we all want to encourage. Current state and federal regulations present barriers or uncertainties in this area. Can a well spouse live in a licensed nursing home without the need for services? Does a well spouse living in a home count as a resident for the purpose of licensed bed calculations?

Recommendation: Form a working group between The Pioneer Network and CMS to identify any federal or state regulatory or program issues related to encouraging well-spouses to continue to live with their partner when nursing home care is required for only one person in the couple. Create and execute a strategy to remove any indentified barriers.

Chapter 4:
Lighting and Glare

Introductory Remarks - Carmen Bowman, Symposium Facilitator:

Lighting and glare in the nursing home. Something we think of often? Or not? In my experience as a surveyor I did not see a lot of focus on the quality of lighting or the problem of glare. CMS regulations do identify adequate lighting as a requirement for nursing homes. However, findings from the CMS funded Quality of Life study found lighting to be at the level of, are you ready?, blindness. This means that in the homes studied, the lighting level was so low in wattage that it was equivalent to being blind. As I've researched this issue in writing the background paper for today, I've come to realize the impact lighting can have on all of us for good or bad. Thanks to the experts here today, I now am sensitized to why certain lighting actually hurts my eyes, usually direct lighting, and how such a simple thing as indirect lighting does not. We have much to learn about lighting and how we can use it to enhance resident's quality of life and staff's quality of work.

With that, I would like to introduce Elizabeth Brawley.

Ms. Brawley, president of Design Concepts Unlimited of San Diego, CA, is a consultant and senior interior designer who specializes in supportive, therapeutic environments for aging and Alzheimer's special care, and encourages exploration of innovative design solutions. She has served as a board member of the national Alzheimer's Association and currently holds an advisory position with IESNA (an acronym you will be familiar with by the end of her presentation) the Illuminating Engineering Society of North America. IESNA developed national building standards for lighting, for senior environments adopted in 2001 by ANSI the American National Standards Institute.

Betsy has gained national and international recognition as an expert and industry leader in the area of environmental design for aging. She was awarded the 1998 Polsky Prize for her first landmark book *Designing for Alzheimer's Disease: Strategies for Creating Better Care Environments* published in 1997.

And she is the author of the newly released *Design Innovations for Aging and Alzheimer's - Creating Caring Environments* published in 2006 - a detailed guide for a broad range of design issues essential to maintaining independence and functional abilities, maximizing mobility, staying socially connected and encouraging good health.

Welcome Betsy Brawley.

Elizabeth Brawley Presentation – "Lighting: Partner in Quality Care Environments"

Thank you Pioneer Network. Thank you, thank you, thank you CMS. Thank you Karen Schoeneman and thank all of you for being here. I'm one of the ones who has a little bit of perspective on how far we go back on this. I was a new advocate with the Alzheimer's Association in 1986, and in 1987 Nancy Mays who wrote *The 36 Hour Day* sat up with me all night long before we hit the hill the next day to promote OBRA '87. I had the privilege of going into Representative Henry Waxman's office to talk to him about OBRA '87 and why we thought it was so important particularly from the perspective of the Alzheimer's Association. We all work in nursing homes and we know that the percentage is somewhere between 50 and 70% of the people that we work with have dementia. So it was incredibly important. I sat down with Ruth Katz, his assistant, who as it turns out knew ten times more than I knew about OBRA '87 even having after having sat up all night long with Nancy Mays. This was also my first visit to anyone on theHill. Now I have new respect for all of the advocates that go out. But Ruth was kind, was incredibly kind. What I did not know was that she really was one of the people responsible for writing that entire legislation. She was kind enough to set me straight on a couple of points that I had gotten a little confused about and was very gracious when we left to thank us for coming and thank us for the work we were doing in supporting that. So I didn't realize until Gaius said it was 21 years ago, I have to tell you that it is 21 years ago and it feels like it was about 5. But the good news is we've come a long way in those 21 years. We're not there all the way, but it's with the cooperation and the coalitions of working together that we've come the distance that we've come. I'm just incredibly grateful for where we are today with the new models of care that we're coming up with, with a lot of the things we're trying to do.

One of the fields I've been interested in, in the last few years particularly is lighting because I think it is one of the things that is the least understood and one of the things we need to do more with than almost anything else in the settings we work in. I bring this to your attention with this particular slide, not that we're going to try to cover any of this. But we work with people who are aging. I happen to be one of them right now and was just talking to a few people earlier saying, "We're designing the nursing homes that we're going to be living in." And you know what? We are. And as much as I don't ever want to think that I'm going to be there. And I'm sure there are a lot of other people who feel that way; probably the people that live there now feel that way. I want to be sure that it's a place that I can live in and I can be happy in. I know that we have the potential to do that, knowing how far we've come.

Some of the age-related changes that we deal with are arthritis, hypertension, hearing impairment, vision impairment, mobility impairment, depression, diabetes, osteoporosis. Interestingly enough, most of these things are affected by light and lighting. So improving the lighting can substantially affect [them]. Hearing impairment for one, a lot of people read lips whether they're conscious of doing that or not. And when they can't see, it makes it even harder for them to hear. Vision impairment, mobility impairment - when people can't see they don't get up and move around. So we really need to make a lot of changes.

Our eyes actually do change as we age. Mine unfortunately look more like the one on the right than the one on the left now (slide 3). But what we want to do is to keep the vision as sharp as possible. Some of the things that are normal age-related vision changes, the pupil gets smaller, and I'm going through this because why we need lighting changes really makes a difference. These are things that happen. These are normal age-related vision changes. The pupils get smaller and almost fixed in size so they let

in less light which means we have the ability to see less. It's difficult to adjust to changes in light levels. And we see that most commonly when people come from high light levels outside coming into a building and very often the light levels outside are a hundred times or more greater than they are inside. When you come from light levels that may be 3,000 foot candles into a building where it's five in some of the entry ways, it's very difficult to make those changes and almost impossible to see. Now there are ways that we can address that by adjusting or adapting the lighting in entryways for a start. In the entry is a good place to start. We can also provide places for people to sit down for a minute while their eyes adjust. These are not costly changes to make. There is a lot about lighting that is. It is amazing the technology that is out there now. But there are some things we can do; at least it is interim measures until we get to the others that are very effective.

The lens thickens; it starts to discolor. Color – people see color differently. People have difficulty focusing, and we have a loss of contrast sensitivity. These are some of the changes to the lens that happen. If you can notice the one on the left is from a 10 year old child. When I said that the lens thickens, this is a 65 year old person on the right. Most people in nursing homes are not 65; they're older than that, closer to 85. So it starts to show you why some of the things that we do, do make such a difference.

Some of the vision issues that we deal with are reduced vision acuity. And again, when people don't have enough lighting, they can't see, they don't know what's in front of them, they're not going to move and we need to keep people mobile. They have a restricted field of vision. They have a high sensitivity to glare. Changes in depth perception. This is why what we put on the floor makes such a difference. Impaired ability to adapt to changes in light levels that I just mentioned. Contrast sensitivity and restricted color recognition. All of this, by the way, will be on the website [both the paper written by Elizabeth Brawley and the Power Point presentation she used are on the Pioneer Network website www.pioneernetwork.net]. So if you don't want to take notes that's okay for right now. Eye diseases are more prevalent in older people than they are in younger people. In just a minute you're going to see a couple of slides of what it looks like if you have macular degeneration which is the foremost cause of blindness in people over 60. Cataracts – about a three minute operation but by the time people get into the nursing home they don't have cataract surgery. It's also one of the most successful surgeries that we deal with as well. Glaucoma is huge and diabetic retinopathy, and I know that all of you are aware of how much diabetes has increased recently…another major cause of blindness.

You're going to see a couple repetitions of this same slide (slides 8, 9, 10, 11). This is what you might see if in fact you had normal or close to normal vision (slide 8). This is what happens when you have macular degeneration (slide 9). You notice the white spot in the middle. And that expands as the macular degeneration increases. By the way, there's not anything you can do to stop that right now. There's an immense amount of research going on and we're very hopeful that things are going to happen. Interestingly enough I think it's Gentech [that] has a drug out, Avastin, a cancer drug, that has been found with some effect with macular degeneration, but it doesn't cure it right now, and we're not there.

This is what happens when you have cataracts (slide 10). It's why contrast is so important. Can you imagine if you got up every morning, and this was as good as it got? I don't know what I would do honestly. We need to be very careful with the way we design so we can make it as good as we can make it. This is glaucoma, and it's for all practical purposes the effects are about the opposite of macular

degeneration (slide 11). Instead of taking out central vision it takes out peripheral vision. But it obviously shrinks your world immensely. Very often you'll see people who walk down the corridor walking somewhere and they're moving their heads from side to side. It's to use that range of vision that they have left to see what is going on in the environment. The purpose for doing this is not to teach you everything you need to know about eye disease, but this is what we're dealing with whether we're aware of it or not in nursing homes. This has nothing to do with multiple other reasons or probably most of the reasons people are in the nursing homes but this we deal with as well. And if we're going to talk about quality of life we need to be well aware of this and some of the things we can do to change it.

Some of the implications of age-related vision loss… [one] is an increase in falls. Falls, unfortunately, lead to many hip fractures and broken bones. People who get hip fractures in nursing homes, sometimes a third of those people are dead within six months to a year. Now, it's unfortunate, and it doesn't have to be that way. I'm not saying we can eliminate every fall. We want people to get up and walk, but we've got to provide lighting so that they can do that. A third of the people 65 and over fall each year. This is not even related to nursing homes. A third of people 65 and over fall every year [in the general population]. Half of the falls are recurrent. One in ten falls results in serious injury. And 87% of the fractures in the elderly are due to falls. So, lighting contributes about 100% to the effect that we have on falls, fractures and mobility.

Some of the risk factors of falls are age, vision changes, weakness and strength loss, balance, fear of falling, cognitive loss, incontinence is now on the list, environmental hazards, lighting is the number one or poor lighting is the number one environmental hazard on that list, and medications. The rest of this [slide show] is really pictures. I hope you'll enjoy it. I'm going to try to point out some of the things that we can do successfully to ameliorate some of these problems. Environmental supports encourage mobility and mobility is huge. We need higher light levels. We need to control glare, provide strong contrast, and if you'll notice the difference between the color of the floor and the color of the wall including the base color. People have problems with depth perception. Very often when we either cove carpet up a wall or we use a base color that matches the carpet, it gives a false sense of where the horizontal plane is and where the vertical plane is. These are things that contribute to falls. There is a strong contrast from one to the other and it's in the right place. Handrails for support. I agree with Gaius we don't need handrails at every single possible opportunity including the doors into the rooms but we do need the kind of handrails that people can use. The little round handrails do not work for older adults. The number one chronic problem for older adults is arthritis. And they usually have it in the knees which affects mobility or in the hands which affects the joints there which means they can't grasp a little round handrail. We need a broader, flatter, bull nosed handrail so that people can use their forearm for support or grasp of whatever ability they have to do that.

So how do we improve the lighting? We need to have higher light levels, even illumination - that means even lighting from one wall all the way to the other and from front to back. This is not a place where we want to do drama lighting for anybody. We need to eliminate glare. We need to provide task lighting for the tasks that people are doing whether that's eating and having plenty of light to see what's on your plate. Strong contrast. Broccoli looks good on a white plate. Rice does not show up on a white plate. I think very often people don't eat because they can't see what's there. These are things that we can do something about. We need to balance day light and electric light. We need to combine direct and indirect light and provide gradual changes in light levels. You're going to see some photographs on this.

Lighting, I'll grant you, is not probably the least expensive change to make. There are some things, and we try to point out the things that really work. The first thing that I would suggest for any of you is to get a licensed lighting designer. Lighting is immensely complex, and I can't give you five steps to successful lighting on do-it-yourself. It's not something that most of us are familiar with other than buying a lamp that we like or maybe even buying light bulbs or even the new compact fluorescents the CFLs. But we see a lot of lamps in nursing homes, but I can promise you that even if we switch all of them out to the compact fluorescents, it isn't going to improve the lighting and it's not because of the CFLs, it's the wrong kind of lighting and it doesn't provide enough.

This is a slide from the Abrahamson Center that used to be the Philadelphia Geriatric Center where the renowned Powell Lawton was (slide 17). I was privileged to work with Dr. Lawton on the redesign or the design for the new center. One of the things he was also passionate about was light and lighting. Interestingly enough, the fixture that we've used is above the window wall and a lot of people would say, "Why would you put a light fixture on a window wall?" The window wall is usually the darkest wall. The light comes through but it comes through and hits the opposite wall. This is a lighting valance that we've used that provides up light and down light. It's also one of the things that helps to control the glare. This one you can write down. This happens to be one of the least expensive light fixtures that I know and really effective. This one is a product from Crown Lighting. You can go to their website. We've used it and you'll see it in a couple of slides coming up on three walls along with dimmer controls as well. This will light the perimeter of the room. That will be in most cases not the only light you will need. You will probably need a light still in the middle of the room or maybe more than that depending on size of the room.

This is from an Alzheimer's facility that we did (slide 18). We put this lighting on three walls. This was new construction; for any of you using new construction, get a good lighting designer because it will make all the difference in the world, and it will get your lighting to a point where it is economically feasible to incorporate a lot of these things. We used the cove lighting on three walls. As you'll notice, we used some light fixtures in other places in the room as well. We used light controls – a new word in lighting in the last 10 years - but we used dimming switches. Interestingly enough, when we came to the valueless engineering that we all deal with if we're doing new projects, they've value engineered out the lighting controls. The comments we got from the residents, they loved the lighting most of the time but they didn't like bright light at night, imagine that. They couldn't dim it because they took out the dimmers. Three years later they went back put them in and it cost them almost double to do it instead of putting them in with the system to start out with. So, you know, bite the bullet decide what some of the things are that are the most important, and try to do it right from the start.

This may not be the most beautiful bathroom in the world (slide 19) and unfortunately the interior designer was diagnosed with colon cancer and had to leave the project. They did get the bones of the project right which is the most important thing. We ended up with European showers which have immensely cut down on the number of falls. It's very interesting and Maggie, you're a researcher, I don't know any research has been done on this, it doesn't seem to matter how high the threshold is, it's the fact that there is one. A lot of people as they get older don't really pick up their feet when they move forward, and it doesn't matter whether it's one of those rubber dams or whether it's a higher threshold, it's [the] fact that it's there. The European shower eliminates that. We also put lighting in the shower. The part that they missed was the contrast. They did put the grab bars in but they used white tile and white grab bars. May I tell you, that older people who have vision problems, even younger people who

have vision problems can't see when there's no contrast. For what they spent on the grab bars, I don't know how useful they are. Obviously with the European showers, you can also use the shower chair rather than a built in shower seat which again doesn't work well for older people for the same reason. They use the same color, the same tile, and on the shower seat as they do on the surrounding wall so they can't see that either. So, they either fall over it or don't use it. The contrast again is missing on the counter top on the lavatory. It makes it hard to find the basin. We do have, very limited, but some limited research that shows when people see things they actually use them. It would be nice to have that on the grab bars on the toilets too which is one of the most effective grab bars that we use anywhere in this configuration for older adults. It allows independent toileting, it allows assisted toileting, it allows one-person assist, it allows two-person assist and we have lighting, again this inexpensive cove fixture that goes all the way across the wall and lights both the toilet and the vanity top. So, I can't give them an A+ with what they did with some of the rest of the things but at least they got the things in there that mattered and what we need to fix is fairly easy to fix there.

For some of the country kitchens that we do, one light fixture is not going to do it. There are some inexpensive fixtures here actually (slide 20). The above-the-counter lighting and the below-the-counter lighting is just strip fluorescent - the cheapest thing that you can use and one of the best forms of lighting for this which lights the task on the countertop and also throws indirect lighting up to the ceiling. We have another type of lighting which is pendant indirect meaning it hangs off of the ceiling. It gives you indirect glare free, or controls the glare, from the light throwing the light up to the ceiling and has some light that comes through a shielded base. They do use some direct lighting as well. I mentioned before we need to use combinations of lighting as well. Also not having quite such a slick finish on the floor, we could just get rid of the wax. The fact that it's waxed within an inch of its life has nothing to do with whether it's clean. It's a slip hazard and it's a glare hazard and for people who don't see well, it's not all that great.

We're using more and more day lighting. Hooray for day lighting. It's the strongest form of light that we can get in. It's also one of the cheapest forms of light. Right now we have no regulation and no charge for using sunlight. I'm sure that someone is going to come up with it but for right now it's a great form of lighting done well. We need more natural light inside and outside. We need to use large skylights. We don't use glass for skylights now. We use different products. The one that I use most frequently is Calwall, but one of the things about this is [that] it's insulated so it helps you control the temperature. You're not getting a temperature or a heat gain from that sort of thing. We also need to use large windows, but the biggest point that I can make is that we need to use both windows and skylights so that you get sufficient light from above and light from the sides. It's not a case to use one or the other. I'm not suggesting you eliminate windows if you have them or not to use them and use large windows if you're in a building process. But the most successful is to use both.

This is an Alzheimer's facility that opened up I think about four years ago in Connecticut (slide 22). So it's wonderful in bad weather, but it's also wonderful in good weather as well and the space is insulated. One of the things that was done, it was one and a half floors, total 78 beds and I think there were 48 on the first floor. It was built on a clustered neighborhood model here. One of the things that we worked very hard to do was to try to make it easy for staff to get people to this space. One of the most wonderful things that came out of this is that staff rarely has to ever direct or help anybody into the space. They find it on their own. Now again, this is total Alzheimer's and they're finding their way. I don't know what their system of way finding is, another research project, Maggie. We do know that

with very little assistance they're finding their way to this space, and this is where, by choice, they spend their days. Now there are other spaces where they do different activities. Between each one of these clusters is a garden that they have access to in good weather. They're all secured and most of them are different. However, the high light levels that we get through the expanse in this room is one of the things that really draws people in there. This is a jazz band that they had in the same space. So not only do they do a lot of the activities we do in nursing homes. Please go to adult day care. They have the greatest activities in the world. I mean just life is their activity. There is something always going on, and the people are really happy. I think that if you're stuck on activities, go visit an adult day care center. But this was wonderful. I want to go back one of these days when they're actually doing this. I think they come in once every couple of months to do it.

This is an example of how when using natural light we can really enhance the light in a lot of spaces (slide 23). This atrium is just to the rear of this space. So you get a lot of natural light that comes through there. They've used a combination of cove lighting, pretty inexpensive, and also pendant indirects. And I've noticed they've used several. This is not one suspended light fixture in the middle of a room. We have to have more than just one or two. They have plenty of windows. They have shades on the windows (slide 24). These are set with solar timing so that nobody has to do anything. As the sun gets at a different pitch in the sky, the shades automatically came down to shade the space. It also saves on the system well because you don't have 50 people making changes all day long. It's a cost to put it in to start with. The payoff comes within 2 – 3 years with almost all of these features.

These are sky lights (slide 25). This is at an adult day care center where they've used multiple smaller sky lights in conjunction with good electrical lighting. Large windows - they did something that I thought was really unique here - they have storage underneath and have created an indoor gardening space (slide 26). So instead of just putting in big windows, they made something more out of it. This is another example of large windows. It's not necessarily the architectural type that you would use across the country. This happens to be, guess what, in the south and it works very well. They have open access to the outside to secure garden spaces. Other types of large windows (slides 27 and 28).

We also are doing everything that we can to encourage people to go outside. Providing an unlocked door and a secured space is not going to do it. We have to have an unlocked door and a secured space, but that's not what's going to get people outside. It's your staff that's going to make all the difference in the world, and having things to do. Move your activities outside. There's almost nothing that we do inside that we can't be doing outside at certain times of the day. We use porches, sun rooms, green houses, walking and gardening and gathering spaces. We need to get more day light exposure for the health benefits as much as anything else. It helps to maintain circadian rhythm; it helps to promote better sleep quality. Who in here is in a nursing home that doesn't have sleep problems? I don't see any hands in the air. One of the things we use most frequently is medications. Medications are directly related to falls and one of the things we can do is get people outside for about 20 minutes or so in the earlier part of the day up until around 11:00 even or in the later part of the afternoon. People do not have to sit directly in the sun and look directly in the sun to get the benefits of the sun. So start having tea or coffee in the mornings out in the sun outside or whatever you do, your exercise class or whatever. Promotes vitamin D synthesis which builds healthy bones with exercise, prevents depression and reduced agitation. And we do have the research to back that up.

Sleep disorders are experienced by about 50% of people over 65. This doesn't even count people in the nursing homes. 72% of nursing home residents are poor sleepers especially those with Alzheimer's. Sedatives and hypnotics are often used, and these things are directly related to fractures. This is the same material on the roof of this porch as we use in skylights which means that people can sit outside; they get the benefit of sunlight without sitting in the direct sun, and it also insulates this area as well (slide 32 and 33). This is one of the projects we advised against some of the furniture that they wanted to use for outside. Against our advice they got the furniture anyway which promptly broke, but these were great people with a lot of imagination and they decided to have a furniture refinishing class. These are just other residents who are sitting on the porch doing whatever they do. Make your porches deeper because there's no reason that we can't do activities on the porch but you've got to have the space, and if you have a narrow porch it doesn't work (slide 34). What we've found is that if we can get people to come outside - the lemonade, cookies, whatever you use to bribe people to get them out there at first - that if we can get them out, within a couple of weeks we'll have them out walking in the garden and out in the greater part of it.

This is an atrium space (slides 35, 36, 37). There are lots of ways to provide shade, and if you don't, people won't go out. There are lots of different ways to do planters. Things that are activities that people can engage in. Meaningful activity means a lot to the residents as well. It's not something just to keep them busy. Exercise. Get them out walking on the walking paths. Be sure that you tint your walking paths so that you don't get the glare from the sun that bounces up in people's eyes. Interestingly enough if we can get two people walking together - there a lot of residents who don't like to be touched for whatever the reason -this is a social acceptable form of touch that we can do by getting people outside and walking together. Lighting can and will make a greater difference in the success of a health care setting than any other single feature other than the healthcare itself. Ultimately, and I don't think there's any dispute about that, it's your staff, the care that you offer that make the difference.

Now, I have several recommendations but I'm going to spare you the rest of them for the moment. I have one particularly and that is someone said earlier that you do adopt other regulations, that you don't instigate all these things but you do adopt them. The IESNA which is the Illuminating Engineering Society of North America put together a document which Carmen told you about earlier. It was adopted in 2001 as an ANSI building standard - American National Standards Institute. So whether or not you're aware that there are national standards for senior lighting, there are. We're asking that CMS adopt the ANSI/IES RP-28 as the standard for lighting. It's been adopted by the American Institute of Architects so it is being included in a lot of the new construction. It was put together by some of the top experts and top researchers in the country so the work is done. The revision was just completed. The new one will be out in May of 2008, and thanks to my colleague and conspirator Eunice Noell-Wagoner, you will all when you come back from lunch have an order form for the RP-28. And I bring that up only because it's probably the best single lighting document. It gives you the light levels that you need to try to achieve in different areas all the way from the janitor's closet up to main activity rooms, dining spaces, whatever. These are minimums not optimums, but they're light levels that we should be trying to achieve in the best interest of our clients and our residents, our mothers and our fathers and our grandfathers and for us as well.

Carmen Bowman, Symposium Facilitator:

Thank you Betsy.

There are two Responders for the subject of Lighting and Glare:

First we have representing the The Long Term Care Professional Leadership Council - which is a combined group of the American College of Health Care Administrators, the American Medical Directors Association, the National Association of Directors of Nursing Administration in Long-Term Care, and the American Society of Consultant Pharmacists. Representing the LTC Professional Leadership Council is Marianna Kern Grachek, President of the Council and also CEO of the American College of Health Care Administrators.

Representing Wellspring Innovation Solutions is Tom Lohuis, CEO of the Wellspring Institute.

Marianna Kern Grachek, Long Term Care Professional Leadership Council:

Ms. Brawley's presentation emphasizes the importance of improving the quality of life and photobiology of older adults through adherence to enhanced lighting specifications for building design and construction. She advocates for: a) compliance with the ANSI/ESNA RP-28-2007 ANSI approved edition of the *Guidelines for Design and Construction of Healthcare Facilities 2006* which contains specifications for *Lighting and the Visual Environment for Senior Living;* b) Increased specificity for the quality of lighting requirements in state and federal regulations; and c) a more consistent enforcement process for lighting in nursing homes.

