The Deep Seated Issue of Choice

Linda Bump, MPH RD LNHA

This paper addresses the issue of resident self-determination through a focus on the dining experience. Its contents have been shaped through 35 years of personal and professional advocacy for resident self-determination and quality dining experiences. However, the collective passion, vast knowledge and rich experiences of pioneers in culture change from around the country shared in this paper shed a bright light on the challenges and possibilities of the topic. It is the author's hope that this piece will provoke a sense of urgency for the need to honor elder self-determination in dining and ultimately, all aspects of their lives through increased regulatory support, collaboration of all stake holders and actions to remove the varied barriers to this goal.

QUALITY OF LIFE – QUALITY OF CARE: WHERE DO WE START?

As Americans, we enjoy the privilege of defining quality of life from our own personal perspectives. For most, if not all of us, freedom and choice are central values in defining a good life.

Similarly, we each prioritize our constitutional rights a bit differently, but with common themes and emphasis. The rights of freedom and autonomy, including the right to choose and to refuse and to make good and bad decisions, top the list of importance for most of us. These rights are defined in our Constitution, enforced in most every aspect of our lives, and supported and respected by the general public and the legal system alike.

Prior to OBRA '87, the rights of residents in our nursing homes were often seriously compromised by the institutional nature of their lives that prioritized quality medical care over all other considerations. OBRA '87 clearly recognizes the importance of individualization, home, community and even daily pleasures in defining a good life. The writers of OBRA '87 repeatedly reaffirm resident rights and dignity throughout the document, including the rights to self-determination, (as well as the right to refuse treatment), autonomy, and the dignity of risk and choice.

Our personal preferences in food are unique and individualized, presenting the opportunity for each of us to be experts in defining the role of food in our quality of life. It is not happenstance that, while our tastes are inconsistent from one person to another, there are common themes in the definition of a good life as it relates to food. This paper explores the common themes that define a quality dining experience, and then considers the challenges of providing this quality dining experience to each of our residents. Deep organizational change is often required. This change is not easy. Challenges include survey and best practice barriers, professional standards of practice and related agency guidance that must be successfully overcome if resident self determination in dining is to be advanced. These barriers will be explored and our commitment to the status quo questioned. Recommendations are offered to guide our personal and professional actions in minimizing or eliminating these barriers and clear the way for our residents to enjoy the same quality of life in dining in long-term care that they enjoyed in their community homes.

A HISTORICAL PERSPECTIVE

The challenge of resident choice and quality of life in long-term care was foundational in the Institute of Medicine Committee (IOM) on Nursing Home Regulation report in 1986, *Improving the Quality of Care in Nursing Homes*. Consider these excerpts (additional excerpts in Appendix A):

> The attributes of quality in nursing homes are very different from those in acute medical care settings such as hospitals. The differences stem from the

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> characteristics of the residents of nursing homes, their care needs, the circumstances and settings in which the care is provided, the expected outcomes, and the fact that for many residents, the nursing home is their *home*, not merely a temporary abode in which they are being treated for a medical problem. Thus, quality of life is very important for its own sake (that is, as an outcome goal) and because it is intimately related to quality of care in nursing homes.
>
> The physical, psychosocial, and environmental circumstances and outcome expectations of nursing home residents distinguish the goals of nursing home care from those of acute medical care. In acute care, treatment goals are based on medical diagnosis. In nursing homes, the care goals are based on physical and psychosocial assessment. They focus on restoration, maintenance or slowing of the loss of function, and on alleviation of discomfort and pain.
>
> In sum, long-term care is directed primarily at relieving conditions that result from chronic physical or mental disorders or the chronic after-effects of acute disorders. Equally important is relief of pain and discomfort.
>
> Conflicts of values and ethics are inherent in nursing home care – for example, conflicts between care requirements, as judged by professions, and the rights and preferences of the resident. Should a very old, perhaps mildly demented resident, who is not legally incompetent and who declines to eat, be fed by naso-gastric tube even if he strongly objects to it? What about residents who decline to take medication or other treatments prescribed to manage their chronic disease? Should dietary preferences of a resident override adherence to a medically prescribed dietary regime? Should a frail, unsteady resident with osteoporosis, who insists on walking by herself, be permitted to walk around unescorted even though there is a substantial risk that she will fall and suffer a hip fracture?
>
> …residents who receive good personalized care and opportunities for choice have higher morale, greater life satisfaction, and better adjustment.

Twenty-three years later, we come together to consider many of the fundamental questions detailed in the IOM report on the deep seated issue of choice, specifically: what is possible, who owns the care plan, how do we effect the deep organizational change needed so that a person's right to choice in their own home is honored, what makes these new ideas so difficult. Twenty-three years later, far too many of our elders are still waiting for meaningful choice.

THE CHALLENGE OF QUALITY NUTRITIONAL CARE

The epidemic of malnutrition, dehydration and weight loss in our long-term care institutions is well documented, well known to all and the subject of in-depth medical focus, legislative inquiry and legal investigation. Landmark research in 2000 by Burger, Kayser-Jones and Bell, *Malnutrition and Dehydration in Nursing Homes: Key issues in Prevention and Treatment,* supported by the Commonwealth Fund, found:

> Four issues are key to the prevention and treatment of malnutrition and dehydration: inadequate staffing, poor environment, insufficient data collection and lack of enforcement. Finding solutions that address these issues will require

> understanding and cooperation from all involved – residents and their families, nursing home directors, geriatricians and nursing home staff and government regulators.
>
> Not only may malnutrition and dehydration result in readmission to the acute hospital—a stressful event for frail elders—but they also contribute to a decreased quality of life, morbidity, and mortality. In addition to these physiological, psychological, and pathological consequences, nursing home residents who do not receive adequate nutrition and hydration during the last months or years of their lives are denied one of life's greatest pleasures—the enjoyment of food and drink of their choice in a pleasant, social environment.

Two of the nine specific approaches they recommended in 2000 are uniquely descriptive of nursing homes that have adopted the culture change movement, specifically the neighborhood and small house or household, and all nine approaches are compatible with it. Specific to the neighborhood/household model are:

- Utilization of all nursing home personnel to assist at mealtime; cross-training of administrative and other indirect care staff as CNAs; supporting and training family members to help residents to eat; training volunteers in tray set-up and mealtime socialization…
- Creation of an environment conducive to eating, including the provision of homelike surroundings at mealtime, smaller social neighborhoods, attractive food, choice in food, attention to ethnically sensitive/appropriate food choices, and making foods available 24 hours a day.

Among their conclusions: "Some nursing homes have already discovered that creating small neighborhoods within larger nursing units to increase the social aspects of dining, and instituting cross-training of other nursing home staff to help at mealtimes are effective in preventing malnutrition and dehydration." (Burger, Kayser-Jones, and Bell, 2000)

CULTURE CHANGE – SUPPORTING QUALITY OF LIFE AND CARE

According to a recent survey, *Culture Change in Nursing Homes: How far have we come? Findings from the Commonwealth Fund 2000 National Survey of Nursing Homes*, "Although The Nursing Home Reform Act, passed in 1987, established residents' rights and quality standards for nursing homes nationwide, serious concerns remain about quality of care and quality of life for nursing home residents. The culture change movement is working to radically transform nursing home care, and help facilities transition from institutions to home."

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The Commonwealth survey reported that while almost all nursing homes are familiar with culture change, "progress has been slow in transforming long-term care facilities from institutions to homes. Of the 1,435 nursing homes sampled, 5% reported that the definition of culture change or resident-centered care 'completely' described their home, another 25% reported that the description fit 'for the most part', to total 31% (adopters). Another 25% indicated the term describes their home 'in a few respects' (strivers), while 45% responded 'not at all' (traditional)."

Study results indicated, in part, that:
- Fifty-eight percent of culture change adopters allow residents to determine their own schedules, compared with only 22 percent of traditional nursing homes.
- Seven of 10 culture change adopters report that residents are involved in decisions about their facility, but only one-quarter of traditional nursing homes (27%) involve residents in such decisions.
- …only 14 percent currently cross-train staff to play several functional roles (for example, housekeeping, nursing, food service and activities) to serve a variety of resident needs.
- On average, nursing homes report that only 8 percent of residents currently reside in neighborhoods and only 1 percent live in households.
- While more nursing homes are making the dining experience resident centered…About three of ten nursing homes (29%) in the U.S. indicate they have implemented initiatives to make dining less institutional, such as offering restaurant, family and buffet styles and providing more dining times.
- Nearly half (46%) of culture change adopters report they have changed how meals are served. In contrast, only 22% of traditional homes report they are making such changes.

The authors also state, "The more culture change principles are embraced, the greater the increase in staff retention and occupancy rates and the greater the decrease in operational costs. As nursing homes become more engaged in culture change and adopt more of the associated practices, staff retention, market competitiveness, occupancy rates, and operational costs also improve…With the examples and best practices gleaned from the culture change movement, nursing homes can begin to make the necessary changes to improve the quality of life for their residents and staff." (Doty, Koren and Sturla, 2008)

Has culture change improved quality of life and quality of care for residents? Evidenced based practices confirming positive outcomes in quality of care and quality of life are beginning to emerge as researchers evaluate culture change. Residents and staff living and working together in transformed homes continue to benefit from resident-centered care.

We are fortunate that there are growing numbers of providers who have adopted transformational culture change which embodies resident-centered care. Growing numbers of residents, family members, community advocates, ombudsmen, regulators and professional care groups are beginning to appreciate culture change as a positive force that will achieve quality of care and life for elders. Most importantly, deep-seated culture change is an important avenue for implementing the national nursing home reform law (The Nursing Home Reform Law, Title III,

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Social Security Act, December 1987), cited in this paper as OBRA '87.   The contents of this paper explore the issues, opportunities and challenges awaiting us all.

WHAT IS POSSIBLE: QUALITY OF LIFE – QUALITY OF CARE IN DINING

QUALITY OF LIFE IN DINING – *What is Possible?*

Normalcy is Possible

The Pioneer Network phrase, "rampant normalcy," aptly defines the goal to continue the dining experience that is "normal" to the resident, whatever that might be, with the transition from community home to long-term care home. Steve Shields, in *Restoring "Rampant Normalcy": the Power of Small Moments,* describes those small moments in normal dining, "the little choices and rituals that make up the fabric of our lives."

> "Our residents control the rhythms of their own lives now. First meal schedules were expanded; now they're being replaced by 'continual dining,' meaning people eat what they want when they want. We still have the standard menu options, but there's a meal being cooked somewhere in this place at any given hour – and anybody at all might be cooking it – to order. We're still discovering what choice means, how deep that word goes, but we're getting there. Spontaneity has found its way here in ways it would never have before. Relationships are deeper.   True friendships have formed.   And the small moments flourish." (Shields, 2004)

A note of appreciation: Stories, concerns and comments in italics throughout this paper were shared by others in informal communication in response to the author's commitment to address the topic through the eyes of providers, professionals and others working to improve resident quality of life through culture change, specifically through resident-centered dining in long-term care.   A sincere thanks to Lori Madalone RD, for her invaluable challenges to the status quo and to all who shared their expertise with a special indebtedness to the following organizations for their encouraging stories that provide insights into the possibilities of dining transformation in households: Bigfork Valley Communities (formerly Northern Pines Communities), Bigfork, MN; Meadowlark Hills, Manhattan, KS; Pennybyrn at Maryfield, High Point, NC; Garden Spot Village, New Holland, PA; Perham Memorial Home, Perham, MN; Nielson Place, Bemidji, MN; Lyngblomsten Care Center, St. Paul, MN; and the Cottages at Brushy Creek, Greenville, SC.

The Minnesota pioneer of deep culture change, the Service House at Lyngblomsten Care Center, was patterned after the Swedish Service House system. The Swedish model focuses on autonomy and self-determination by maintaining normal life routines in the transition from community to Service House living. Service Houses have individual apartments, each with a full bath and kitchenette where breakfast and supper are prepared by staff with each residents' own food, allowing them to get up in the morning and go to bed at night when they choose, and take meals of their choice at times of their choice. Lyngblomsten's first Service House opened in 1997 as a demonstration project and served as the catalyst for culture change in Minnesota. It was described in detail in "A Case Study Brief" by Paul Mikelson in *Culture Change in Long-Term Care*, 2003. Today, Mikelson reports:

> All 14 of our "neighborhoods" use most of the features of the original Service House program, though the one truly wonderful aspect of having your own food for breakfast and evening meals has largely disappeared due to families not being

> willing to support that program (grocery shopping, etc.) and staff being hard pressed to comply with the rigors it demands. Time marches on. One impact of culture change on an organization is that after 11 years, what is "normal" is what was "unusual" before the change. So, we don't give a lot of thought to transformative happenings, as they don't strike us as anything out of the norm. (Mikelson, 2009)

To be sure, "normal" is different from one individual to another, and to each individual in differing stages of the life cycle, but common elements come together to create a resident-specific quality dining experience at home.

Home is Possible

With food quality a given, several additional elements most often define a quality dining experience at home:

Create Quality Dining through Choice
Simply speaking, it is all about choice. It is as simple as asking, "What does the resident want? How did they do it at home? How can we do it here?" Asking those three simple questions, pushing away "the way things are done," connecting with the resident and his or her preferences and letting choice rule, you realize the "the way things are done" is certainly not the way you would have done them in your house, and you are on your way to individualized resident-directed care.

Choice of what to eat, when to eat, where to eat, whom to eat with, how leisurely to eat. True choice, not token choice. Not the win-lose choice between a hot breakfast and sleeping to the rhythm of your day. Not simply the choice of hot or cold cereal, but also the raisins and brown sugar that make oatmeal a daily pleasure. For dining, true choice is exemplified in point-of-service choice, for how often do we know what foods will appeal most to us tomorrow, next week, in three weeks? Perhaps we know what we will want for a special celebratory meal or for breakfast if we are a creature of habit, but probably not for lunch and supper on Thursday of next week.

Yet traditionally we define choice in our dining services as the opportunity to express our likes and dislikes during an admission interview, or to circle a menu one day, or week, or month in advance. We may also define choice by the presence of the steam table in the dining room, but it quickly becomes token choice with the use of computerized tray ticket systems which control the food served from the steam table to a specific resident. What could be worse than seeing and smelling a tempting food, only to be served a different food specified on the ticket laying on the pre-set table -- resident autonomy at this particular meal is overridden with preferences stated during an assessment process or a therapeutic diet extension. And sadly, acknowledge to yourself how often the dining and nursing staff expresses their frustration with impossible-to-please residents who select something they have previously asked us not to serve them. Consider the control you personally exercise daily in dining choices, and the pleasure that control brings to you each day with food. While taste and texture and tolerance may change with aging, the

pleasure of control likely remains the same. Challenge your service to the residents: If you pre-pour it or pre-dish it – stop it, as you are limiting true choice.

When dining at home, we all have the right of point-of-service choice, and our residents are dining in their home; they deserve true point-of-service choice. The challenges are being met by dining professionals in homes committed to resident-centered care. They are proving to be cost effective with skilled forecasting, elimination of waste (food, supplies, tasks and time, not to mention supplements) and creative service system re-design facilitated by a hospitality perspective.   Trained chefs are joining the dining services team in long-term care (not just CCRCs, but frequently small, rural homes), bringing their culinary experience to support resident satisfaction with dining.

> *The first day of breakfast in the dining room, Miss S asked for eggs. The aide serving her panicked, saying, "She never gets eggs, she can't have eggs." We checked her allergies and preferences sheet and sure enough, eggs were listed under dislikes, so she hadn't been served them on the breakfast trays. We talked to the dietary manager and learned that a couple of years ago, she had mentioned she was tired of scrambled eggs on her tray.   The dietary manager charted them as a dislike, and with our efficient tray line, she never received them again. But to our delight, when she asked for them, we served them, and she ate them all on the first morning, and on many mornings to follow.*
> Pennybyrn at Maryfield

> *During survey it was noted on a meal card for Sister R that she had "soup" listed as a "like." Observing the meal, the DON panicked and stopped service, insisting the elder needed soup because her card stated she liked soup, so the elder was served soup at every meal until, on the last day of the survey, the elder motioned to a staff member. She said she was frustrated with always being given soup on the demand of the nursing staff. The best intentions to merely state a resident's "like" and for her to receive it whenever it was planned and available or when she was unhappy with other meal choices had instead become an absolute. It created confusion, waste, and frustration for the elder. She stated that our best intentions for efficiency created doubt about our ability to care for her. (*Madalone*, 2009)*

Create Quality Dining through Accessibility
Foods of choice are available whenever residents are hungry, not just at scheduled meal times. And when they long for a specific food, it is available. Foods of choice are available 24/7 and someone is available 24/7 to prepare it.

> *One lady who will soon be 101 years old is eating whenever and whatever she wants. Prior to this, staff had a very difficult time getting her up and having her eat anything. Now she does it her way and everyone is happy. There is no doubt she will make it to 102.* Garden Spot Village

> *A resident moved into Starkey House from another facility. The resident had significant weight loss and was stated to have very poor appetite. The first morning after he arrived, the caregivers asked what he wanted for breakfast. "I can have anything I want?" the resident asked. "Yes," the caregivers responded. He ate everything he ordered and when asked if he would like anything else for breakfast his eyes got wide. "I can have more?" he asked. In the first week he started eating two or three breakfasts each morning. At first, caregivers were*

> *worried he was eating too much. The resident told us that where he was living before, caregivers would bring in a room tray, sit it next to his bed and leave. They did not help with set-up and the food would become cold. The caregiver would return and take the tray without asking if he needed anything. I told the caregivers not to worry too much about the resident eating two to three breakfasts, because when choice is given back to someone, they might indulge at first and then taper off. As the weeks went by, the resident did decrease how much he ate because he knew we would always provide the breakfast items he requested whenever he wanted them.* (Generali, 2009)

> *Recently, a new resident was admitted to our French Country House. She had been in another nursing home awaiting a room with us. A household staff member was conducting the initial tour of the house with the resident. When she got to the kitchen, the staff member began explaining how this was the residents' kitchen and for her to let us know what kind of things she would like to keep in her refrigerator so she could have them anytime she wanted. The resident asked the staff member 'Do you mean I can come to the refrigerator and get anything I want whenever I want?' When the staff member said 'Yes,' the resident said, 'This is heaven.'* (Hollingsworth, 2010)

Create Quality Dining through Individualization

Favorite foods, comfort foods, foods prepared from residents' favorite recipes, foods they chose to eat in their own home, foods that make them look forward to the day…foods that are good for them, from a therapeutic perspective, or foods that they have enjoyed for their whole life even though they may not be the best choice from a medical perspective…for most elders, these foods will not come wrapped in individual snack packs, but rather from real kitchens, from caring staff. But for some, a candy bar and soda, or chocolate chip cookie and milk may be the "supplement of choice." Knowing what specific foods tempt specific residents can make the difference between weight loss and gain, and between supplement and food first. Knowing the residents, their choices, their preferences and their daily pleasures in dining leads to optimal intake and optimal quality of life in dining.