The Long Term Care Professional Leadership Council, representing the professional disciplines of Medical Directors, Nursing Home Administrators, Pharmacists and Directors of Nursing in long term care, advocates for a person-centered culture and environment that supports optimum functioning, safety and quality for both residents and staff. The care environment exemplifies: a) staff with demonstrated competency in managing the physical environment (including optimal lighting) to best support and meet the individual care needs of persons served; b) evidence-based lighting requirements that support enhanced visual functioning; and c) the availability of resources to meet the identified needs of the unique populations served.

The Council's position is that appropriate lighting is critical to optimal vision in our nation's elderly. To that end, our recommendations address that link to optimal functioning and the need to educate providers and staff about that link. The Council's recommendations are several:

- To ensure environmental competency, clinical and administrative disciplines must receive formative and continuing education and be held accountable for conceptual learning through proficiency testing and implementation in the practice setting:
  - ✓ Education curricula must include a conceptual awareness and appreciation for the impact of environmental light on vision and quality of life and its photo-biological benefit for older adults.
  - ✓ The development of clinical skills must incorporate the importance of conducting a comprehensive, individualized assessment of each person served to identify vision needs that are impacted by the presence and/or absence of adequate light.

- ✓ The interdisciplinary plan of care must address all environmental factors, including the impact of lighting on vision, that affect the delivery of individualized, person-centered care. Lighting adaptations must be individualized and include, but are not limited to the following:
  - light is appropriate to meet the visual acuity needs of the individual served;
  - lighting levels in bathrooms is sufficient to support independence;
  - illumination is sufficient to reduce the risk of falls, especially for individuals with dementia;
  - there is visual contrast in the environment to help individuals adapt to reduced contrast sensitivity;
  - there is a reduction of glare through dimmers, blinds, anti-glare screens, low gloss floor care, window filters, etc.;
  - there is sufficient time for individuals to adapt to changes in lighting;
  - vision health is addressed, including low vision rehabilitation, the diagnosis and treatment of underlying age-related eye diseases, and barriers to vision care;
  - adaptive eye wear (glasses, contact lenses, visors) is available, accessible, labeled with name, and in good condition;
  - there is environmental adaptation for reduced color discrimination and color sensitivity;
- ✓ Supervisory and managerial staff must coach and mentor staff to monitor the environment of care to ensure appropriate/sufficient lighting is available *and* utilized and that vision care is embedded in the culture of care.
- ✓ Administrative staff meets the needs of older adults who are working in our nation's nursing homes. They can do this by:
  - Providing well-lit work surfaces and task lights;
  - Remove fluorescent tubes;
  - Use diffuse or coated lamps to reduce direct glare; reduce indirect glare by proper positioning of luminaries in relationship to the task or surface and low surface brightness of the luminaries.

- The blueprint for professional licensing requirements and testing must include the impact of light on vision, health and well-being for older adults.

- Evidence-based best practice research is needed to demonstrate the cost-effective impact of appropriate lighting on vision (acuity, contrast, glare, and color discrimination), photo-biologic health, and quality of life. Results must drive professional/clinical preparation and testing as well as regulatory oversight.

- Evidence-based research is needed to demonstrate best education practice for instilling environmental/lighting competency and the environment of care culture in staff.

- The long term care organization must be equipped with adequate resources (including lighting to support the health and quality of life) to meet the needs of the population served. To that end, to the extent that regulatory mandates are utilized to achieve the desired positive outcomes, governmental reimbursement programs should recognize and fairly compensate for, added expenditures.

The challenge is to link economic and intellectual capital to ensure optimal lighting and vision in our nation's nursing homes. And reflecting on a comment that Elizabeth Brawley made, it is the staff that is going to make all the difference in the world.

Tom Lohuis, Wellspring:

Good morning everyone. I'm Tom Lohuis. I'm from the Wellspring Institute. When I was first asked if I would speak at this conference, I said, "Certainly, I'd be interested in seeing change with regulation and with CMS." When they asked me to speak on glare and lighting I thought this was a perfect example of CMS in their infinite wisdom being an oxymoronic phrase because I'm a registered nurse, I'm a certified nursing assistant and I'm also a nursing home administrator. But I wanted to take a few moments to discuss the publication that was already addressed today and how helpful it is as a clinical document.

Not only does it help you identify information about what sort of adjustments can be made on a global level within the institution, but also on a level that can meet individual resident needs. That there are different approaches other than intensity but also sort of other implications that lighting has and doesn't have. It also provides you with tangible approaches to address specific deficits and abilities of our elders to maintain their maximum level of functioning. It also talks about the necessity of having clear and consistent lighting throughout the facility, not just in certain areas but near elevators, near stairways, near room entrances. It also talks about sufficient lighting to identify access ways to both rooms and to toilets. And also something I didn't think about, but the necessity of Vitamin D with the decrease in access to natural lighting, it increases the needs for Vitamin D usage, thus also preventing falls and fractures.

Some of the recommendations that are in this document are:

- assess elders for all types of visual difficulties;
- reduce the perceived correlation between hygiene and cleanliness and a highly buffed floor;
- consider glare and lighting in which behaviors might be problematic, such as socialization. My mother who was recently admitted to a nursing home didn't know that two other people were sitting at her table just because of where they were placed at her table in front of the light prevented her from actually seeing them.
- their expressions of fear. If you're coming down a hallway and they're back lit, what does that actually look like coming at you? Is that a human being or something else? It looks like a big black blob to you.
- there are falls when glare reduces visualization of the floor surface so that they're not seeing where they're walking or where they're stepping and missteps can result in falls and fractures.
- lighting intensity that draws elders to unsafe areas. That light at the end of the hallway, if you're in that sort of facility, that attracts people and that's an unsafe area for that individual.

As a clinician I can say for certain that advocating for more assessment is not going to make me very popular but currently with the MDS 2.0 you're taking a look [at] simple things such as whether one can read newspaper or headlines. We need more assessment than that. It will also allow for improved socialization as people are able to see one another and recognize people. It also allows for the

continuation of some of the hobbies, cards, games, sewing that many people are unable to do because of their visual acuity. It will decrease the risk of falls and unsafe activities. And it will improve mood states. I knew a facility that simply had a very large fish aquarium but the light system they used behind it had the same number of lumens that were needed to treat seasonal affective disorder so activities were held around this aquarium so it was a double benefit to the residents.

As you can see, looking at lighting and being sensitive to it and the implications for our elderly, I think all of this is well worth it and I will stay on my time. I found frequently that ending early has never really bothered anyone.

Carmen Bowman, Symposium Facilitator:

Thank you Responders

Chapter 5:
Home and Homelike

Introductory Remarks - Carmen Bowman, Symposium Facilitator:

CMS's Tag 252 may sound familiar to most of you. It is the regulation requiring a Safe, Clean, Comfortable and Homelike Environment. Did you know that CMS's interpretive guidance defines a 'homelike environment' as one that de-emphasizes the institutional character of the setting, to the extent possible, and allows the resident to use their personal belongings that support a homelike environment? Wow.

The term "homelike" was one of many great forward steps of OBRA '87. Now the culture change movement is taking another step forward in creating something even more than homelike which is simply "home." Miguette Kaup said it best when she said, "'Homelike' implies 'Pretend this is your home.' Whereas, 'Home' means 'This is where you live.' Although the culture change movement is moving beyond the term "homelike," CMS is to be commended for including it in the regulations so long ago. The attempt on CMS' part to require nursing homes to create a "homelike" environment that "de-emphasizes the institutional character of the setting" is exemplary and certainly in accord with both OBRA's and the culture change movement's intent to help a person live out their highest quality of life possible.

What we invite you to "grapple" with today is why is it that nursing homes continue to look the same as they did decades ago even with a resident outcome-based survey process, even with this requirement for a homelike environment? I cannot help but wonder if we have all become immune to the institutional environment. We all – surveyors, providers, ombudsmen, residents, families - see it week in and week out, expect it, and aren't bothered by it because it has become the norm. Why is it that we have also accepted as norm that someone else decorates and decides what this home should look like? Dr. Calkins is always asking the question, it is designer-decorated or resident-chosen? The administrator of Littleton Manor in Colorado, Roger Harper says it best when he said on Colorado's public radio, "Why should I pick the paint? I don't live here and if I pick a color they don't like, I'll hear about it later, so… Why should I pick the paint?" It's become one of my favorite lines. So, how do we create true home where it is, like Steve Shields says, you sigh "ah" when you get there? How do we ensure residents feel "at home" and not "in a home?"

With that, we turn our attention to this very subject. There is so much material on this issue, that we've invited two speakers to present from their research and their experiences.

We have all had the privilege of already meeting Dr. Maggie Calkins.

So, I would now like to introduce to you Dr. Lois Cutler.

Dr. Lois Cutler began her career as a National Institute of Aging post-doctoral candidate at the University of Minnesota, where she initiated a program of environmental research into ongoing studies of quality of life in nursing homes and assisted living homes. After her post-doctoral fellowship she

joined the University of Minnesota's Division of Health Policy and Management in the School of Public Health as a research fellow.

She is an expert in conducting post-occupancy evaluations to examine how long-term care environments are actually being used by residents, family, staff, and visitors, and how they are evaluated. Her current and recent projects include:

- a longitudinal study of the Green Houses in Tupelo, MS;
- development and testing of a self-assessment tool for nursing homes to examine their environments with reference to quality of life;
- development and testing of an idea manual for improving physical environments without major construction;
- a resource module on physical environment for Quality Partners of Rhode Island, the lead Quality Improvement Organization for culture change;
- studying the capacity to provide good care and generate good outcomes for persons with Alzheimer's disease in small house nursing homes, and
- developing recommendations for the 2010 Guidelines for Design and Construction of Health Care Facilities, Section 4.1 Nursing Facilities.

Dr. Cutler's most recent publications include new measurement approaches for physical environments and use of outdoor space by nursing home residents.

Dr. Cutler is on the board of the Episcopal Church Homes of Minnesota, where she is a member of the Design Committee that has developed prize-winning designs of low-income housing including the first HUD 202 building to utilize geo-thermal energy.

Welcome Dr. Lois Cutler and again Dr. Maggie Calkins.

Dr. Lois Cutler Presentation - "Nothing is Traditional about Environments in Traditional Nursing Homes"

This morning you witnessed the art of the possible and now my presentation is going to show you the reality of what actually is out there. The session planned today includes typical nursing home environments based on ten years of my research, findings from the Quality of Life study, I'm going to introduce you to our wonderful new website Nursing Home Regs Plus and then I'm going to provide recommendations at four levels: the federal, the state, for developer/designers and for staff and administrators.

The Quality of Life (QoL) in Nursing Homes study was funded by CMS. It included five states, there were 8 nursing homes per state, 131 units, 21 special care units and it included 1988 residents. For the environmental component, we had an environmental team that included the late Powell Lawton, Rosalie Kane, Howard Degenholtz, Les Grant and myself. And we developed three assessment tools. Now think of this, 1988 resident rooms. The Resident Room and Bath [tool] had 112 items. Can you imagine checking off 112 items in each of these rooms? For the Nursing Unit, we came up with 140 items that included the shower/tub room, the lounges, the multi space rooms, the corridors, etc. Then we looked at another 134 items that were part of the Facility-wide [items]. And what's so special about these assessments and the data we collected is that we have the specific objective environment of each individual and you can link it to the quality of life functional data including the MDS. For this study, and for most of our work, we have a definition of physical environment that includes the fixed, semi-fixed and unfixed components of physical structure and furnishings, fixtures, decor and equipment. We did not study any of the spaces that the residents do not use, for example, the administrative offices or the kitchen. But we did look at odors and noise, etc.

For the QoL study, 11 Quality of Life domains were determined. Now as you go through this list (slide 5), I want you to associate some part of the environment, some feature of the environment that connects with autonomy - either enhances autonomy or inhibits autonomy. For example, automatic door openers. Fire doors are required, but automatic door openers are not. Privacy. Private rooms. Dignity. I mean the signage… There is so much in our environment that takes away from the dignity of the individual. I think as far as time, I won't go through all the different domains but I think it is useful. As you look at your facility, think of these 11 domains and say, "Okay, it's either enhanced or it is inhibited."

Now I'll describe some of the findings. Sharing space. Of our 1988 residents, 580 were in private rooms, 58% were in two-bed, 178 were in 3-bed, 78 or 4% were in 4-bed to 6-bed. And yes folks, there were 6-bed rooms, I saw them. Whereas, four [bed rooms] is supposed to be the max.

Bathrooms. Oh, this was so tragic. 25% of the people had private bathrooms. 42% shared with two people, 5% three, 18% with four people – those would be your connecting rooms most likely. 10% shared the room with 5-20 other residents. 13% of the residents had to travel outside of their room in the corridor for the bathroom, for their primary bathroom. And the longest distance – some of them had to travel up to 82 feet. Can you imagine having to go to the bathroom and having to walk 82 feet?

Storage. Regulations require that storage be accessible, individual, private closet space. Now, when I think of accessible, I think, "Okay, I can go to my closet and reach something." Wrong. 7% of the clothes rods were accessible and 65% of our participants used wheelchairs. Now all it takes is a simple bracket, you can move it up or down, under a dollar. But I remember time and again there was a resident sitting in her corridor, she pushed her call button mainly because she wanted somebody to come in and retrieve her sweater. It's just unnecessary. We found 37% with lockable storage, only 41% had counter space around the bathroom. Now you wonder, nine bathrooms had space 2 by 2 by 2. What's the importance of that? The importance is that a space that size can enclose incontinence products. I mean, how many bathrooms, 9 out of all of them had that space? Whereas the time it takes for a staff member to run into the resident's room wherever they're stored, it would be so simple to store them in the bathroom. And even though it is a dignity issue, when we looked around, it was one of the items we checked, in 14% of the rooms, you could see incontinence products.

Sharing space. One counter and one chair. We found 23% of the rooms did not have a chair for either the resident or a visitor to use. And how we determined the space that a resident had was the area within their curtain. And here if you can see this one (slide 8), two bed – they shared the one chair. Although when we would count it, we would have to count it as a part of within the curtain. Now many of these older facilities, they're configured with the storage space on one side, double loaded storage and then the other is just possibly drawer storage if they're lucky. But that's often the only flat surface. So here you have storage on one side, two TVs on the other (slide 8).

There are so many barriers to autonomy. Long, undistinguishable corridors, as seen here (slide 9). One thing that I thought was interesting and Gauis even talked about it this morning is each state, many states have different regs as far as the specific distance to a nurses' station. Minnesota is 140 feet and that ruling is that from the furthest bedroom, the distance should not be more than 140 feet to the nurses' station. Well that's understandable but time and again I would go into a facility and I had my little push measurer and it was often 280, 380 … totally disregarded. In fact, one administrator didn't have a clue. So I strongly suggest set up satellite nurses' stations, well the only reason you need a nurses' station is to receive a call and now that wireless technology is coming you don't even need a nursing station. In fact, the Otterbein communities, the small houses, they do not even have the lights above the doors. So technology is changing things. We found limited use of automatic door openers. Main doors 19-yes, 20-no. For Unit, only 2 yes. And I think the saddest part for us was the bathroom key needed for the central shared space. Often there were signs that said, "For visitors or staff use only." Not for residents. I mean how would you feel about that? I remember once up at Eventide there was one resident, I was pushing my little measurer and he was at the end of the corridor and he said what are you doing and I'm measuring how far it is to the main Town Square this gorgeous Town Square and he said, "It's almost a quarter of a mile" and truly it was and then he said "when I get there I have to go another 50 feet to get the key from the concierge desk in order to open the bathroom which was such a heavy door." The policy of the facility, they were so proud was that yes our residents can use it but at what effort?

Here are just some examples of distances. There's your primary toilet .02 miles, think about that. The bathing area - 270 feet. I remember one gentleman just flailing with his sheet around him as he was pushed down the corridor. These traditional nursing homes - there's a lot of distance to be traveled.

Inadequate light levels. Betsy did such a wonderful job this morning. There's a little story about this. But first I took 3053 total light meter readings. In each of the areas, we took four readings so it was not

like you [just] walk in a room. There was a protocol that Les Grant designed and we followed it. But Karen [Schoeneman] was with me when I was in Florida. She was a good trooper, she was doing assessments and measuring chair height etc. So I sent her in a bathroom. You remember, Karen? And she came out, she said, "This thing isn't working" one of the light meters. So I said let's take it to a window and see. Of course then it was, of course working. And she came out and it was literally one, one foot candle. And as Betsy said, we wonder why people fall. On top of it, it was a yellow light bulb. But time and again it was ridiculous. What I'm so proud about this study is that we cannot just say it's dark in here, no we took 3053 light meter readings.

Corridor clutter. And you can read about this but what we did with the items was we created scales and our corridor clutter ended up to be a 10 item scale. This is a nursing home up in northern California. As you can see, the facility is so proud because they not only had everything on one side but they had duct tape on the floor to see where to store items. But the sad part is, as I remember one person, a resident, she was in a wheelchair and she had had a stroke so she could only use one side and she was pushing, you know, grab bars are important, and she was pushing her way down. I kept wondering, how is she going to get back? Is she going to go backwards? Because she just could not have done it. So possibly she was pushed back. I won't go through all of these different categories (slide 12) but my favorite was the 40% Other. And, what we saw. Once I saw this leg prosthesis and I asked the nurse and she says, "Oh my gosh, he died a long time ago." What it shows and what we found is that we become so used to our environments that we don't see what's there. There were so many bird cages out in the corridors. One I like [to tell about], a podiatrist was working on feet right in the corridor because so many of these nursing homes are so desperate for space but there are ways to accommodate it.

Personalization – very little personalization. 8% had individualized drapes. I had to include a nice picture (slide 13). This is Perham. It's a private room. They've done a lot of good stuff with storage. So, there are examples that we can use out there. This is my favorite, another one of my favorites (slide 14). This is a resident's space and when you think that 160 feet - each resident should have 80 feet. Okay, you stick the curtain in the middle of the room. But in this case, you've got your heater and cooler unit which protrudes into that person's space but look at what she's done with it. She has her own curtains, she has a wonderful bedspread – she has a jar of peanut butter there too - but what's kind of hard to see, see that thing hanging up next to the drapes? That's her fly swatter.
You can find our checklists on the CMS website and published papers on our long term care resource center website at the University of Minnesota. So all the checklists are available; just print them off. We have to realize that most nursing homes aren't going to change and as I kept going into them I kept thinking "Oh, they could do this and they could do this." They could go to Target and buy new shower curtains for a couple dollars. And so with the wonderful support of the Retirement Research Foundation, we developed self-assessment protocols and a manual that nursing homes could assess their own environment in every category and also we have a book that has some low cost strategies and that's available at the website [www.hpm.umn.edu/NHRegsPlus.org]. Now, when I came home I thought how can people live in these deplorable conditions? I hadn't really been exposed to nursing homes, where are the regulations? What do they say? So I got home, I gathered all the relevant regulations, Rosalie Kane, my boss, she's very tolerant. I printed off all the environmental regulations in 50 states. Low and behold, Rob Mayer and the Rothchild Foundation came up with an RFP and said, "Gee maybe we could put this on a website." So, NHRegsPlus has been developed and if you've not been there, it's an incredible resource. We took every topic from the federal regs, subdivided them, by table. I wish I could demonstrate it now, please, please, please go on it. And for the environment, I got a little crazy

and I divided it into existing facilities and new construction. With that, I further divided it into topics and categories and that's 17 topics for existing and new construction ended up having 19 topics. But it's a wealth of information. You just push a button and you can compare yours [regulations] to every other state.

So, not Dave Letterman but wanting to be, I put together 10 examples of my favorite state regulations. Alright, do you know, and these are verbatim, I'm not kidding you, you can punch on your state if you're from these and this is what they say maybe not in its entirety. But I don't have much time here… Several states require a body holding room. But in Connecticut, "this room may be used for other purposes when not holding a body." "Rags from patient bedding or clothing shall not be used in dietary services."

"In resident bathrooms – some are so common sense - all sinks shall have hot and cold running water and toilet paper." Some regulations are wonderful. Washington state has done an incredible job with new construction. They say, , "you need an alternative to a public address system." I remember a facility owner that was so proud of his new Musak system that he chose all the music for. Okay, in Virginia, "all unique design solutions shall be described with outcome measures". Pennsylvania, "provisions shall be made to keep clothes dry while resident is bathing". And in my home state of Minnesota, I don't know how many ceramic kilns they have but they "must be installed in accordance with the Uniform Mechanical Code." And contrary to Green House, "if patient is allowed to scrape trays, there must be a physician's order." "Household straw brooms shall be used only at the entrance and exit of a building" in Arkansas. And, "deodorants cannot be used to cover up odors." In Idaho you cannot have a raccoon as a pet - I bet you didn't know that.

But my time is up and so you'll have to look at the resource. There are a lot of good recommendations that we have for federal regulations, state regulations, for builders and owners of new construction and for administrators and staff. Thank you for listening and please visit our websites.

Dr. Margaret Calkins Presentation - "Creating Home in the Nursing Home: Fantasy or Reality?"

Hi again, it's great to be back. I want to first reiterate what Lois said about the website, the NHRegsPlus website, it really is a fabulous resource. What she did was to talk about what's out there. What I'm going to do [is] a continuation of this morning and talk about what's possible. We've been talking all day about creating home, getting away from just being homelike, although that's a better step than the institutional model. Being at home, being comfortable, having the right to make decisions about what you're doing, having "refrigerator rights." We've had several comments, both [from] speakers and from the comments people were giving us just before lunch about language, and how important language is and that language needs to lead change. How many of you use the phrase "person-centered care" to describe what you're doing? How many use something that's more like "resident-centered" or "resident-directed care?" I look at language a lot and one of the things that I notice about this language is that it is still third person. It is still "we" are talking about "them," the resident. And it is not really getting at the heart of it. So the language that I like is "self-directed care." "Self-directed care" is first person. You can't get away from it being the resident needs to be making these decisions. If we can get people thinking about how do I support "self-directed care," that's really the goal of what we're talking about.
So we've got lots of images of the old. These are all scenes that you're familiar with. For all I know, some of these may be your nursing homes. I take images from all sorts of places. But there's also the possible. We can make places, people are making places that feel at home. That feel comfortable. Where you can be a host to someone who's going to come in and visit. Where you can play the different roles that we all play in our lives of homemaker, of gardener, of care giver, of all these different kind of roles. And that's what we really need to do. Home is layered in lots of different ways. It is a psychological state. It is an expression of self and it is a design typology. There are certain features in a home in terms of the layout of space that in American culture that we are familiar with.

Let's start with: home is a psychological state. It is a place generally where we feel safe and secure. There are always exceptions. There are people who are not safe at home. But when we're thinking about the idealized image of home, it is a place where you are comfortable, you're safe, you're secure, you're in control of your actions, you're in control of your environment. You can decide when you get up, what you're going to wear, what you're going to eat and we tend to be in relationship with people that we choose. All of these components are necessary for someone to really feel at home. I've spent a lot of time in hotel rooms. There are some pretty nice hotel rooms. There are some pretty not so nice hotel rooms. Just like nursing homes. But I never mistake a hotel room for my home because I may feel safe and secure, I can lock the door and I may be in control of my actions but I'm generally not in relationship with the people or the animals that I choose. In a traditional nursing home, staff have all of the control, they determine when meals are served, they determine what activities people are engaged in, they often determine when people can go outside. We need to change that thinking. I encourage you to stretch the thinking to what decisions *can* residents control. Not starting with "Well, we will *let* them do this," "we will *allow* them to bring in personal items" that is their fundamental right. It is in the CMS regulations, it is a fundamental right. They can determine when they want to wake up, when they want to have breakfast.

You may need to figure out how you change your breakfast service. Maybe you don't even change it but you allow a continental breakfast early and late. So if you want a hot breakfast you get up between 7:30 and 9:00. If you want to sleep later, you get a continental breakfast after that. But you need to be

able to do that in a way that supports somebody's ability to get food later in the evening if they want. This is a facility in Washington where they took a small closet out of the dining room and created a kitchen (slide 7). This is someone from the dietary department who comes in and cooks-to-order breakfast. So when you wake up, you say, "I want scrambled eggs" or "I want fried eggs" or "I want French toast" and she stand there and cooks it for you. Same thing at lunch, it is a made-to-order lunch. This is a small 40-bed nursing home attached to an 8-bed critical care hospital.

Residents can control when and where they bathe. Everybody asks when somebody moves into a facility, you know, what's your preference, do you like shower or bath and do you like morning or evening. It gets written down and never to change. If you say I take showers in the morning, you will always get a shower in the morning. Sometimes, you know, I actually take a shower in the evening. My schedule changes. So, we need to develop systems where people can choose on a daily basis what they're doing, what they do each day and how it happens, in short, residents really can make all of those decisions. They know they're living in a group residential setting. You can get people to agree to work together cooperatively. It's not "me, me, me, me, me, it's us," we're in it together but we want to have some say in how we are living.