> *We had a lady who was dying and her daughter felt that she wouldn't last through the night, and neither did the MDs. We found out that she ate breakfast really well and started feeding her breakfast several times a day over that weekend. She perked up and is still with us happily eating breakfast almost a year later.* The Cottages at Brush Creek

Lori Madalone, RD, confirms, stating: "The majority of our successes lay in the fact of residents' choice and control in dining, and that liberalization is huge with regard to outcomes. Consider the story of one gentleman from a Metro Denver home with Alzheimer's care and his choice to dine 'at leisure' – while not meeting conventional needs of a traditional nursing home."

> *Norman was frustrated with having to share a meal table. When staff brought him to the dining room, he would show his frustration by refusing to eat, yelling and becoming disruptive. Staff attempted to 'cue' him, but meal time would end in disappointment with Norman wanting nothing to eat. Open dining was implemented with the hours of meals flexible to allow for early and late diners. Staff's education about making meal time more flexible was far reaching. Choice was offered and selections made. This process took a year before its impact was realized. The choice process was still not acceptable to Norman because his food items were chosen from the planned menu and the planned alternate — all in*

> *compliance with regulations. Choice for Norman meant meeting his whims and desires on a daily basis, and when they were accommodated, he ate. Having a stocked 'pantry' in the dining area with items normally found in kitchen cupboards – cereals, soups, snacks, a variety of drinks and more – allowed him to choose and eat as he had at home. When Norman wanted to 'come to the kitchen', he came, sat by his window and had a 'meal.' His meals might be at anytime between 8am and 7pm…whenever he was hungry, not just when meal time was scheduled. This returned Norman to a sense of normalcy – alone, smaller meals, snacking and at times socializing when his mood was consistent with eating socially. Accommodating his needs rather than the desires of the nursing home by simply making food and choices available for Norman when he was naturally hungry led to success. Norman's food intake is acceptable even with what are sometimes smaller than normal meals. His outcomes for weight, laboratory values and skin health are always monitored. Self-determination even with the disease that affects memory can be life altering with something that meets a basic human need – food.* A Metro Denver home

In the article *Providers Urge Flexibility & Sensitivity to Better Serve Residents' Nutritional Needs*, Gretchen Robinson is quoted: "We need to look at the simple things – what is the resident's quality of life, and how can we provide a positive (meal-time) experience?" When planning residents' meals and dining experiences, she adheres to a basic rule inspired by Emma Luten, former CMS Central Office lead dietitian: "Food has to look good, taste good, and be offered courteously." (Henkel, 2004)

Madalone sums it up well:

> *Just seeing elders order from a menu in so many of our homes and allowing SO much choice daily has impacted so many lives with meal consumption and health maintenance as something we 'measure,' and to me good consumptions means satisfied elders. Regulations that give us guidance on menu development are just that – guidelines to be in our profession a template but not an absolute. In the aged, six servings of… five servings of….four servings of….the RDIs mean nothing to an elder who wants to enjoy her last daily pleasure. Cheeseburgers and pie are GOOD! If you want those daily, I say give'm PIE!!!!* (Madalone, 2009)

Community is Possible

Steve Lindsey, CEO of Garden Spot Village, sees the kitchen/dining room of a household as what Ray Oldenburg calls a "social condenser" in his book *The Great Good Place* (1989). Lindsey says this view can help us "to begin to draw out the integral role that this space has in the development of true community within a household. 'Social condensers,' the places where citizens of a community or neighborhood meet to develop friendships, discuss issues and interact with others, have always been an important way in which the community developed and retained cohesion and a sense of identity…according to Oldenburg. They are distinctive informal gathering places, they make the person feel at home, they nourish relationships and a diversity of human contact, they help create a sense of place and community, they invoke a sense of civic pride, they provide numerous opportunities for serendipity, they promote companionship, they allow people to relax and unwind after a long day at work, they are socially binding, they encourage sociability instead of isolation, they make life more colorful, and they enrich public

life and democracy." (Lindsey, 2008)

> *A resident moved in who had received culinary schooling in Germany. She loved to cook. She asked if she could prepare meals in the house. We said yes. She developed the menus and gave us the recipes so we could make sure to order the ingredients. She would make at least one meal per week and sometimes would make treats for the staff. She did this for several months. Many different people heard of her good cooking and she was asked to prepare a meal for the quality council team meeting. The meal was delicious and she enjoyed catering the meal.* Meadowlark Hills

> *Dining in our house is a time where everyone watches out for each other. Our residents really look out for each other, making sure everyone has what they need. They also support each other even in times where their assistance needs grow, for example, when one resident suffered loss and needed increased assistance with eating. Family members come often and enjoy eating with all the residents of the house. It is like a great big family.* Pennybyrn at Maryfield

> *Mr. G, a resident at Neilson Place, has always had a passion and love for cooking, which started when he was still single and was cooking meals for his friends. This led to taking a cooking class at Bemidji State University and then into forming a gourmet cooking club. He also spent nine months at a commissary in Greenland and worked alongside world-renowned chefs. His passion turned into his work as he owned and operated a restaurant and catering businesses. Since living at Neilson Place, Mr. G has continued his passion for gourmet foods and has helped cook and serve several meals including grilled fruit stuffed pork loin and stuffed hamburger on the grill. He has no problem coming up with menu ideas and deciding what to serve with them and has treated staff and residents on several different occasions. His most recent menu served in the Strawberry Neighborhood on April 24 was:*

> *Apricot Orange Glazed Cornish Game Hens*
> *Minnesota Style Wild Rice (with Celery, Onions, Bacon, and Mushrooms)*
> *Seasoned Asparagus*
> *Vanilla Cheesecake with Strawberries or Chocolate Topping*

> *From seasoning the game hens to prepping the asparagus, Mr. G participated and supervised the entire meal from start to finish. He also had to improvise as the initial plan was to grill the hens, but due to the approaching winter storm, decided to bake them in the neighborhood oven. They turned out perfectly and the pictures outside the window of the snow falling made memories for a lifetime!* (Zellman, 2009)

> *This August, residents from all skilled households participated in freezing corn for the holidays. Two hundred ears of corn were purchased from local farms. Residents husked, cleaned and assisted in cutting off the cob. Homemakers completed the cooking, cooling and bagging process. On Thanksgiving Day, all households enjoyed their fresh corn. The remainder of the corn will be used in Chicken Corn Soup, a Lancaster County favorite.* Garden Spot Village

Pioneers in culture change have successfully created normalcy, home and community in dining, offering their residents an enhanced dining experience. Rich Newman, President of Pennybyrn at Maryfield, shares his observation of the importance:

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> *One of the outcomes we have experienced, and I know many others have also, is a significant decline in depression. I know there is no way to make the link to what specific part of the household experience contributes to what degree to quality of life, happiness, and reduced likelihood of depression. There are obviously many contributing factors to that, but I definitely believe the dining experience is a major part of that new reality for many of our residents.*
> (Newman, 2010)

GUIDES TO PROGRESS ON THE CULTURE CHANGE JOURNEY

The Artifacts of Culture Change, a tool co-developed by Carmen Bowman and Karen Schoeneman, measures actual policy and building changes that many culture change innovators are making on their journey. "These concrete changes are the markers and artifacts of the change of mind that occurs in a journey toward home," Schoeneman notes. The HATCh (Holistic Approach to Transformational Change) model used by the Person-Centered Care pilot (Quality Partners, 2005) domains categorize the artifacts of culture change. This tool collects concrete artifacts of the culture change process that a home has, and serves as a guide to progress in moving care and workplace practices, policies and schedules, increased resident autonomy and improved environment on the culture change continuum. (Bowman and Schoeneman, 2006)

In *A Stage Model of Culture Change in Nursing Facilities*, Leslie Grant and LaVrene Norton introduce a conceptual model of the culture change process in which they use an expertise elicitation method. They note, "Just as people progress through distinct stages of human development, going from infancy to childhood to adolescence to adulthood to old age, nursing facilities undergoing culture change progress through distinct stages of organization change and development." They define four stages of culture change – institutional model, transformational model (awareness and knowledge begins to spread, consistent staffing may be initiated and minimalist changes to the physical environment occur), neighborhood model (traditional nursing units are broken into smaller functional areas and resident centered dining is introduced without full kitchens), and household model (self-contained living areas with 25 or fewer residents who have their own full kitchen, living and dining room; staff work in cross-functional self-led teams and traditional departments are eliminated). (Grant and Norton, 2003)

Focusing on dining, outcomes in each stage are described in an Action Pact training manual, *Through New Eyes – Studying Changes in Processes and Systems*:

> *Traditional facilities* can begin by offering residents more dining choices on special event days and making small accommodations to resident choice. Community meals, facility cookouts, fine-dining with family, celebratory birthday meals begin to happen regularly, for all residents.
>
> > *Millie is encouraged to get up by 6:30 in order to be in the dining room for breakfast at 7:30. She is often dressed and lined up in her wheelchair in the hall waiting for the dining room doors to open. Perhaps, because she's cooperative, she's actually gotten up at 5:30 by the night shift and falls asleep waiting in the hall. In a progressive facility, staff has learned*

that Millie likes getting up at 6:30 if she can feed her cat before going to the dining room at 7:30. This has shortened her wait in the hall and she often has something to talk about to the others at breakfast. Staff has succeeded by helping Millie enjoy her life within the efficiency model.

Transitional facilities can consider a variety of systems changes in dining that honor resident choice and individuality. Decentralized service with steam tables in dining rooms, open dining times, buffet or restaurant style service, family style service, the five meal plan or four meal plan (and) refrigerator rights offer point of service choice to all residents.

Millie gets up at 6:30 because of breakfast at 7:30. But, because one of her daily pleasures at home has always been to have her first cup of coffee in her pajamas, her caregivers have gone the extra mile to figure out how they can provide that to her daily. And it wasn't an easy task – they had to come up with a coffee pot, find a safe place to keep it, work with dietary to get the coffee, and a staff member found a lovely cup, which also meant the caregivers washed and sanitized it each day.

Neighborhoods can begin to create home by cooking some special meals to order and involving residents in meal planning and preparation. Kitchenettes, full kitchens (and) shared decentralized production kitchens offer foods and beverages of choice to residents around the clock.

The neighborhood team discovered that Millie and others have different ideas about breakfast – what to eat, when to eat it. So, they met many times, studied regulations, determined resources available, (and) worked with the dietitian and dietary supervisor and the other shifts. They figured out how to provide substantial snacks to meet the 14-hour rule. Now Millie and her friends in the neighborhood have coffee, cold cereal, toast and hard boiled eggs available and easily accessible to any elder upon request before and after their traditional breakfast.

Households are true homes where residents can choose their meals and direct their lives with the assistance of their household family team of care givers.

Millie, (and everyone else's) breakfast is prepared to order, upon request by any of the cross-trained staff. The refrigerator and cabinets are stocked with items known to be favorites of individual elders. Dishes (including Millie's coffee cup) are washed in a dishwasher in the household, and as a result, they all enjoy beautiful and colorful dishes, often of their own choosing. (Action Pact, *Through New Eyes*, 2003)

QUALITY OF CARE AND QUALITY OF LIFE COME TOGETHER WITH RESIDENT CHOICE

While researchers evaluate, residents benefit! As a registered dietitian, it was professionally and personally rewarding to me to confirm a 69% reduction in the prevalence of weight loss during the first three months in Northern Pines Communities (currently Bigfork Valley)—from 15% to 3% in the first quarter, and to NO "unavoidable" loss within six months—concurrent with a 50% reduction in nutritional supplementation through fortified foods. (Bump, 2003, p 20)

Repeatedly around the country, weight loss is replaced by weight gain as residents respond to individualized care with positive clinical outcomes. Improvements in clinical outcomes are now becoming expected outcomes of the journey to individualized care. While the residents cited below live in households and neighborhoods, similar stories abound from transforming facilities around the country. We might ask: Coincidence? Chance? Repeated observations would suggest not, but rather, that clinical improvements are now the anticipated outcome of individualized care.

> *Miss K came to us several years ago. She was on a pureed texture diet with nectar liquids, assisted with meals by staff, underweight and very unhappy. She did not enjoy meals and would tell us we were giving her way too much food, and that this overwhelmed her. The CNA started encouraging K to try assisting herself. We started open dining, allowing elders to make their own food choices from restaurant style menus. Elders are also able to choose when they want to get up for meals. K is a late sleeper and the choice of when to eat really started making a difference. Her meal intake started improving and she got stronger. Before long, K was able to upgrade her food texture to mechanical soft, then to regular, while also drinking regular liquids. K makes her own food choices and usually orders off the menu at supper and occasionally at lunch. She loves grilled cheese sandwiches. She eats a big breakfast, small lunch and very little supper. She does not feel overwhelmed by the food served to her on her plate now that she is in control of what she is getting. This has helped K put on several pounds. We met our goal for weight gain and were able to take her off all supplements. Holly Nursing Care Center, Holly, CO*

> *Mrs. L had been basically in a vegetative state with end-stage dementia for several years. As we moved into households, the staff in her house began bringing her out to the living room to be present when the staff and the other residents were playing games, and they always included her in conversations, whether she responded or not. They always baked a cake for the resident on their birthday, and when they brought her chair up to the table, put her cake in front of her and they sang "Happy Birthday" to her, she joined in and sang every word along with them. Prior to moving into the Household Model, Mrs. L was on a pureed diet, fed totally by staff and supplemented with Resource due to poor appetite. When staff had a chance to know her and find out what her day was really like, things started to change. She started to feed herself, converse with staff and become aware of her surroundings. She was able to answer questions such as, "Would you like your scrambled eggs and toast separate or should we make it into a sandwich?" We discovered that scrambled egg sandwiches were one of her favorites and she could eat them all by herself. On one doctor's round, she greeted the doctor when he entered the room. After her check-up, he*

came out to the nurse and asked, "What are you doing to Mrs. K? She's talking!!" Perham Memorial Home

Mrs. K was not alone in her personal transformation after moving to households at Perham Memorial. Their dietary director shared: "We alter the (food) texture for very few individuals since the household model became the norm. Previously about 25 of our 100 residents had food texture altered to some extent. Currently, we have six residents on mechanically altered diets. When residents are able to sleep in the morning, are rested and ready to eat, they can tolerate most textures of food…which also greatly reduces the need for supplements."

Their DON affirmed: "We also experienced a significant reduction in the risk of choking. It's amazing what a good night's sleep will do for a person!! When residents come to the dining room well-rested, they are ready to eat instead of sleeping at the table. I remember having to rouse a resident from sleep for every bite of food – when they are awake the risk is much less. We do alter the texture of food, but it is regular food that is altered. For example, we had waffles one morning. The staff knew that one of the men couldn't eat a regular waffle with syrup, so she added strawberries and cream and mixed it to a texture that worked for him. He was able to enjoy a 'real' waffle, fresh from the griddle, with the rest of the residents around the table. We find that residents' diabetes are much better controlled even though we don't adhere tightly to a restricted diet. We have had residents whose HgA1C is so low the physician considered taking them off insulin…We have found that as long as we assess the situation, discuss the risks and benefits with the residents, care plan the approaches and 'follow' the care plan – we have been able to do what the resident wants." *(*Krumwiede and Oelfke, 2009)

Oelfke summarized Perham's expected and unexpected outcomes in *Household Model's Impact on Quality of Care Impresses,* noting, "We never expected to see improvements in quality of care – our focus was to improve the residents' quality of life. We have been amazed at the outcomes…Historically, we have used our Quality Indicator reports as a measure of quality of care…The average percentile ranking has improved from 47.4 percentile in 2002 to 27.3 percentile in January 2008…Indeed, quality of care improves as we work to enhance quality of life for our residents." (Oelfke, 2009)

Again, we must ask - is this just a coincidence? The recent Pioneer Network Case Studies series on Providence Mount St. Vincent noted similar outcomes, citing "improvement of quality indicators from pre-to post-implementation" as one impact of quality. (Elliot, 2008) Repeated observations would suggest it is not chance or coincidence, but rather, the now anticipated outcome of individualized resident-directed care.

Put into a historical food and culture perspective by Kittler and Sucher:
> Food, as defined in the dictionary, is any substance that provides the nutrients necessary to maintain life and growth when ingested. When animals feed, they repeatedly consume those foods necessary for their well-being, and they do so in a similar manner at each feeding. Humans, however, do not feed. They eat. Eating is distinguished from feeding by the ways in which humans use food. The term, 'food habits,' refers to the ways in which humans use food, including how food is obtained and stored, how it is prepared, how it is served and to whom, and how it is consumed. (Kittler and Sucher, 1989, p 3-5)

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WHAT IS POSSIBLE

Lowenberg's classic 1970 review of A.H. Maslow's theory of human maturation as applied to food habits explains how food use progresses from eating for existence to eating for self-actualization:

1- *Physical needs for survival*: This is the most basic use of food, nearly equivalent to feeding. Daily needs for nutrients must be met before more complex food use can occur.

2- *Social needs for security*: Once the immediate need for food is satisfied, future needs can be considered. The storage of food represents security.

3- *Belongingness*: This use of food shows that an individual belongs to a group. The need to belong is satisfied by consuming the foods that are eaten by the social group as a whole. These foods represent comfort and happiness for many people; for example, during periods of stress or illness, people often want the foods they ate during childhood.

4- *Status*: In general, eating with someone connotes social equality with that person. Many societies regulate who can dine together as a means of establishing class relationship. What foods are eaten can be used to define social status as well.

5-*Self-realization*: This stage of food use occurs when previous stages have been achieved to the individual's satisfaction. Personal preference takes precedence and the individual may experiment with the foods of different economic or ethnic groups."
(Lowenberg, 1970)

Maslow's theory as applied to food habits can contribute to our understanding of the successful outcomes experienced by pioneering culture change facilities as their residents move from eating for existence in a traditional facility (consider the use of the terms 'feeding' and 'feeders') to eating for self-actualization in the transformed facility with individualized resident directed care. It seems logical.

WHO OWNS THE CARE PLAN? WHO ARE WE TO DECIDE FOR PEOPLE WHAT IS BEST FOR THEM?

The deep-seated issues of resident self-determination were clearly identified in the IOM report previously reviewed. Further, the initial surveyor/provider trainings introducing the revolutionary concepts of OBRA '87 to the long-term care world clearly defined the concept of autonomy in surveyor guidelines as a framework for resident rights, and introduced a new perspective on resident rights for survey focus, excerpted below. (See additional excerpts, Appendix B and C.)

> **Autonomy: A Framework for Assessing Resident Rights and Quality of Life**
> All persons have autonomy, regardless of the range of their functional abilities.
> The concept of autonomy – the degree to which a person expresses his or her individuality – is useful to thinking about assessing a facility's compliance with resident rights and quality of life requirements. The new nursing facility requirements recognize that autonomy is a basic human need. Autonomy has three dimensions:
> > -Independence
> > -Self-control
> > -Competence
>
> **Autonomy and the Nursing Facility Environment**
> Your review of resident rights and quality of life reduces to one basic question – how much control over their lives do residents living in a nursing facility have? The new nursing facility requirements challenge the assumption that institutionalization limits personal autonomy more or less by definition. Rather, assume that the nursing facility and environment is neutral with respect to residents' autonomy. Everything depends on the way the facility sets up its institutionalized practices. Set up in one way, the facility is receptive to autonomy; set up in another way, it limits autonomy.
>
> In surveying resident rights and quality of life, you are evaluating the extent to which the nursing facility's social and physical environments advance resident autonomy. Think of your job as searching for organizational traits that assist residents' autonomous behavior – exercising independence, self-control, and competence. Assessing two characteristics are critical:
> > -Flexibility
> > -Controllability
>
> Flexibility means that the facility provides opportunities for residents' autonomous participation.
> Controllability means that to some degree that facility allows residents to have an on-going role in shaping the institution – to have a say in how the facility functions.
>
> Insofar as it is flexible and controllable, the nursing facility becomes an environment with opportunities for residents to live autonomously.
>
> **A New Perspective on Resident Rights**
> **Dignity means more than door-knocking.**

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OBRA 87 gives us the opportunity and obligation to reexamine our attitudes, our routines, and personal assumptions regarding resident rights. We have the chance to re-focus our efforts and in the process, social awareness and ethical practices that emphasize individuality will evolve.

When we reaffirm the dignity of each resident, we will also enrich the lives and values of our staff members. And, as we seek new ways of enhancing independence and offering new choices and opportunities to our residents, staff members will feel rewarded by those they empower.

Enriched lives means more productive lives for our staff. Pride and personal determination will improve the quality of life for our elders.

Busy care-givers are routinely required to make "on the spot" decisions. In the past, these decisions may have been made with the primary focus on efficiency and not on thoughtful consideration to individuality. To place appropriate emphasis on resident rights, we may need to sacrifice some efficiency for the sake of human pride.

Goals must be set that hold individual dignity in higher esteem than overall facility efficiency. It will not be easy. Years of caring practices and habits based on experience will need to be challenged. Ideas once believed to provide quality will need to be reexamined.

The following examples address areas in which quality care and resident rights should be examined.

Quality and the Dignity of Risk
The frail, elderly nursing home resident often must balance the dignity of risk, which enables pride and independence, with the need to be kept safe.

The dignity of risk, individual pride, and the need for adult mastery and independence are valuable human options.

Individual choice after full discussion of risk factors may be the most appropriate choice for many residents.

Quality and the Dignity of Privacy
Visitors, space and privacy are other important areas of concern.

The key to the development of an effective policy that provides dignity and privacy is to remember that residents should make the final decision. In the process, they can learn to lobby and to take into consideration the wishes of the majority when making a decision.

Providing quality in areas of privacy may also extend to cleaning rooms by appointment and respecting the privacy of a resident's dresser drawers or closet space.

Privacy for families to meet must also be considered. Ideally, an administrator will foster family-like units that allow for readily available private space, without a great deal of cost or effort.

Quality and the Right to Participate in Care Decisions
Although residents and their families are routinely invited to attend care conferences, we may need to explore other avenues that allow residents to

participate in care and treatment decisions. Residents are empowered by being given the choice about their method of involvement.

The areas in which we must address resident rights continue to grow. Consider:

- the right of the life –long smoker versus the right to a smoke-free environment;
- the facility need to supply "optimal nutrition" versus the individual need to satisfy lifestyle or fast food habits;
- the facility need to document perfection in grooming versus the individual right to grooming habits;
- the right to refuse treatment versus the nursing obligation to provide care;
- the right to refuse food versus the need to feed and offer supplements.

The list goes on.

This new perspective on approaching resident rights is appropriate as we enter a new decade of providing health care services. It is an opportunity to affirm that quality goes beyond hot meals and clean sheets. It is the chance to acknowledge that quality perhaps has more to do with meeting, to the best of our abilities, each resident's right to maintain his or her dignity, pride, and self-esteem while in our care. (HCFA Training Manual, OBRA, 1987)

The origin of many of our current survey processes, and the foundation of Karen Schoeneman's oft quoted statement that "OBRA mandates culture change" is clear. However, the intent of deep-seated choice so apparent in these early documents has been significantly diluted in the traditional institutional practices that have survived all these years. Facilities often continue to offer merely token choice, flexibility and control to residents. The dignity of risk is clear in these foundational documents, so how did we as an industry come to elevate safety over resident dignity and choice? How did the culture of traditional long-term care come to the expectation that we can, or should, prevent any risk? Over two decades later…many, perhaps most, of our elders are still waiting for meaningful life, increased choice and increased control assured through their real participation in planning their care and their life.

RESIDENT RIGHTS: Opportunities and Challenges

In their inspiring forward to *In Pursuit of the Sunbeam*, Norton and Shields challenge us all to a noble calling, quoting Alexander Hamilton: "The rights of mankind are not to be rummaged for among old parchments or musty records. They are written, as with sunbeam in the whole volume of human nature, by the hand of Divinity itself, and can never be erased or obscured by mortal power." They challenge us all to "acknowledge the pursuit as central to who we are as human beings…assure choice in the daily lives of leaders and in our own future, and to act upon these rights to assure our humanity." (Shields and Norton, 2006, ix)

These rights of mankind are guaranteed to nursing home residents in the federal law and regulations, OBRA '87, excerpted in shaded boxes below.

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> **483.10 Resident Rights**
> **The resident has a right to a dignified existence, self-determination, and communication with and access to persons and services inside and outside the facility. A facility must protect and promote the rights of each resident, including each of the following rights…**
>
> **F151**
> **483.10(a) Exercise of Rights**
> **483.10 (a)(1) The resident has the right to exercise his or her rights as a resident of the facility and as a citizen or resident of the United States.**
> **483.10 (a)(2) The resident has the right to be free of interference, coercion, discrimination, and reprisal from the facility in exercising his or her rights.**
>
> **Interpretive Guidelines 483.10 (a)(1)**
> Exercising rights means that residents have autonomy and choice, to the maximum extent possible, about how they wish to live their everyday lives and receive care, subject to the facility's rules, as long as those rules do not violate a regulatory requirement.

In *Reassessing Autonomy in Long-Term Care*, George Agich acknowledges the paradoxical realities of long-term care when viewed from the perspective of autonomy. Pat Maben, retired pioneering reformer of the regulatory environment in Kansas, says this article changed her life by having a profound effect on her, first as a DON, and ultimately forcing her to look at her role as a regulator and what she should promote in Kansas. With the full support of the Secretaries of Health, by 1995 the ideas of Agich and others were influencing resident-directed care and nursing home design in that pioneering state.

Agich asserts that in moral life, a fuller conception of autonomy than the common abstract liberal concept is required – one that "acknowledges the essential social nature of human development and recognizes dependence as a non-accidental feature of the human condition. Such a concept would systematically attend to the history and development of persons and take the experiences of daily living into account; it would view individuals concretely and see choice as a problem of positively providing options that are meaningful for concrete individuals, rather than as an issue of removing obstacles to choice or impediments to action." (Agich, 1990)

Agich further develops the concept in *Dependence and Autonomy in Old Age*, with the goal of developing "a framework for rethinking and reconsidering the everyday ethics of long-term care. I accept that ethical conflict, dilemma and tragedy are inescapable features of this setting…I strongly believe that well-motivated caregivers can improve their practices if they could be provided with a useful way to think about respecting the autonomy of persons needing long-term care…I have the confidence that those who are situated closer to the phenomena of old age and disability are better able to devise solutions to problems or to make improvements in programs than someone trained in bioethics and philosophy." (Agich, 2003)

Development and implementation of best practice tools to achieve that end could bring the right of self-determination to most, if not all, long-term care residents.

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THE RIGHT AND DIGNITY OF CHOICE AND RISK

Inevitably in many cases someone involved will begin to raise questions about risks or potential harm to a resident, even when a resident makes a choice. Sometimes this is because the person raising the question (provider, family member, surveyor, advocate, ombudsman) believes the resident's choice will lead to harm. Raising questions is sometimes necessary and helpful. But it can become complicated and the final decisions rarely offer certainty.

The idea is not new to long-term care. In 1976, eleven years before OBRA '87 emphasized the issue, Langer and Rodin published results of a field experiment on a group of nursing home residents in which they demonstrated that the experimental group (the group with objective control) showed a significant improvement over the control group in alertness, active participation and general sense of well-being. Specifically related to food, they noted: "Should an elderly diabetic be allowed to have ice cream? The relationship between diabetes and sugar is probabilistic even though it is treated by many people as absolute. Whether or not that ice cream will hurt the person depends on what else was eaten that day, how much ice cream is consumed, whether or not the person has exercised, and so on. Recent evidence, in fact, suggests that no sugar is more dangerous than a small amount of sugar. Regardless of the finding, I think nursing home staff should make recommendations, but leave the final decision up to the resident. One cannot know today what 'facts' will turn up tomorrow." (Langer and Rodin, 1976)

Does it not logically follow that lack of choice can harm a resident's general sense of well-being?

> **F242**
> **483.15(b) – Self-Determination and Participation**
> **The resident has the right to—**
>   (1) **Choose activities, schedules, and health care consistent with his or her interests, assessments, and plans of care:**
>   (2) **Interact with members of the community both inside and outside the facility; and**
>   (3) **Make choices about aspects of his or her life in the facility that are significant to the resident.**

In their recent study, *Depression in Older Nursing Home Residents*, Choi, Ransom and Wyllie acknowledge, "More effective approaches are likely to be the ones that not only incorporate the residents' choices and preferences to the greatest extent possible, but also encompass the changes in nursing homes' institutional environments and culture." (Choi, Ransom and Wyllie, 2008)

> *Not long ago we admitted a woman who brought her iron and ironing board with her – her simple pleasure. She was admitted with dementia and even as long as we have been working in the households, staff questioned whether she could safely iron. They worked with her to develop a schedule for 1:1 visits giving her time to iron while supervised. Guess what happened – it didn't take long until she stopped ironing. She didn't want to take up the staff time so that she could continue to iron. The team came back together and talked about what is the worse thing that could happen. They decided together that it was more important*

> *for the resident to be able to iron as she wished than to take it away from her under the guise of keeping her safe. She irons every day – has not burned herself or anything around her – I think we could make money by selling her services! We see examples of our "overly protective" nature all of the time – we are continually questioning those decisions. "Risk taking" needs to be accepted as a normal part of life. (*Oelfke, 2009*)*

> *I feel fortunate that we have not experienced some of the difficult situations other facilities have as they moved to households. We pay attention to the regs but interpret them from the resident's perspective. We have become "okay" with deficiencies as long as they don't affect what we are trying to do in creating our home…We have never had a deficiency that in any way challenged what or how we are doing things. Maybe that means we "haven't pushed" far enough?* (Oelfke, 2009)

THE RIGHT TO REFUSE TREATMENT

Similarly, the right to refuse treatment is a clearly defined personal right, yet so often challenged for residents of a traditional nursing home. It seems logical that, as citizens with rights living in their home (albeit a skilled nursing home), residents be offered choices of treatment options and encouraged to make a positive choice within the boundaries of their personal goals identical to the best practice process of health education for community-living elders. Health professionals do not expect universal compliance with their recommendations to community-living elders; we respect a person's right to make a choice deemed inappropriate from our professional perspective. Our residents deserve the same respect.

Yet in long-term care, we traditionally expect compliance, and our care-giving systems default to compliance rather than to free choice. We label those making what we judge to be poor choices as "non-compliant," continue to re-educate, re-educate, re-educate, (could this be harassment?) and sometimes even attempt to manipulate or trick residents into compliance. Do you serve decaffeinated coffee to all residents, sugar-free lemonade to all residents? Do you serve only "lite" fruits to all? If so, are your residents aware of the choices you have made for them? Free choice should be the same in an elder's home, whether it be in the community or in your nursing home. Honor the dignity of choice. Ban the label of non-compliance. Honor your residents' rights.

> *My latest issue is the constant pressure we are under in the nursing home industry between the battle for human dignity and quality of life versus safety at all costs. There is enormous pressure both from the survey teams and the insurance industry due to wrongful death lawsuits that cause many to fear any injury to residents, sometimes compromising quality of life. My latest example is with thickened liquids. I completely understand the rationale… I have had residents and family members complain about this, and I think to myself if I was really thirsty would I want to drink a glass of glue? There is the Frazier water protocol that allows un-thickened water to be given in small sips since we have water in our bodies anyway. But I know some facilities won't "allow" that because there is still some aspiration risk and concern over resident safety. I have seen many examples of safety over resident dignity, and I vote for dignity most of the time... (*One administrator's view)

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> *The needs and controls needed by elders living in the community do not always apply to elders in the long-term care setting. Control is given to scheduled medication administration and meals, and food is available but not in the LARGE quantities that would exacerbate someone's glucose levels. Then the doctor chastises the elder for "poor food choices" and new orders return to the home with the elder for more strict controls on meals, food availability and more. The continuum needs to be educated on what makes "home" in long term care and we need to work with the professionals on "the other side."* (Madalone, 2009)

> A regulator comments: *The requirement to work out refusal issues with the resident cannot be waived.*

> An RD: *I don't believe we should treat pneumonia if the resident refused thickened liquids. Why should we treat it when they refused the treatment that would have avoided the negative consequence?*

> A regulator asks: *How do you balance quality nutritional care and resident choice?*

Is there a balance, or do resident choice and the right to refuse treatment after appropriate education and exploration of alternatives take precedence over the professional recommendations for quality care? They do for elders living in the community. Our elders deserve the same.

F 155
483.10(b)(4) – The resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive as specific in paragraph (8) of this section;

> *One of our favorite foods in Lancaster County is our potato chips, especially those made with lard. We had two gentlemen, both good Dutchmen, for whom swallowing problems made eating chips unsafe. Physician, family and residents made the choice to continue with their favorite food despite the risks.* Garden Spot Village

COMPETING CHALLENGES TO SELF-DETERMINATION

The federal regulations or interpretive guidelines often seem to be competing with one another as it relates to application and/or enforcement, as indicated in the excerpted provisions below.

F279
483.20(k) Comprehensive Care Plans
Interpretive Guidelines
The requirements reflect the facility's responsibilities to provide necessary care and services to attain or maintain the highest practicable physical, mental and psychosocial well-being in accordance with the comprehensive assessment and plan of care. However, in some cases, a resident may wish to refuse certain services or treatments that professional staff believe may be indicated to assist the resident in reaching his or her highest practicable level of well-being. Desires of the resident should be documented in

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the clinical record…

F280
483.20(k)(2) Comprehensive Care Plans
Interpretive guidelines
The resident's right to participate in choosing treatment options, decisions in care planning and the right to refuse treatment are addressed at 483.20(k)(2)(ii) and 483.10(b)(4), respectively, and include the right to accept or refuse treatment…

The resident has the right to refuse specific treatments and to select among treatment options before the care plan is instituted…

While Federal regulations affirm the residents' right to participate in care planning and to refuse treatment, the regulations do not create the right for a resident, legal surrogate or representative to demand that the facility use specific medical intervention or treatment that the facility deems inappropriate. Statutory requirements hold the facility ultimately accountable for the resident's care and safety, including clinical decisions.

F281
483.20(k)(3) Professional Standards of Quality
Intent
The intent of this regulation is to assure that services being provided meet professional standards of quality (in accordance with the definition provided below) and are provided by appropriate qualified persons (e.g., licensed, certified).

Interpretive Guidelines
"Professional standards of quality" means services that are provided according to accepted standards of clinical practice. Standards may apply to care provided by a particular clinical discipline or in a specific clinical situation or setting. Standards regarding quality practices may be published by a professional organization, licensing board, accrediting body or other regulatory agency. Recommended practices to achieve desired resident outcomes may also be found in clinical literature…

The following CMS interpretive guideline seems to stop short of granting full residents' rights as it relates to the final responsibility of the facility for the resident's care.

F280: Interpretive guidelines - *While Federal regulations affirm the residents' right to participate in care planning and to refuse treatment, the regulations do not create the right for a resident, legal surrogate or representative to demand that the facility use specific medical intervention or treatment that the facility deems inappropriate. Statutory requirements hold the facility ultimately accountable for the resident's care and safety, including clinical decisions.*

Is this interpretive guideline the base of that unanswered question of how to balance quality of care with resident choice? We need to accept the premise that all involved want to get it right –

to do the right thing for the right reasons. We need to acknowledge that one challenge is knowing what is the right thing to do. Furthermore we need to acknowledge that a second challenge is honoring residents' rights as human beings. We have all been taught that the care plan actually belongs to the resident, but who really owns the care plan?