Home is also an expression of self. We talked earlier about Tag F252 [saying nursing homes] must provide a homelike environment allowing residents to use their personal belongings. The interpretive guidelines do spend sort of a fair amount of time talking about deinstitutionalizing and residents bringing in personal items. But that's really only one side of deinstitutionalization. And it tends to focus on personalization in the bedroom. That's how it gets interpreted. So, we see the personalization in the bedroom but we don't see the individuality, the autonomy, opportunities for self-expression, and links with the past and family members. And we need to do that outside of the bedroom because people live in places other than their bedroom at home. So we need to focus on the shared areas of the house. I mean if you're going to create a living room and you're going to create a dining room, you're going to create a kitchen, why does it have to be all of the china that the facility provides? What if I have my favorite china? What if I want to bring my china to the nursing home? Okay, it might get broken, I have to live with that but if I want to eat off of my plates, why can't I do that? Or if everybody brought in some of their china, it could be different every day and that could be really interesting. I could have a different plate every day. It doesn't have to be the same institutional china for everyone.
So it's more than just a few knick knacks in your bedroom. It's bringing your favorite artwork, your ancestors with you and if they're large portraits, hanging them in the living room. These are examples of what we see in bedrooms (slide 13). And there are some great examples but we need to go beyond that. It's also about control and autonomy and decision making, being able to rearrange your room in different ways. This is Woodside, this is Creekview that Gaius was talking about earlier, and they did the bedroom layout so that there are seven different places where the bed can be placed (slide 14). You can choose whether you want to be able to easily see out into the hallway to sort of see what is going on or whether you want your bed tucked behind where the bathroom is so that you've got more privacy. You can have it on the outside wall, you can have it on the inside wall. Yes, they had to deal with being able to put the nurse call system on the different walls but there are ways of doing that particularly as we move to more wireless systems. This is a facility down in Australia and other than the two chairs and the sofa, all of the belongings are brought in by the residents (slide 15). So when you come out to sit in the living room, you're sitting with your belongings. Again, another example of art and knick knacks that are brought by the residents that are put out in the public areas, the shared areas of the house. Your

favorite kind of art. All of these things help you feel like the whole place is your home, not just your bedroom.

So we also have home as a design typology. The typical house has the front porch, some kind of entry foyer. You come into the public areas. Gaius [Nelson] talked about this earlier. You've got the public areas, the living room and the dining room. Typically the kitchen is attached to that. Then there is some passage, some separation between these public areas and the private areas of the house. And as Gaius mentioned, we don't have nursing homes typically that have followed that plan. We build institutions. So you open up the front door of the unit and you now call it the household and the first thing you come to is hallway and bedrooms. That's not the way houses are arranged.

So, typical plan, we've seen this a billion times as opposed to the smaller household plans. This is an interesting facility (slide 20), it is 144 beds so it's fairly large. Each one of these L-shaped sections is a household. Each household is completely independent. And it is arranged the way a house is arranged so that you come in the front door and there's your living room and your dining room and the kitchen behind the dining room. And look, there's a back door. How many of you have a back door by your kitchen? Right, so friends get to come in the back door. Most people will enter this household through the backdoor and then there is this transition space before you get to the hallways which are only two or three rooms long which is not a very long hallway with all of the bedrooms on it. So, we can arrange spaces so that they feel from the resident perspective like the way house spaces are arranged and you can do it in a large facility. You can do that in a multi-story building. You can take that same arrangement and take it up in an urban environment. So you can create these kinds of spaces that feel very much like home within existing [buildings]. This is a renovation of a nursing home. This is Providence Mt. St. Vincent (slide 21). This is the facility I was just showing you the Wellshire in Chicago. It's very easy to do that. The top left is a Green House Project. You can do it in existing buildings as well. Take our typical long corridor plan that has the central nursing station that has visibility down the hall in all directions and take a look at just the top part of this space (slide 22). What we've got here is the dining room this central blue space (slide 23) and then the space on the end of the building is the shared social space. If you want to create something different, you want to create households in here, what you do is you take out a couple of rooms in each one of these hallways the way they did at Meadowlark Hills and you make the front door to the house here and you create your living room and your dining rooms here. In this plan, we've shown taking out a lot of bedrooms which isn't feasible but what we did was to take the space down here that was open activity space and converted that back into bedrooms so they didn't lose any bedrooms. This was an early conceptual plan and I don't know what the final numbers were but they could make it work financially. So they ended up with four households. You can do it in an older building.

So let me just go over some recommendations really quickly. We need to eliminate the institutional icons. Nursing stations are not in the federal regulations but they are in a lot of state regulations. This facility calls this the largest nursing station in the world (slide 25). This is only half of it. It repeats over on the other side of this wall. This is for about a 40 bed, they call it a unit. This is not a household. As opposed to something like this (slide 26), we saw these images this morning that Gaius showed at Creekview. This is the nurse work space, the staff work space in a different unit. So you can get rid of those institutional icons and there are lots of institutional icons that we need to be looking at (slide 27).

We need to focus on care, not documentation (applause). We need to develop the systems, the technologies. CMS wants to know what we're doing but we spend so much time on documentation. Quite honestly I know so many facilities that maximize their documentation just to maximize the reimbursement and it's not necessarily the care they're giving or the care that the resident needs. So we need to develop systems that focus on the care. We need to encourage efficient technologies that allow for that kind of documentation and maybe we can circumvent some of the excesses that we see in some of the documentation. We need to look at different kinds of passive monitoring systems that are intelligent, that tell staff only when something is an issue do I need to go and pay attention to it. We need to eliminate tray service. (Applause.) We need to have regulations that say food cannot be served on trays. There is nothing homelike about eating food off of a tray.

We need to make self-directed care a core value. It needs to be included in training for all staff. Not just the nursing staff, not just the dietary staff, not just the housekeeping staff but for the administrators, for the business office, for new board members. You need to have a core training program for your ownership and management team. We need to incorporate it into the job descriptions. Nursing assistants know what they are evaluated on and you can preach resident-centered, self-directed care all you want but if you evaluate them based on how many beds they made and how many residents were dressed by 7:00, that's what's going to happen.

We need to increase basic training requirements. I think it is a travesty that requirements can be as low as 40 hours for a nursing assistant half of which is in a classroom and half of which may be following someone on the floor and in fact they're really working already. Manicurists are required to have 400 hours before they are certified… to do your nails. We need to think about where we are valuing what people who are providing care to our elders are doing and how we are providing support for them. We need training and buy-in from the top. I think owners, administrators and board members should be required to work one day a month or one day every other month (applause). I think owners and board members and stakeholders need to spend 24 or 48 hours as a resident. They need to have that experience. They need to be bathed. They need to be fed. (Applause.) You've got to know what's its like. Again, I think it's a travesty that we let staff give baths to other people when they don't know what the experience is like of being bathed in that equipment. Control, control, control. Residents get control. Who they share a room with, more options on the food, style, location, companion, bringing personal belongings for the bedroom and beyond. I think residents ought to be controlling who is being hired to work, who is going to be providing care to me. I want a say in that. It's more than just a Resident Council. It's really empowering the residents to say we get to determine what we want to do and how our life is run. Thank you.

Carmen Bowman, Symposium Facilitator:

We will now hear from the following three Responders:

Representing the Association of Health Facility Survey Agencies – also known as AHFSA – is Ray Rusin, Chief of the Office of Facilities Regulation with the RI Department of Health and the current President of AHFSA.

Representing the National Citizens Coalition for Nursing Home Reform – also known as NCCNHR - is Janet Wells, the Director of Public Policy for NCCNHR.

Representing the Eden Alternative is Nancy Fox, the Executive Director of The Eden Alternative.

Ray Rusin, AHFSA:

Good afternoon. After following those two fine researchers, I don't like being this far away from an exit. Let me say on behalf of AHFSA we appreciate this opportunity and want to thank the Pioneer Network and CMS and all the supporting acronyms for making this event happen. Five minutes is clearly enough time to ruin anyone's career. However, in five minutes I don't think that in representing AHFSA I could appropriately respond to the all of the issues; and I just thank God that Rhode Island didn't showed up on Dr. Cutler's list. Let me just say that I think that changes on the regulatory level are at least as complex as changes anywhere. And often it can be potentially more so for us because many of the states have to deal with legislative review bodies which tend to get very political and don't get down to really what is the issue we're looking at.

So what I thought I'd do is focus on some highlights of our regulatory world that we live in and kind of in the form of good news and bad news. And I'll start with the bad news and I'll try not to sound like I'm whining. Let me first just say, regarding myself, between 1975 and 1980 I became totally committed to the concepts of Mark Gold and Carl Rogers in my early work in developmental disabilities, specifically around person-centered therapy and unconditional positive regard. Interesting core issues then and they continue to be core issues now and not just in developmental disabilities. but they haven't transitioned out of developmental disabilities into our LTC world. Later in the '80s I was schooled in the Dr. Wolf Wolfenburger's *Program Analysis of Social Systems Implementation of Normalization Goals*. PASSING – it's a great acronym. If you had wanted to predict where we are today you should've taken that course in 1986 and you would've been able to do that. It talks about all the environmental issues and how they impact populations, especially populations that are at risk. Then between 1987 and 1999, I was the director of the first New Hampshire community-based residential medical management program for individuals with developmental disabilities and medical insults. We individualized resident care in a home. We did all our own cooking. We did everything right there. We did this with residents who could have never, on their own, made a home in the "normal" community. So, I tell you all that to basically let you know that as a regulator, I get it. I understand resident-centered care. I think a lot of us do. So, the regulations as they stand are not my fault.

The truth is we know that many regulations stem from statutes that are the result of tragedy and abuse. They're written by well meaning individuals without much regard for the broad statutory impact that they might have on lives of individuals. Regulatory agencies often must balance their responsibilities for routine monitoring of compliance with their responsibilities for investigation of complaints of compliance. This does not leave a lot of time to fit in long-term planning and appropriate changes in regulatory language. Many directors of regulatory agencies find themselves with rules with little history of their impetus but strong oppositions to making any changes because there was "a reason for it at one time." Sometimes, no one remembers those reasons. It's unfortunate but the phrase, "Hello, I'm from the government and I'm here to help." is not humorous because we're not trying. We are trying; we just

don't always succeed. We don't always get at the target we're shooting at. We understand the concepts and we're willing to change.

So now the good news: First, many of us are listening. A lot of us are listening. (Applause.) Many of us are stuck in systems that are very difficult to move or change. That's not because we don't want to change them. There is a prevalent perception that regulations are a barrier to culture change in long term care, and while I recommend to any regulators that we not become complacent or accept that, it is prevalent, it's out there. We've heard today that there is ample evidence and data that some people are doing it anyway. They're accomplishing it within existing regulations. So it's possible. Although the regulations, written in black and white can be a barrier, they can be overcome and there are ways to work around them. It's difficult when conditions are in statutory language because we don't have authority to change statutory language. Part of the problem is that as regulators we do live with some homes that kind of perpetrated those issues that prompted the original changes in the first place. So we're very leery about a change that opens up that door again for those individuals. For many of us it's dangerous because of the ultimate high price that can be paid by a regulator office who has the appearance of "failing to protect." So, lastly let me just say that we are in the middle of an unprecedented time of collaboration. Probably the largest group of stakeholders that I've ever seen is in this room, all listening and talking about the same subject. It's a powerful moment and we really need to seize it and do something with that. There's enough evidence, there's enough data now. We've got places that are doing it. We need to exemplify them, we need to put them out there and we need to show people here are the examples of how to do it. If I made any suggestion at all it would be that this would be a great time for a concerted educational initiative directed at legislators.

I do have one recommendation. I believe that regulatory leaders across the country are prepared to move this agenda forward. My only recommendation to this group at this time is, don't wait for the changes in the regulatory language and don't wait for the regulatory agency to come knocking on your door. Call them up and tell them you are interested, you want to be on this journey and you see something in the regulations [and ask], "What can I do about that?" I really believe regulators are willing to find ways to work around those. Even if we don't actually change the language, it's not impossible. Thank you very much.

Janet Wells, NCCNHR:

Response to Panel on Home and Homelike

By Janet Wells, Director of Public Policy
NCCNHR: The National Consumer Voice for Quality Long-Term Care

Many participating in this symposium knew Janet Tulloch, a Washington author and activist who lived in a nursing home for more than 20 years. In spite of her physical disabilities, Janet was an active member of the NCCNHR board of directors and an articulate, insightful public spokeswoman for nursing home residents. In 1975 she published an autobiographical novel called *A Home Is Not a Home*. In the preface, she wrote: "Millions of words have been written abut the horrors of living in nursing homes and other institutions. However, indifference and insensitivity are more devastating crimes than intentional cruelty and premeditated assault." In spite of her strenuous criticism of the insensitivities of institutional life as she experienced it, Janet acknowledged that her nursing home had "sheltered and cared for her under such favorable conditions" that she had been able to write a book. Her nursing home *was*, after all, a home.

This has been brought home to us at NCCNHR a number of times in the past year and a half as CMS and states have stepped up decertification of poorly performing nursing homes. The conditions in these facilities are often horrendous, and yet almost universally, the residents do not want to leave. As dysfunctional and even dangerous as the facility is, it is home, a place where they have built relationships and developed some sense of trust – possibly misplaced – that they will be taken care of.

This makes it all the more imperative that we work to make nursing homes real homes – both homelike *and* safe.

NCCNHR[1] is probably best known for its criticism of poor care in nursing homes and advocacy for better regulation, enforcement and staffing. It may be less well known to some that NCCNHR has been equally strong in encouraging and giving voice to providers who practice good care and develop innovative, resident-directed practices. The handful of providers who initiated the Pioneer Network first met each other and conceived the need for a culture change movement at a NCCNHR Annual Meeting. It was also NCCNHR – working through inspired consumer advocates such as our founder Elma Holder, Barbara Frank, Sarah Greene Burger, and Carter Catlett Williams – that organized the Campaign for Quality Care to pass OBRA '87, the Nursing Home Reform Law, which requires that quality of care and quality of life be provided to each *individual* resident. The Campaign for Quality Care was an unprecedented effort by consumers, providers, and workers not only to respond to serious problems in nursing homes and improve care but also to change the environment in which care is offered – to make it more homelike. Advancing Excellence in America's Nursing Homes is a successor to that campaign, bringing providers, consumers, professional and paraprofessional workers, and government under one umbrella to facilitate and assist improvement in staffing, clinical care, and quality assurance.

[1] In 2007, NCCNHR members voted to change the name of the National Citizens' Coalition for Nursing Home Reform to NCCNHR: The National Consumer Voice for Quality Long-Term Care, to recognize transitions in the delivery of long-term care to the elderly and people with disabilities.

Last year of course was the 20th anniversary of OBRA, and NCCNHR was asked numerous times to evaluate the law's success in improving care. As I read the excellent papers for this conference, it struck me that – as with so many issues related to how successful OBRA has been – we do not need to change the law or regulations. We just need to enforce the law we have, and to recognize that a homelike environment and safety are not mutually exclusive but in fact go hand-in-hand. For example, Lois Cutler writes about:

- Shower rooms that are "dark, dank, dismal places," cluttered, cold, and lacking privacy. She notes that surveyors do not often survey shower rooms.
- Hallways so cluttered with equipment that residents cannot walk down them safely.
- Lighting so low and uneven that it hinders vision and creates accident hazards.

Margaret Calkins addresses the problem of theft of belongings, and asks, "In what other realm of life do we, as a society, simply tolerate this level of inexcusable behavior?" And yet theft is one of the most intractable and tolerated problems in nursing homes.

Some changes are needed to ensure quality of life in a safe environment. Fire-related Life Safety Code concerns (such as use and venting of ovens in neighborhoods) could be alleviated if not eliminated by requiring automatic sprinkler systems – in addition to hard-wired smoke detectors – in every nursing home in all resident rooms, public areas, and other parts of the facility. It is 30 years and many deaths late, but CMS must move forward to require retrofitting older buildings with sprinkler systems.

Environmental changes will not independently result in a homelike environment – the adequacy of nurse staffing is an issue that has to be resolved. Lois Cutler found resident rooms with commodes placed in them, "trading off dignity and privacy for convenience [presumably of staff]." Margaret Calkins notes that the traditional nursing home configuration of 60 beds along a double-loaded corridor was adopted because that was the number of residents one nurse could supervise on the night shift. Unfortunately, in most nursing homes, staff-to-resident ratios today are still far from adequate to provide safety and quality of care in a homelike environment.

Overworked nurses and nursing assistants do not have the time to provide quality care or develop the relationships that are precious to residents and necessary to making a home of the nursing home. Many of the staff will leave because the job is unrewarding. NCCNHR has been engaged with the Advancing Excellence campaign particularly to promote consistent assignment and provider efforts to address turnover, even as we continue to also support mandatory minimum nurse staffing ratios.

As I read the background papers for this symposium, I wondered whether residents would always agree with the experts – for example, whether there would always be a preference for carpet, in spite of its advantages in reducing noise. The answer of course is that residents should be consulted about environmental preferences. Discussions in resident and family council meetings would help administrators and other staff to identify the best environmental plans for that facility.

In some nursing homes, families worried about abuse advocate for and sometimes install video cameras in residents' rooms and public areas. None of us would want to be on camera 24 hours a day – few would install cameras inside our own homes to record our every movement and interaction with others – but families' fears and desire to monitor their loved ones' care are often understandable and justified.

NCCNHR's board decided after months of discussion to support cameras in resident rooms as long as the resident and his or her roommate do not object.

The camera issue highlights the disparity between the promise of culture change as the Pioneer Movement becomes mainstream and consumers' continuing experiences with understaffing, mediocre care, neglect, and abuse in so many nursing homes. I have worked as a consumer advocate in this field for more than 20 years and have been thrilled with the improvements in outlook, vision, and practice that have occurred. (It isn't unusual for family members to volunteer, when they hear what I do, that a loved one is getting excellent care and loving attention in a nursing home.) But we cannot forget that the purpose of public regulation is to protect, and I want to reiterate NCCNHR's objection to regulators assuming the role of "collaborators" with providers of care, particularly when this role diverts resources from the protective function of their agencies. By coincidence, the April 4 Washington Post led with coverage of hearings on the FAA's relationship with the airline industry, disclosing the dangers to airline passengers when the FAA went "from aggressively regulating airlines to treating them like customers or clients." The regulatory role is necessary and appropriate.

I will close by quoting again from Janet Tulloch: "Growing old and infirm happens to everybody, and this is the future life-style most people are going to experience under present social conditions. Grim though this picture seems, it can be faced with a reality which either can seek to change the system while one is able—or to prepare oneself to live as fully as possible within its confines."

Nancy Fox, Eden Alternative:

The Nursing Home Environment:
Home vs. Homelike: A Matter of Authenticity

By
Nancy Fox, Executive Director
The Eden Alternative, Inc.

Responder for:
Creating Home in the Nursing Home:
A National Symposium on Culture Change
and the Environmental Requirements

April 3, 2008

The Eden Alternative is grateful for this opportunity to respond to the question of Home vs. Homelike as it relates to the physical environments of nursing facilities and the federal and state regulatory requirements governing those environments.

The Eden Alternative is a foundational philosophy for culture change in long-term care with widespread and sustainable application, both in the United States and abroad. Founded by Dr. William Thomas in the early 1990's, the philosophy uses the garden metaphor to help us understand and teach complex ideas related to the transformation of long-term care's physical and social environments.

Because we are taught to think as gardeners, it is our natural proclivity to go to the "root" of the matter. When we examine the federal regulations as they relate to the physical environment of nursing homes, we see the root of the matter is one of **authenticity**. In the physical environment, there has been a decade's long pursuit of the **inauthentic** that is unmatched in any other aspect of life in the world we have created for our infirm and elderly. If we were to apply this same standard to other regulatory codes, the shortcomings of this approach become obvious.

Can you imagine a regulation that states: "The facility must provide "food-like" substances?"; or "The facility must provide "quality-like care?"; or "The facility must have a "fake" infection control program?"

We know that to sustain the body, human-beings require real food and real care. We also know that to sustain the human spirit, human-beings need **real home**. The Eden Alternative believes it is always better to set a goal of the authentic, even knowing that at times we may fall short, than to settle for the inauthentic. We understand that when a mother makes her daughter promise not to put her in a nursing home, she is not concerned about the quality of the food, or even the quality of care. She is absolutely terrified, however, of homelessness and the crushing blow that will have to her spirit. We know that when residents of institutional model nursing homes attempt to escape, they are not in search of a restaurant to get real food, or a hospital to get real care. They also are not in pursuit of a "homelike"

environment. Every single person who has ever attempted an escape from a long-term care facility wants the same thing. They want to go HOME.

Yet, we continue to design and build large institutional environments, usually in the shape of some letter of the alphabet, (the X, the Y, the H, the T), or the infamous "cartwheel" with a large nurses' station at the center of the universe with long hallways, or spokes, coming off it. Daniel Boone with a GPS would have trouble navigating these unfriendly environments, while people living with dementia must suffer the humility of constantly being lost in them. We continue to ask our Elders to live in intimacy with strangers. We continue to create large central dining rooms and centralized shower rooms and large central kitchens that lock their doors at 8:00 pm, denying access to food and drink until the morning. We continue to ask Elders to attempt to traverse long hallways to access food and care, and when they are unable, we put them in wheelchairs and whisk them rapidly down them. These environments are so unnatural for human beings that an entire industry has been created in an effort to keep people in them. It is quite astonishing to realize that 50 years ago the people who care for and regulate the care of animals recognized that animals do not thrive in places that are unlike their natural habitats. There was an entire social movement around the transformation of zoos to create natural, authentic homes for animals. Yet, here we are 50 years later, still asking our Elders to live in places that are unnatural to them.

The Eden Alternative says it is time to stop. The plagues of the human spirit run rampant in these environments. Our Elders' spirits are bleeding, and it will take more than a Band-Aid to ease their suffering. It will take a heart transfusion. Our eyes are wide open. We must now open our hearts, our true hearts, and stop the madness. With their power, our state and federal governments can just say, "No!" **Never again approve any architectural design that is not authentic home.**

But how will we know if it is authentic home? It is certainly true that your home and my home are completely different. Authentic homes should reflect the people who live and work there. That is why we must follow the rule of discretion when using the regulatory hammer to build home. Imposing the ideas of a few onto millions has yet to result in the fulfillment of our hopes and dreams. But there are some very clear and present concepts on which we can all agree. A simple reconstruct when asking these important questions is warranted.

Imagine that you and your spouse are visiting the architect to begin the design of your new family home. And the architect excitedly tells you about this wonderful new design in the shape of a "K" with new modern features, such as – a common neighborhood bathroom, meant to conserve water! Or he shows you 8 foot wide by 75 foot long hallways between your bedroom and the huge dining area, where all your neighbors can eat together, with no option for a more intimate setting, or a shared master bedroom with a "privacy curtain" between your bed and your neighbor's bed. There are certainly some obvious elements of design that no one would choose, given the opportunity to decide. Our governments must recognize these elements and stop approving designs that have no chance of even approaching authentic home.

Next, state governments must abandon their moratoriums on the construction of Medicaid beds. The current criteria of need for new Medicaid beds, based on demographics and existing licensed beds, is an "institutional" way of defining need. The determining criteria for new beds should be, "How are you promoting privacy, dignity, and choice, in this new construction?" or "How are you creating authentic

home?" in lieu of demographic criteria based on arbitrary political boundaries. The current system denies the elders their right to the benefits of choice in a free market economy, where the consumer's desires drive the market.

Even if no further institutional designs are allowed to be built, we still have the issue of existing buildings. Short of bulldozer therapy, the answer here lies where it usually does, listen to the wisdom of our Elders. They know what makes home. They have been doing it for years. With focus groups of Elders and other stakeholders, we should examine all the current regulations that are stifling the creativity of our Elders and staff living and working in culture change homes, and work hard to remove those that are no longer valid, those that impose unnecessary hardship on creating real home, and those that serve the regulator, not the Elders.

Your Elders would go on to tell you that, "You get what you pay for!" It is time for CMS and state governments, through their reimbursement system, to stop incentivizing illness, and start rewarding performance. "Pay for Performance" must become the norm, not the exception. Those providers who are willing to take the risks and sacrifices associated with true cultural transformation should be rewarded for those efforts. Pay for providers to convert un-private rooms to private rooms. To offset the costs related to this initiative, allow families of Medicaid recipients to pay the difference in cost between an un-private room and a private room, if they are so inclined. Pay for providers to develop advanced neighborhood models or to remodel into households, when the existing design allows for that transition, through a higher rate of return in the property component of state reimbursement systems. This higher rate should also apply to the new construction of authentic home.