The issue was strongly addressed over a decade ago by Rosalie A. Kane, Robert L. Kane, and Richard C. Ladd in *The Heart of Long Term Care* as one Principle for Change:

> Safety must give way as the number one quality indicator, because that is a recipe for oppression of the consumer. Without being foolhardy or encouraging negligent care, long-term care authorities must recognize that complete safety is an unrealistic goal for any population and that excellent health and elimination of injury, disease, and death are impossible goals for the disabled, often sick, often very old people who need long-term care. (Kane, Kane and Ladd, 1998)

Steve Shields spoke directly to the issue in *Old Age in a New Age*:

> Risk is inherent to being alive. One of the mistakes we have made in long-term care is to eliminate risk…We're so averse to risk that we'll tie people up to avoid it. We will eliminate life's enjoyment to avert it. But the fact is, getting up in the morning is a risk, from the moment we're born to the day we die…So we all make choices. Life is full of risk. We make peace with that…We have made our decisions about where we fit into all that, relative to risk. And there's no acceptable reason that any influence, whether it be regulation or attorneys-- nothing should interrupt a person's sense of continuing that dynamic about life. (Baker, 2007)

In *My Nursing Home Experience*, Imogene Higbie, at the age of 87, expressed:
> "During my own experience, I was dismayed by the lack of personal autonomy and involvement by residents in making decisions about their personal lives and the pervasive assumption staff knew what was best for us better than we knew for ourselves." (Shields and Norton, 2006, p 16)

But consider some of the complexities challenging the care team as expressed by providers and professionals working to honor resident-directed care and to create true home…

Challenge: Health care professionals are mandated in F279 and F281 to provide necessary care and services to attain or maintain the highest practicable physical, mental and psychosocial well-being in accordance with the comprehensive assessment and plan of care and to assure that services being provided meet professional standards of quality and are provided by appropriate qualified persons.

> *Residents on dialysis are often challenges to nutrition care, both because they often do not follow their therapeutic diet, and because the standards of the dialysis centers for nutritional parameters are often difficult, if not impossible to achieve. The expectations of the dialysis centers are often based on financial incentives for outcomes rather than resident outcomes, and often fail to acknowledge the residents' right to refuse dietary modifications in a long-term care facility. (*A Registered Dietitian response)

> *I just feel that the emphasis on care planning, monitoring, re-evaluation and documentation processes besides the MDS protocol is out of hand. I find that with less competent dietary staff options out there and the turnover that occurs,*

> *there is so much more kitchen supervision needing to be done. One person cannot find the time to do justice to both kitchen supervision and making sure food stays safe, (while also) doing the in-depth care planning, assessing and evaluation for 95-100 year-olds who only want to live their last days in peace in a loving and caring environment with people who care. We can't make them physically be 60 anymore, or fight Mother Nature in the overall aging process, but I feel that is what the regulations are asking us to do. (*A Certified Dietary Manager response)

Challenge: Administration and health care professionals are held ultimately accountable in F280 for the resident's care and safety, including clinical decisions, while also accountable in F151 and F242 for honoring resident rights and self-determination.

> *When speech therapy and a modified barium swallow show severe dysphagia, the resident diet is modified to a level one puree diet. The resident complies with the MD order for awhile, but is embarrassed to eat this food in the dining room and in spite of attempts to make the puree as presentable as possible, despite follow-up education by the SLP and RD and RN, the elder isolates herself in her room at meal times and social isolation and depression now become a part of her "problems" list and care planning for this becomes a focus. The elder soon develops weight loss and feels "ganged up on" each time she "complains" about the food that she does not want to eat and her rights are never a focus because our professional licensure is at risk if we do not uphold the MD order. If we do not offer more follow-up to progress the diet, we do not recognize the problem for what it is. Dysphagia is an ever increasingly recognized need in our institutionalized elders. Liability is in the forefront when there is a negative outcome. We fear to allow self-determination when liability is a threat. Our elders are captive and held to a different standard from what our communities expect.* (Madalone, 2009)

> *It is company policy that all supplies come from one national company, and our ability to buy produce locally has been taken away from us. Hence menus are limited to what the national company supplies. All orders had to be sent in advance and although the cook consulted with the residents, their choice was limited. If a resident fancied a steak for his meal, he could have it the next week as it had to be ordered, so residents with memory impairment did not stand a chance of daily choice. We used to have fish and chips, an English tradition, but it is no longer available…economy versus resident choice is a hard nut to crack!!*

> *We are fortunate to have a very supportive administrator willing to stand with our staff (in meeting) with surveyors, if need be, to support what we want to do. We all knew in the beginning that we would be doing things differently, (thereby) setting us up for deficiencies, but were determined not to let that detour us. We chose to work with the residents and families to determine how they wanted to live and then work within the regs to make it happen. I can't think of a single regulation that we haven't been able to meet within our households. We have found that as long as we have assessed the situation, discussed the risks and benefits with the residents, care planned the approaches, and followed the care plan, we have been able to do what the resident wants.* (Oelfke, 2009)

> *Protecting our personal liability and professional standing places (the) most barriers against self-determination and participation, and (against) our stance as the "expert;" it is intimidating and coercive to our elders. Food is so often NOT dangerous, but too many CONTROLS for perceived health benefit or life extension does the opposite and impacts negatively on an elder's quality of life. I*

see this far too often in overzealous parents with children with perceived allergies. Our challenges are to find the nutrients for that child around fears and obstacles. Apply the same thinking to the elder care industry and we need to find nutrients for ground we have lost by too much restriction. (Madalone, 2009)

We feel one of the biggest barriers to enhancing the dining of skilled nursing residents are those staff members – dietitians, dietary service managers, physicians and our professional staff -- who stand behind the restrictive dietary protocols they have embraced throughout the years. If we consider this the residents' home, they should have the ability to choose whatever they want to eat, without answering to anyone. We discuss and document risks and benefits, but in the end, it should be the resident's choice. (Weber, 2009)

Challenge: Residents' right to self-determination, including the right to refuse care as residents often seek an acceptable balance between quality of care and quality of life.

I didn't realize that this place is a prison. (Resident interview)

Challenge: Family concerns on occasion include hidden agendas counter to the residents' right to self-determination.

This is a health care facility, isn't it? I brought my mother here because she was not following her diabetic, salt restricted diet at home and I expect that you will make sure she follows it here. That's what I am paying you to do! (Family interview)

There is such a threat of liability that impacts this area. Who is to blame, or at fault if a bad outcome occurs? "We don't want mom to have sweets because she has diabetes." But mom is 95 and just wants to eat. Then because we follow the families' wishes, mom's intake declines, mom's weight declines, mom "cheats," mom steals food from other's plates, mom uses petty cash to hit the vending machine daily, mom uses the outing to Wal-Mart to buy Ding Dongs and hides them in her room…you all know the scenario. (Madalone, 2009)

Challenge: Surveyors, the silent members of the care plan process, represent regulatory compliance concerns.

Our state surveyor said, "Let them cook, but then just throw away the food."

I would replace all of the nurse surveyors with other disciplines. Having nurses audit nursing homes is like the wolf guarding the hen house.

A CMS regional dietitian said, "I'm very concerned when resident are given choice, staff fail to monitor their intake of the needed nutrients."

As a surveyor, I am informing the homes that there is no regulatory barrier to the personalization of the dining experience in particular, and in promoting personal choice in general. We are encouraging the homes to be creative and to call us if they have concerns regarding the regulations.

As a surveyor, I want to see the process by which decisions were made and the education of staff, family and residents regarding safety. Otherwise, our position

here is that individual preferences need to be honored and there is no regulatory barrier to doing so.

We have been fortunate to have a "forward thinking" group of surveyors – they value what we are doing and are willing to look at things from the perspective of the resident outcomes. We have worked closely with them throughout the transition of the facility, keeping them informed about changes and "educating" them on our perspective. When they enter the facility, they find happy residents, families, and even staff!! It sets a whole different tone for the survey. Several have commented about how happy everyone is – they specifically noted that the residents seem to enjoy each other – they have "real" conversations around the tables at meal time. Apparently the surveyors don't see that often. (Oelfke, 2009)

Clearly the care team must relentlessly balance the often conflicting accountabilities between quality of life and quality of care. Only a high functioning, self-led team with highly involved members working and thinking creatively can anticipate success. As noted in *Pursuit of the Sunbeam*, "Self-led teams in long-term care are unique because they include the consumer. Elders are involved in their own care. They drive and direct the team." (Shields and Norton, 2006) They have expressed the ultimate goal of the interdisciplinary care team in long-term care. But what must we do to empower our elders to drive and direct the care plan team?

Know the resident. Nancy Fox comments in *The Journey of a Lifetime* that culture change organizations understand the concept of "becoming well-known as the single most important strategy we have as caregivers. Under this paradigm, the care plan becomes a living story of the Elder and her needs…What is most important is that the Elder is now seen and known as the whole person she is." (Fox, 2007, p 71)

Unfortunately, some well-intended facilities are simply rewriting their traditional care plans in the recommended "I" or "narrative" format; this is not the intent, and perhaps even counter to the intent, since the result would indicate that the resident actually chose the facility-generated care plan goals and approaches. Only when we begin with the residents -- their personal story, their personal goals and priorities -- can we generate a plan of care that is truly meaningful to them.

Advocate for the resident. Fox shares her personal story in *The Journey of a Lifetime*. She states, "I told my social worker she was first and foremost the Elder's advocate. I know this is what social workers are suppose to be, but how many actually have the courage to stand up to the administrator? A better question is how many administrators are willing to listen when they do?" (Fox, 2007, p 59)

Too often, the care plan reflects the needs of the staff by limiting approaches to those already successfully implemented in the facility and advocated for by department leaders out of necessity by the realities of limited time and money. Only when the resident and nursing assistant can say that the care plan simply details what they really want to do together every day have we generated a resident-centered plan of care.

Care plan with flexibility to honor resident self-determination. The care plan controls the care given and must reflect the individuality and flexibility of resident choice. It must reflect the

resident's "normal" choice, but if written too specifically, it can actually limit the right of the resident to change their mind in the moment. Only when we care plan their right to choose, rather than simply a predetermined choice, can the care plan support self-determination.

Communicate the resident's individualized care plan in a convenient, accessible way to the care-giving team. Traditional task-oriented care plans are relatively simple for staff to honor, as only exceptions must be learned. Individualized resident-directed care plans, on the other hand, are complex and variable, specific to each resident and must be communicated in a real time and in an accessible format. Only with new technology can this be simple, but with some effort, it can be communicated effectively, even with paper care plans.

Educate the team on resident self-determination and monitor their effectiveness in QAA. The concept of accountability for facilitating resident self-determination in the care planning process may well assure the success of the team. Yet it is often lacking in the professional education of team members and during their internships completed in traditional facilities. Only through education and accountability can we expect true change. Only with the development of best practice guidelines can we grow together, assuring resident rights and regulatory compliance.

In a Pioneer Network Issue Paper, *Nurses Involvement in Nursing Home Culture Change: Overcoming Barriers, Advancing Opportunities*, Burger et al. detail recommendations for nurses working in nursing homes that comprehensively address the issue for nursing professionals in long-term care. (Burger, 2008) Work in progress is addressing these needs for administrators, medical students and medical directors. Only when all professional disciplines explore their role in overcoming barriers and advancing opportunities in nursing home culture change will the team be whole.

Fortunately, pioneering facilities across the country have modified their care planning process to support resident self-determination. Krugh and Bowman show us the way in their workbook, *Changing the Culture of Care Planning: A Person-Directed Approach.* (Krugh and Bowman, 2006)

Madalone observes: "The care planning process and the interdisciplinary team have different levels of understanding of the impact of allowing choice, and of their role in advocacy for the elder, and as an educator to all who impact on that elder's quality of life, to the MD, the NP, the PA, the therapist, the MD's office staff, the hospital with transfer, and more. In addition, the problem statements and goal statements that focus on the outcome, leaving the elder out in a lot of our documentation, and at times forgetting what the elder has agreed to accept all contribute to the problem of honoring resident rights. *Collaboration is key, for resident control is restored.*" (Madalone, 2009)

Only when true resident-centered care planning is incorporated into best practice through survey interpretive guidelines will the resident truly be the central focus and really own the care plan. And only then will the role of all other care plan team members in supporting resident self-determination be clear.

THE DEEP SEATED ISSUE OF CHOICE
WHO OWNS THE CARE PLAN

MEETING THE CHALLENGE OF RESIDENT SELF-DETERMINATION

While the pathway to modifying care planning to support individualized care is well described, the path to facilitating resident self-determination is not as clear. How do we define "normal" and "meaningful" for each resident? How do we assure that residents are supported in defining their personal choices, particularly residents with the increased complexity of the presence of cognitive loss? While this work has been the subject of much research for over 20 years, absence of an accepted best practice approach leaves much opportunity for less-than-optimal approaches for many of our elders, and confusion among health professionals regarding outcomes and regulatory compliance.

This challenge is not new. Several distinguished researchers have devoted their careers to addressing it. In 1991, Rosalie Kane co-authored *Values & Ethics for a Caring Staff in Nursing Homes: A Training Guide*. It guided the transformation of the care planning process and resident decision making at Bigfork Valley Communities. Developed with the hope of assisting those struggling with the implementation of OBRA '87, "It was derived from a research project funded by the Retirement Research Foundation that examined personal autonomy in the everyday life of nursing home residents and the way nursing assistants can contribute to appropriate autonomy, dignity, privacy, sense of control and general well-being for the residents under their care." (Kane, 1991) Yet most facilities still struggle with these issues daily.

Far too few residents can easily express their true choice. Some, on admission, are so affected by the losses of transitioning from their community home, that simple pleasures and personal choices in matters of daily living seem insignificant. Many, after living in the traditional nursing home environment for just a few months, come to believe that "normal" is the institutional way. Others, when presented with options, endorse the expressed or perceived opinions of their caregivers out of fear of reprisal or concern for their caregivers. Vocal residents may claim spokesperson rights for their more quiet peers. Realistically, why would a resident want to eat every meal off a drab grey tray? Why would they want to wear a pink and blue stripped terry cloth bib at every meal? Why would they want to get up before the sun if they were a person who preferred to sleep in prior to moving in? Are they answering from true personal choice or from institutionalization or concern for staff convenience? But going back to the simple questions … *What does the resident want? How did they do it at home? How can we do it here? …* is almost always a reasonable approach.

Consider the "terry cloth bib" debate as one simple example. Some argue residents want the pink and blue stripped bibs because they don't want soiled clothes, or because our laundry services don't get the stains out so clothes are ruined from spills, or because napkins don't work as well. Consider what did they do at home? Perhaps an apron, or even a smock; at a restaurant perhaps a lobster bib or a spaghetti bib? If they spilled spaghetti on a favorite blouse, did they use Shout, or soak it so the stain did not set before washing, or run a small washer load right away? So what could we do to give our elders better options than the traditional terry bib? We could provide other options that work just as well, we could change the way we handle

soiled clothes, we could perhaps even change the way we assist the resident in dining to avoid the stain from occurring. If an elder moved in with a terry cloth bib (which they don't, because people don't wear bibs in society), it would be appropriate to continue to use it. But, if we institutionalized them to wear it, we need to return to the question: *what did they do at home*?

Similarly, consider the "institutional tray" debate. Some argue that residents want the tray to be sure they get their own food, or that families want them to be sure they get the food they need, or that they need the tray to define their personal eating space, or that they need the tray to keep others at the table from snatching their food, or that they don't want to make extra work for staff taking the food off the tray. How sad. Unless a resident always ate on a tray from a far-away kitchen before they came, we need to address their concerns, resolve them by changing our meal service, and honor their historical way of dining. The fundamental reason to eliminate the institutional tray is not so much the appearance of the tray as it is the limitation of true choice when meals are served from a remote kitchen with no point of service choice. Yes, the tray is institutional in appearance, but much more than that, it is institutional in restriction of true choice, just like in prison, in school (before cluster kiosks) and in the hospital (before room service). Like these service sectors, we need to change our service now.

The greater challenges of self-determination for residents with limited decision-making capacity have been successfully addressed by others, as in the United Kingdom's *Mental Capacity Act 2005 Code of Practice* that provides guidance to "those who have a duty of care to someone who lacks the capacity to agree to the care that is being provided." (Department for Constitutional Affairs, 2007) The recent Nufield Council on Bioethics publication, *Dementia: Ethical Issues,* provides a comprehensive review and extensive references and resources. (Nufield Council on Bioethics, 2009) Why do so many of our peers resist the premise of resident choice for our elders with limited decision making capability? We must learn from those working in developmental disabilities and mental health, here and abroad, and apply their best practices in our daily work.

Resources abound in the United States and Europe from academia, state Quality Improvement Organizations, professional care-giving peers in developmental disabilities and mental health, advocacy organizations and others. But translating resources into practice is a challenge for all involved. We need an individualized care practice guideline specific to long-term care that could be incorporated into regulatory overview, interpretive guidance, protocol and investigative procedures. Such a document could guide us all on a pre-determined path to excellence in honoring self-determination both for residents with full and limited mental capacity. Hopefully, a national workgroup with representatives from all stakeholders and peer organizations will carry out the sacred work of developing individualized care practice guidelines that will then be universally incorporated to serve our elders' right to self-determination.

THE DEEP SEATED ISSUE OF CHOICE
WHO OWNS THE CARE PLAN

MEETING THE CHALLENGE OF PROFESSIONAL STANDARDS OF QUALITY FOR NUTRITIONAL CARE OF THE ELDERLY

As with the issues of self-determination, resources related to clinical nutrition best practice abound, but translating them into practice in long-term care is a challenge to all and an impossible task for most. We need a best-practice document specific to long-term care which could be incorporated into regulatory overview, interpretive guidance, protocol and investigative guidelines in areas of clinical concern. This document, by defining professional standards of quality for nutritional care of the elderly, could eliminate the potential for less-than-optimal approaches for many of our elders, and confusion among health professionals regarding outcomes and regulatory compliance. It is hoped that a national workgroup with representatives from all stakeholders and peer organizations can carry out the sacred work of developing best-practice guidelines for professional standards of quality for the nutritional care of the elderly.

Clinical and professional literature on the issues of nutrition and aging is prevalent, but unfortunately, not centrally indexed for practitioner access and not always clear and consistent in recommendations. Single studies are published consistently in selected professional journals, but often they are easily accessible only to members of a select profession and not widely read or even acknowledged by other professions. For example:

The Journal of the American Dietetic Association, September 2007, included two such articles:

> *Benefits of Snacking in Older Americans* validated the importance of making elders' favorite foods accessible 24/7. "Snacking is an important dietary behavior among older adults…(and) may ensure older adults consume diets adequate in energy," it concludes. (Zizza et al, 2007)

> *Changes in Type of Foodservice and Dining Room Environment Preferentially Benefit Institutionalized Seniors with Low Body Mass Indexes* confirms the impact of elders' surrounding on their nutritional intake, stating, "Bulk foodservice and a home-like environment optimize energy intake in individuals at high risk for malnutrition, particularly those with low BMIs and cognitive impairment." (Desai et al, 2007)

The Journal of the American Geriatric Society, Volume 56, 2008, published:

> *Prevention of Unintentional Weight Loss in Nursing Home Residents: A Controlled Trial of Feeding Assistance.* The authors concluded, "Two feeding assistance interventions are efficacious in promoting food and fluid intake and weight gain in residents at risk for weight loss. Both interventions require more staff time than usual NH care. The delivery of snacks between meals requires less time than meal time assistance and thus may be more practical to implement in daily NH care practice." (Simmons et al, 2008)

> The American Medical Directors Association consistently publishes relevant, clinically respected studies and articles on nutrition in long-term care, but unfortunately, these

articles often fail to reach the practicing physicians and other health care professionals in nursing homes. In fact, they often fail to reach medical directors who are not actively engaged in AMDA.

In *Changing Perspectives on LTC Nutrition and Hydration*, Steven Levenson, MD addresses several challenges of nutritional care for the elderly:

"…non-essential dietary restrictions should be loosened or removed, since very few individuals benefit from special diets or disease-specific supplements…This is especially important when there is continuing weight loss in the face of altered consistency or other restricted diets."

"Management of all geriatric conditions involves some risks. No known evaluations or interventions can guarantee that someone will not aspirate. It is important to note that many elderly individuals with swallowing abnormalities and aspiration risk do not get aspiration pneumonia. In fact, there is evidence that altered consistency diets may increase the risk of nutrition and hydration deficits. Thickened liquids and pureed foods are often poorly tolerated. Tube feedings do not materially decrease the risk of aspiration."

"Multidisciplinary team members, including health care practitioners, should be involved in balancing the risks of aspiration against the potential benefits of more liberal diets and food consistency, and deciding whether there are viable alternatives. There should be a discussion of the patient's progress, goals, and objectives. Often, aspiration risks must be tolerated because of other, more immediate or probable risks such as nutrition or hydration deficits." (Levenson, 2002)

In, *The Facts about Dysphagia & Swallowing Studies*, Levenson reports on a 1995 study published in the Journal of the American Geriatric Society by Groher et al., summarizing: "This study aimed to determine the appropriateness of dietary levels of residents with suspected feeding and/or swallowing disorders. Thirty-one percent of the residents in two facilities were prescribed a mechanically altered diet. Ninety-one percent were at dietary levels below that which they could tolerate safely; four percent were at dietary levels higher than they could tolerate; five percent were considered to be at the appropriate diet level." The authors conclude that "many nursing home residents may be inappropriately placed or maintained on mechanically altered diets. Regular reevaluation of the dietary level is necessary because most may be able to eat safely at high levels." (Levenson, 2003)

Specific to the issue of consistency modification as addressed in the 1995 study, standard practice in most facilities in 2009 still does not include regular reevaluation of dietary level, and may not include interdisciplinary care plan team (IDT) review of dietary level. And until the 2009 interpretive guidelines from CMS regarding quality of life specifically addressed the right of residents to refuse a consistency modification, some facilities so strongly enforced the professionally-ordered consistency modifications that they considered discharging residents who

refused to comply with the ordered restriction after appropriate risk benefit education. Clearly, our residents can benefit from clarification and communication of best practice in a timely manner.

The American Dietetic Association (ADA) Position Papers are a statement of ADA's stance on an issue, which is derived from pertinent facts, data and the research literature. They are not a comprehensive literature review of the topic, but rather present current facts, data and research. Current Position Papers on *Ethical and Legal Issues in Nutrition, Hydration and Feeding, Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in Long-Term Care and Nutrition Across the Spectrum of Aging* all provide relevant guidance to long-term care professionals, but are often not widely recognized or adopted by the medical community.

The ADA Evidence Analysis Library is a synthesis of the best, most relevant nutritional research on important dietetic practice questions, available free to ADA members and by subscription to non-members. These evidence-based nutrition practice guidelines are developed to help health professionals and consumers make decisions about health care choices. The recently introduced guideline, *Unintended Weight Loss in Older Adults,* concludes there is scientific evidence that medical nutrition therapy increases the effectiveness of efforts to address unintended weight loss through consideration of MNT, caloric needs, diet liberalization, modified texture diets, medical food supplements, enteral nutrition, dining environment and feeding assistance. While directly relevant (and generally supportive of the practices of resident-centered care and culture change), it is not yet widely disseminated or adopted. For example, selected recommendations include:

> "Diet Liberalization: For older adults, the Registered Dietitian should recommend liberalization of diets with the exception of texture modification. Increased food and beverage intake is associated with liberalized diets. Research has not demonstrated benefits of restricting sodium, cholesterol, fat and carbohydrate in older adults."

> "Dining with Others: The Registered Dietitian should collaborate with other health care professionals and administrators to encourage all older adults to dine with others rather than dining alone. Research reports improved food intake and nutritional status in older adults eating in a socially stimulating common dining area."

> "Improvement of Dining Ambience: The Registered Dietitian should collaborate with other health care professions and administrators to promote improvement of dining ambience. Research indicates that improvements in physical environment and atmosphere of the dining room, food service and meals, and organization of the nursing staff assistance may result in weight gain in older adults."

> "Creative Dining Programs: The Registered Dietitian should encourage creative dining programs for older adults. Research indicates that dining programs, such as buffet-style dining and decentralization of food service, demonstrate improvements in food intake and/or quality of life."

"Resident Involvement in Meal Planning: The Registered Dietitian should collaborate with other health professions and administrators to encourage older adults' involvement in planning menus and meal patterns since studies show that this may result in improved food and fluid intake."

"Collaboration for Modified Texture Diets: The Registered Dietitian should collaborate with the speech-language pathologist and other healthcare professionals to ensure that older adults with dysphagia receive appropriate and individualized modified texture diets. Older adults consuming modified texture diets report an increased need for assistance with eating, dissatisfaction with foods, and decreased enjoyment of eating, resulting in reduced food intake and weight loss."

"Contraindications for Enteral Nutrition: Enteral nutrition may not be appropriate for terminally ill older adults with advanced disease states, such as terminal dementia, and should be in accordance with advance directives. The development of clinical and ethical criteria for the nutrition and hydration of persons through the life span should be established by members of the health care team, including the Registered Dietitian."

Unfortunately, these evidenced based guidelines are not yet widely accepted as standards of practice, and even more unfortunately, standards of traditional best practice developed for individuals at earlier stages of the life cycle are currently applied to elders, often limiting their choices, limiting their quality of life, while well-meaning practitioners practice a medical model of care. Madalone sums it up well: "Life extension with medically advanced treatments or imposed chronic condition management at an advanced age negating choice or satisfaction often leads to negative outcomes that are then managed with more liberal approaches that should have been the approach from the beginning." (Madalone, 2009)

From an admittedly elementary, superficial and incomplete review of only three current issues in nutritional care of the elderly (therapeutic diets, consistency modified diets, end-of-life care), it is evident to this practitioner that development of appropriate professional standards of practice is beyond the scope of individual provider practice. Yet, such standards are essential to assure quality of care and quality of life in nutritional care in these and other unspecified issues of nutritional concern for elders in long-term care. The consistency of observations of improvements in both quality of care and quality of life for residents living in transformed pioneering facilities that adopt the professional recommendations quoted herein cannot be merely coincidental, and with proper professional focus, may be codified into professional standards of practice.

As an industry, we have successfully faced the painfully difficult challenges of restraint reduction and gifted our residents their right to mobility and freedom of movement.   Joshua Weiner et al. reviewed progress in quality assurance in the 20 years after the passage of OBRA 87, citing the decline of restraints and a decline in the organizational culture that supported their use from 38% prior to OBRA 87, to 28% following the implementation of OBRA 87, to less than 6% (of long-stay nursing home residents had been restrained during the last 7 days) in 2007. (Weiner, 2007)

THE DEEP SEATED ISSUE OF CHOICE
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We are now called to the equal challenge of gifting our residents their rights to self-determination and to the right to take risks, including, but certainly not limited to, the complex nutritional concerns of therapeutic diets, consistency modifications and end of life care. We can, we must, now!

DEEP ORGANIZATIONAL CHANGE FACILITATES TRUE RESIDENT CHOICE

THE WHY AND THE HOW OF DEEP ORGANIZATIONAL CHANGE

In *Culture Change in Nursing Homes: How Far Have We Come?,* the authors note: "In general, nursing homes have been most successful at increasing residents' involvement in decision-making, and there is some evidence that management is accommodating collaborative and decentralized decision-making to empower direct-care workers. However very little organizational redesign has penetrated the field and very few homes have changed their physical environment to support culture change. (Doty, Koren and Sturla, 2008)

Yet organizational design is recognized by leaders in cultural change transformations as key to creating a vibrant meaningful life for residents. *In Pursuit of the Sunbeam,* authors Shields and Norton, state:

> If you have to choose between changing your organization and creating a pretty
> space, change your organization. One thing worse than traditional nursing home
> service in a traditionally designed building is a traditional nursing home service
> in a building designed as a Household Model. It simply doesn't work." (Shields
> and Norton, 2006, p 153)

The importance of organizational redesign is affirmed by Deborah Heath, DON (Clinical Mentor) at Lenawee County Medical Care Facility:

> "You can change the physical environment all you want, but if you don't do all
> the work ahead of time to change the culture, it's never going to work.
> Education, team building and trust, that's what makes culture change -- not the
> multi-million dollar renovation." (Norton, 2008, p 19)

Organizational Design Gives Life to Culture Change, asserts Norton. She unequivocally states, "The Household Model works only if decision-making and all care-related systems are decentralized and brought close to the elders. This means flattening the top-down hierarchy and dispersing departmental staff into the households. Rather than reporting up the chain of command to the Administrator, caregivers in the new culture report to local, self-led work teams and are more directly accountable to those they work with and serve." Realistically, Norton also acknowledges the challenge, "This shift from top-down decision making to household-based authority and operations is the most wrenching aspect of deep culture change for staff…"

Norton further details the strategies for successful organizational design as:
- Involve everyone in planning: Encourage all stakeholders to contribute questions, concerns and ideas; strive for 100% involvement.
- Flatten the departmental hierarchy: Decentralize departments; cross-train staff and permanently assign them to households where they report to the Household Leadership

team; embed previous department leaders in households where they mentor the household staff and their peers.
- Build community, commitment and self-led teams: In the household community of residents and staff, the residents should make decisions and the staff, working as a self-led team, facilitate those decisions as much as possible.
- Cross-train staff for multiple roles: versatile workers, cross-trained in roles they choose, and blended-roles prepare staff to serve the resident with "immediate responsiveness and seamless service

In conclusion, Norton states - "Versatility, blended roles, the team approach and cross training all assure that 'it's not my job' is never heard." (Norton, 2008, p 24)

In *The Power of Circles: Using a Familiar Technique to Promote Culture Change*, Norton details the technique: "The Learning Circle is a common-sense approach for both conducting meetings and facilitating less formal gatherings in a way that encourages high involvement of all stakeholders in planning and implementing culture change, engenders mutual respect among participants, builds a sense of community and facilitates both personal and organizational transformation." (Norton, 2003)

These strategies of deep organizational redesign support the development of strong interdependent relationships between residents, staff and families. In *Relationship: The Heart of Life and Long Term Care*, Pioneer Carter Catlett Williams firmly states her conviction: "Relationships are not only the heart of long-term care, they are the heart of life. And life ought to continue, wherever we live." Building on the belief that care giving is not charity, but rather a relationship, she explains: "Care giving is not one person doing a favor for another or giving to another who is simply a recipient. Rather, it is a relationship in which there is give and take and a bond that is made, person to person. Moreover, it is a living and growing bond which both participants shape and nourish." Williams further notes "Systems that grow out of greater resident decision making, development of community and a more normal environment encourage healthy, meaningful relationships." (Williams, 1999)

The outcomes of this deep organizational design are further described in *Close to You: How choices and relationships flourish in the Household Model,* as*:*
- Staff are able to be more responsive to life in the household as it unfolds and can solve problems and make decisions on the spot.
- Genuine personal relationships are encouraged between individuals, both staff and residents.
- Daily household life decisions are made by the residents.
- Individual residents direct their own lives.
- Self-led teams report directly into households instead of departments, moving decisions close to the resident. This allows a quick and seamless response, even to complex issues.
- Staff know residents well enough that they can recognize and respond to needs before they become problems.
- Residents have trust in staff that haven proven loyalty through relationships.
- Embarrassing or difficult situations can be more easily and comfortably dealt with.

- Individual household budgets encourage responsible stewardship as money is spent on the household in ways that are most appreciated and useful and at the same time lessen waste." (Norton, 2008, p 6)

Deep organizational change facilitates true resident choice in dining by honoring resident-directed care, putting the resident in charge, and putting the decisions closest to the resident with the hands-on caregiver when the resident is not able to express choices independently. Residents who cannot verbally express preferences express them clearly, food by food, to those assisting them in dining!

As a practical matter, deep organizational change does eliminate "it's not my job," as noted by Norton. It also works to eliminate the negativity of "we/they" in an organization, and, as Shields noted *In Pursuit of the Sunbeam, "*It's not that 'they' can't do it. It's really that 'we' can't. The truth is, when 'we' and 'they' become 'us' and align around a common purpose, great things happen…a self-led team broke through two barriers that 99.99 percent of health care executives in America couldn't pull off." (Shields and Norton, 2006, p 61)

Deep organizational change creates "places where elders feel at home, family members enjoy visiting, staff are respected, listened to and appreciated, the care is good, life is worth living, and legal action is unnecessary," according to the vision expressed by Dr. Bill Thomas in *Evolution of Eden*. (Thomas, 2003)

DINING SYSTEM CHANGES IN DEEP ORGANIZATIONAL REDESIGN

While many of the policies, procedures, protocols and systems of dining in a traditional facility are continued in deep culture change, the context of these systems changes dramatically from institution to resident-directed and to home. These deep dining system changes are successful when guided by the organization's vision and values, framed by the principals of the Pioneer Network, the Eden Alternative and Shields and Norton's Essential Elements of the Household. (See Appendix E) One example of deep system change is detailed in the Household Matters Toolkit. This system transformation is achievable but is complex as the implementation of new dining systems interfaces with systems in almost all other departments. *In Pursuit of the Sunbeam (*Chapter Nine, *"*Organizational Transformation") details many of these complexities, at the same time noting, "We often start with dietary because it allows for incremental shifts in resident service that often lead to highly visible and positive results and creates those 'ah-ha' moments that energize teams and the process of change. There are seemingly endless opportunities for change in dietary, and each requires the development of a system to support it." (Shields and Norton, 2006, p 141)

> *Deep organizational change and moving away from the old ways of directing individuals is critical in achieving an environment where resident choice and excellence in dining is possible. With eight commercial kitchens at Pennybyrn at Maryfield, the pride that each of our lead homemakers in each house takes in their home and their kitchen is the driving force for all that the household teams have accomplished. Flexibility and the ability to deliver an exceptional dining experience while meeting all regulations is dependent on knowledgeable and empowered staff and leaders. Each house has a lead homemaker . . . (all) from various backgrounds and (who) worked together to all become certified dietary*

managers. This team of leaders continues to work together and with their household team to make dining a special time for our residents while achieving all the clinical care requirements.

We began our journey with the goal of taking our effort as deep as it could go. We continue to this day to grow, to learn from each other, and to look for ways to provide better care and better quality of life. The empowered teams and individuals implement ideas and experiences faster than any one person can keep up with, but each is done with the resident in mind, and the standards of excellence that each person is committed to.

The degree that dining can be made special for the residents is only limited by commitment, creativity and a willingness to do the 'hard thing.' Our program took a significant jump forward when our Dining Services Mentor, a chef by training and experience who was new to healthcare and Pennybyrn at the time, began to consider the plan to cook breakfast in the houses and then have cooked food delivered for other meals and put in warming trays. He questioned "why would we do that, so much more is possible." The plan that he proposed, worked through with the teams, and then eventually implemented was to cook or prepare the meals in each household---all three meals!! It was his insight and the commitment of the entire team that took the vision and ultimate reality to heights that previously hadn't even been considered. The quality of life for residents and clinical outcomes related to dining were impacted significantly by this. The message is one of not only thinking outside the box, but get rid of the box, and don't get a new one. (Newman, 2010)

These dining system changes create an environment with the pleasantness of home -- from sitting at the kitchen table having a cup of coffee while the homemaker works in the kitchen, to staff engaged in meaningful table talk and stimulating real conversation among the residents, to having content for conversation bubbling out of community circles done through the PersonFirst® initiative.

It is for certain that deep-seated culture change is a challenge. To be most successful on the journey, it is important to include and provide education for all – staff, residents, family members, family and resident councils, ombudsmen and other concerned and involved community groups.

DEEP ORGANIZATIONAL CHANGE – FROM A REGISTERED DIETITIAN'S PERSONAL PERSPECTIVE

Specific to the deep organizational change at Lenawee county Medical Care Facility and the professional transformation of their clinical dietitian chronicled in *One Nursing Home's Tale of Transformation*:

Two Weeks Before Move-In: Hopeful But Skeptical
Suzanne Hiltner was intrigued by the prospect of working in a 'cutting edge' culture change organization when she applied for a position at Lenawee. But as the day approaches for moving into neighborhoods, she grows anxious. As Clinical Dietitian, her responsibilities have typically revolved around nutritional needs assessments, quality assurance and inventories. She has worked at the nursing home for less than two years and never in a leadership role with staff outside her department. But now she is about to wade into the broader stream of

people and everyday events at Lenawee by becoming a neighborhood coordinator and receiving CNA training. Her main concern: Building relationships with residents, family members and other staff. 'My first love and training is as a clinical dietitian, so to be asked to supervise the kitchen or coordinate an activities person or housekeeper, those kinds of requests are way outside the box,' she explains.

Three Weeks After Move-In: So Far, So Good
'So far, so good', agrees Hiltner. Elders' food intake has increased, and 'we're getting a lot of positive comments from families and residents.' Her dual role as Clinical Dietitian and Neighborhood Coordinator is working out as co-workers pitch in. The dietetic managers have lighted her clinical duties by taking over some (parts) of the nutritional assessments, and the neighborhood nurse leader is helping her stay on top of her coordinator responsibilities. Frequent meetings and learning circles are enabling her to build relationships with staff, residents and family members.'