Pay for providers who are creating authenticity, not only in their physical environments, but also in their social environments. A word of caution here: We must be sure that the performance we are rewarding is truly what we want. There are plenty of institutional nursing homes that, by all the current standards, are performing well. Yet, inside these well-run institutions, people are suffering. Eden Mentor, Steve Shields, likes to say, "We can provide quality of care in a concentration camp, but what is the point?" Therefore, we must examine what we are measuring and redefine quality and performance in terms of creating well-being, not just quality of care. Elders can experience quality of care without well-being, but the opposite is not true.

The Eden Alternative is happy to have a voice in this discussion of the physical environment as it relates to home. But we also know through our work with hundreds and hundreds of organizations around the globe, who are struggling to create authentic home, that true home is not found in the physical environment. It is not about walls and carpet and chandeliers, any more than it is about fur and feathers. The physical environment is merely the container in which the human spirit can either grow or wither. The current physical environments are sorely pressed to support growth. They are like frozen tundra, devoid of warmth and growth. So we certainly need to address the issue. But the most important part of a true human habitat is the soil. Every gardener knows that a rich and nourishing soil is vital to the garden. The soil is the social environment that exists in our long-term care facilities.

We know through our work that there are providers who are currently creating authentic home despite the shortcomings of the physical environments they have inherited. These highly creative people are transforming what they have been given, and in the smallest of ways creating home in their physical environments, while concentrating mostly on creating a warm, caring ethos, where every person has the

opportunity to give and receive care. It is in these types of environments that Elders will truly find home and a sense of belonging. We also know through our work with Eden At Home™ that even an Elder's own personal home can become like an institution when she needs care and all the focus is on the care of the human body while her human spirit is neglected, and her rights to autonomy and choice are removed.

Some of you may be thinking, "We can't go that far. These ideas are just too bold. We need to take our time and go slowly. The Eden Alternative would remind you that over a million and a half people live in institutional nursing homes in this country. These people are at this very moment in harm's way. There is **widespread immediate jeopardy and actual harm** being caused by this pursuit of the inauthentic. There are people suffering and dying from the plagues of the human spirit. That kind of pain is far greater and much deeper than any pain of the body. We do not have the luxury of taking this slowly. We must act swiftly and we must act boldly.

This is **the hour**. And we are **the ones** our Elders have been waiting for. The Eden family is honored to be on this journey with you.

"The elements required for human survival are simple and few. A person can get along with a couple thousand calories a day, a liter of water, a sprinkling of vitamins and minerals, and a steady supply of air to breathe. Shelter that offers protection from extremes of predatory activity (human and animal) is important as well. More than we might suppose, though, human life also depends on easy access to affection. It is affection that brings meaning and purpose to the mundane affairs of daily life."

-Dr. William Thomas

Carmen Bowman, Symposium Facilitator:

Thank you Responders

Chapter 6:
The National Fire Protection Association and Life Safety Code

Introductory Remarks - Carmen Bowman, Symposium Facilitator:

The next two segments of the symposium have been designed differently, so rather than hearing recommendations resulting from research and followed by national responses, we will be purely educated and hopefully inspired.

First we turn our attention to something that many of us do not really know much about, the Life Safety Code and the National Fire Protection Association – or NFPA - who creates it. We have invited the NFPA to come teach us more about the association and how the Life Safety Code is developed, and they graciously accepted our invitation. To introduce them and explain how CMS does not create the Life Safety Code but rather adopts it, is James Merrill. James is the Life Safety Code Lead within the CMS Division of Nursing Homes.
Welcome James.

James Merrill, CMS Division of Nursing Homes, Life Safety Code Lead:

Thank you Carmen, thank you. Originally when I started to work for CMS, I worked in a Regional Office, we did a lot of comparative surveys and things like that. And I came to Central Office and over the years Karen [Schoeneman] would come up to me and say, "Here's a question that a facility brought to me. They said one of your life safety code surveyors on a fire safety inspection said you can't do this, or they want it done a certain way." And sometimes I would say to Karen, well let me show you here in the life safety code where that is. Then there would be other times that I would say to Karen, "You know, that's not true, that's not a life safety code element" and she would say, "Well I'm confused." And I would say, "Well, I can show you in the book where it doesn't say that." And she would say, "Why do you keep referring to this book? And I said "Well, I said, because in the infinite wisdom of Congress, when they designed some of the nursing home rules they said, 'Okay CMS we want you to be involved in fire safety, but we don't want you or we don't think you can write a document to protect the safety of residents, the fire safety of residents in health care facilities.' They said for nursing homes there already exists a document out there. And that is the Life Safety Code. So, you guys don't have to write that, just go and adopt the edition that you want or that is appropriate for health care." So, although they said, "Hey go and adopt this," that's a little easier said than done because you never know what you're getting until you read it.

Now, we [CMS] participate on the code writing portion of it. We have representatives that sit on the various committees. There are committee members here in this room on the various committees, and we thought that Karen had a good idea to show people what the life safety code and the NFPA is and how they came up with it. And it's not really the NFPA. The NFPA is more or less an umbrella organization that brings together people of industry, regulators, consumers and others come together in a committee format to come up with the document, they're a facilitator. And hopefully over the next few minutes, they will be able to explain a lot of how the codes and standards are written. We've heard about range hood extinguishing systems, somebody brought up fire places and things like that. Some of those items are regulated specifically in either the Life Safety Code or some of the other standards. We have two

people here today from the NFPA. We have Nancy McNabb and Robert Solomon that hopefully over the next few minutes, like I said, will be able to explain this.

I'd first like to introduce Nancy McNabb.
Nancy McNabb is the Director of Government Affairs for the National Fire Protection Association at their Government Affairs Office here in Washington, DC. She is responsible for working with Congressional and federal agencies as well as allied organizations to promote the NFPA mission about fire and life safety. Ms. McNabb joined NFPA in September 2001 as the regional manager of the building code central field office, located in Dallas, TX.

Before joining NFPA, McNabb was a service coordinator for Building Officials and Code Administrators International, where she facilitated code adoptions, conducted trainings on code interpretations, and represented the organization at legislative hearings. Previously, she served as a staff architect for Building Officials and Code Administrators, working with building officials in New York State and providing member services throughout the region. Nancy has also served as assistant director for code development and code interpretation for the New York State Department of State, Codes Division. So her background is very wide and has a lot of depth in this specific area.

We also have Robert Solomon who is the Assistant Vice President for Building and Life Safety Codes at NFPA. He oversees the operations of the department whose projects include NFPA 101, which is the Life Safety Code and the NFPA Building Construction and Safety Code, NFPA 5000. Since 1986, he has held several positions at NFPA, including staff liaison for the NFPA water extinguishing systems projects. He has been an editor for several technical handbooks for NFPA including the Automatic Sprinkler Systems handbook, NFPA Fire and Life Safety Inspection Manual, the first edition of the NFPA Building Construction and Safety Code Handbook and he currently serves as the Associate Editor for the NFPA Fire Protection Handbook 20th edition.

He has been involved with numerous investigation projects for NFPA including the Dupont Plaza Hotel fire, the Meridian Plaza office fire in Philadelphia, The Station nightclub and the Greenwood nursing home fire. He has managed much of NFPA's effort in developing code analysis and subsequent changes following the 2001 attacks on the World Trade Center. He is also an active member of the JCAHO Committee on Healthcare Safety; Chairman of the Healthcare Interpretations Task Force; the Council on Tall Buildings and Urban Habitat; the AISC Fire Engineering Steering Committee; the Underwriters Laboratory Fire Council; the Building Security Council Advisory Council, the Infrastructure Security Partnership; and he serves as Secretary-Treasurer of the World Organization of Building Officials.

Please welcome both Nancy McNabb and Robert Solomon.

Nancy McNabb Presentation - "NFPA Codes and Standards Making System"

Good afternoon and thank you for having me. As Jim said, I work for the National Fire Protection Association and we're traditionally known as a "red" organization. So there should be plenty of contrast today between all of the discussions you've had about green and the red that I'm going to speak to you about right now.

At NFPA we say that safety is everybody's business. We don't like to leave safety to some sort of experts or as we do so often in America we count on someone else to tell us what to do. We think that safety is everyone's business, so our mission really is very compatible with all of the exciting ideas and concepts that I've heard today. We are a voluntary, non-profit membership organization. We are not-for-profit and very mission driven. Our mission has been expanded over the years so that we think about the burden of fire and other hazards on the quality of life, and we do this by providing and advocating consensus codes and standards, research, training and a lot of education.

We were organized many years ago, 1896, by a group that got together up in the Boston area because they were concerned about having sprinkler systems that worked in the mill buildings that were very common in that part of the country at that time. We now are headquartered in Quincy, Mass. We have a number of regional offices throughout the U.S. I used to be out of Dallas, Texas. But we have offices throughout the U.S., and we have a number of international offices, in Paris and Beijing and Mexico City, etc. We have over 80,000 members. They are not all fire people. They come from many different walks of life, healthcare being another important area that we have a lot of different codes and standards on, as well as international groups. You can see the different organizations, the different sections that we have (slide 6). We do the National Electrical Code, so we have an electrical section. We have an aviation section. The aviation standards are used worldwide as well. Metro chiefs, the fire chiefs from all the major metropolitan cities throughout the country. So, many different kinds of groups have sections in NFPA.

The fundamentals of our process are that we don't do it with staff. We have about 100 staff, but we do it with many, many members and we do it with volunteers who come together. Some of them serve on our Board of Directors, some of them serve on our Standards Council and some serve on our Technical Committees. The Standards Council is sort of like the Supreme Court. It's got 13 members, they're appointed by the board and they adjudicate appeals. They issue documents and what we call temporary interim amendments, they appoint members and they meet about three times a year. The Technical Committees do the bulk of the work and these are consensus bodies in a system. They're really the group that sits down and hashes out all of the changes that occur to our documents. The maximum size is about 30, but they can grow and shrink depending upon the year and the subject matter. We have over 7000 volunteers that work on about 225-250 committees. They're all balanced by interest categories. In addition to the Life Safety Code that Robert's going to talk to you about, we do about 300 different codes and standards. There are different ones that are hot here on the Hill. Last week we had a combustible dust hearing on dust explosions. We do the standards on combustible dust. We have about 7 documents in that area. Mine safety is an issue. We do standards on mine safety. I mentioned the FAA standards as well. So, lots of different things.

The Technical Committees are reappointed annually. There are many different categories of members on those committees, and you don't need to be an NFPA member to be on a committee. As I mentioned before, there is Labor Category, Installers, Manufacturers, Special Experts, Users, all of these different categories of members come together to form these committees. We usually follow the money. We've had college professors say well I think I'm a special expert but if their funding comes from special industry, then we categorize them as whatever that category may be. We have a Third Balance rule so that our balance is maintained so that we can never have more than a third of a committee in any one interest category. That's an inherent safeguard against dominance - that requirement that we balance the

committees. We also have a consensus requirement. Our committees are balloted and we need a two thirds vote on all changes. So we are very careful to have that balance. It's not complete consensus. We don't sit in a room until everybody agrees to agree like a jury but it is a two thirds majority in most cases.

We have an ANSI [American National Standards Institute] accredited system. It's open. Our meetings are open. There is due process. If you don't like what happens at a meeting with your change proposal, you can pursue that through various phases eventually up to actually a Standards Council decision. What it is that is so nice about this process, and it is the typical American process, our standards making process typically is a grass roots one. What's wonderful about that is that it's an acceptable level of risk for all of the people involved. The electrical inspectors tell me, "You know Nancy when we go into a Mom and Pop store and we see a bunch of electrical cords strung together we never feel bad about telling people you can't do that because we feel like everyone in the electrical business agreed that this is the threshold of safety for electrical equipment." So we're not the electrical police, everyone agreed. Sometimes there are a lot of arguments that occur before we come to the final rule for what those standards should be.

It's a uniquely open process. I'm going to flash through the process pretty quickly. We call for proposals initially, and we certainly solicit your proposals in the nursing home healthcare subject if you would like to submit them. There is a proposal form online. There is one in the back of all of our codes and standards. Then we issue a report on those proposals. We go through some more committee meetings. We have a Report on Comments. Then we have a Technical Committee Report and finally the Standards Council issues the document. So there are typically two revision cycles per year; one in the fall and one in June. We have one association meeting per year and many committee reports in between. So, first step is Public Notice. We have a proposal closing date. We solicit those proposals and anyone can propose a change. Again, they're on the web. Then the Technical Committee or committees, because many of our standards like the Life Safety Code has many committees, and then they have a Technical Correlating Committee that sort of decides which committee trumps which committee more or less, or how to organize the results of those various committees. They act on the proposal and they generate proposals, and for every proposal the technical committee must either accept, reject, accept in principle or accept in part. So in other words, they can accept the idea but not the specific language and they can tweak the language if they accept it in principle or they can accept part, sometimes people submit page long proposals and they can accept part of a proposal. That's balloted even after the Technical Committees meet and vote verbally, they're balloted and they submit written reports and then that's published in a document, the Report on Proposals.

After that, if you're a person who submitted a comment, or you're a person who's watching the process or interested in the process, you again can comment on those proposals, and those Technical Committees meet and look at all those comments again. So if you submitted a proposal and it was rejected you get a second shot. You can comment. You can say, "You know what, the committee misunderstood my proposal, this is really what I meant." Or you can provide data. If the committee said there's nothing that substantiates this proposal for change, you can submit data and additional comments. Once again, for every comment, the Technical Committee can accept, reject, accept in principle or accept in whole or part.

So, at that point we move on to the Report of Comments which again is a publication. It's available on line. It's available to anyone. It's widely distributed. Then we go to our annual meeting where we gather public input. Our membership vote at NFPA is not binding. It is our Technical Committees that we return to for a vote if something is changed at the annual meeting if there is a large objection. At that public gathering session all the members meet and decide which documents will be reviewed. We have something called NITMAM - Notice of Intent to Make a Motion. Where if we have a document and nobody has objected to anything at that final stage it can just go forward. But if someone wants to discuss a document that is being presented at the annual meeting they can have what is called a NITMAM – Notice of Intent to Make a Motion. Once that occurs, everyone can get up one by one on the floor and discuss that issue.

The final step is the Standards Council will adjudicate all appeals. So again, it is a very American process, grassroots, everybody involved like a democracy coming eventually to some final decision that is balanced. It is a balance of, we're not cavalier about safety, it's a balance of the risk, the cost, all of the things that go into the considerations for safety. In your case, it is a consideration of the quality of life with the safety, right? The Standards Council then issues the document, hopefully.

So, a little summary of the Report on Proposals, the Report on Comments, Annual Meeting, and the Standards Council issuance. It's about a two year process and our documents all are on 3-5 year cycles. The Life Safety Code is issued every 3 years. The first year after its issued is typically sort of a restful year but the committees could meet if there's a lot to be done. And then those last two years they begin their meetings, and if not on a special task force, they gear up and go through the whole process.

We have many resources at NFPA to help us develop these codes and standards. We have what's called the One Stop Data Shop. We have a library that's a world class library of documents related to fire and other hazards. We also do fire investigations and research. So the One Stop Data Shop issues reports on electrical fires, reports on the cost of fire in the U.S. We do something for the U.S. Fire Administration called The Needs Assessment of the U.S. Fire Service, many specifically having to do with topics that we do codes and standards on.

We also do fire investigations. We investigated the first bombing of the World Trade Center and did many of the recommendations that were used in the second investigation that we also participated in. Some of our recommendations were credited with saving the lives that were saved. We did the Greenwood Nursing Home fire investigation that has been mentioned as well as the Station Night Club fire in Rhode Island. We have a research foundation that sort of partners private sector with public sector to research topics that need to be researched in order for us to move forward in these codes and standards.

In summary, I guess we are the developers of what I would call full consensus model documents. I tell people they're model because it's like a model house. It's not a home until somebody moves in. I tell all audiences that but it seems very appropriate here today to be talking to you about model standards. They're model because we don't enforce them. Whoever adopts them enforces them. And many of our life safety codes, of course, are adopted at the state level and also by agencies at the federal level. We don't tell them don't change any lines in these documents. If they feel that they need to [in order] to cover their specific situations we hope that they will make them their own. I know CMS has many, many regulations other than the Life Safety Code that they use to regulate health care.

It's a decentralized approach. One of the things I deal with on a constant basis here in Washington D.C. is something called Public Law 104-113 and that is a law that says in the U.S. you must use a voluntary consensus standard if you have one. If it's available you must use it instead of developing your own regulations. So, the various agencies whether it's the Nuclear Regulatory Commission or whatever it is, they have to use these voluntary consensus standards before they go out and reinvent the wheel and write their own regulations. Some of ours that are used are of course the 101, and 501, etc. We're working to make the NFPA state of the art. We welcome your input. We hope that we can find a balance between acceptable risk and commitment of resources. Certainly we hope in the healthcare arena we can find regulations that will make people safe but still make them feel at home and thrive in the end. If safety is everyone's business, safety should make you thrive not just in an emergency by getting to the stairway but in a day-to-day basis by making you want to go on breathing and seeing the sunshine. Thank you very much.

Robert Solomon Presentation - "History, Use and Application of NFPA 101, Life Safety Code"

Thank you very much. Appreciate the opportunity to be here. I have been sitting in on all the sessions, and I have learned more today than I probably have in any of the 2 or 3 conferences I've attended in the past six months. I'm finding a lot to like about this. What I want to focus on is the Life Safety Code, specifically the provisions the Life Safety Code has in dealing with healthcare occupancies. I've developed a list of areas that I think that obviously we're going to have to take a second look at, but I'm pretty hopeful for what I kind of see coming around the corner here in the future.

First off, as Nancy mentioned, we look at this all inclusive process. In our system, we don't think that just the insurance industry or just the code official groups or just the manufacturers should be making final decisions on what goes into these codes. We think it's that collective body, it's that collective knowledge and we talk about the interested parties. We have our own acronyms obviously, most of these you are aware of but if I look at the roster of Technical Committees of Healthcare Occupancies, within the NFPA Life Safety Code project, we probably have some other groups we want to consider adding in here. But at the moment we have representatives on that committee from American Health Care Association, American Society for Hospital Engineers, International Fire Marshals Association, CMS, Jim, you've already heard from Jim, the Veterans Administration, they participate actively, the Joint Commission, Indian Health Services. We have representatives also from the Association of Heath Facility Survey Agencies. We also have representatives from the Department of Defense. So those pretty much represent the bulk of organizations that run, operate, manage or have some oversight responsibilities for both hospitals and nursing homes. And again, we're always looking for other organizations to help craft the provisions.

You've heard a little bit about the background of NFPA in general. The genesis of the Life Safety Code dates back to about 1911 - The Triangle Shirt WaistFactory Fire in New York City. That was kind of the first thing that popped up on the NFPA board's screen in respect to life safety issues. Prior to that, a lot of the focus had been on property conservation and primarily interest of the insurance industry. Now, what we do with the Life Safety Code, again the edition that we are working with right now at NFPA is the 2006 Edition, in about two months from now the NFPA membership, the body politic will be asked to pass judgment on changes that are proposed for the 2009 Edition of NFPA 101. These updates are a result of a number of things I have here in the last bullet item (slide 3). The changes we make to the code are not willy nilly, they get a lot of thoughtful debate, a lot of argument and again moving towards that development of building of consensus. I've heard a number of presentations this morning, and I can't totally disagree with them about, you know, the rules are too rigid, the rules are too inflexible. How will these provisions be changed in the future? Well, I can tell you the NFPA process is very robust, very dynamic and it's very open to those sorts of things. As you've heard, 10 years ago we wouldn't have thought we were looking at designing precise or explicit provisions for terrorist attacks on buildings. Ten years ago I don't think we would be thinking that the upcoming edition of the Life Safety Code would actually developing requirements to figure out how to keep neonatal areas locked in hospitals because of the problem of infant abduction. But those are the exact types of things we've been working on for this upcoming edition of the Life Safety Code. So the code is very robust and I'll tell you, the committee members that volunteer their time, they're just the best in the world, there's no question. I still get amazed that they do this for free for us. It's amazing.

I don't know if anybody has touched on this, we've heard a little bit of it, but back in 1967 .the Social Security Act was the thing that kind of brought the Life Safety Code into being, if you will, within the federal healthcare system [note added later: the Life Safety Code came into the Conditions of Participation based on the 1967 amendments to the Social Security Act]. I think it was called Department of Health Education and Welfare (HEW) back then, they did have the foresight to say, look if the private sector addresses it, don't go reinvent the wheel, let's rely on it, make sure we're involved in that process and even back then there were many representatives from the federal government including HEW that were involved in the committee structure back then. Most of you know the NFPA Life Safety Code is one of those things, if your facility doesn't comply with it, then you have potential for penalties or in the worse case a loss of funding or something even more dire than that. Again, with CMS and its different names over the years, you know, they started out with the 1967 Code. They make periodic updates, 1976, 1985. The NFPA 2000 of 101 is the current edition that they're looking for.

Now how does this kind of dance between NFPA and CMS work? As Jim said, CMS does not develop the Life Safety Code but Jim and Mayor Zimmerman are key members of that Technical Committee on Healthcare Occupancy. So a lot of their ideas come in. Sometimes the committee likes their ideas, sometime the committee tweaks it a little bit and sometimes the committee rejects their idea. But they keep trying, and they are very excellent participants in the NFPA process. So we make the code available but every once in a while we have some special issues that we want to deal with. We have some recent examples maybe: the ABHR - the Alcohol Based Hand Rub provisions. The CDC report came out. We got that at NFPA. We had the healthcare industry say we need to figure out how to get these dispensers in the corridors. We had the fire marshals saying that's crazy you can't put flammable liquids in corridors. So we figured out how to get those two book ends to meet in the middle and the criteria that you now follow that was published as a proposed rule that criteria first appeared in the Life Safety Code through one of those emergency changes back in 2004. So, we have provisions like that. Currently, at federal rule making we have a provision that says that all existing nursing homes shall be protected with automatic sprinklers that is a rule that is maybe going to be finalized in August of this year, that was the latest update I got but again that's that interaction there. We work it through the NFPA system and then CMS will take a close look at that and decide if they're going to move forward. So those are the kinds of things that we work on.

Now in healthcare, in the healthcare chapters as they currently are designed, we talk about providing safety to life and we have this thing about we say we're going to protect the occupants not intimate with ignition. We heard one example this morning one resident who was in close proximity smoking with oxygen we didn't have a lot we could do there. The code would like to get to that point but we're not quite there yet. What we want to do regardless of what that ignition source is in whatever area, we want to make sure we have features in place to protect the surrounding occupants. In the healthcare chapters, we refer to that as the Total Concept. And Total Concept looks at these three distinct areas (slide 7). I think you all know that this presentation is on the website if you want to download it later on. Design and construction compartmentation, detection and suppression and then this third bullet, we've heard about the staff involvement several times, the staff absolutely plays a crucial role in keeping the residents of nursing home facilities (oops, I shouldn't say that word) nursing home environments, safe from the effects of fire and other perils and other hazards. The operating features of the Life Safety Code have, they're directed not only at the administration but also at the staff. The administration has to make sure there is an executable plan. The staff has to make sure that they know what to do and kind of right down the line. In our role, the staff is absolutely crucial.

Now, what I've done is I've identify a couple of areas, and the presentation we heard from Gaius [Nelson] this morning, I was pleasantly surprised because we didn't compare notes but we seem to be on the same page here. So what I've done, in the blue text you're going to see what the current rule (slide 9), the current regulation is and then as Robert Solomon, Staff Engineer at NFPA, not speaking on behalf of anyone else but my own personal opinion, these are the kinds of things our committees are going to have to get more knowledge on, they're going to have to put a little more time and effort in to figure out how to make them work. So the very first one is, we have this definition of a nursing home which sounds pretty edgy (slide 9) but I think one is going to be what collectively are we going to call these types of these environments? We've heard Green House but I don't know if that's trade-marked or a registered name so we need some other generic name that we might have to come up with.

Will there be certain sizes that the code will have to address? In other words, will we have small size or medium size or large facilities? I can tell you there will be a difference in the protection schemes if you're talking about a standalone campus environment with maybe 8 or 10 bedrooms in a building versus if I want to try to make this work in a 15 story building. So there are going to be some different protection schemes that we can look at but scoping provisions will allow that to happen.

Building construction requirements. Healthcare facilities and detention correction facilities happen to be two of the safest places to be during a fire event with that because both cases require that defend in place approach to the extent that we can manage it. So, we have conservative requirements but again my view is they're pretty flexible, they're pretty favorable I think for any future changes we're going to make in here. I heard about sprinklers twice already today. No question. That won't even be a debate. We already have sprinkler requirements in all new healthcare occupancies and regardless of what we call this I'm convinced that will be a key, key feature for protection. Means of egress issues – another one. Doors minimum widths, intervening spaces, the corridor concept. Right now the codes, the codes love corridors. And we've got to have the corridor go from the room to the corridor to the exit, the thing we call the means of egress. So I think we will be able to rethink the whole notion of corridors. I think we're going to see a separate bullet item on that momentarily.

Hazardous areas of separations. Probably nothing too major there. Those provisions are not overly burdensome by any case. If we have medical gas storage, again a lot of medical gas storage provisions are kind of, my opinion, set around the hospital environment. Cooking facilities. Obviously we've heard that one many many times today. Why not? Let's go in, let's take a look at this standard called NFPA 96 which covers the cooking equipment and the extinguishing systems and the ventilation systems. There probably is a (applause), wow, I usually get applause when I shut up, so that's very nice. But there probably is a way to come up with a system that doesn't look like its industrial, it doesn't look like it's a big metal grey thing. We have committees that can go in and look at issues like that.

Fire alarm and detection. This one is going to be a little tricky again depending if we're in a larger structure with multiple staff around versus the campus environment with the 8 or 10 bed model with maybe only 1 or 2 staff people, how do I summon other help if I do have an emergency there? Again, there's the item on corridors. The smoke barrier provision becomes relevant because I think it's in Carmen's paper about, you know, the whole provision about locating fire places and smoke compartments where I have patient sleeping areas. The whole notion of smoke compartments, we'll have to take a close look at that. Right now we don't have any standing requirement that says you

never need a smoke compartment per se. Utilities, illumination, means of egress, illumination of means of egress, backup power systems. Many times those are standard features that come along as soon as you're tagged as healthcare you get a lot of these things. Will those be as necessary? Again, that one I'm not so sure which way it will go. Again, here is my fireplace issue. We do have some provisions that allow it. Probably some changes are going to be needed there to make it work a little better but I'm confident we can figure out some safe ways to do that. I already touched on the operating features and that huge responsibility that's imposed and placed on the staff of those facilities.

So, in summary, as an engineer that has been with NFPA now for some 20 years I have seen these committees just do remarkable things. Any challenge we give them, they figure out how to make it work. As Nancy said, we take input on these proposed changes from anybody who is out there. The only people in the world that can't submit a proposed change with NFPA code or standard are the 300 or so employees that we have. But anyone else that's out there has this ability. You don't have to go to meetings. You don't have to be on a conference call necessarily. So that change is always out there. As I said, we look at things now we never thought about 8 or 10 years ago. I think a precedent for this is what we refer to in our Life Safety Code as the provisions we developed over the years for Residential Board and Care occupancies. Some states might refer to those as assisted living facilities but we use that term residential board and care and that's a good example of where we used to lump those into the healthcare chapter with the very stringent requirements but we found out they don't quite need all that. They need something a little bit less but a little bit more than an apartment and there is another example where we have some size limitations. We've got a couple of items there. For this cycle we're too late, again we're voting on the new code in about two months but next summer, summer of 2009 is going be the next time you'll see or hear about it's time to start considering changes for the 2012 edition of the code which is pretty hard to believe. Again, I'm confident that we can move the needle on this one and looking forward to the input from the group and see where we are five years from now. Thank you very much.

Carmen Bowman, Symposium Facilitator:

Thank you Nancy and Robert.

Chapter 7:
State Success Stories Panel Presentations

Introductory Remarks - Carmen Bowman, Facilitator:

Next we have invited a panel of state and federal regulators to share their success stories of being involved in culture change efforts in their respective states. These regulators are helping to lead the way for change, role modeling to all states what can be done, and we thank them for their efforts.

I would like to introduce to you Cathy Lieblich who will moderate our State Success Stories panel and introduce each panelist as they present.

Cathy Lieblich is the Coalitions Coordinator for the Pioneer Network, a newly created role within the Pioneer Network that she was selected to fill. In addition, Cathy has been the Director of the Florida Pioneer Network since its inception in 1999, and she has 28 years of experience working with and on behalf of elders.
Welcome Cathy Lieblich and our panelists.

Cathy Lieblich, State Coalitions Coordinator Pioneer Network, Panel Moderator:

Thank you. One of the things that I've learned in my short time as the Coalitions Coordinator for the Pioneer Network is that in some states the state survey agency is actively promoting culture change and in other states they are not…yet. I'd imagine that the same is true of the CMS Regional Offices. Our panelists have been invited to speak to you today because of their leadership in advancing culture change in their respective states and in one instance, in an entire CMS region. Three of them are from a state survey agency and one from a CMS Regional Office.

Our first speaker is Carol Shockley.
Carol Shockley is the Director of the Office of Long Term Care in the Division of Medical Services of the Arkansas Department of Human Services. She has a Master's degree in speech pathology and has served in various divisions in the Department of Human Services for thirty-four years. Carol, as Director of the Office of Long Term Care, has instituted a number of innovative programs and processes, including the development of process indicators for best practices and the Arkansas Innovative Performance Program (AIPP) for skilled nursing facilities. She'll be telling you what her state survey agency has done to encourage and nurture culture change. Carol.

Carol Shockley, Director Arkansas State Survey Agency:

Greetings from Arkansas. As a regulator, my primary job is to assess what you already know, the state and federal regulations. However, my role is also inclusive of assessing the landscape of long term care in our state and to determine if what is being offered is what the residents need and if resident needs are being met. But my passion, my true passion, is to develop and work with providers to provide an environment that people want to live and thrive in. The passion that I have evolved to - I think that when you develop something you love, whether it's a hobby, whether it's your work, it's a growth situation, and in mine my growth came with my Dad's diagnosis of Alzheimer's. Watching him through

his stages has led me through my stages of assessing what we are not doing and what we need to be doing in long term care.

Now thankfully, when I had this epiphany that we were going to be able to look at things differently and to craft some regulations that had great meaning to residents, I had some partners. I had some partners that have never let me down, and I hope I have never let them down in trying to see that we can do things differently. And those partners are the Arkansas Health Care Association, the Executive Director is here. When I say partner, we do things together and they followed me to Washington D.C. Randy White is Executive Director of AHCA. When we discuss projects we're including the QIO, and the QIO is represented by Betty Bennett. You just cannot get a more grounded nurse consultant than you will find in your QIO if they have long term care experience, and I think that is the key. So many of our offices and so many of our QIOs may not have the expertise in nursing homes that they will need. Then I have another partner. She hits the road burning everyday trying to be not only an Executive Director of a multi-branched provider group but she's also serving on every committee of culture change and enrichment and collaboration to be found, and that's Peggy Moody.

I thank them not only for their friendship but for their partnership. The partnership that we've been able to establish in Arkansas is one that I think we feed off of each other's energy. We feed off of each other's ideas. And as my friend at the QIO puts at the bottom of every single email and I have never read a more true statement and it has become our catch word, our catch phrase so to speak, and that phrase is "It is amazing what we can accomplish if no one cares who gets the credit." Now when I went on the internet to find out who said this, about eight people claimed it so you can just put Everyone. Everyone needs to believe this. Everyone needs to know that you don't have to have your name beside an idea when it comes to fruition, you don't have to have your agency when something is espoused as being good and that can lead to change.

[The] Arkansas partnership to craft culture change and quality improvement began in 2003 and we've had some stormy days. We've had some stormy days and we've had some days where we can look back and smile and say, "Do you remember when we were arguing about that?" And those are the good old days, and those are the days that we cherish when we have made progress. Not to forget the ombudsman. The ombudsman came on a little bit later in our coalition perhaps because we were not inclusive of her. She is giving us some new ideas that are truly, we believe, going to find their way in the future. Early on our coalition determined the barriers could and would overcome our goals if we weren't very careful. So we tried to road map what those barriers are and our way around the barriers. There are statutory barriers, everyone is familiar with those laws whether we like them or not.

The regulatory barriers. We've all heard the horror stories. I even heard one reference Arkansas [today] about the rags in the kitchen. More about that later. The funding barriers are renowned. I won't be addressing those directly, but I'll tell you what we've done to go around them a bit. To think that any of the individual members of our coalition could accomplish anything that we do is Pollyanna and will never come to fruition. It takes the cooperation and the encouragement of us all to make an idea succeed. To the surprise of many, the Arkansas Health Care Association and the Office of Long Term Care are in lockstep in exploring and implementing culture change. Together with the QIO as the bridge, AOLTC and AHCA are breaking ground every single day on something new regarding culture change and quality improvement.

AIPP was mentioned as one of the things that we've been able to do. I call it APE for short - Arkansas Innovative Performance Project. It has done some phenomenal things in relieving facilities that were unable to hire nurse consultants. We're putting Medicaid money into a program adjacent to the QIOs' 8th and 9th Scopes of Work. And this money is paying off in spades because facilities are able to address some critical clinical issues that they have never been able to address, and we take a great deal of pride in AIPP as a group because it definitely has been a group effort. If the effort had not been put forth to put the group in place, it would not have happened, but if the acceptance by the providers had not happened it would not have worked. But everyone was ready for change and they were ready to do things the right way.

I'd like to describe some of the accomplishment of our work that will never be completed, it will be ongoing. In 2005 I attended an Eden workshop and determined that we needed desperately to look at some new issues, some new ideas. The idea I came away with was that we could do Green Houses. We are largely a for-profit state. And that makes Green Houses almost impossible to erect because of the capital costs. In my mind the Eden Alternative and Green House concept gave promise to both quality improvement and quality of life and gave meaning to culture change. AHCA grasped this and said, "Let's go for it. Let's draft some bills and see what we can do." We drafted two bills because our laws do not allow the use of universal workers because of our minimum staffing regulation that we love because it has increased staffing, but in the right environment such as a Green House, we absolutely embrace universal workers. We changed that law, and we can now in Green House and small house homes have universal workers. And we also crafted a bill that I can determine what CMP projects will be put in place for quality improvement and specifically for the growth and enhancement of Eden Alternative and Green House. Why did I not make it more generic? I wanted something that was grounded and proven and thankfully Rosalie [Kane]'s study had just come out, so I was able to put that forth in front of the legislature.

With me every step of the way was the health care association and the QIO. For me to go into the legislature and ask for this, I would appear pushy. For them to go in front of the legislature and ask for it, they would be greedy. So, what did we do? We went together and we had a balanced attack. In the 2007 [legislative] session our bills were passed unanimously. We had a great guy, Coach Frank Broils who came out of the hills and he endorsed it along with some other Alzheimer's initiative training that was going on in our state and no one could say no.

The second barrier is regulatory. Well, we couldn't have new laws on the books without new regulations, and boy did we need new regulations. Ours dated from 1984. They are antiques. Everyone has backed away from revising our regulations simply because "Oh my, what a job" and "Oh my, what a job it's been." We are almost finished with re-drafting our regulations for traditional facilities. Those regulations are going to be as flexible as possible to allow culture change. Either I or my assistant play the devil's advocate with every single regulation that we're taking out or that we're putting in. Why is it there? What will it do? Is it going to be so involved or so technical or so hyper-technical that people will not be able to grow and develop new ideas? If it is, it's out of there. Then we take it to the health care association and the ombudsman and the QIO to say "New ideas, help us spin them. Does it say what it needs to say?" So when we come out with this group of regs, when I go to the legislature to say I want to promulgate these, I won't be sitting at the end of the table alone. I will have the support that I need when I go in because it's "our regs," it's not "my regs."

With commitment and much work, we believe that culture change can thrive. We're not there yet by any mind at all. We have the fertile ground to plant the Green Houses. We have a willing provider or two, and now we'll have to see what we can do to perpetuate that energy. We will have assisted living Green Houses as well as the nursing home because of our situation of only for-profit homes in Arkansas. NCB [Capital Impact] has given us a little bit of grace to say assisted living can be Green Houses. And if you start looking at these assisted livings that give so much press about being community, what do they look like? They look like little nursing homes that are cropping up. They've got the long hallways they've got it all. So our work still goes on in assisted living. To further assure we regulators keep our heads screwed on tight and don't go a little crazy when we go into the small homes and the Green Houses, all of our surveyors are becoming Eden Associates. One by one, little bit by little bit. I have 21 of them thus far. (Applause.) We're going to be able to do as much as possible in that direction. I have some examples, but I'm out of time and they're madly telling me to shut up. We do have the Civil Monetary Grants that we will be giving to the different companies that come forward and want to build Green Houses. They were arranged for $200,000 to $500,000 each. Sounds like a lot of money to me and to you. It's a drop in the bucket if you're going to be building a Green House. It is for incentive. It will pay for architectural fees and for some training. And for that we thank them very much. And remember what I said, If you don't try to take the credit, spread it around and let it become "our idea," you can have success in your state with culture change.

Cathy Lieblich, Panel Moderator:

For the record, I do not say "shut up." Our next speaker is Mary Gear. Mary is the Administrator for the Office of Licensing and Quality of Care in the Oregon Department of Human Services. Mary has 19 years of experience in clinical, medical and legal social work - hey Karen [Schoeneman], another social worker - in a wide variety of settings with a variety of consumers with functional limitations across the life span. In addition to her work in Oregon, Mary has worked in the long-term care systems in the states of Washington and Michigan. She'll be telling you about Oregon's unique culture change initiative that involves collaborative teams that involve nursing home staff and a state surveyor. Mary.

Mary Gear, Director Oregon State Survey Agency:

Good afternoon. It's a real pleasure to be here, and I bring you greetings from beautiful Oregon where we really, really like pioneers a lot. (Cheers.) My Oregon contingent is down there. I'm really pleased to see the turnout here today and the energy that has been created in talking about culture change. I was introduced to culture change in the state of Michigan where the Eden Alternative was embraced and had the opportunity to become an Eden Associate. And when I moved to Oregon 14 months ago to be the survey agency director there, I was delighted to see that Oregon too had embraced some culture change, and had a wonderful program up and running, and I've been very proud to continue to support that. Oregon is unique in that we applied for the first home and community-based services grant, the waiver, back in the 80's and have a very strong community-based care system. Just for example we have about 28,000 people who receive long term care services in Oregon. Five thousand of those people are in nursing facilities, the rest, most are in their own homes and the rest are in home and community-based services. So, part the reaction from some folks in Oregon is why do we worry about whether nursing

homes are homelike or not, we're moving everybody to community-based care? Well, that's a fairly easy answer when you look at some of the community-based care. As Carol said, we're looking at long hallways, we're looking at rooms off of hallways and really want to support culture change throughout our long term care system so that community-based care really is home as well as nursing homes.

We're really proud of our culture change coalition. It started in 2004 and is a very collaborative effort of stakeholders across all of the different parts of long term care and across the state of Oregon. We have a very broad membership. And as Carol described, it is very collaborative. Everybody brings a little bit different piece of the puzzle and pie together so that we get a good picture of where things need to go. There is a leader in our culture change coalition who we also contract with through the survey agency, her name is Linda Crandall and she's been instrumental in getting the initiative for culture change going in the state of Oregon. She helped create MOVE which is Making Oregon Vital for Elders which is our culture change coalition and also in starting the culture change initiative through the state agency. We contract with Linda to help implement the CCMU culture change initiative. CCMU is our Client Care Monitoring Unit, that's the surveyors. We have surveyors that do both community care surveys and nursing facility surveys. What our initiative does is it pairs a surveyor with a nursing home that is wanting to do culture change. In 2005 we did our first Request for Proposals and had 23 nursing facilities that applied to be paired with a surveyor. We were limited mostly by surveyors. We had six that we able to cut loose to provide technical assistance. We had six homes that started in 2005, and we just finished the process of pairing again another six surveyors with six nursing homes. So we have 12 who are on the culture change journey at least in a formal way in partnership with the state survey agency. We have other homes that are on a culture change journey that we support in other ways, but it is this collaboration that's really most remarkable I think.

There are a couple things that are important about that relationship. One is that it is a relationship. The state surveyor is expected to sit on the culture change team in the facility. Not be the leader, not be the person who comes up with all the ideas, but to provide technical assistance, you'll notice I'm saying technical assistance not consultation to the nursing home as they're looking at what it is that they want to do and how that might be affected or not by the regulations. The surveyors do not act as a surveyor in that facility ever. So that surveyor who is in collaboration with that particular nursing home will not perform a survey in that home. Because it is a very different hat that they wear. It is a very different relationship that they need to have in that setting, so I'll talk a little bit more about training in a minute but keeping their roles and boundaries real clear what they are there for and how they are in relationship is very important. We do use our civil penalty fine fund to support this project. We use that to fund our consultant Linda Crandall to help us keep the project going. We use it to fund tools and resources for the nursing homes that apply that we're not able to provide a surveyor to collaborate with. We've used those funds to bring Nancy Fox to bring training to providers and surveyors about culture change and what that means. We also use those funds for small grants as Carol mentioned to the facilities too. It certainly doesn't fund all that they want to do, but it is a gesture that we want to help you in a financial way along your journey to culture change.

There are a couple challenges I wanted to talk about and then offer some suggestions. As I mentioned, there are more nursing homes wanting collaboration with a surveyor than we can accommodate, and staffing is a real issue. We struggle like all regulatory agencies to keep up with the federal and state requirements for surveys and staying within the timelines. Recruiting surveyors has also been an interesting process. It requires a special person who has survey experience who can think broadly

enough to take on a little bit different role and relationship with a nursing home. And it requires someone who can see that the regulatory process is not an adversarial relationship; that it can be a collaborative relationship. It also requires a surveyor who is willing to have their relationship with some of their team members fellow surveyors challenged at times, fellow surveyors who might not be very comfortable in that kind of a role or who might wonder if there is a conflict there. So it really does challenge some of those relationships that might exist. The other issue that comes up is workload for the surveyors. And that shows up in a couple different ways. One is that we have had to clearly define that a surveyor's job description includes technical assistance to nursing homes in culture change as well as the survey process and make that part of the expectation of their job. For some surveyors they've had to wrestle with that sense of they're letting their team members down because they're not available to do surveys and that increases the workload for their fellow surveyors. And so struggling always with the resource issues and how do we keep the essential work going.

One of the things that I think is really important for the surveyors in this process is for those who have participated in recruiting new surveyors to help out the ability and the opportunity to focus on the positive is huge. You all know, providers all know, we go in looking for deficient practice. We don't go in looking for the good stuff. We go in looking for what's gone wrong and wanting you to fix it. So the ability for surveyors to collaborate with a provider about doing the cool stuff, as I call it, is really a wonderful opportunity. I've been in Oregon for 14 months now, for the first six months on the job I would say to providers, "If I know your facility's name, that's not a good thing." I only hear about the bad stuff, so the opportunity to hear about some of the wonderful things that are happening is really great.

The next challenge for us will be bringing in our local and state fire marshals for technical assistance to facilities wanting to do culture change. I've let them know that I would be coming to this conference and will be traveling back home with information about the Life Safety Code and what's coming and how we can help facilitate that.

In terms of some suggestions, one of the things that I really like about what Oregon's done is that it's not huge but it has a big impact. It didn't require change in legislation. It didn't require a huge change in funding. It didn't require all kinds of staff. It just required some motivated folks to make it happen and some support from leadership. It's not expensive, those kinds of things. Really what's most important about it is training, training, and training. Not only training from folks like Nancy [Fox] about what does culture change mean but training and support for surveyors about their different role and the different hat they wear and support for taking on a little bit different role in their relationship with providers. I would hope that as my colleague Ray [Rusin] said earlier that we in our project could enter a nursing home as a surveyor and say, "We're from the state and we're here to help, really." Thank you.

Cathy Lieblich, Panel Moderator:

You've heard from Ray Rusin before as a Responder so in addition to being the Chief of the Office of Facilities Regulation in the Rhode Island Department of Health, he serves as President of the Association of Health Facility Survey Agencies which represents all 50 [states]. So he is a very important person for us in terms of communicating with all 50 state survey agencies. But what you don't know and now will is that Ray is Chair of RI Generations, the state's Culture Change Coalition. A

state survey agency [director] is the chair of a culture change coalition. It's wonderful. He is a Certified Trainer for the Mediation Training Institute International and currently serves as the Director of International Cooperative Programs for them having conducted *Workplace Mediation* training in Singapore, Hong Kong and this coming summer in India. Ray will speak to you about Rhode Island's Individualized Care Pilot and tips for working with your state survey agency. Ray.

Ray Rusin, Director Rhode Island State Agency:

Thank you Cathy. Good afternoon. I learned two important things in the last 15 minutes. One of them is Steve has to go last and that thing that Carol said about not having to have your name on everything increases the likelihood that I won't end up parking cars. Thank you and I'm very honored to represent a state that is at least perceived to be being successful. I think we're perceived as being successful because of an Individualized Care Pilot that we're running that I'll talk about shortly. It's not that Rhode Islanders are not pretentious, because we are. Even though we're a small state, you'll often hear our traffic reports often say something like "traffic's backed up to the border." Duh. Everything's backed up to the border in Rhode Island.

This is the slide that I prepared for them because they told us it had to be one page which is probably better for you in the long run. The first item I'm going to talk about is leadership and I'm sorry that I didn't put on here at the time leadership and "followship" because I think they go hand in hand. You can't just have leadership. People need to hear what you want and they have to be ready to implement that. This has been leadership and "followship" on all levels. From our director, Dr. David Gifford who is the Director of the Department of Health in Rhode Island to my staff working, my program managers and surveyors. We've had an incredible working relationship with Quality Partners of Rhode Island who is the QIO in Rhode Island and with CMS who has been a partner with us in the Individualized Care Pilot as well as with all that other stuff we do for them.

Our Individualized Care Pilot, it is mentioned on the Pioneer Network [website] and there is a link to the Department of Health's page that goes in-depth on what we're doing. It has been quite a ride, and I want to very quickly tell you we got the grant from the Commonwealth Fund. I'm sure many of you recognize the little symbol here on the sign that the Commonwealth Fund is a sponsor here. And we're really proud of the fact that the Rhode Island state survey agency is one of the few state agencies, one of the few government agencies that has received a grant from the Commonwealth Fund. So we think that was a feather in our cap and we hadn't even done anything yet. But having that grant and having the support of our director allowed us to at least sit down and ask what should we be doing? What should a regulatory agency be doing about all this? What is all this talk about culture change and how does the survey process get impacted?
I want to mention some names because they're here today. We put together a national technical advisory panel. This is going to be some name dropping. Mary Tess Crotty is here. Barbara Frank whom you were introduced to earlier. Maggie McLaughlin from Quality Partners of Rhode Island. Steve Shields. Carol Benner who I believe is here. Pat Maben from Kansas who was a state survey director and I now believe works at Meadowlark in Kansas. Bonnie Kantor and Dr. Koren and Karen Schoeneman who all came together in Providence, Rhode Island. And oh by the way, Carmen Bowman. An incredible group of individuals who came together and really processed us for two days and moved us forward. I'd like to be able to say we took all of their advice and did something with it but we didn't. We're regulators so we don't have to.

Very quick on the Individualized Care Pilot, this was part of our licensure survey really. We do standard federal surveys and licensure at the same time predominantly focusing on the federal regulations. Rhode Island does have a few regulations in licensure that are a higher standard. But truthfully, we're only looking at certification. So everything we did under this pilot was done under the auspices of licensure. So we ended up focusing on just three areas; 1) Resident-directed Choice; 2) Staff and Resident Relationships; and 3) Personalized Environment in terms of how does that feel like home? Very quickly we were asking, the basic premise was, what would happen if surveyors asked different questions? What would the industry do? What would providers do if we asked completely different questions? There are 41 facilities in Rhode Island, you might want to talk to, they'll tell you how they feel about that.

On Resident-directed Choice we asked the residents: When do you get up? When do you go to bed? And, who asked you? And what were the conditions under that? When and where did you determine whether you were going to take a shower or a tub bath or none at all? How did that happen? We asked staff, NA's [nursing assistants], which traditionally is not part of the survey process, we asked them very specific questions. We basically asked them how do you know what the preferences are for a resident? How do you learn about that? You might think that is a simple answer, well, they all say the same thing: I ask the resident. But just having a surveyor ask that question of an NA is a powerful question. And the next question is, How often does the resident get to work with the same nursing assistant? We're trying to get at the issue of a lot of people say they are doing consistent assignment, we wanted to see if they were actually doing consistent assignment from the residents' perspective. On the Personal Environment, we were looking at how are the rooms, how much is under the control of the resident in terms of decoration and their personal stuff? Looking at bathrooms and showers which sorry to report, they were pretty dismal across the board. And then access that residents have to other areas. We haven't summarized all our stuff but we are looking forward to. We just received word that we've been accepted to the Pioneer Network conference in August. My staff will be presenting there, so if you're going to that conference you'll have the opportunity to get more in-depth information.