Three Years After Move-In: We Are Households
'Professionally it's a challenge for me…that's the way you want any job to be. You don't want the same old experience. You want something that's going to make a difference in somebody else's life. That's why anybody chooses this type of profession, you want to make a difference.' On her dual role as Clinical Dietitian and Household Coordinator - Hiltner recalls her pre-move jitters about becoming a neighborhood (now household) coordinator, and how often over the last three years she felt her leadership role distracted from her chosen profession as Clinical Dietitian. Though stress is still part of her job, experience and personal growth have cut it down to size. 'I worked into it a bit better… delegating more to the dietary managers and getting them involved in some of the hands-on supervision,' she explains. As for sacrificing some of her dietitian duties to household coordinating, 'I think it's a decision each individual has to make about what they're comfortable with and how they want to balance their jobs,' she says. Hiltner sees a bigger picture with more options and shades of grey. 'It's not the black and white, straightforward, do this, put the food out, count our numbers, meet the regs. It's definitely more people oriented now,' she says. (Schaeffer, 2008, p 10-18)

DEEP ORGANIZATIONAL CHANGE – FROM A STAFF AND FAMILY PERSPECTIVE

Northern Pines Communities embraced deep culture change and experienced actual outcomes that far exceeded expectations. Karla Nieman, CDM and Community Coordinator, notes, "We've had miracle after miracle. Residents walking who were not before, elders wearing new dentures who had refused to even go to the dentist because they just didn't care anymore...it just doesn't stop."

In *Better Than We Ever Dreamed*, Linda Bump explains: "The central role that food plays in caring, comfort and family, and the central role that the kitchen plays in family and community in all of our lives was confirmed as consistent staffing allowed caring staff to respond meal by meal to residents intake with tempting meals of personal choice, illustrating that when residents can eat what they want, when they want, prepared and served with fellowship, weight loss can be 'avoidable' in long term care…"

"Refusing to eat and repeatedly pulling out the feeding tube inserted in an effort to rebuild her strength and renew her former zest for life, Mrs. L's weight had dropped significantly to 90 pounds. when she chose the room with the view of the deer feeding station and her family lovingly filled it with memories of personal friendships and wonderful vacations, with seashells gathered during barefoot days on both Atlantic and Pacific shores. Her interest in life and eating rekindled daily, and her weight steadily increased without supplementation (which she refused) to her ideal weight of 105 pounds within seven months. Surrounded by home in her room with her adopted cat, she is further strengthened by giving care to a devoted feline companion who transferred its affection to her after his original owner died in a nearby room."

Her attentive daughter's perspective: "Watching the change in my mom from the move to communities was like watching a Phoenix arise from the ashes." (Bump, 2003, pp 18, 22)

WHAT MAKES NEW IDEAS DIFFICULT

A note of limitation: Recommendations in the following pages are offered from the practical perspective of providers' experiences and are not intended to meet the rigors of the more professional policy, research and educator perspectives. They are offered in the sincere hope that they may provide useful insight into the current perceived and real barriers met by providers working to honor the rights of and create home for our elders, and as a result, assist all in working together, from each of our personal and professional perspectives, toward these lofty OBRA '87 goals.

HISTORICAL BARRIERS

In *Culture Change in nursing homes: How far have we come? Findings from the Commonwealth Fund 2007 National Survey of Nursing Homes,* the authors note that cost, regulation and staff resistance are often cited as barriers that must be addressed or dispelled before more nursing homes adopt the principles of culture change and resident-directed care. Then they offer observations and evidence that these traditional barriers are diminishing in importance.

> Cost: "As in any new venture, there is an upfront investment but increasing evidence shows that considerable saving accrue as a result of culture change in terms of reduced staff turnover, decreased reliance on agency staff, and increased revenues from high occupancy rates…"

> Regulation: "CMS…has been in the forefront of the movement to promote culture change. Likewise, the Quality Improvement Organizations…provide technical assistance to nursing homes. Part of their work includes measuring several performance areas that reflect a culture change philosophy."

> Staff Resistance: "…Among nursing homes that have embraced culture change, staff members say that once they have experienced working in a culture change nursing home, they could never go back to the old way." (Doty, Koren, Sturla 2008)

Their conclusions are supported by a growing body of information derived from the observed success of early culture change adopters and from customer and workforce satisfaction surveys. In *Elements of a Quality Job for Caregivers – Key Research Findings*, the Paraprofessional Healthcare Institute (PHI) describes nine essential elements that comprise a quality job and notes that culture change initiatives are a recognized approach in three of them. "Consistent scheduling" is noted as an example of staffing and scheduling practices shown to improve the stability of hours and income and achieve balanced workloads. "Combining clinical and interpersonal education with organizational culture change initiatives and/or payment incentives" is linked to positive impact on workforce stability and on care quality. "A culture that promotes worker's participation in workplace organization and care planning" is linked to better care quality and increased workforce stability. In addition, a "coaching and mentoring approach to

leadership and the participative management style*"* of culture change appear to support two additional essential elements of a quality job. (Paraprofessional Healthcare Institute, 2007)

Resident autonomy and self-direction is not costly, is clearly supported by OBRA'87, and as one CNA so powerfully expressed, "Finally I get to do what my resident wants instead of trying to make her do what 'they' (administration) want!"

All providers should mindfully consider that pioneers in culture change have demonstrated through case studies and anecdotal evidence that culture change can result in positive resident and staff satisfaction outcomes in individual facilities, even with limited physical plant improvements and within current staff education and training budgets; that it can be budget neutral with existing staffing, and budget neutral with programming and ancillary costs in practice, and that based on individual facility quality indicator data, it can do so with concurrent positive impact on quality of care. Recognizing that caution must be applied to generalize from such information, as research continues to validate best practice and policy recommendations are developed to support it, organizations must begin to make positive changes to increase true and meaningful resident choice and self-determination, using the experiences of the early adopters as approaches to consider for implementation.

> Recommendation: Providers act now to assess their organization and its climate, to study what the early adopters have done and take action to increase resident self-determination in their facility.

OBRA '87 SUPPORTS CULTURE CHANGE – SURVEY BARRIERS OFTEN IMPEDE IT

In *Regulatory Support for Culture Change, How OBRA '87 Regulations Support Culture Change,* Bowman notes that F242 Self-Determination and Participation is "the shining star regulation for culture change. It not only supports culture change, it leads to it." (Bowman, 2006)

Survey Focus Can Be A Barrier

Shields and Norton, *In Pursuit of the Sunbeam,* suggest that the real problem is that systems in the traditional model were designed for the traditional context of, "We know what's best for you," and in the new context, old tasks continue, but must be reframed in the new context of, "This is your home, how can we best serve you?"   They stress it is important that providers anchor the organization in standards of practice that fit the philosophies and practices of the new culture, and that regulators do the same. (Shields and Norton, 2006, p 21)

Franco Diamond, Administrator at Idylwood Care Center in Sunnyvale, CA has, for a number of years used food as a focus to feed his residents' lust for life. Residents share gardening, cooking, and eating in a celebration of life. Building on his conviction that food holds an answer for almost every ailment of institutional living, his residents transformed a weed patch into a beautiful garden where they grow produce for their group cooking activities, the facility's regular

menu, a farmer's market, an intergenerational program teaching children to garden, and celebrations around food.

> *F-tag 370 is not clear on what is an approved food source. We became certified through the county department of agriculture to sell produce grown in our garden in a community farmers market. Does that certification also qualify our garden as an approved food source, allowing us to include our produce in our meals? No one really knows. Though licensing officials like what we are doing, they cannot state that our county certification qualifies our garden as an approved food source as defined in F-tag 370...and we have not asked them to do so. We have had no issue during survey. After more than two years trying to get clarification from county and state licensing and agriculture officials and from the USDA, we have concluded that our certification through the county to sell produce at a farmers market is the best we can do.*

> *We use F-tag 242 that states the residents' right to make choices in the facility about aspects of their lives that are important to them. The residents' right to self-determination supports what we do at Idylwood. All residents have a choice about whether or not to attend cooking groups, and their physicians approve. All our harvested produce goes through a three-step sanitation process. We do this to ensure resident safety and state compliance. (It's strange that CMS might think it okay to serve our residents tomatoes grown, for example, in Chile, stored and shipped thousands of miles; but not to serve tomatoes we've grown on site, cleaned and prepared—all under the oversight of a licensed dietitian.)*

> *Despite all this, we still question whether we are an approved food source. This regulation's lack of a clear definition of an approved food source causes great confusion for all those trying to do good for people living in nursing homes.*

> *This and OSHPD/fire regulations about the use of stoves and other cooking techniques make it extremely hard to bring the heart and soul of kitchens and gardens to mainstream nursing facilities. For example, when the fire marshal required us to remove a stove from an activity/kitchen area, attendance in our cooking groups dropped 50%. We continue to do what we do with cooking and gardening while trying to demonstrate and inform government regulators how to give people living in nursing homes reason to get up in the morning. In sum, we are trying to make a skilled nursing facility into a skilled living facility.*
> (Diamond, 2010)

Strengthening the interdisciplinary nature of the survey team can refocus the survey process to a more holistic emphasis. Increased representation from all helping professions on both the survey team and in technical consultation roles in the survey office is needed, however it is imperative that each helping profession represent their own specialization and advocate for resident self-determination within their professional expertise rather than merely attempting to adopt the medical or nursing focus of the traditional teams. Simplistically, a resident who expresses satisfaction with food service, demonstrates active choice and self-determination in dining, and appears well-nourished within the basic parameters of weight and hydration should be considered a positive outcome. Frequently facilities are cited for inadequate documentation although required documentation is not defined in regulation or guidelines. Even a resident with weight loss and/or the potential for negative outcomes may be, in the final analysis, a positive outcome if resident rights, including the rights of self-determination and the dignity of risk, have been mindfully considered. As a practical matter, if resident self-determination is to receive increased focus, the role of the resident and/or family interview in the survey process must be increased. Today,

citations are written without personal communication with involved residents or family members. Increasing the weight of the resident and family interview in the investigation, and in informal dispute resolution is an important part of refocusing the survey process. Some residents and family members may be uncomfortable with an increased role in this process; ombudsmen can strengthen their voice, or be their voice, if ombudsmen have adequate time in the facility to establish the relationships essential for appropriate advocacy. Appendix D offers a detailed set of recommendations for wording changes in the guidelines and investigative protocols to support resident choice and self-determination, and turns the focus on dining from a medical, technical, prescribed meal service to one offering quality of life in dining. (Recommendations for revision of the actual regulations are not included, due to the immediacy of the perceived need for reform.)

> **Recommendation**: CMS support interdisciplinary survey team composition by reducing the nursing component and increasing representation of social service, therapeutic recreation/activities, nutrition services and administration.

> **Recommendation:** CMS review interpretive guidelines and investigative protocols to strengthen the outcome and resident satisfaction component and decrease the current focus on process and documentation (see Appendix D).

> **Recommendation:** All investigative protocols default to resident rights and self-determination, whenever applicable. All IDRs include resident and/or family involvement if there are issues of resident rights or choice, and ombudsman representation if family/resident are unable to participate or desire an ombudsman's presence.

Survey Variability Can Be A Barrier

Rosalie Kane and Lois Cutler's website, NH Regulations Plus, is a work in progress, comparing and cross-referencing nursing home rules from all 50 states. In *Aging Today*, they offer 10 maxims to inform the long-term care field attempting to bring about change. Their maxims:

1. When you've read one set of state regulations, you've read one set of state regulations.
2. State rules are more prescriptive than federal rules.
3. Almost all states have developed specific nursing staff-to-resident ratios.
4. Waivers drive innovation in new construction.
5. State regulations are moving toward greater disclosure requirements.
6. Paradoxically, regulation can sometimes promote resident freedom and autonomy.
7. Reasons for state regulations are sometimes shrouded in mystery.
8. Some rules interfere with the ideal of the universal worker.
9. It ain't necessarily so. Rules for nursing home, voluminous as they are, cannot be blamed for all restrictions on residents.
10. When contradictions abound, a specific rule trumps a general one.

Their elaboration on Maxim 10 is particularly relevant:

> "Even federal nursing home regulations contain contradictions, a situation that is inevitable because some sections call for resident choice and individualization, whereas others establish protocols for safety. State rules multiply the contradictions. When advocates for culture change have sought federal interpretation of state rules that seem to restrict residents, regulators have rendered decisions that those states were within their rights in making more precise safety rules than were federally required – even though these rules interfered with resident choice. Some states do specify how facilities must seek and honor resident consent and preferences, but most apply regulatory fine points only to safety concerns." (Kane and Cutler, 2007)

How can states limit residents' constitutional rights to self-determination? Obviously this is a policy question beyond the scope of this paper, and beyond the knowledge of this writer, but one that clearly needs immediate resolution if resident rights are to be universally honored.

Even within a specific state, variability from one team to another, and from one team member to another on the same team, present a barrier of inconsistent support and challenges for culture change. Lindsey shares his thoughts, identifying survey variability as the biggest barrier to moving forward:

> *While we didn't really encounter any significant barriers in moving to households, I believe that was because we had (survey) people locally who 'got it.' The problem with our current system is that so much is left to the interpretation of the local field office, surveyor, housing inspector or fire code enforcement officer. We were fortunate in all of these respects, but we have heard from many others that they have not been as successful. When we received our occupancy survey, one of the surveyors had a real issue with plates being stacked in the cabinets of the kitchen...she felt that this could be a safety issue ('What if a resident pulled a whole stack of dishes down on themselves?') Fortunately, her supervisor literally slapped her on the shoulder and said, 'Come on...do you really think that will happen?' That exchange set the tone for the rest of the survey...but if it had gone the other way, we could realistically be storing all of the dishes and other supplies in another room, where the residents would not have access to them. It is those kinds of decisions, based on the judgment and interpretation of a local surveyor, that can make all the difference in the environment that is created for elders. Multiply that by all of the life safety issues (open kitchens) and fire code enforcement decisions that are made and you can end up with situations where something may be perfectly acceptable in our area but rejected in some other part of the state or country.* (Lindsey, 2009)

Three other facilities who chose not to be identified in this paper share their stories:

> *Our latest change has been to work closely with the DOH to set up a program where nursing personnel can cook or prepare simple items for the residents on the unit. A food safety specialist with the DOH visited our facility and read our newly developed policies and gave us a variance to be able to provide this service. There is a regulation which states those involved in direct care (CNAs and nurses) could not prepare food. After training with a certified food safety instructor, we have begun a breakfast program on one unit.*

THE DEEP SEATED ISSUE OF CHOICE
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We had a nursing home that came up with a special dining program that would encourage residents to come out of their rooms to eat.   It was a great idea to encourage social activity among the residents. It was set up buffet style and included such things as real fried chicken, buttery corn on the cob, yummy mashed potatoes and hand-dipped ice cream. The residents who stayed in their rooms to eat were served the old stuff – baked chicken, canned corn, potato flakes and cups of ice cream. The state agency received a complaint from a woman whose room was close to the buffet. Every evening she smelled the wonderful aroma of the buffet. She liked to stay in her room and eat her dinner while she watched the evening news, so she wasn't served the buffet meal. Instead she received a tray from the kitchen with the traditional institutional food. The surveyor investigated and then wrote a mammoth deficiency citing a violation of civil rights! The IDR was wild. The nursing home, which was a really good nursing home, said, "We're trying to do a good thing! Why is it a deficiency?" And the surveyor was just as passionate, "Why does this lady, who is alert and bright, have to smell this wonderful food and then be denied because she wants to stay in her room and eat when she watches TV?" Finally reason prevailed. We acknowledged the positive aspects of the program and the good intentions of the nursing home. However, you can't use food as punishment and so it was a resident's right deficiency, reduced from a G to a D.

We implemented 'made-to-order' breakfast in our nursing home in May 2007. Breakfast is served between 7 and 9:30 AM. A cook from the kitchen would come to the dining room and prepare made-to-order eggs (scrambled, over easy omelet, poached), French toast or pancakes. Bacon, ham, cream chipped beef, danish, toast, hot and cold cereal juices and regular and decaf coffee were also served by our nursing staff. Nursing staff took orders and the breakfast was prepared when the resident was ready to dine. If the resident wanted to eat in their room, the tray was delivered as soon as it was completed. If the resident chose to come to the dining room, they could see their food cooked right in front of them. Cooking was limited to eggs (boiling water for poached eggs) and pancakes, using induction cookers and a residential griddle. French toast was toasted and all meat items were cooked in the kitchen and brought over to avoid the chance of grease fires. We were surveyed by the Department of Health in mid-May 2007 and received no dining deficiencies. A complaint survey initiated by a family member was not substantiated in the fall of 2007 as the surveyor agreed that the made-to-order dining was a great improvement (we had already fixed the problem, which was related to a space issue, by implementing a two seating arrangement – we preferred open dining, but too many residents were coming at the same time, which was overwhelming our ability to provide residents with made-to-order meals). So after being surveyed twice on the new dining, we thought we were in good shape with DOH…until the May 2008 survey. One surveyor noted that she could smell breakfast throughout the nursing home and that 'residents shouldn't have to smell that…' We noted that the aroma of food cooking is normal in a home and that it stimulated the desire to eat, which is critical for good nutrition. She didn't accept that. She said we needed better exhaust systems. As she looked at our setup she noted that there was no exhaust and no fire suppression system. Remember we were only cooking eggs and pancakes – a process that many culture change-focused nursing homes were and are still doing. The surveyor called Life Safety and reported her findings. I received a call from DOH Life Safety telling me to cease cooking immediately. Did I understand? I told him I did. No deficiencies were given. We have not cooked in the dining room since that time and all food is carted from the kitchen in small batches. The breakfast program has not been the same since that time. In fact, it set back our whole culture change mindset and focus for many months, and nursing home residents have not enjoyed a freshly made breakfast in over two years.

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The ongoing controversy in the field over food temperature at point of service illustrates the variability of interpretation. In the fall of 2008, a Health Quality Review Specialist for CMS provided a widely distributed professional opinion stating, in part: "The minute food leaves the tray line, the temperature will drop. Hence, the food that the resident receives will probably not be at 135 degrees unless it is something that will hold the temperatures (soup, mashed potatoes, etc). Once the resident receives the tray, it becomes a palatability issue." Yet in January 2010, facilities are continuing to receive citations for point of service temperature for foods below 135 degrees when served to residents on trays from a centralized kitchen. And while it would seem logical that the same reasoning would apply for cold foods, related citations are being written today regarding cold food temperatures.