Some very quick summary statements. Things that we found out, not surprising and it's not surprising that we know these things and we inherently know these. I think that it was very good that it was a regulatory agency that was coming to realization; actually it was my surveyors coming to realization on this. One of them was that the physical environment and the medical trappings those things that we talked about: med carts, nursing stations, shared rooms with wall lights over the beds – these things speak much louder than words. The general consensus is that residents are acquiescing in advance of being asked anything or offered any choices. My Mother is 88 years old. She lives independently, she's never been in a nursing home. She continuously tells me a list of things she will not be able to do when she goes into a nursing home. So this whole issue of the environment and its impact on people is powerful, it's very powerful. And it's not only affecting the residents, its affecting the staff that is working in those, and it's affecting the surveyors that go in to survey them.
One of the things that we've found out in almost all of the 41 surveys that we've done so far - accommodations, the staff and facility making accommodations for the residents was rampant. They're doing it all the time. They really care about what they're doing. Many of them really care what they're doing. They're making great accommodations. So our question is, why are your questions systems-driven? If you're willing to make accommodations, just make the accommodations. Change the way

you ask the questions. And the last thing I think is the opportunity for education. This has been an incredible opportunity.

One of the things we stumbled over early on was this whole issue of consultation and technical assistance. And as much as many of the surveyors would like to do technical assistance, the juxtaposition of the survey process and technical assistance doesn't necessarily work well together. There is an inherent fear on the facility and survey staff level so we opted to partner with Quality Partners of Rhode Island to give the facility the opportunity to talk to a different face, to talk to a different expert and to hear options, things that they can do or ways that they can do things better. That also turned out to be a secondary effect in that it gave the facility someone to talk to. They're afraid to talk to the regulatory agency. They're afraid of saying, "We're doing such and such." And we might say, "Oh really? What was that address?" By having another person who wasn't connected to the survey process and again it was our QIO but it wouldn't have to be the QIO. It needs to be somebody who is technically an expert in culture change and who can talk to them about that and is outside the regulatory process. It was a powerful tool and I think that that may be one of the best things that is working for us.

In terms of my points here, one of the issues again is this issue of "followship." People have to have a willingness to analyze the regulatory outcomes. We just do surveys over and over and over again and rarely have time to step back and actually look at what did we find? What did we tell the provider? What did we accept as a plan of correction? It's hard sometimes to find the time to do that as a regulatory agency. Incrementally we're designing the questions. We have interpretive guidelines from the federal government. One of the benefits of having their cooperation here was to kind of signal them - we might be asking different questions - we might get different answers. It could lead us down a whole different path and it has. It is important to partner with like-minded individuals. You have to find those organizations who understand what you're doing and can offer other supports and services. And last, the whole issue of collaboration. The state survey agency can't do it alone. I don't really believe an industry or a provider can do it alone. You need to talk to other people who tell them it's the right thing to do, it's the right time to do it, and it's okay. So, collaboration is a critical piece. With collaboration we can clearly make it all happen. Thank you.

Cathy Lieblich, Moderator:

Okay now for the CMS Regional Offices. Our next speaker is Captain Steven Chickering. Steve is currently the Western Consortium Survey and Certification Officer with responsibility for the survey and certification programs in the Denver, Seattle and San Francisco CMS Regional Offices. Captain Chickering entered the U.S. Public Health Service in 1979. His first Public Health Service assignment was working at an Indian Health Service clinic and hospital as the director of nursing services on the Navajo Reservation in Chinle, Arizona. Steve has been with CMS for over 23 years. He will be telling you about the CMS Regional Office's activities in support of culture change. Steve.

Captain Steve Chickering, Western Consortium Survey and Certification Officer, CMS Regional Office IX:

Good afternoon. It is really a pleasure to be with you here today. I've just really been inspired by all of the information that has been presented and comments that have been made. It certainly has given me many things to think about when I return home. I really appreciate the opportunity to share some of the activities that we've been fortunate to be able to do in the Western Consortium particularly in Region IX in San Francisco. I'm going to limit my comments to some of the activities that we've done in the state of California.
From my perspective, the Western Consortium Division of Survey and Certification particularly Region IX in San Francisco, has a history of establishing and maintaining effective collaborative relationships with many stakeholders including long term care and non-long term care provider associations, advocacy groups, one being here today, the California Culture Change Coalition, the Quality Improvement Organization, I know there are representatives here from Lumetra, and of course the state survey agencies. From my perspective, CMS Region IX has a history of championing the rights of individuals living in nursing homes and considers quality of life requirements to be equally as important as quality of care and other long term care requirements. Are we perfect? Absolutely not. Is there more we can do and should do? Absolutely. But I believe Region IX continuously looks for opportunities to work with its partners to ensure individuals receive the best care and services they need and deserve. In fact the opportunities are greater than resources of personnel and funding that are given to us that allow us to do.

One thing that I'd like to add before I continue is CMS is listening to some issues and concerns raised about inconsistencies among the ten regional offices and all the state survey agencies. One response has been to restructure the Regional Office Divisions of Survey and Certification into one consortium that's called the Consortium for Quality Improvement and Survey and Certification Operations. Dr. Randy Ferris, the former Regional Administrator for the Dallas Regional Office serves as the Consortium Administrator for this consortium. He is an advocate for access of quality care for all. He wants to ensure that and fully supports the regional office to work collaboratively with all stakeholders and to do so to the extent the resources permit us to do that. He works closely with Thomas Hamilton and other Central Office folks. He is challenging all the Divisions of Survey and Certification to look internally and work towards the consistency when it's appropriate to do so. I'd like to echo two of Ray's [Rusin] comments that he made earlier today that we're in an unprecedented moment of collaboration. We have many examples to demonstrate that, and I believe Region IX has some examples as well. I believe regulators are open to change but rightly so have to limit its limited resources to address ever present critical situations which often are or potentially could be life threatening to individuals. And the volume of complaints, incidents, sentinel events that need to be investigated and the number of complaints that increase every year really put a strain on our ability to do all the things that we would like to do.

I would like to move on to some of the examples that we've been able to do in Region IX. One of the fun things that we did was the Culture Change Caravan that occurred in August of 2005 was sponsored by a number of partners including CMS but also Lumetra and a number of the provider organizations. It was a time where Dr. Bill Thomas came to California and joined a team of stakeholders, and after a kick off press conference in San Diego boarded a culture change bus that traveled throughout the state really promoting culture change in nursing homes throughout the states. At the various stops there were either press events or workshops that were going on focusing in on culture change and specifically focusing in on the prevalence of pressure ulcers. How could culture change help in really reducing the prevalence of pressure ulcers and also reducing the use of physical restraints? The bus tour ended in Sacramento. If you can imagine, it was a bus with Bill Thomas and others. It was joined by a caravan of seniors

riding their Harley Davidsons as it toured through Sacramento, circled the Capital and ended at the workshop site. I can't say that I've ever ridden a Harley Davidson, but on that day I had the opportunity to have my picture taken in my uniform sitting on a Harley Davidson. So that was quite a moment for me.

Other activities that we've done. CMS Region IX has attended and hosted meetings of stakeholders to discuss and formulate strategies to promote culture change. One thing CMS Region IX has become an active member of the California Culture Change Coalition. This is something that I felt was so important that I've been able to dedicate a staff person to be a part of the culture change coalition team by attending meetings, working on strategy sessions as well as developing some training and other culture change opportunities throughout the state.

In January 2007 CMS Region IX co-sponsored and presented a Director of Nursing conference among other things that helped in decreasing the prevalence of pressure ulcers and decreasing the use of physical restraints. That conference was followed by seven workshops throughout California for not only providers but for state and federal surveyors as well to focus on quality improvement approaches to address issues of pressure ulcers and the use of physical restraints and to promote and achieve culture change. And we happened to have Joanne Rader as a featured speaker at each of those sessions.

One of the things that we think is really critical in Region IX, I know we're not the only region doing this. It's really critical when there are presentations on culture change that any of your organizations [do] please do invite your federal surveyors, do invite your state surveyors. Again as Ray [Rusin] said, we can't, none of us can do this alone, we need to work together, collaboratively. This is so critical to have the providers, your staff, advocates and federal and state surveyors together to hear what needs to be said and learn about strategies for culture change. (Applause.) September of 2007, the California state survey agency director Kathleen Billingsly and myself provided welcome remarks at the California Coalition for Culture Change sponsored Bridge to the Future conferences for providers and federal and state surveyors to learn how current regulations do support culture change. We had Carmen Bowman there, and she did an excellent job in reviewing how the CMS requirements really do promote culture change and do not need to be a barrier to promoting change.

Also I'm very pleased to say that Region IX took a very active role in California's initial statewide culture change project titled Person-Directed Dining Pilot that was initiated in the fall of 2007. In fact, a letter from me was mailed to providers throughout the state inviting them to join the dining pilot to demonstrate their support for change. The goal of this pilot is to identify practice and implementation guidance which promotes the adoption of dining practices that accommodates resident choice in nursing care centers in California. The main objective of this pilot, at the conclusion of the project there are hopes to be a dining practice package or packages that will be available to all care nursing homes in the state. So as they consider some changes that they would like to perhaps consider in their homes, they will have some resources to do that. These are just a few highlights that have occurred in Region IX. All I would suggest is that the Regional Offices under the direction of Randy Ferris, we are really looking for opportunities to partner with you. At times as we get focused in our day-to-day work they may not be aware of those opportunities. Call them. Meet with them. And they will be responsive. Thank you very much.

Chapter 8:
Public Comments

Morning Public Comments

Wes Baird, President of Lutheran Home, South Berry, Connecticut:

Thank you for having this conference. I think we should have these conferences for our state regulators and state legislators and they be forced to attend a full day session or spend time in a semi private room so they can take that change. I also want to make two comments related to Maggie Calkins' private rooms. She talked a little bit about the end of life. One thing please do not forget when you research end of life, the roommate that remains alive. Recently we had a resident whose roommate died on the impact to a person of a roommate or multiple roommates dying. We brought somebody else in and within a month that person died. Somebody else came in, they died within three months. We were getting ready to bring someone else in. I have the greatest staff in the world. The staff said "no more." We went and held that room empty for thirty days so that resident could recover. So please research that as well. I know another thing that we mentioned is that we're doing this for the residents but I think that close behind the residents is our staff. We're currently designing 128 bed all private room facility. I've told our board of directors this is for our staff as well as our residents. They deserve to have that type of environment when they work so hard everyday. So we really do this for the staff as well as the residents.

Charlotte Eliopoulos, American Association for LTC Nursing and Maryland Wellspring Alliance:

And to kind of build on what he said about staff I was pleased when Larry Minnix spoke when he reminded us that these are nursing homes and that we are dealing with sick people. As we're talking about private rooms. At the same time we're talking about a resident population with increased medical acuity so these private rooms are going to have an impact on staffing needs.
And I do think that this is something that needs to be considered. When you're observing and monitoring people who are in private rooms it impacts staffing and we need to bump up the hours per resident day to accommodate that.

Mary Hamil Parker, MKHP Associates, Institute for Palliative and Hospice Training, formerly with HUD and Federal Home Loan Bank Board:

Maggie [Calkins] mentioned mortgage finance briefly and the affect of these changes on the cost of construction or actually the recouping of the costs of construction. It's been my experience that finance agencies lag behind the changes and developments of senior housing and senior housing construction. And their underwriting standards lag behind. And therefore when they underwrite mortgages for these facilities and provide mortgage insurance for these facilities they don't give benefit to changes that improve functionality and marketability of nursing facilities, assisted living, and other senior housing facilities and tend to look at them as health facilities not living facilities. So that also needs to be an area of inquiry.

Joanne Kaufman, Institute for Family Centered Care, Bethesda, Maryland:

Everyone's been talking about a culture change but nobody has mentioned including the residents as part of an advisory committee. I think that in order to get at what people want, you need to ask them and you have to really treat them like they're a member of the team. The President of our organization, Bev Johnson, recently received the Change Maker award from the Center for Healthcare Design this year because she has helped institute patient and family advisory committees in over 35 hospitals in the United States. I think that one of the things you will find that if you include residents and or their families in a regular meeting; things like they could be part of the architectural design committees, a lighting committee. They could help you ahead of time. In addition to that recommendation I want to tell you that on our website www.familycentered care.org there are a whole bunch of assessment tools that you can download for free that asks "How patient and family centered am I?" and you can do them within your organizations so please do.

Written Comment
The principles underlying patient and family centered care can serve as a framework for making geriatric care responsive to the concerns and priorities of older people. Four principles guide its practice:

- People are treated with dignity and respect. The expertise, preferences, and culture of each individual and family are valued. These features form the basis for communication and relationships.
- Health care providers communicate and share complete and unbiased information with patients and families in ways that are useful and affirming.
- Individuals and families build on their strengths by participating in experiences that enhance control and independence.
- Collaboration among older people, their families, other community caregivers, and health care providers occurs in policy and program development and professional education, as well as in the delivery of care.

Kate Ricks, Voices of Quality Care, Maryland:

I wanted to reinforce first what the lady just said. I don't know how many other advocates are here but there is only one resident. We need to have residents and the families as an equal part of all assemblies like this; otherwise you're going to miss the mark. And because they're not here if they don't understand it, you've not only lost a great advocacy you're going to have people against this because they don't understand it. And we're seeing that already. So we really need to make a real effort to bring in families and residents and Resident Councils and Family Councils. And on the private room, a personal note, my mother-in-law has gone through a number of deaths. There's a limit. We don't deal with death on that regular of a basis. When a roommate dies it's a long process. The death itself is a traumatic experience. The family is in there. When you do that over a period of time over and over again we've come to the point where the lady in the other bed is "that woman over there." All her other roommates had names but now we're at "that woman over there." And this takes a great toll that really has to be considered when we look at what we're doing with our rooms.

Christa M. Hojlo, PhD, RN, NHA Department of Veterans Affairs:

In the VA itself, our 130 nursing homes and our approximately 12,000 beds, we have actually launched the initiative to transform the culture of care in our system and have been doing so for a number of years and are actually moving forth with a number of initiatives you have mentioned today including we have some proposals on the table for which I believe we will be getting some funding for some Green House initiatives. Also in keeping with the notion that this a paradigm shift, and I believe that when you're shifting a paradigm, language has to change. So, in the next week we will be publishing an official document expecting all of our nursing homes in VA to change the name "nursing home care unit" to "community living centers." I think this is a major step forward in our initiative for culture change. I'm very proud to be able to stand up in front of you and be able to say this because in the federal government things can get kind of… well you know what it is. Lastly, I would like to compliment CMS, particularly Karen Schoeneman and the folks who developed the HATCh Model. Those of you who are articulating concern about including the workforce, the HATCh Model is something that we've adopted that we're using as a framework for culture transformation particularly of the fact that the resident is at the center, at the heart and in order to really move cultural transformation along from my perspective as a whole, it is important to integrate work practice, care practice, and the environment of care principles that you are promoting today.

Nancy Zweibel, The Retirement Research Foundation:

Just a couple of very narrow references for folks in the room that might be alluded to later in the day but just in case they're not. On the issue of vision loss, I would love to see the regulators in the room pay attention to the implementation of appropriate but not acute care types of interventions particularly around vision. We funded at the University of Alabama at Birmingham who found a very high level of untreated vision loss even to the degree of you know you need your eye glasses adjusted. She did a randomized control trial and identified dramatic improvements in quality of life as a result of cataract surgery and new eye glasses. So there is just too much of this being untreated in nursing homes. Given what people are paying, that's inappropriate.

Written Comment
I would like to see CMS, AMDA and The Pioneers address the inadequate use of cataract surgery and regular vision/refraction adjustments in eyewear for LTC residents. I recommend research by Dr. Cynthia Owsley of University of Alabama/Birmingham who documented the prevalence of untreated vision loss; also the quality of life improvement from appropriate vision care. Care cannot be person-centered if the elder cannot see well!
Second point is a lot of the interventions of single rooms and the lighting and the design stuff presented this morning obviously is or appears as if it is appropriate primarily for the higher income facilities, and of course the majority of long term care money comes from Medicaid and Medicare, and I just want people to know that we have funded and will be funding again the dissemination of a document by Rosalie Kane and Lois Cutler about low cost environment modifications. Practical strategies that the facilities on more fixed incomes might use. Strongly encourage folks to contact Dr. Cutler to get their hands on that document because we all know that the small modifications that people make to start their journey, many places start small with culture change and once they begin to see the impact it has on the staff and the residents, then that blossoms into something bigger. [Low Cost Practical Strategies by Rosalie Kane and Lois Cutler is now available on the Pioneer Network website at www.pioneernetwork.net as part of her presentation files.)

Elsie Norton, Senior Vice President for Quality Care, ACTS Retirement Life Communities:

About three years ago, Larry Minnix opened an AAHSA conference by saying it was titled "A Place Called Home." And I sat there for the next three days and listened to every presenter bar none call it a facility. At ACTS, "facility" has become my "F word." And I think as policy makers, as providers and as regulators we need to change language much as the gal from the VA indicated. But until we stop calling it a facility it will still resemble a prison in our mind.

Stephanie Spinelli, Wallace Roberts and Todd Architects:

Amy Carpenter and I have worked very diligently, we've coordinated a lot of efforts with our owner and we have implemented a lot of the things we've been talking about today. I will agree with the architect for Creekview that we're having problems with the hood issue. We're trying to make things more residential. We're fighting with the locals. We're fighting with the state and we're fighting with CMS to try and get a more residential look than the stainless steel Type I Ansell grease hood system. It takes away all the effort we've put into it to try to make this a home. It is a household model, but it is [called] a home in our office. We're making people's homes whether it's our grandparents, our in-laws or otherwise. I would like for everyone to try to get on the same page and the regulators work with the designers. In some states it's been very difficult, in others it's been very easy but we need to get a solution on this one very large institutional project [problem].
In the household model, CMS requires the compliance with NFPA '96 for nursing care. This hinders the aesthetic and noise volumes in the kitchen of the "house." Is there anything available or any way to get CMS/NFPA to approve a substitution for the Type I hood system? Even a smaller hood (stainless steel) is still too commercial. Can we utilize a Guardian Fire Suppression System with a residential hood system directly vented to the outside? NFPA 96 and 101 need to work with the CMS and designers to come up with something that is residential looking but provides the required life safety provisions.

Mellissa Peters, Columbia National Real Estate Finance, Baltimore, Maryland, formerly with US Department of HUD as Chief Underwriter:

The largest number of mortgages insured with FHA in the last five years has been healthcare. And traditionally as most of you know HUD has been an affordable housing provider. Healthcare is really something they don't understand. These facilities are inspected by folks who are mostly trained in apartment inspection. So there is a lot of learning that needs to go on. I would stress to those of you who own facilities, who may have HUD insured mortgages to go meet with your HUD offices. Get your lenders well educated about health care because it is a special field. A lot of the policy in HUD now, the debate is to move the policy making from the Department of HUD's housing side to the Office of Insured Healthcare within HUD that insures the hospital program. So again it's an education process and I think a lot of the HUD folks would love to hear from those of you who could educate them as well as the CMS folks as well as the state people.

Dr. Lynn Snow, University of Alabama; VA Medical Center of Tuscaloosa Alabama:

We've heard lots of great ideas about research that needs to happen to further our knowledge about how to implement successful culture change and I just want to take this opportunity to CMS and our other

federal and foundation research funders that we really need some calls for research funding that are asking us to specifically look at culture change models and how to make those successful. What are the facilitators and barriers to successful culture change? We also need a wide variety of funding mechanisms. Because unless we have access to those mechanisms, it is very hard for us to do this kind of research. When I say a wide variety of mechanisms, we need the ability to apply for large projects but also for small projects. And we need the ability to apply for projects that allow for proximal resident outcomes - shorter- term and more affordable in smaller research projects such as frequency of resident movements in a lighting study - as well as distal resident outcomes such as resident quality of life if we're really going to understand the kind of processes that move along culture change. Right now it is sometimes very difficult to find research mechanisms that allow us to do, for example, ethnographic or qualitative studies that really help us understand the kind of culture change initiatives that are going on in the real world right now.

Bonnie Darwin, California Culture Change Coalition:

I worry that what we need in order to make the next step is some advocacy of this at the state levels. We have a fairly, actually enlightened, Office of Statewide Planning and Development in California and recently in a meeting, one of the staff persons who is in charge of architectural review showed us a plan of the standard nursing home with the long corridors and the two bed rooms and what he said was, "I have to approve this. I don't want to approve it but I have to approve it." So what we need to do is give our regulators in each of the states the ability to be more forward thinking. And to that end, I would love to see the Pioneer Network take all of this information, the expertise that we have and pull together a model set of statutes that each state could adopt because just doing it at the federal level isn't sufficient.

Eileen Bennett, Montgomery County LTC Ombudsmen Program and representing the National Association of Local LTC Ombudsman:

Need emphasis on inclusion of residents' feedback and opinion in the development of physical changes to the environment. Need inclusion of the regional and local ombudsmen in the discussion of resident needs – they have an overall vision and practical application experience of best practices that may be successful; they also have the voice of residents that are unable or unwilling to be put "on record" for fear of reprisal if they speak up about new ideas.
Recognize that the population is not only the elderly resident. Continue to include ombudsmen in survey preparation. We have discovered that often we are able to help support the creative opportunities that enhance the quality of life and have the survey regulators "to see it" too.
Regulators should be able to accept standardized investigations completed by ombudsmen and their findings as valid for complaints that cannot be observed during an annual survey i.e. staffing patterns, call bell responses. Support the fact that dental hygiene is a routine part of care. Continue the collaboration.

We would encourage you to include your local and regional ombudsmen in your discussions. We work with our residents. We bring them to the table all of the time, so I'm going to introduce you to the only resident that is in the room because she didn't want to come up front.

Lyn Miller, Nursing Home Resident:

I hate to tell you this but they really aren't communities. It's the equivalent of being, say, in the army. You get up when they tell you to get up. You take a shower when they tell you to take a shower. There's no, you don't have a choice about a whole lot of things. My comment is that one of the major things that needs to be done is an attitude change not only for the people who run the facility but also for the patients as they can be very rude to the staff people. And those are the people who are going to help you. So both sets of folks need to get together and talk about what it is we need to do at whatever facility you're at and then try to improve it. You can't improve it if you don't talk about it. Most of the administrators don't talk to the residents. They're not very excited to talk to the staff. So it's like there is no communication at all.

Roxanne Tenna-Nelson, Continuing Care Leadership Coalition of New York:

One thing I want to bring to folks' attention to think about is when we think through support for person-centered care and culture change; I encourage us to keep in mind the challenges faced by the urban environment. When folks from New York City look at some of the things that are being done around the nation, I mean we would love to do that kind of thing, but there are so many, so many challenges that face us with regard to the actual environment. Many of our members are really trying to do as much as we can in the urban environment with the challenges faced, but just to keep that in mind as well as the experience of the people who live there. Not everybody grew up with a country kitchen and a hearth and such. So to rethink for urban dwellers, what is the residents' experience, and what do they bring to the table as people who grew up in a different environment.

Carmen Bowman, Edu-Catering, Symposium Facilitator:

I really want to thank our one resident in the audience Lynn Miller. Lynn is reminding us of something, everyone. We can change language and we need to. But something Karen Schoeneman says is hopefully changing language will lead to changing practice. It's one thing to start calling it a home but it's another to create a true home. It's one thing to change calling the lobby to calling it a living room, but it is better to make it a living room. So thank you for reminding us of that Lynn.

Afternoon Public Comments

Chris Mallet, American Healthcare Association:

Good afternoon. The leadership and staff of the American Health Care Association have asked me to say a few words of thanks to each of you for participating in this fantastic symposium today. AHCA is proud to support this symposium, and we are eager to begin tomorrow's workshop that will give our collective effort to advance the culture change agenda a jump start. AHCA appreciates CMS and its willingness to reach out to work with the Pioneer Network in tackling this important topic by offering evidence-based information and by developing concrete strategies. We know our efforts will make a difference. I thank the members, leaders and staff of the Pioneer Network who have established a cross-cutting community that cultivates and empowers each of us to step up to create and innovate person-centered care. I extend a special thanks to Bonnie Kantor, for her support and work with AHCA on a Provider magazine feature article on the Business Case for Quality which will appear in an issue this summer. I challenge each of us when we return home to stay engaged and to share what we've learned

here about how changing and improving the physical environment in which we deliver long term care and services can help us to better long term care's capacity to respond to residents' needs and thereby help to improve the quality of care and quality of life for both staff and residents. Again thank you for being here today, and we look forward to even more progress beginning with tomorrow's workshop.