Variability abounds, surveyor-to-surveyor and state-to-state, placing the provider in the difficult position of attempting to clarify during survey, or in the IDR process. With the sophistication of modern technology, a "real-time help-desk or information base" available to providers and surveyors alike could help eliminate the confusion with the immediate availability of common information.

Variability could be further decreased through centralization of training and consultation at the federal level to decrease state variability in interpretation of federal standards. A strong, centralized, national technical consultation and training section to field questions from providers and surveyors, to disseminate relevant information to all stakeholders and to produce educational and best practice training materials for use by facilities in implementing best practices would greatly reduce the opportunity for varying state interpretations to be inserted into the intent of the federal regulation. State training efforts could be transferred to support consultation and collaboration in state coalition efforts, to support providers in implementation of resident-directed care, and to work at reducing the variability in state regulations. Providers could then focus on the delivery of quality care rather than independently researching practice standards or individually and independently developing training materials.

The variability between state and federal standards, and the lack of consistency in support of resident rights and self-determination, leads to confusion and inequalities from state to state. This variability must be addressed through a coordinated effort between states and CMS, and could perhaps be a national program for focus through either state coalitions or a national program of state advisory groups, formed to assure representation of all stake holders at the table when regulations are reviewed and revised. National adoption of appropriate programs such as dining (feeding) assistant and medication administration aides should be a priority focus to assist in the provision of quality dining and quality care.

As for the now infamous "food from approved sources" guideline, there appears to be agreement nationally that, with proper education of residents, families and staff, residents have a right to choose to eat foods from unapproved sources. But that is the end of the common ground. Some states require education on food safety for residents and staff; hundreds of training programs are being developed by individual facilities, but one training program, developed by federal experts and available to all providers through the wonders of downloading, could likely

do a better job. Similarly, the rules from one state to another vary greatly in what foods can be served, their requirements for documentation of who ate food from an unapproved source, the education of the preparer and the availability of the preparer for interview.

> **Recommendation:** CMS mandate joint provider and surveyor training shared nationally through a web-cast format.

> **Recommendation:** State coalitions and state advisory groups work aggressively to decrease the variability between state and federal standards, and to universally promote residents' constituional rights to self-determination.

> **Recommendation**: CMS workgroup research available technology to facilitate communication of interpretations and other guidance to surveyors and providers in a high tech format that would make all relevant current guidance and clarifications available in real time.

Survey Process Can Be A Barrier

Historically, the Institute of Medicine Committee on Nursing Home Regulation report in 1986, *Improving the Quality of Care in Nursing Homes*, identified the need for survey process reform to "reliably distinguish the very good from the poor or merely acceptable performers." Consider this excerpt:

> Modern management theory holds that excellent results are more likely to be achieved when the members of an organization are motivated not by fear of sanctions for inadequate performance, but by pride, accountability, cooperation and loyalty. The HCFA (now CMS) and state governments can apply this concept in their dealings with nursing homes. The current federal regulatory system is structured only to punish poor behavior. Good behavior goes unrecognized. Only a few states have developed systems for rewarding good or outstanding facilities. In part, it is attributable to the crudeness of the survey instruments. After the HCFA has implemented the new survey process recommended in Chapter 4, and after some statistically derived outcomes standards are developed, it should be possible to reliably distinguish the very good from the poor or merely acceptable performers. It will then be possible to reward facilities for excellent performance and thus to encourage continued excellent performance.

Twenty-three years later, the industry still waits for this reform. Shields and Norton state it simply: "As CMS and state regulatory agencies begin requiring changes, they are obligated to consider these same changes within their own systems. The regulatory system they ultimately establish, while it should have the teeth to deal strongly with providers who do not routinely comply, should also focus on educating, coaching and assisting providers during and between surveys as a primary methodology for ensuring quality. Such a system would be effective while creating a partnership in mission and purpose." (Shields and Norton, 2006, p 23)

Miller and Mor, in *Out of the Shadows*, raise the issue of survey process as they explore the question of the role of surveyors as "Cops vs. Consultants." (Miller and Mor, 2006 p 71) This

dichotomy of survey process is one that most all providers and surveys have faced, often with frustration, as well intended professionals, working toward a common objective of quality resident care from sometimes differing perspectives. The need for survey process reform, to distinguish "very good from the poor or merely acceptable performers", as the IOM 1986 report referenced, is still present and strong.

Supporting Culture Change: Working Toward Smarter State Nursing Home Regulation, a Commonwealth Fund Issue Brief by Stone et al., suggests that the states and federal government must strike a balance on the deterrence-compliance continuum, recommending a "responsive" or "smart" regulation that would "seek to encourage cooperation, information-sharing, and negotiated agreement between regulators and providers while retaining the powerful incentives and sanctions of deterrence regulation." The authors further state, "A growing number of advocates, providers and regulatory officials have recognized the need to shift the regulatory paradigm toward a more collaborative and cooperative model." The issue brief is provided in Appendix F. (Stone, 2009)

> Recommend all stakeholders should work aggressively to support survey process reform supportive of "smart" regulation as advocated by Stone et al.

OBRA '87 SUPPORTS CULTURE CHANGE – LACK OF CLARITY ON BEST PRACTICE OFTEN IMPEDES IT

Pioneers in culture change have moved forward, doing what they believed to be the right thing to do as gleaned from the experiences of others in related care giving fields and from their own personal experiences, but without a strong base of empirical research to support specific approaches.

Rahman and Schnelle propose that research address five key questions in moving forward:

What are potential outcomes?
What care processes are related to these outcomes?
What factors limit staff ability to implement the intervention?
What are the staffing costs of implementing the intervention?
Do all residents, including those with cognitive impairments, benefit from the intervention? (Rahman and Schnelle, 2008)

The hope is that the answers to these and related questions can quickly be learned, in time to guide the work of future adopters of culture change toward the most successful practices as the movement evolves. Additional research can also strengthen the ongoing work of the pioneers and "early adopters" who continue to explore new opportunities for honoring resident rights and self-determination. While lack of research has not been a formidable barrier to these early pioneers and early adopters, it will likely be more so to the 45% of nursing homes in the country who still consider themselves "traditional" as they ponder advancing to "striver" status and beyond.

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Summarized well in recommendations by Christine Mueller in *Nurses Involvement in Culture Change,* "…the transformation of nursing homes is too important to be slowed down for a research agenda. The current living situation of the great majority of residents in nursing homes is unacceptable and must be attended to. Researchers are encouraged to also see the urgency in strengthening the empirical base for Nursing Home Culture Change and act accordingly." (Mueller, 2008)

While the growing research base refines knowledge of best practice, and is clarifying the statistical significance of outcomes from varying approaches to transforming organizations, to date, no research has confirmed harm, or negative outcomes from the new approaches. When the right answer seems morally obvious, delaying any action that could make life better for residents waiting for empirical proof seems morally wrong. While some approaches may eventually be defined as best practice, honoring individuality seems to assure that a variety of outcomes from any specific approach could be expected as individual organizations establish new practices for their individual staff and individual residents.

Recommendation: Researchers aggressively address research agenda in academia, while providers continue to be encouraged by CMS and all other stakeholders to aggressively increase opportunities for resident self-determination in their organization.

Self-Determination and Professional Standards of Quality

Meeting the challenges of resident self-determination and professional standards of quality were reviewed in the previous section on the complexities of the care planning process. Eliminating the barrier of lack of clarity of best practice in these areas is one of the greatest challenges to honoring resident directed care.

Recognizing that additional research is needed to establish validated processes supporting resident self-determination, it is hoped the work of related service sectors can be accepted as an interim standard to provide much needed guidance for immediate provider implementation pending the final researched guidelines. In the absence of such guidance, providers are left with the daunting (or impossible) task of individually developing their own approaches to resident/family education on the risks/benefits of choice, and the interpretation of the appropriateness of each facility approach of is a purely personal matter to surveyors, consumers and attorneys.

Recommendation: National workgroup with representatives from all stakeholders and peer organizations develop guidelines to self-determination—including the right to refuse treatment for residents with full and diminished cognitive ability—to provide regulatory overview and interpretive protocol and investigative guidance, and prepare related educational materials to facilitate implementation.

As with the issues of self-determination, resources related to best practice in clinical nutrition for elders abound, but translating them into practice in long-term care is a challenge to all and an

impossible task for most. Clearly, defining professional standards of quality for nutritional care of the elderly could eliminate the potential for less-than-optimal approaches for many of our elders, and reduce confusion among health professionals regarding outcomes and regulatory compliance. It is hoped that a national workgroup with representatives from all stakeholders and peer organizations can carry out the sacred work of developing best-practice guidelines for professional standards of quality for the nutritional care of the elderly.

Recommendation: National workgroup with representatives from all stakeholders and peer organizations develop guidelines to clinical nutrition individualized care practice for disease management, to provide regulatory overview and interpretive protocol and investigative guidance, and prepare related education materials to facilitate implementation.

But the challenges do not end with the identification of best practices in support of resident self-determination and professional standards of best practice for quality nutritional care. These best practices must then be widely disseminated to all stakeholder groups, communicating a consistent message with clear recommendations for consideration in individual decision making. It is critical that consistent messages be delivered in each state for purposes of education and advocacy and be respected as advisory to state decision makers, and that these functions also be coordinated nationwide. Regardless of the partnerships identified as the most appropriate for dissemination, a centralized focus will assist in reducing variability from state-to-state and will free scarce resources from duplication of effort wasted in developing related materials.

Recommendation: National workgroup with representatives from all stakeholders identify appropriate group (coalition, advisory council, QIO, etc.) to assume lead role in each state for dissemination of all individualized care practice guidelines for education, advocacy and guidance to state decision makers, and to coordinate these functions nationwide.

Only when the expectations of residents, families, providers and advocates have a common base can the dignity of choice and dignity of risk be addressed and professional standards of practice be met with confidence in practice. A centralized approach to education would provide the strongest possible base, particularly in consideration of the development of advanced directives and by the interdisciplinary care plan team in the care planning process. Here again, the role (and the availability) of the ombudsman as a team member trusted by all involved should be expanded in both the educational process to residents and families, and in mediation of the care planning process as needed. It is hoped that by detailing specific questions and issues, the choices of the elderly as expressed in their advanced directives can truly direct the care plan, and can stand more strongly than the wishes of the Power of Attorney for health care after the resident is deemed unable to express rational choice, or of the staff fearing litigation if resident advanced directives are followed. Using the resident life history as a starting point, expressing the residents true wishes and choices even in difficult to attain goals and approaches, abandoning the medical problem-based model, communicating to all in a resident centered format that would guide all efforts in resident care… would be a dream-come-true for establishing true resident-directed care. Only then will we as caregivers be able to gift our residents with the full circle of quality of life, a quality end-of-life.

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> **Recommendation:** National workgroup develop guidelines for living wills and advanced directives that clearly address the issues of nutritional care outlined in individualized care practice guidelines to clarify the resident's choice on key decisions in both disease management and end of life care.

> **Recommendation:** National interdisciplinary work group address individualized care practice in the care planning process as it relates to resident directed care.

OBRA '87 SUPPORTS CULTURE CHANGE – LACK OF CLARITY ON PROFESSIONAL STANDARDS AND ACCOUNTABILITY OFTEN IMPEDE IT

The rights of our residents seem clear, but the accountability for ensuring their rights is not as clear. The competing challenges discussed previously in the context of care planning illustrate the complexity of advocating for resident rights. In the final analysis, we all are accountable, both professionally and personally, for honoring the rights of our residents to self-determination and quality of life, in addition to providing quality clinical care. But as a practical matter in the day-to-day complexity of competing challenges, just who is ultimately accountable for self-determination and quality of life in nutritional care? The medical director, physician, administrator, director of nursing, social worker, speech therapist, dietitian… just who? Each profession must embrace the challenge and evolve as leaders in resident-directed care.

Medical Accountability Is Receiving New Emphasis

For over 30 years, Medicare regulations have required medical directors to implement resident care policies and coordinate medical care in skilled nursing facilities. *Improving the Quality of Long-Term Care,* a 2001 Institute of Medicine Report, found their authority and accountability unclear, one factor leading to the 2003 AMDA revision of *Roles and Responsibilities of the Medical Director in the Nursing Home* and the *Role of the Attending Physician in the Nursing Home.* In <u>Patient</u> <u>Care-Clinical</u> <u>Leadership</u>, the medical director is to "help review policies and procedures regarding the adequate protection of patients' rights, advance care planning, and other ethical issues." In <u>Provide</u> <u>Appropriate</u> <u>Care</u> <u>to</u> <u>Patients</u>, "The attending physician should: in consultation with the facility staff, manage and document ethics issues consistent with relevant laws and regulations and with patients' wishes, including advising patients and families about formulating advance directives or other care instructions and helping identify individuals for whom aggressive medical interventions may not be indicated." (Wilson, 2005)

These documents and AMDA's position statements are consistent with the recently revised CMS guidelines regarding the medical director, and should assist in clarifying the authority and accountability of the role as suggested by the IOM report.

Reviewing the revised federal guidelines, Jeffrey Levine notes that, in addition to the barrier of maintaining appropriate reimbursement for the medical director, "another barrier to regulatory compliance is lack of physician training in such critical spheres as geriatric medicine, team dynamics, the regulatory process, and leadership skills. Lack of proper training in geriatrics is

widespread, and the current rate of certification in geriatric medicine will not meet current demand." He concludes:

> Finally the nursing home industry must rise to support the proper level of physician professionalism and to achieve the new expectations of regulatory compliance. There must be administrative support for the medical director in terms of salary and resources to maintain levels of quality expected under the new guideline. The medical director must enter this position with the confidence that his/her input will be respected and appreciated. The federal government now formally recognizes the importance of an informed, involved medical director, and it is time for the nursing home industry to do the same." (Levine, 2006)

A recent study by Rowland, reported in the *Journal of the American Directors Association*, used a weighting system of F-tag scope and severity on dimensions of quality potentially impacted by the medical director. It concludes that, "The presence of certified medical directors is an independent predictor of quality in US nursing homes." (Rowland, 2009)

Many providers have experienced physician professionalism with elder care at the highest level, but unfortunately also at levels that leave much room for needed improvement. It is hoped that increased medical director involvement and professionalism can have a positive influence on quality of life and quality of care by impacting both resident care policies and coordination of care.

Nursing Embraces Accountability, Addressing Barriers and Opportunities

We can only speculate what Florence Nightingale might think of how nursing in the care of the elderly has evolved since her day. She is often quoted, "Were there none who were discontented with what they have, the world would never reach anything better."

Leaders in the nursing profession recently addressed their evolving role in resident-directed care and culture change in a recent issue paper, *Nurses Involvement in Nursing Home Culture Change: Overcoming Barriers, Advancing Opportunities.* Their recommendations, stated below, could well form the base for consideration of the issue by all professions:

> Recommendation 1: Develop and distribute a statement of goals for practicing nurses in culture change homes.
> Recommendation 2: Develop competencies for nurses practicing in culture change homes.
> Recommendation 3: Conduct a comprehensive review of culture change content in pre-licensure (associate degree and baccalaureate) nursing programs.
> Recommendation 4: Disseminate existing tools/resources on culture change and nursing's role in culture change to academic nursing programs, including strategies for incorporating this content into the curriculum.
> Recommendation 5: Create new tools/resources based on the competencies for practicing nursing in nursing homes.
> Recommendation 6: Identify research priorities for examining the role of nurses in nursing home culture change. (Burger et al, 2009)

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Social Work Accountability to Resident Self-Determination Is Clear

The history of social work in social change is addressed by Norton in *The Power of Circles:*

> Social work pioneer Jane Addams would never have stood for it: Relegated to finding lost socks when a whole culture needs changing…Addams undoubtedly would have seen her role in long-term care a little differently than that. Many of the hurdles she helped new immigrants and the urban poor to overcome 100 years ago parallel those for nursing home residents today. That is, the struggle to survive and thrive in strange and often cold, indifferent surroundings. Addams and her associates established settlement houses to provide social services, educational classes, recreation, workshops, childcare nurseries and theaters in poor neighborhoods where immigrants lived. They not only brought their clientele into the mainstream of society by helping develop the individual skills and abilities of the poor, but also worked to create a sense of community and change in the environment in which they were living. (Norton, 2003)

The role of the social worker supporting resident rights and self-determination is reaffirmed in The NASW *Code of Ethics,* which serves as a guide to the everyday professional conduct of social workers. The Preamble opens with:

> The primary mission of the social work profession is to enhance human wellbeing and help meet the basic human needs of all people, with particular attention to the needs and empowerment of people who are vulnerable, oppressed, and living in poverty. A historic and defining feature of social work is the profession's focus on individual wellbeing in a social context and the wellbeing of society.   Fundamental to social work is attention to the environmental forces that create, contribute to, and address problems in living. (NASW Delegate Assembly, 2008)

The Social Worker's Ethical Responsibilities to Clients include, among others:
> 1.01 Commitment to Clients – Social workers' primary responsibility is to
> promote the wellbeing of clients. In general, clients' issues are primary…
> 1.02 Self-Determination – Social workers respect and promote the right of
> clients to self-determination and assist clients in their efforts to identify
> and clarify their goals.
> 1.03 Informed Consent – Social workers should provide services to clients in
> the context of a professional relationship based, when appropriate, on
> valid informed consent. Social workers should use clear and
> understandable language to inform clients of the purpose of the services,
> risks related to the services, limits to services because of the requirements
> of a third party payer, relevant costs, reasonable alternatives, clients'
> rights to refuse or withdraw consent…
> 1.14 Clients Who Lack Decision Making Capacity – When social workers act
> on behalf of clients who lack the capacity to make informed decisions,
> social workers should take reasonable steps to safeguard the interests and
> rights of those clients.