Susan Weiss, American Association of Homes and Services for the Aging:

Larry [Minnix] is sorry he couldn't stay for the whole session. I just want to say from AAHSA's perspective, today was not only educational but very interesting education. The stories made a big difference. How people are making incremental change and even giant change is very hopeful. I think AAHSA sees culture change as really a sign of hope. It's not going to be overnight. Some people won't do it at the same rate of speed. Some residents still won't get everything [they] need and everything they want. But the fact that this particular group with all its diversity is gathered around this one theme, and that we've had examples of how it can work and how well it can work and how people overcome struggles is just one of the most optimistic things we've heard in a long time. So thank you for the opportunity to participate.

Janet Wells, NCCNHR – the National Consumer Voice for Quality Longterm Care:

[In response to panel presentation of surveyors assisting culture change committees in particular homes in Oregon,] I'm very troubled by the concept of surveyors as collaborators and partners with facilities. I don't think that's why we have a survey agency. The QIOs play that role. We think it rightfully plays it. It's hard for me to understand, I guess I really sympathize with surveyors in Oregon. We feel it's a conflict of interest to try to play both of those roles. Once you're a collaborator with a facility, how do you then cite that facility if there are serious violations? And also if you're taking resources away from surveying facilities with serious problems, I don't see how you can justify that as part of the survey process. There are still very critical problems in nursing homes in this country. As someone else said, I think it was from CMS, [there is] still quite serious harm to residents that needs to be addressed. So while we support culture change I really question that this is the appropriate role for the survey agency.

Ruta Katanoff, The National Green House Project:

I'd like to thank CMS and the Pioneer Network for such a rich conversation, and I do hope it's just the start of an ongoing dialog of these important issues. I wanted to thank Mr. Solomon for the comments of some areas of NFPA that may be potentially modifiable, and I realize they were just your opinions. But I hope that they will hold true, and the one thing I was kind of dismayed by though is the timeline that I heard in that discussion. And that is that CMS is currently in 2008 using the 2000 version [of the Life Safety Code] even though the 2006 exists, so if the timeline that you outline holds true which is changes maybe get made in 2012, is it like another eight years beyond that before they get adopted? So I would just hope and appeal to all of you who have a say in that process to make these things happen quicker because I think our elders deserve to see these changes happen that can create true home that looks, feels, and is home for them in less than another decade.

Nancy Kriseman, Geriatric Consulting Services, geriatric clinical social worker:

I really want us to think about today too the importance of, what I would call, relationship centered care, which I think is even more important than anything else we've talked about. My experience especially with my mom who lived in a nursing home for fourteen years, it's very important that the family, the staff, the residents, everybody, the community remember it's a relationship that we all have to build upon. It's great to have these wonderful environments, but I hope we have another workshop on building relationship. I'm also very worried about our frail elders. I'm struggling with how do we care for our frail elders in this country? And I'm not sure that we've answered that.

Written Comment
We need to put together "mini conferences" around the country sponsored by CMS and Pioneer Network to present what we talked about today. I would be more than willing to help with one in the Georgia/South Carolina/North Carolina/Alabama area.

Susan Polydorf, Dental Hygienist, Coordinator for the Senior Dental Programs with Montgomery County Health and Human Services, Maryland:

I want to reference Dr. Calkins in speaking of her increased basic training requirements. I think we should all be looking towards training staff in the importance of oral health care. This should be implemented in all of our oral health care treatment plans. Residents could be taught to take care of their daily oral hygiene needs. Dental hygienists could be hired to provide guidance to the residents, staff and families. They could also be hired or volunteer to provide needed preventative oral health care treatment. We all are aware that oral health enhances the overall general health of the residents. With the arrival of the Baby Boomers, many of whom will be coming to these facilities and homes with their natural teeth, this population will ask and demand to continue visiting their dental hygienist and dentist for treatment. I would like to encourage CMS and the Pioneer Network, who put on this wonderful symposium, to include oral health care for all their residents.

Barbara Frank, B and F Consulting, Rhode Island:

First of all I just want to say congratulations from the bottom of my heart to CMS and the Pioneer Network for sponsoring this event. It's incredibly wise and "foresightful" to do this. The gathering together of people of different perspectives to look at what we can collectively come up with and what the current knowledge is. When we look at a historic event, something is historic when it has grown out of a large movement of effort which Carmen you beautifully documented in your paper. It's also historic when it sets the stage for work going forward. What we note today is that we have a decade of work in front of us to gather together and work on what has been said here.

I wanted to offer two comments. One is that in looking at the ten year piece of work that we might have ahead of us, there are some things we can do immediately right now. I want to zero in on one specific area which is how we navigate the whole negotiation of plans of correction. When we look at where are the regulatory barriers to going forward, most of the time the regulatory barriers are not what's written in the regulations but what gets negotiated and navigated in a plan of correction. So when somebody falls and the surveyor expects to see a new plan for how to prevent that person from falling, it will probably be something like "they'll sit by the nurses' station so we can watch them all the time." And then that plan of correction becomes what the nursing home has to do and what the surveyors expect them to do. So that what we can do now - there was such phenomenal information by all the presenters

today - the stuff on lighting and glare was so eye opening - no pun intended. We can have a challenge to our surveyors and to the providers in this room that next time someone falls and there is a citation about it and a plan of correction for it, that we go to what we really know is the source of that instead of saying we are going to re-teach our aides to make sure the chair alarm is in place. Instead what we are going to do is an assessment of the lighting, an assessment of the visual abilities and look to see if there are some ways we can make the space support mobility. These are things we do not have to wait for a regulatory change. It's about how we're living now with our obligations.

Along those same lines and this is a very important feeling. We've been focusing on all of this environmental work largely under the rubric of quality of life. But Carmen, your paper amply pulls together that this is about quality of care. This is as much about delivering good care as it is about the quality of our emotional well-being. As [for] the NFPA, it was so thrilling to hear that you're going to work on this issue. To know that it's not just about the immediate safety versus the long term thriving and well-being, it's about the immediate safety from fire versus the immediate safety from falling. There are clinical issues that are in play right now.

Last thing is, Janet you raised the question about how can surveyors be consultants and still have a strong ability to be a surveyor and that if time is being taken away from oversight of bad homes; that's a concern to you. I could feel the whole room give a collective gasp when you said it, I'm sure you could feel it as well. There's always a fear that how come the homes that don't do a good job keep getting to not do a good job and how come the survey agencies never have enough resources to do what they need to do and yet we're putting resources into other things? So from that point of view I understand where your comments came from. And yet we cannot go forward unless everyone who has an impact on what is sits down together and puts their heads together around what is. So we have to make sure that we have the resources to do all aspects of the job, to do the enforcement well because we have the resources to do it and to sit at the table when there are areas of our jobs [that] are putting us as a hindrance of implementation of these ideas going forward.

Written Comment
Many states have a goal of reducing the number of nursing home beds in their state. Other states are losing beds due to enforcement or reimbursement action. Usually there's not a strategy for which beds to lose. Recommendation: States - use policies on reduction of beds and on CoN (Certificate of Need) for new construction, to drive private rooms and culture change. For example:
1. Create incentives for a nursing home to cut its beds in half by converting them to private rooms.
2. Create rules that require private rooms and culture change for any new nursing home construction.
3. Allow a nursing home to convert its beds to a new construction that is for households and for private rooms.

Mary Gear, Oregon State Survey Agency Director:

I can really appreciate the comments from my colleague from NCCNHR and concerns about not addressing poor performing facilities or special focus or whatever we're calling them these days and diverting resources. So there are a couple things that came to mind when I heard those comments. I bet I speak for most if not all of my colleagues when I say we didn't get into this business of regulating in order to cite facilities for bad care. We got into this business because we care about quality of care and quality of life. And so I see it as a very appropriate role for a regulatory agency to care about changing

the system so that we can have a better system for quality of care and quality of life. And that isn't going to happen through our traditional regulatory process. It's going to happen through conferences like this and through providers doing the kinds of things you're doing and as the research we've heard today and as the research continues to come out that it is culture change that contributes to quality of care and quality of life for residents and staff and communities and all of us. I really do believe it is the role of a regulatory agency to support that in whatever way we can. So we can use all of our resources to focus on the poor performers or we can take a step back and help use some of those resources to make everybody better, and I think it's the latter that is going to help us make progress. I would also say in Oregon that the focus on culture change and the exposure of surveyors to culture change has made us as an organization much more willing to address the poor performers in an aggressive way because we see that it can be different and we don't have to put up with that anymore. So we have really beefed up our regulatory action in saying to our poor performers it's not acceptable anymore and really see that as a very positive thing. So thank you for the comments and I'm hoping that we can all move forward.

Fran Savard, AOPHA, Ohio State-Affiliate of AAHSA:

I too would like to echo the sentiments on how much we appreciate CMS giving all of us the opportunity as providers and stakeholders to come together today. I think it is extremely important as we move forward in how we are going to take care and provide care for our elderly. I think the one part of this that has concerned me a little bit is that it is obvious in both the pre-symposium paper that Carmen has presented and also by the lack of participation by all of the states' departments of health, it is rather obvious that not everybody was willing to come and participate with both providers and CMS. How is CMS going to move forward with those states that are not actively participating with us in trying to move Green Houses into our states? I know that we are having that right now. I am hoping that CMS will start acting as a facilitator for those of us that want these types of Green Houses and small houses, satellite kitchens where we're not having to pay extra for them and moving that culture into our states.

Sue Misiorski, PHI and Past President of Pioneer Network:

I want to thank all of the presenters today who put so much thoughtfulness into presenting the impact of the environment on those who live there. I want to add into that discussion the impact of the environment on the people who work there. Unfortunately, the most recent data we have available about individuals who work in nursing homes says that nursing assistants have the highest incident rate of injury and illnesses of any occupation, exceeding that of construction laborers, tractor trailer truck drivers, roofers and welders. These reports are 2 to 2.5 times higher than service-producing industries in general. That data is from the Survey of Occupational Illnesses and Injuries published in 2006. Additionally, the Substance Abuse and Mental Health Services Administration recently reported that among all workers in the U.S., personal care workers experience the highest rates of depression lasting two weeks or longer. The good news is in spite of the fact that that's really depressing data, the culture change community has also made wonderful changes in their physical environments that have also produced very positive impact and outcomes with the workforce. And I'd like to see those interventions and those innovations added into the discussion as the dialog continues.

Karen Love, Center for Excellence in Assisted Living:

I thank and applaud both CMS and the Pioneer Network. I feel that we are sharing a really important event in the growth and movement of the culture change movement and it is very exciting. One of the components that spoke out to me especially is the collaborative element. This isn't an "us" and a "them." To make progress and to continue to grow and move forward out of our traditional modalities, it has to be a "we" initiative. To that end [I] wanted to share one of the things that CEAL has been involved with in a "we" type of initiative that is a little bit different pioneering and maybe to just plant the seed for some of the others of you as you consider some of your research projects. We're involved in a project. The research methodology is called Community Based Participatory Research, CBBR. It is a recognized scientific form of research, but it is different in that you materially involve the community with the research team. When I say materially involve, for example on our project, we have a project funded by AHRQ, the medication aide that's a partner in the project has as much decision making power as the research team. So a consideration used by CDC and some of the other public health initiatives but we have not tapped into it for the aging community, so what a perfect thing to look at for culture change.

Sandy Fitzler, AHCA:

Like everyone else I'd like to thank the Pioneer Network, CMS and people in this room for creating vision and promoting change. Now while all this change is going on there is also changing that is occurring in nursing homes, so based upon that I'd like to see more discussion and articulation on how nursing home culture change movement and effort interacts with changes in resident populations and public policy related to Money Follows the Person. Now the majority of nursing home patients or residents or individuals are short stay. That means the average length of stay is 25 to 30 days and the longer stay residents are being impacted by discharge to community settings. So when we talk about culture change, we need to be inclusive in addressing the needs and desires of the short stay population, and for the long term residents returning now to the community, we need to ask if the culture change extends beyond the nursing homes to community-based living and resources. I thank Mary Gear of Oregon, glad to hear you are stepping out and already doing this but I would like to see other folks do it as well.

Ken Moore, South Carolina Department of Health and Environmental Control:

We have five representatives here today. It has been interesting to us to see that others are struggling with the same problems that we are struggling with trying to incorporate culture change programs in our state. The program here today has been enlightening to the five of us, I can tell you. Something we would like to do is we would like to applaud our sister states particularly for collaboration with providers to improve care. We like the idea that surveyors are working with providers to provide technical assistance. We're trying to do the same thing in our state. We're finding the biggest difficulty we are having is with our own staff, with the philosophies that our staff has. We're going to bring that change. We recognize that the old way of doing business will no longer work.

Heidi Gil, Planetree:

Thank you CMS and Pioneer Network. Planetree was started by a patient, a patient who had a horrible experience in a hospital environment. Angie Teriat was her name. She really wanted to combine the best of hospitals with the best of technology but with the best of spas and the best of hotels and make an experience in a hospital where just being there would be healing. Angie's vision started back in 1978. Can you imagine - we thought she [was] crazy when she said that. That vision 30 years later is now in 140 hospitals across the country doing phenomenal work for the environment as well as in behavioral transformation, in attitudinal transformation to make environments more personalized and humanizing, and demystifying healthcare. I am on the continuing care side and am fortunate enough to work with Planetree in how we can adapt Planetree to continuing care. I have learned so much from the hospital setting, and the hospital setting has so much to learn from us. So I challenge us to look at the transitions of care and that experience from one environment to the next from the environmental standpoint as well as from the clinical and financial standpoint. I also challenge us to think about the fact that many of our residents come initially from the hospital to a short term environment where they really don't want to feel like they're going home because their home is one step beyond where they're staying for short term care. So looking at how the environment for our short term versus long term residents is important in moving forward as well.

Charles M. King, Community Care of Rutherford County, Inc. Tennessee:

I think I'm the only person here from Tennessee. And that speaks volumes. I won't tell you why that is, but you'll have to figure that out yourself. Culture change is something that I personally have been on for about 11 years. And I'm nowhere near where I need to be. Several years ago I made a decision that I needed to experience what a CNA does day in and day out. I don't do that day in and day out, but I went through that course … fearfully. I am certified. I do work enough hours to keep my certification. I do answer call lights. I'm not a good CNA, but I do have some experience with that work. The emotional side of it, I think someone alluded to, there is nothing like it.

We talked about language a little bit earlier. You may not realize this but I'm going to preach to you a little bit. Our heart speaks. When our mouth opens up you're speaking something. It says something about our purpose, our values. Our language incriminates us or it benefits those who hear it. When you start referencing any language that demeans a person you've just done something to them that you can't take back with your actions. They've heard your words. So we need to recognize that institutionalization is a demeaning concept. I work in a nursing home. I make my living on it but we've got to change some things. It doesn't mean every nursing home's bad, but there's so much about what we do system-wide that is dehumanizing. Transparency coupled with trust will promote collaborative relationships. It takes both. I'm willing to be transparent with you if you'll come be my CNA. Isn't that what we expect our residents to do? Where does the trust come in? Where do they learn how to trust that you won't violate me? That you won't expose me to things that I don't need to be exposed to? That you won't go out into the hall and make fun of me. Transparency with trust. Now that's a resident issue, isn't it? But it's also a regulator issue. We talked about the Oregon association trying to collaborate and mentor and provide technical assistance. That is a fearful thing for you, I'm sure. I'm sure you didn't look at that and say, "Oh I want to do this tomorrow." Because we have those very thoughts of "Is this going to work?" Are we going to be willing to take the hit that we're going to take when we try something that we haven't every tried before as Mr. Moore (regulator who spoke from

South Carolina)? has referenced. It's a hard thing to change. And many times I don't think we've accepted that we don't know the answers. Most of us don't even know the questions.

We talked about building homes but I think first we need to recognize we're building a house to be a home. Today is about an environmental issue but it is so much bigger than that. You can put the walls up but until you put it in your heart, until you walk in and are willing to give you're cell phone number as an administrator to your residents, until you'll be a resident for some period of time and see what an immobilizer on your knee does to your knee for about four hours you start to get a little raw red spot back here on your bottom where you can't move - that's all it takes is about four hours - it is not a home. We need to recognize that the residents we serve are some of our best resources. I'm going to close, I could go on. I'm going to take a risk with you. We took some residents to a cabin for two nights, three days. Probably were violating the Medicaid rules when we did it but we did it. We did have RN coverage. We had plenty of staff. I think we had 8 residents and 12 staff so we were covered. Seven of those eight residents were in wheelchairs. For the two nights we were there, five of those seven wheelchairs weren't needed. One resident who is a chronic "I need pain medication" sat on her knees for over two hours in a boat and fished and never complained about pain. Is that risky? Yeah. Did it violate regulations? Maybe. It's not can we or will we change its how can we change.

Sarah Burger, Coalition for Geriatric Nursing Organizations:

I spent 17 years on the consumer side of things. And much to my delight it was a very exciting place to be. When I graduated from there I went back to my nursing community because I am a nurse. I coordinate the Coalition for Geriatric Nursing Organizations now, 24,000 nurses from eight different organizations most of them working in long term care. I'm pleased to say they are so excited about what's going on and will be working very, very hard in the next year to support the kinds of things you are talking about. And in fact this day is kind of a dream come true for many of us here. I think we have two leaders of those organizations. Charlotte Eliopoulis and Diane Carter are here. So it is not just me here representing them. We look forward to building the coalition very, very strong just as each of you have done in your own states and hope to help you in any way that we possibly can.

Rosalie Kane, University of Minnesota:

Like everybody else I want to thank CMS and the Pioneers and Karen Schoeneman for envisioning this and bringing it to fruition. It's very, very exciting. I was thinking that it's been a long time since 1983 when the IOM committee met that I had the privilege of being part of. My kids were younger then, twenty [something] at that time all three of them. This year my father celebrated his 100th birthday. So you have to think it's been a long time. I do think as Barbara Frank said and as others said this meeting has attested there really is change in the wind. I'm always in favor of research, actually it's my occupation, but there's a lot of things we'll be able to do without research and one of the things will be around implementation and how to get to the next step. It thrilled me to realize – I hope I just wasn't seeing in it what I wished - a clear consensus, a practical and moral consensus to single occupancy unless by choice. Obviously we're not going to wave a wand and have it happen right away. It's going

to have to be gradual. It's going to have to be considered around new construction and major renovation. But I don't know if you realize but back in 1986 when that IOM committee came out with its report, there was a strong recommendation that CMS immediately do a study to determine the cost and benefits of that single occupancy for different kinds of residents. So to move towards that outcome and now it just thrills me to think that that could be coming. I hope that we will move rather quickly towards that and consider what has to be thought about in terms of reimbursement. There will be some implementation challenges. But I hope we won't have any more studies about whether it's a good idea. Maggie did the last study that needs to be done about that. I've done my own studies over the years. It seems very important to me to be looking at the physical environment. I appreciate people saying, "Well, it's only a vehicle for the rest of it all" but it's a very important vehicle. Physical settings and how they are used help shape behavior and its going to shape the behavior of staff and visitors and most importantly residents. I think that there are components, and you'll be able to see some of this when you get the full text of Lois' paper. There are issues around the physical environment that also require training. We're training at the facility level, culture change agents doing their stuff. For instance, you can have the most wonderful windows but if the blinds aren't drawn in a regular way; if you don't happen to talk to residents about whether they like them drawn, that light never comes in anyway. You can have the wonderful private spaces that should be nurturing of residents' own relationships, but there are steps to take to make that happen. But it's a very, very exciting chapter we're moving on and I'm grateful.

Eunice Noell-Wagoner, Center of Design for an Aging Society:

We're a non-profit based in Portland, Oregon so we do have quite a contingency of Oregon residents here, so I'm proud to be here for that. I also worked with Betsy [Brawley] for the Guidelines for Lighting for Older People it was produced by the Illuminating Engineering Society. There is one thing that I think is very important that we need to bring up and it has to do with the NFPA. They are the ones who set emergency lighting levels in care facilities. I will credit them for changing and increasing the light levels on stairways from 1 foot candle, which Karen [Schoeneman] couldn't see on and that's what currently the international building code that most buildings are built under, they still only require 1 foot candle on a stairway for an emergency fire exit. However, the NFPA has in their wisdom increased that to 10 foot candles on the stairway. But we still have to deal with exiting corridors or what's the safe passageway to get to that, and we desperately need to look at increasing that light level for exiting. And also not just to use the - what I call "bug eye" – the battery pack thing. Betsy talked about glare in her presentation as being enemy #1 for seniors. What is a bug eye? A bright beam of light shining in both directions so that no matter which way you're supposed to go you get glare in the eyes. So they need to take the existing lighting system and put a battery backup in the existing lighting system so you have even and consistent lighting maybe at lower level but at least the older person doesn't have to go to this sudden change of brightness to try to see to get out of there. So try to encourage the NFPA [to] look at senior issues when they start revising their regulations, and I realize that waiting until summer of 2009 to file an issue about this I get frustrated by it, but I do know about the consent process. Maybe it could be under emergency conditions that it gets raised up a little faster.

Gary Marsh, CEO of the Masonic Homes of Kentucky:

I came here today to confirm what we are doing in terms of the development of our new care center in Louisville, Kentucky. And I feel very comfortable with 29 million dollars that we are going to spend to serve 136 residents which we'll start construction on next month. I realized very early in the process that building a building of this nature is only a very small part of achieving the success that one must have in the culture change movement. One of the things I have observed, a very small thing if you will, is that I've noticed that in everything that I have seen and even today we saw in the slides is that the staff, especially the direct care staff, are still wearing scrubs. I feel there is a missing link that if it really is a part of the person-centered care culture change movement, the lack of institutional clothing on the part of your staff is a very important part of the environmental growth that one needs to have.

Kathy Greenlee, Kansas Secretary of Aging:

I want to tell you about an experience I had about a year ago. During the legislative session I was called over to the State Capital in Topeka by a state representative who was all wound up about a survey we had done for one of his constituents. The family members flew in, the administrator flew in, the president of the board flew in. This was a 20 or 30 page survey. I think on the last page we cited peeling paint and so that became the whole conversation. Not the quality of care, about pressure ulcers or falls, I mean just bad stuff. And I sat there with these family members and tried to explain to them why 90% compliance is just not good enough. That what am I going to tell the other 10% of the residents and their families that they don't have to comply with the law? When it's time to enforce the bottom of the barrel, the people in the bad facilities, it is a lonely job. And I got all wound up after Pioneer. I went out to dinner with some very progressive administrators in Kansas and I said at the end of the day it's CMS, it's the state regulator, and Janet [Wells] reminded me of this, its NCCNHR and the consumer advocates at the end of the day who sit there and struggle about what to do with the poor performers. I love everything about this work. The only thing that disappoints me is that there is not the same quantum energy on what we do in the states to deal with the people who are struggling to even comply with the old model, and we'd be really happy if they could get to the old model. And I'm not naïve, I only get invited to the good places. The bad places don't want to see me. And I think those residents honestly may need my attention more than the places we're talking about today.

Rosalie Kane, University of Minnesota:

I was just going to do a quick follow-up on the good issue of wearing of scrubs. It kind of illustrates how we can get to a new level of problem solving once we've committed ourselves to more freedom, authority, and autonomy first of all and most importantly for residents but also for line staff. Mary Tellis-Nyak who is sitting here and her husband Vivian, years ago in those grand old days I was recalling, wrote a paper about how both of those parties [residents and line staff] have very little power and tend to be pitted against each other. And when you get into what you're going to wear, and I certainly saw this in the first Green Houses in Tupelo those elder assistants made their decision that they would actually prefer to wear something that resembled a uniform. It was free to them, they're easy to keep up, etc. That just means that if the scrub carries the wrong imagery to residents, and we don't quite know that yet, then we're going to have to think also about what's important to the staff in terms of the clothes they wear.

David Farrell, Lumetra, California's QIO:

Piggy backing on Rosalie's comment, I've had the unique opportunity over the last three months to visit a special focus facility. And these organizations truly are special when you think about it because they're non-responsive to the most serious fines and penalties that most other nursing homes truly do respond to. Going in there every week, on weekends sometimes, nights sometimes, these organizations, the problem, the root cause is the culture, the solution is culture change. Just merely speaking with conviction in front of their staff about person-centered care and seeing those words resonate and seeing their eyes light up, what we need really is an early detection system so that we're not going in so late. I'm not sure we'll pull this facility out of it, but they're truly well intentioned and they're good people, they just weren't perhaps exposed to these principles early enough. And so the solution truly lies in changing their organizational culture.

Mary Tellis-Nyak, Vice President for Quality Initiatives for My Innerview :

I would just ask all of you because basically what Sue Misiorski was saying it's not only in the environment that our front line workers work in, it is the management. I invite you all to go to the My Innerview website: myinnerview.com and download the report which was the first national workforce report on employee satisfaction. The new one will be coming up in May. The 2006 one which is there has the responses from 107, 000 employees who work in nursing homes. And what you see is that management, that means nursing director and administrator, are very positive. The least happy employees are the nurses and the frontline CNAs. And the difference is astounding. We know that there is a relationship. If you look at the JAMDA article that my husband [Vivian Tellis-Nyak] wrote in January of 2007 there is a core relationship between the quality of the workplace and everything else. The key issue is there is a major correlation between how CNAs score the quality of their work environment and how residents score the quality of their life. If we are not taking care of our CNAs, everything here is for naught.

Joan Devine, Lutheran Senior Services, St. Louis, Missouri:

I would like to obviously commend everyone for this program and very much commend the regulatory agencies that are working to work with us as staff, as we try to embody the ideals of culture change, as we work to build households or neighborhoods within our communities. I work with eight distinct CCRCs, and they are very different. Each one of my care centers has a unique personality. One of them is going to have the fortunate opportunity to build from scratch and really build a household. Others are old cinderblock buildings where they can't count on their environment as being the thing that they need, and so their deep culture change comes so much from attitude. We tell our staff, we tell our leaders it's how you treat your staff. And then the survey process comes in and it's very punitive. That does not fit with the model that we are trying to share with our leadership; it's how you lead in this new organization, how you create this new world, so I commend those who are moving along in that same way.

Carmen Bowman, Edu-Catering, Facilitator:

Bringing environment and language together, can you imagine what people in other fields think when we say, "It's a 40 bed facility" or "I work in a 120 bed facility." If we're going to talk about environment and language and person-centered care, I just toss it out there for all of us to think about. I sort of hate it that we've minimized people to beds, without meaning to, it's the license on our wall but we don't have to say it, so maybe we could start referring to the *people* that live in our homes.

Written Public Comments

Voices for Quality Care (LTC), Inc. Maryland:

- Once again there seems to be no recognized place in this movement or in this program for the residents living in these nursing homes or their friends, families, and advocates.
- It was seriously distressing to hear the Arkansas Office of LTC describe her work with the nursing home association in such glowing terms while briefly touching on a relatively new relationship with the State Ombudsman Program and with absolutely no mention of the Arkansas resident/family/citizen advocacy organization. Without equal participation of resident/family advocacy groups these projects will never reach their full potential. You cannot "do" culture change without the residents.

Al Kaul, Provider Lutheran Homes of Michigan, Inc.:

I applaud the efforts of the organizing entity to bring together such a diverse group of presenters and participants. Today's sessions have been extremely informative and I am greatly encouraged by the future. I graduated from high school in 1987 and have been in the field of aging services for less than 10 years. I am greatly concerned by what I see across the spectrum of the field of aging:

- Providers tend to blame regulators and government for punitive regulations and lack of funding.
- Regulators tend to pass the buck and not take responsibility of reforming regs.
- So called "advocacy" groups tend to make poor assessments of the intentions of providers and regulators.
- Academics tend to make recommendations about what needs to change without offering realistic, practical solutions.
- In all groups, there tends to be inappropriate blame and self-defense.

We must all begin with the assumption that we all do this work for the betterment of the Elders we serve and our communities in general. We are all on the same side and must truly believe that about each other so that we can finally make changes that are critical to the Elders we serve. They depend on us, and because of age and frailty they are running out of time. We must work together with greater urgency.

Jack Carman, FASCA Design for Generations, LLC and past chair of the Healthcare and Therapeutic Design Professional Practice Network of the American Society of Landscape Architects:

Suggestion for the Next Symposium: "Completing the Home"
Maintaining our relationship to the outdoor environment the "room" that all too often gets ignored in the nursing home is the outdoors. Patios, gardens, walking paths, raised planters, fish ponds, bird watching and many other elements are all a part of everyone's lives – and missing from nursing homes. America's number one hobby is gardening and number two is bird watching. The holistic focus must be connecting the building to the patio, the garden, the yard and the community thus creating the house.

Dr. Calkins started the conversation showing a picture of a room with a door to the outside. Gaius Nelson talked about feeling the sun on your face and access to the outdoors. Betsy Brawley showed pictures of dining room opening to a courtyard. We need to create universal access for elders to the real authentic natural environment of living environments. I would like to discuss the opportunities to discuss these ideas for future sessions

Emi Kiyota, University of Wisconsin – Milwaukee:

As for personalization issue, current systems and design solutions focus more on how to fit personal belongings into residents' rooms. However, little attention is paid for "how residents use and connect with those belongings." For instance, some residents told me that "I don't have any space for plants," although deep windowsill was provided in their rooms. The problem was that they are not able to reach and water plants on the windowsill from wheelchairs. Most of the time, the bed would block wheelchair to access to windowsill due to the limited space. Also, they needed to park sideways to reach out the plants to water. These mistakes can be easily fixed if we understand how residents live their life in their room every day.

Auditory privacy should be taken into account in order to create comfortable living environments. While one has private room, various noise from outside room seem to constantly irritate residents. This situation can become a serious problem, if a resident who lives next room screams all night long in most of the facilities at this moment because residents' rooms are not treated sound proof.

Cynthia NoThom, Goodwin House Bailey's Crossroads:

Delighted to see such a gathering of government, regulators and Pioneers together for we who are traveling along the path of culture change.
Speakers excellent – credentials impressive . I would prefer to have credentials listed on overhead and not announced to full detail – I like to hear what experts say and trust Pioneer Network to only use appropriate credentialed folks.
I wish LSC would have talked more about LSC. Most needing attention in NH. Not so intense of NFPA process.
Said VA (Virginia) was so poorly represented. Am proud Joanie [Latimer] was part of the symposium. Thank you.

Karen Nichols, RN Administrator Cottages at Bushy Creek, South Carolina:

I would like to recommend that a topic that is added to this conversation is the survey process itself. In other words, there needs to be an acknowledgement that in a smaller environment the survey itself disrupts the lives of the elders and thusly, is not truly accurate in what they "see." Most traditional nursing homes are most sent a team of one surveyor per 12 elders but a transformed organization with smaller environments should not.
In addition, I would add that we have and will continue to have self-directed care in our job descriptions and evaluations but shouldn't our federal and state regulators have the same in theirs?

Bryant Hall, Jr. SHW Hadley Hospital and SNF:

How do you:

1. Is it practical to scale-down environmental culture change when there is no money?
2. For the Urban Center with varied cultures, ethnicity and different "home" environment, besides getting residents' input, how would you suggest making it a "living" community taking the urban differences into consideration?
3. What type of signage is not appropriate today if environment culture change is being considered?

David Seitz, Vice President, Development and Corp. Properties
HCF Management, Inc. Lima, OH:

In Ohio, our enhanced, shared rooms with shared bathroom are required to have an "additional" passage way to each resident through a separation wall. In effect, there would be two completely separate, and private sleeping and living areas with their own door for entry from the corridor without this additional "passage way," a three foot framed archway. It is in complete conflict with resident privacy. Its' elimination would create two private rooms sharing a bath. do you have a phone or email for this guy, I'd like to find out what he is talking about

(Betty) Etta Hancock Missouri State University M.E.P.A.P. Program:

The conference was great. Putting our seniors first, their needs first. Finding funding to help nursing homes have private rooms instead of double occupancy. I think it will bring about happier days, final days, for a lot of our residents. The lady that brought up the fact that regulations are there but not enforced is very sad. We need surveyors to be fair but enforce the regs. Yes, we need more training for all nursing home employees. Higher standards for activity directors are there but some states do not recognize them. In many homes of 60+ residents 1-2 staff is all you will find and there is no way they can provide quality of care for all their residents. All staff should be held responsible for improving the residents' quality of life and seeing that each resident can continue with lifelong activities. Why is there so much difference between states with the survey process?

Christine White, LCSW, Director, Resident and Dementia Care Services Kindred Healthcare:

I commend CMS for their role in moving culture change reform forward and look forward to coming changes. There is an issue that prevents progress that is escaping recognition. In case mix states, independent Medicaid reviewers develop their own rules seemingly independent of regulations. They are often compensated based on the amount of funds recovered from nursing homes. Their demands for documentation are at times ridiculous and unreasonable and require caregivers to [do] double and triple charting. I hope that CMS can collaborate with states to provide some logic and consistency to this issue. (Note: Outside Medicaid reviewers impact culture change by redirecting effort back to that which we are trying to move away from.)

Sheila L. Molony – Claire M. Fagin Fellow – University of Pennsylvania School of Nursing/Assistant Professor Yale School of Nursing:

Three recommendations to supplement the excellent content in today's sessions:

1. Need to increase geriatric expertise in LTC environments (geriatric nurses, geriatric advanced practice nurses, geriatricians, etc.).
2. Need to facilitate opportunities for "journey" into our plans (home feels more like home when you leave and then come back to it; if you never leave, it feels like a prison for some).
3. Consider increasing "sacred spaces" into environment.

Thank you for this opportunity.

Tiffany Musselwhite, SWAN – Regional Ombudsman Illinois:

Research needs to be done on the topic of rural settings and culture change including how to overcome socio and economic barriers that are unique to small, low-income and sparsely populated areas. As with urban settings, rural areas have unique hurdles to overcome. We need to have research based information to take to providers to really encourage culture change and show them why this is so important.

Paula Cornell, West Central Illinois Area Agency on Aging, Quincy, IL:

As we discuss the need for language changes in culture change, we NEED to develop a different name for the survey process that better and more positively reflects the process. Maybe we could call it "Evaluation Process" or some other words to reflect a "collaborative team effort to improve quality of life for elders." How negative surveyor and plan of correction sounds! Thank you for the opportunity to be here.

John Shoesmith, AIA Wattenbarger Architects:

- There is a danger when rewriting existing standards/regulation that their history comes with them. The language of the recommendations or documentation that arises out of this is very important and I would encourage you as you move forward to strip language that directly or even perhaps unintentionally suggests old medical models and ways of doing things. Even by inference this type of language can do much to undermine what has been talked about today by miring us in the past instead of pointing us to the future.
- Dissemination of ideas and materials needs also to go to the local building official level. In practice some of my bigger challenges in doing innovative designs has been less at the state level and more at the local building department level because they are unfamiliar with nursing home residents and operations. How might we educate them?
- Bravo to NFPA to stepping up and offering an opportunity to partner in changing regulations!

Debra Zehr, Kansas Association of Homes and Services for the Aging:

If buildings are fully sprinklered, providers shouldn't have to incur unnecessary costs and residents shouldn't have to put up with non-homelike requirements such as industrial hoods in household kitchens, spraying "everything" with fire retardant spray, fire doors in super short "corridors" in free standing small homes (example at the Cedars in McPhereson, Kansas).

Some states "over-interpret" food sanitation concepts and require multiple sinks dedicated to specific purposes in kitchen areas.

Do we really need full spa rooms in households with private shower/bathing rooms?

Attachment email to Debra Zehr's comments:

Debra,

Based upon our participation in and observation of facilities around the country, Diane and I put our heads together and have the following observations:

1) State nursing facility environmental regulations favor the "traditional" nursing home. As a result, architects are guided to the traditional designs, e.g. large, isolating and centralized nurses' stations. Additional costs and construction are incurred when the certifying agency requires features that are not relevant. These can include a) privacy curtains in private rooms, b) shower curtains in a private room's "European" bath room, c) dirty utility closets when the laundry room is only a few feet away, d) bathroom doors in private rooms of dementia residents, e) full nurse's stations in small households when an armoire or built-in is all that is needed, and f) isolated medication rooms when adequate medication storage is in the resident's room or integrated into kitchen cabinets, etc. In addition, the state environmental regulations often do not consider the special needs of dementia units; we still see new SCU designs that are no more than warehouses.

2) Added costs are one of the perceived barriers to culture change. The more we can eliminate costs the quicker culture change will be accepted. The following add cost but little or no benefit to the resident or there are cheaper alternatives for small households:

a) Requiring full spa rooms with commercial whirlpool tubs in each small household when there is a private shower in each resident's room.

b) Regulations that require isolation of the kitchen do not contribute to culture change. Isolated kitchens remove the social gathering place that many resident are accustomed to, inhibit the smell of cooking food which can stimulate appetite (sorry crock pots and food warmers are not the same), and restrict the resident's the ability to participate in meal preparation activities that have been an integral part of their life.

c) Requiring centralized and prep kitchens is a redundancy that also limits culture change for the reasons stated in #b above.

d) Fire safe areas in small, independent households. This adds a fire wall that provides minimal protection. When evacuating you try to keep at least two fire walls between the residents and the fire. In a small household, a single fire wall would not suffice; evacuation would need to be to a companion building. This is a feature that requires evaluation to ensure the safety of residents.

e) Requiring three compartment sinks in the household kitchen for washing pots and pans. In the household, pots and pans are smaller and dishwashers can handle them, just like a normal home.

f) Commercial hoods on household stoves. (We have no objection to these hoods but alternatives are worth evaluation, e.g. sprinkler curtains.)

g) Locks on all cabinets, doors, and ovens. Locks give "you do not belong" and "you are helpless" message. Only those cabinets and doors that need locks should have them, e.g. medicine cabinets or rooms that contain potentially harmful equipment.

h) Gates or other isolators to kitchens. We have observed numerous small households that do not isolate residents from kitchens and have no adverse circumstances. Gates may be the result of over analysis.

i) Requiring quiet rooms when residents have their own private room to go to.

3) Significant additional costs are incurred when a facility is built with culture change in mind (e.g. a Green House) but the State must apply "hospital" like standards at the certification survey. We have seen this happen several times and seen the additional construction costs that are incurred and the lost income due to delayed certification and opening. In addition the culture change intent of the facility was diluted by application of out-of-date "hospital like" standards.

4) Failure to take into account modern materials when evaluating design can also limit culture change. For instance regulators required squeegees in private bathrooms to wipe down floors that had a non-slip surface when a towel would have sufficed. Do you keep a squeegee in your bathroom? (When Ted spent ten days in the hospital, he showered in a "European" bathroom with a non-slip floor. There was no problem with slippage when the floor was wet. There was no squeegee.)

5) Requiring noisy nurse call systems and individual room lights for small households. Again, there is the hospital atmosphere that can be eliminated by a pager system and the small household.

6) Promotion of personal alarms. The literature supports the limited utility of personal alarms, indicates that they are effectively a form of restraint, and documents that their effectiveness as a fall prevention device is limited to only a few cognitively aware residents.

7) States' failure to publish and update interpretive guidelines. Kansas has not updated their guidelines since 2003. Missouri does not make any guidelines available on the web. Without guidelines, there cannot be consistent interpretation of the regulations. Providers are left to interpret the regulations without the documentation to base their interpretation on. Note that we do not consider guidelines to be set in concrete. A guideline can be changed (weekly, if necessary).

8) Limited use of the web to communicate guidelines, regulations, and other pertinent information. This includes State ratings. Kansas does a fairly good job. Missouri is behind but coming up. Texas is has a very good survey data communication system. Some other States do not even have their regulations on the web.

9) Some survey agencies use a rote method of surveying which tends to interpret regulations without consideration of the residents. This lack of such consideration can inhibit culture change.

10) The SOM emphasizes process and quality assurance. From Ted's experience, using ISO certifications is an effective supplement to regulatory surveys (see #9 above). ISO surveyors implement internationally accepted standards of evaluating quality and processes. Adaptation of ISO certifications is a potential cost savings to governments and providers and promotes culture change through quality improvement and commonly accepted standards. In addition, scarce surveyor resources could be applied more efficiently.

11) Providers are dissuaded away from culture change when surveyors severely ding facilities that are implementing culture change or have been given (State sponsored) awards for implementing culture change. This leaves the impression of a mixed message. This is probably a communication problem that is exacerbated by the rote survey instead of an outcome and QA based survey.

12) In the best of all possible worlds, States would have a joint commission of regulators and providers that review cumulative survey data, identify lessons learned, and publish and educate those lessons learned. Lessons learned would include better practices, provide QA and, when necessary, revision of guidelines or regulations.

In a word, outdated environmental regulations, lack of up-to-date guidelines, inconsistent interpretation of regulations among surveyors, literal interpretation of regulations without regard to the resident's actual needs, and lack of process and QA inspection standards are significant barriers to culture change.

If you have any questions or need additional information, please give us a call or email.

Ted and Diane Atchison

Anonymous:
How are Green House projects different than adult family homes or congregate care houses? Comment – Why did the Green House Responder Robert Jenkins talk about the “Green House Project” instead of respond more to the speaker Gaius Nelson? The Life Safety Code presenters were totally on topic compared to the others.

Chapter 9:
Closing Comments

Carmen Bowman, Symposium Facilitator:

Well, we hope you have enjoyed and learned a lot from today's presentations and from hearing each others' thoughts and ideas that you've shared.

Now, I'd like to invite our two co-sponsoring organizations, CMS and the Pioneer Network to provide some closing thoughts. Representing the Pioneer Network is its Executive Director, Bonnie Kantor and representing the CMS Division of Nursing Homes is Cindy Graunke, the Division Director.

Cindy Graunke, CMS Division of Nursing Homes Division Director:

I have lived in the Washington area for about fifty years. I live about 50 miles northwest of here and every time I come to Washington I'm really reminded of what we do as the government and Ithink about some of the people who have come before us. One of my favorite people to think about is Eleanor Roosevelt. One of the quotes I recall from what she did in her many, many good works was, "What matters now, as always, is not what we can't do. It is what we can and must do." And when I think about the stuff we've talked about today I'm really hopeful about some of the steps we can take tomorrow. As many of you know, there is going to be an invitational brainstorming session to really take what we've heard today and to start planning some things we can do. The other thing I think is very hopeful and hopefully as you've heard some of the public comments that there are some things you can do even before this group starts working together, that there are some connections that can be made. You can go back to wherever you are tomorrow and you can start thinking about how we can make some of those changes. So I'm very excited about that. I want to really thank the Pioneer Network for all the work that they've done to put this session on today and tomorrow and also for the follow up that is going to occur as a result of this. So I want to thank you very much Bonnie.

Bonnie Kantor, Pioneer Network Executive Director:

I want to, as we close, thank all of our speakers, thank all of our responders and actually most importantly those of you who made public comment because you added a great deal and you helped us be true to our word that this is our conference, it belongs to all of us. I really only have one word , although those of you who know me know that I'll say a few extra. And that word is wow. Gaius during his talk talked about a concept about finding flow and actually that is one of my favorite books. Together I'd like to end the day with all of us finding flow together. What I'd like you to do is kind of close your eyes for a moment and breathe in and out and think about today and I can guarantee you as you do that, as we do that, we will have found flow. Right, Gauis? You guys got it. We have found flow together.

In our brochure and as we heard today the federal government is listening. I said at the beginning of my comments that the Pioneer Network is listening as well. I have to thank all of you for not only listening

today but being active listeners. It's not that I have super powers or anything, but I could see all that stuff going today in everybody's brain, all the processing that went from brain to heart and right back again. So that was pretty neat.

I also want to end the day the way we began in thanking a few folks. Certainly Carmen Bowman deserves a great deal of thanks and Karen Schoeneman. We were all able to see their hard work in action. But there certainly is one woman I personally want to thank who stayed behind the scenes but was ever present in everything that happened today. And that is Rose Marie Fagan. Rose Marie if you would just stand for a moment to be recognized [Rose Marie stands].

I also want to, and there is a reason for doing this, "rethank" - I guess there probably is not such a word but if we talked about "followship" I can talk about "rethanking" – "rethank" those folks who have given us such superb financial support for this and that is of course the American Association of Homes and Services for the Aging that participated so closely with us, the Commonwealth Fund who brought the partners together and provided important support for this. Also I want to thank the American Health Care Association, the Maurice and Hulda Rothchild Foundation, Dorsky, Hodgon, Parrish and Yue Architects, the SEIU, the Quality Care Committee, the Continuing Care Leadership Coalition, and the Green House Project and NCB Capital Impact.

Now why am I "rethanking" them? I'm "rethanking" them because, because of their contributions, we at the Pioneer Network - and their contributions were made directly to the Pioneer Network and because of that - we are able to make a commitment to all of you and many around the country and that is we're going to have a dedicated effort in the next year to take everything that comes out of today and the recommendations that will be put forth at the invitational workshop. We have hired an exceptional woman who is directly to my left and that is Cathy Lieblich who is our Coalitions Coordinator and she will be working directly with exactly who you said needed to be worked with and that is the states. It is one thing to talk at a federal level but each and every one of us know if we're going to be effective it has to be at the state and the local level. Cathy will be working with all of you and all of your states, and states that were not represented here today as well, in providing the tools and the opportunities to take this and make and implement change. Most specifically, there is no reason why each state has to reinvent the wheel. We will be utilizing and developing a website that allows each state to network with other states, find out and use the tools such as how you work with your legislature to effect change. We want to let you know that we were listening. I'm also happy to know that we anticipated that which you would want and are ready to provide it.

With that, I want to bring us to a close by letting you know that the next public forum where we will be discussing this en masse and will be able to report the progress will be at the Pioneer Network national conference which will be here back here in August. August 20-22nd. You have a brochure in your folder. Please join us. This is going to be core to that which we are doing. Thomas Hamilton or his representative - but he's going to do his best to be there - will be talking to the group and helping everyone see where we've gotten in that short time frame. If you are an individual or organization that says I'd like to be at the forefront and help support that conference, Cheryl Ritzi please wave, Cheryl is there and will give you any additional information on your way out about the conference or ways you can be involved.

Please one and all safe travels home and thank you so very much.

Chapter 10:
Invitational Workshop April 4, 2008
following the *Creating Home* National Symposium

8:00 Registration

8:30 Welcome and Explanation of Day - Bonnie and Carmen

9:00 Group work by topics and development of recommendations with recommended action steps

10:30 Break

10:45 All wander to view workgroup ideas and offer more

11:15 Workgroups continue and finalize recommendations and follow-up plans

12:00 Lunch

Workgroup Presentations by Guides on Main Issues Assigned
1:00 Research
1:30 Regulation/Guidance/Survey

2:00 Break

2:15 Life Safety Code
2:45 State-level Coalitions and State Regulations/Codes

3:00 Round Robin Closing Thoughts Learning Circle

4:00 Close - onward in answering the call to action!

See Appendices for Resulting Recommendations of the Invitational Workshop

Carmen S. Bowman, MHS, ACC is the owner Edu-Catering: Catering Education for Compliance and Culture Change turning her former role of regulator into educator. She is a nationally-recognized expert in culture change, and is a frequently invited speaker at national long term care and culture change conferences including the Pioneer Network. Carmen was a Colorado state surveyor for nine years, surveying nursing homes, assisted living residences and adult day programs. She is a former policy analyst with CMS where she taught the national CMS Basic Surveyor Training Course. She presented the surveyor segment of the 2000 CMS satellite broadcast "Surveying the Activities Requirements in Nursing Homes" and the 2002 CMS satellite broadcast “Innovations in Quality of Life - the Pioneer Network.” Carmen now serves as a contractor to CMS on culture change projects the most recent being the April 2008 CMS and Pioneer Network co-sponsored national Creating Home environmental symposium focusing on environmental regulations and culture change. With CMS, she also co-developed the Artifacts of Culture Change measurement tool. She recently served on an AANAC grant project regarding The MDS and Culture Change. The first certified activity professional to become a state surveyor and work at the federal level, Carmen served on the CMS Activities Panel rewriting the interpretive guidelines for Tags F248 and F249. Carmen holds a Master's degree in Healthcare Systems and Certificate in Gerontology from Denver University. Carmen is a Certified Validation Worker, Certified Eden Associate and Eden Mentor. In 2002, she co-founded the Colorado Culture Change Coalition. She has authored five culture change workbooks for Action Pact: Building Culture Change Coalitions, Living Life to the Fullest: A Match Made in OBRA ‘87, Quality of Life Regulations: The Difference between Deficient Practice, Common Practice and Culture Change Practice, Regulatory Support and Considerations for Culture Change and Changing the Culture of Care Planning: A Person-directed Approach.