The Social Worker's Ethical Responsibilities to Colleagues include, among others:
> 2.03 Interdisciplinary Collaboration – social workers who are members of interdisciplinary

team should participate in and contribute to decisions that affect the well-being of clients by drawing on the perspectives, values, and experiences of the social work profession…social works for whom a team decision raises ethical concerns should attempt to resolve the disagreement through appropriate channels. If the disagreement cannot be resolved, social workers should pursue other avenues to address their concerns consistent with client wellbeing." (NASW Delegate Assembly, 2008)

Dietetics Accountability Is Evolving in Somewhat Competing Directions

The Code of Ethics for the Profession of Dietetics and Process for Consideration of Ethics Issues was adopted by the American Dietetic Association (ADA) and its credentialing agency, the Commission on Dietetic Registration (CDR) in 2009. It cites as one responsibility to the public, "The dietetics practitioner provides professional services with objectivity and with respect for the unique needs and values of individuals. " (ADA, 2009)

The *American Dietetic Association Revised 2008 Standards of Practice for Registered Dietitians in Nutrition Care…* (which together with the *Code of Ethics* is intended to guide the practice and performance of RDs and DTRs in all settings), addresses in Indicators for Standard 1: Nutrition Assessment, the expectation that the RD will document and communicate "1.7D Changes in clients' perceptions, values and motivation related to presenting problems." Indicators for Standard 3: Nutrition Intervention, notes that "each RD Plans the Nutrition Intervention – Determines patient/client-focused goals and expected outcomes." Examples of Outcomes for Standard 4: Nutrition Monitoring and Evaluation, include "the client/community outcome directly relate to the nutrition diagnosis and the goals established in the intervention plan including but not limited to client-centered outcomes (eg. quality of life, satisfaction, self-efficacy, self-management, and functional ability)." (ADA, 2008)

Standards of Professional Performance do address the responsibility of the RD to provide quality service based on customer expectations and needs, but very generally. These documents do not form a firm foundation for dietitian advocacy for resident choice and resident rights, or for quality of life in long-term care. While these priorities are touched upon in several places, and certainly consistent within those infrequent mentions of patient choice and satisfaction, they are far from a focus of the standards, leaving a void for best practice regardless of the place of practice. Standards of practice for the dietetic practitioner in long-term care are currently being developed, presenting the opportunity to address the standard of resident self-determination with much needed emphasis. Hopefully they will do so.

A review of the mission, vision, values and goals of ADA Practice Groups did not identify a priority commitment to resident rights and resident choice. The mission and vision of the Dietetics in Health Care Communities (DHCC) practice group, formerly Consultant Dietitians in Health Care Facilities, focus on empowering members to be the nation's food and nutrition leaders and to optimize the nation's health through food and nutrition. (DHCC, 2009)

The CDM, CFPP Scope of Practice is silent on the subject of resident rights, as is the Code of Ethics and the Practice Standards.   (DMA, 2009)

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Clinical nutrition, medical nutrition therapy and the role of nutrition in the management of acute and chronic disease appear to be the primary focuses of the RD and DTR. Food service management and sanitation appear to be secondary focuses for the RD, and often the primary focus of the CDM. If these are consistently the focuses of professional education, of professional self-development, of standards of practice…who, then, is the primary advocate for resident rights and self-determination?

> *Our practice needs to focus on the science of wellness in elder care from a psychosocial aspect. What resident rights really address are rights to all choices, good and bad. We need to focus on quality of life from all angles, and redefine wellness or wellbeing as dining with control and choices, community, friends socializing, dignity and respect. (*Madalone, 2009)

Well-Being: Beyond Quality of Life…The Metamorphosis of Eldercare provides such focus and definition. Calling for a metamorphosis of long-term care, the authors define "the ultimate outcome of the person-directed model as 'WELL-BEING'" and the Domains of Well-Being as identity, growth, autonomy, security, connectedness, meaning, and joy. (Fox et al, 2006) What a world away from weight, albumin, BMI, RDI, BUN, HgA1C, Stage IV, mg, mEq, gm, kcal and all the traditional measures of successful nutrition intervention. Dietitians are called to advocate aggressively and work tirelessly for residents to champion their nutritional well-being in all domains.

The realities of scarce resources present a challenge to dietetic practitioner in long-term care. Time is money, and recent revisions in the interpretive guidelines, as well as recent affirmation of the RD role in clinical assessment and the CDM role in production management, leaves many RDs seeking additional hours to complete his/her job. Who, then, is the primary advocate for resident rights and self-determination? Who has the opportunity to build the relationships foundational to resident-directed care? Who has the opportunity to know each resident well, their preferences, stated or silent? To know their goals, consistent with medical recommendations or not? Who has the opportunity to continually support resident right to refuse treatments, while also offering ongoing opportunities to comply? The clinical focus of RDs and DTRs in long-term care leaves little time for chatting over a cup of tea, for observing the service in multiple decentralized dining rooms, indeed for just getting to know the resident as a person…could this be the CDM role, replacing the time historically delegated to nutrition assessment activities? Certainly, the team of nutrition professionals must accept this priority, and while each team may designate primary accountability differently, the full team must be held accountable for the professional advocacy for resident rights and quality of life in dining.

A Challenge to Accountability to All Professionals

Shields offers a challenge of accountability to all professionals, sharing his thoughts on the biggest barriers to advancement of a good life for our residents –

> After years of observation, I am convinced that the people with the power remain the biggest barrier to meaningful culture change in long-term care. They are too easily satisfied. Even as they gravitate toward this new way, their old way of thinking is so strong it keeps leaders from truly changing the organization and empowering teams. The

old mindset makes us way too satisfied with the low-hanging fruit—those positive outcomes that inevitably result from even modest changes.

Because even small improvements are so much better than the old way, it is easy to become complacent and avoid the really difficult work necessary to create true home for elders. The danger is that the literacy of this new model is so dramatically increasing that you can delude yourself into being satisfied with the low-hanging fruit. Meanwhile, our competitor down the street will come in with the full literacy of the new model. The time has passed where making only minor improvements is sufficient. We have the path now, the way is clear, people need to take it or they are going to compromise their competitiveness in the near future.

But people are not moving with a sense of urgency; they still think they have endless time to change the culture of long-term care. Some opt for short cuts. I watch organizational leaders who want to move into this new world but will not spend adequate resources. They try to do it on their own, often re-inventing the wheel. The way is clear and it is being demonstrated by many who are on the path. The expertise is out there, but you have to access it.

A second barrier to meaningful change is that policy advocates and funders are too quickly satisfied because they are so relieved with any improvement. We need to set our sights higher. (Shields, 2010)

Ombudsmen - an Opportunity for Increased Advocacy

The Administration on Aging's Long-Term Care Ombudsman Program is active in all states under the authorization of the National Older American's Act. Funded by the AoA and operated by the National Consumers' Voice for Quality Long-Term Care (NCCNHR), the National Long-Term Care Ombudsmen Resource Center together with the National Association of State Agencies on Aging (NASUA) provides training and technical assistance to state and local ombudsman. Ombudsman are advocates for residents who work to resolve problems of individual residents and to bring about changes at the local, state and national levels that will improve residents' care and quality of life. Program Data for FY 2008 indicated that 1,300 paid ombudsmen and over 9,000 certified volunteer ombudsmen investigated over 271,000 complaints, 77% of which were partially or completely resolved to the satisfaction of the complainant. Food—its quality, quantity, variation and choices—was one of the five most frequent complaint topics. (Administration on Aging website, 2009)

Recall the pivotal role of the National Citizens Coalition for Nursing Home Reform in convening the Campaign for Quality Care, which is credited with leadership in the achievement of the 1987 Nursing Home Reform Law, OBRA '87. Also recall that this same organization first brought together the future leaders of the pioneer movement in an educational session at its 1994 – 95 annual meeting. Throughout the years, NCCNHR has continued to work actively with the Pioneer Network and has consistently conducted culture change educational forums for consumers, ombudsmen and other stakeholders. It is important to continue to trust and involve responsible advocacy for resident rights and quality of life and care. At both the state and local level, long term care ombudsmen in many parts of the country have been key players in bringing people together to learn about and to help coordinate joint efforts to promote culture change and to educate consumers.

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The need for increased advocacy is evident through mindful consideration of our residents' thoughts in "Hear Our Voice," theme of the NCCNHR celebration of Residents' Rights Week. How wonderful that so many residents and facilities contributed to the forum, "The Residents' Voice." But how sad that so many residents considered "a meeting to vote on what we want to do at our facility so that a decision may be the right one for all of us" as the response to how residents are involved in decision making in their facility. One resident boldly defined resident rights as "the right to be treated fairly and the right to say no!" Hopefully our increased focus on resident self-determination will grow and spread to the point that all of our elders soon understand their right to "have it my way."

Education – An Opportunity for Increased Advocacy

Addressing the importance of research and education for **all** professions, Kantor noted, in *Principles and Content of Culture Change:*

> If the culture change movement – and the philosophy and practice of person-directed care – are going to enter the mainstream and become the norm, it must be fully integrated into academic curricula, research agendas and training programs, for in truth, academia has been noticeable absent from the culture change movement… For the culture change movement to grow, we must assure that the principles of person-directed care are taught in training and education programs. For, while people may listen, and while they may believe in "aging with dignity" and consumer choice, this belief is not enough to extend the culture change movement, particularly into academia where we are training our future practitioners. For educators and researchers to be part of the culture change movement, for them to come to the table, culture change must demonstrate precisely – trough translational research, and education and training for the entire team – the efficacy, practicality, and validity of the culture change movement. Without this demonstration, we cannot fully change the culture of aging. With this demonstration, as our providers and educators learn more about culture change and witness person-directed care, they will themselves become change agents for aging with choice, dignity and self-determination. (Kantor, 2008)

As a provider who has personally witnessed the power of person-directed care, I believe this demonstration cannot come soon enough. While we wait, could we focus on just one consideration, the legal rights of the residents of long-term care facilities and current best practices that honor those rights? Our peers in developmental disabilities and in other countries have done so; we must also meet the challenge, and quickly.

Recommendation: National workgroup address the immediate inclusion of professional educational and competency requirements regarding resident rights, including the right of self-determination and the dignity of risk be included in all didactic programs, internship programs and continuing professional education requirements for all licensed, certified, and designated health professionals working with residents living in long-term care settings.

Recommendation: AMDA develop and disseminate guidance for medical director accountability that addresses proper training, competency assessment, and the medical

director's role as an active advocate for resident rights with physicians, administration, and staff, and for resident quality of life in addition to quality of care from a medical perspective.

Recommendation: Organizations attempt to retain a certified medical director, or one actively seeking certification or one willing to complete ongoing continuing education on resident rights and quality of life and act as an active advocate for resident choice.

Recommendation: Each profession serving elders in long-term care develop and disseminate standards of practice for their professional accountability that addresses proper training, competency assessment, and their role as an active advocate for resident rights, and for resident quality of life from a wellness perspective in addition to quality of care from a medical perspective with guidance and financial assistance coordinated through the Pioneer Network.

Recommendation: National workgroup of ADA, CDR and DMA address all previous recommendations and define the role and accountability of each nutrition professional in advocacy and accountability for honoring residents' rights, recognizing that quality time with residents is essential for the development of the relationships that form the foundation for individualized resident-directed dining.

Recommendation: National workgroup develop and disseminate recommendations for in-service training of current staff to introduce the evolving practices in resident-directed, individualized care.

Recommendation: Professional ombudsman component of the long-term care ombudsman program expansion, both in numbers and in level of involvement at a facility level sufficient to provide close and continuing contact with residents, families and facilities, educating and advocating for resident rights and quality of life through culture change and to expand their availability for involvement in care planning on issues of resident rights and quality of life.

OBRA '87 SUPPORTS CULTURE CHANGE – RELATED AGENCY GUIDANCE CAN BE A BARRIER

Incorporation of the <u>Food Code 2009</u> into regulation through the interpretive guidelines presents challenges in creating home for residents. While the implementation of priority, priority foundation and core items in quantity food preparation and in staff preparation of food for residents is, for the most part, manageable, the interface of the Food Code with resident life threatens to negatively impact resident quality of life with the application of "practical, science-based guidance and manageable, enforceable provisions for mitigating known risks of food-borne illness." According to Sundlof, director of the Food and Drug Administration's Center for Food Safety and Applied Nutrition, "The FDA is spearheading an important initiative to improve the nation's food safety system by establishing a fully integrated national system with federal,

state, local, tribal and territorial regulatory agencies. Food Code adoption and implementation in all jurisdictions are important for achieving uniform national food safety standards and for enhancing the efficiency and effectiveness of our nation's food safety system." (FDA, 2009)

> *I spoke with a state surveyor regarding villagers' cooking/baking groups. She said that it was wonderful for villagers to participate in these activities. But, they would need to have their hair covered, wash hands and wear gloves, and follow all food preparation and food safety guidelines. Since there is no guarantee where their hands have been, only those involved in the cooking/baking group should eat what they prepared. The food should not be served as part of the meal or snack for their peers. It is best to throw the food away, and make the same food items in the kitchen and serve it. That way the residents wouldn't be offended and the food would be safe to eat."* An RD

> *We have taken a stand to treat our residential kitchens as home kitchens. Our policies and procedures support that residents and staff do not wear hairnets when working with food. We make sure that everyone's hair is pulled back and out of the way, everyone washes their hands as often as needed and has on clean clothing. We don't want to make the resident and/or staff "gown and glove" to enjoy the opportunity to cook and eat together in their households. But a neighboring facility across the state line had a federal surveyor with their state survey team this summer and they really went after everything that they were doing in their kitchens. Their staff came for a tour shortly after their survey and were completely deflated as a result of it. We have to remember that food is the center of home – everything centers around food – we need to do things safely, but we need to know that in order to truly have an environment of home, those who live here must have true choice and control over how they live in the environment. It can't be home if they can't be part of the life of the kitchen. Whatever we do with regulations, we need to figure out how to safely encourage residents to be an active part of that life.* (Oelfke, 2009)

The subject of bare hand contact with food is easily one of the most challenging compliance issues today. Are universal precautions not adequate? Is there a greater risk from bare hand contact with a piece of toast than with a medication? The issue of state survey variability arises on this subject, with some states requiring gloves be worn when assisting a resident in eating a piece of toast, while others will allow the use of deli paper. Of course, tongs and flat wear can be used, but how normal is eating a piece of toast with a fork? Perhaps this is a dignity of risk issue, but can it be resolved through the residents' right to self-determination? All current indications are that few, if any, state agencies are compromising enforcement. But no residents have been heard to express preference or support for the "safeguard."

> *I would hope that we could use some common sense in the interpretation and requirement for residents and staff involved in the kitchens. We have never had a food born illness that I know of. We have never had a deficiency related to the cross training of staff or infection control or safety. I'm always concerned about that as there are so many opportunities for cross contamination. Our RNCC listened in on a conference with state surveyors and providers not long ago. They spent 20 minutes debating how to assist a resident to eat toast without touching it…seems like we have more important issues?? She couldn't believe that was the biggest issue we had to discuss.* (Oelfke 2009)

It is essential that long term care providers continue to provide quality care as identified by nationally recognized standards, but these standards must be integrated into OBRA '87 as guidance, not as law, and with respect for resident satisfaction, self-determination and quality of life in their home.

> **Recommendation:** National workgroup with representatives from all stakeholders address modifications needed in application of <u>Food Code 2009</u> to bridge the gap of home and institutional applications, and that future modifications be incorporated only through a similar workgroup.

In summary, the thoughts of Audrey Weiner and Judah Ronch are particularly relevant, as expressed in the forward to *Culture Change in Long Term Care:*

> It is not without some irony that Cohen and Eisdorfer (2001) see models for the future in earlier models of charity and compassionate care (beginning with the poorhouses of the 17th and 18th centuries) whose evolution toward medical models of care and reimbursement subordinated care of the person to care of an illness. As the articles in this collection demonstrate, some of the best attributes found in earlier years and other cultures are at the heart of contemporary innovations. But the intellectual, regulatory, economic and attitudinal barriers that have arisen over time still confront innovators from all stake holder groups as they contemplate issues of culture change for the future." (Weiner and Ronch, 2003 p xiii)

ADVANCING RESIDENT SELF-DETERMINATION

The establishment of resident-directed, individualized care that would lead to fulfillment of OBRA '87 is challenged by contradictions in the document itself. The resident right to a dignified existence, autonomy (including independence and self control), self-determination, refusal of treatment, the dignity of risk and more are contested by statutory requirements that hold the facility ultimately responsible for the resident's care and safety.

In *Long Term Care and a Good Quality of Life – Bringing Them Closer Together,* Kane addresses the competing priorities*:*

> "One little-tested assumption is that safety – defined vaguely or not at all – is the be-all and end-all of long-term care. Embedded in most of our rules and regulations is the idea that long-term care should aspire to the best quality of life as is consistent with health and safety. But ordinary people may prefer the best health and safety outcomes possible that are consistent with a meaningful quality of life." (Kane, 2001)

Grant summarizes the challenge:

> "Still, it will be no simple task for policymakers to balance the competing needs for safety and choice in a way that best meets the current and future expectations of key stakeholders such as residents and their families, consumer advocates, providers, payer, and regulators. The goals of nursing home care pose complex ethical dilemmas that must ultimately be addressed through open public debate." (Grant, 2008)

In *Moving to a Higher Level: How Collaboration and Cooperation Can Improve Nursing Home Quality,* Koren addresses the potential for the work of the nursing home component of the Quality Improvement Organization (QIO), the grass roots "culture change" movement, and the "Nursing Home Quality Campaign, Advancing Excellence," to move nursing homes toward a higher level of performance. She cites the work of the Rhode Island Department of Health's "Individualized Care Pilot," which connects surveyor identification of problems with technical assistance from the QIO to help providers improve quality. (Koren, 2008)

In *Supporting Culture Change: Working Toward Smarter Nursing Home Regulation,* Stone et al. discuss the challenges of moving forward in a partnership model. They cite Kansas, where the regulatory and technical assistance functions are separate departments of a single agency, and Oregon, where surveyors team up with nursing home staff to address the challenges together.

Stone emphasizes the challenges of partnership in regulatory reform:

> The success of the partnership approach will depend, in a large part, on the extent to which the stakeholders buy into the process and assume responsibility for successful implementation. The regulatory agency staff at all levels – particularly midlevel managers and front line surveyors – must be committed to this new paradigm and integrate their training in both culture change and new

ways of communicating with providers into daily practice. The same holds true for all levels of nursing home staff – they must shift their mistrust of the survey process to a collaborative approach in which they share failures as well as success. In many cases, organizations that have established rigid policies and procedures will need to move toward a more organized process that focuses on embedding culture change principles into policies and practice. Federal and state policy makers, as well as nursing home corporations and individual facilities, will need to establish incentives to hold the regulators and providers accountable and to reward successful partnerships.

> "Given the pivotal role that consumer advocates played in the creation of OBRA '87 and their ongoing efforts to ensure consistent oversight and enforcement, this group's buy in of smarter regulation is essential."

> "It is also essential that the most important stakeholders – nursing home residents and their families – assume responsibility for the success of this approach. Resident and family councils must weigh in on how partnerships should be structured and implemented. Consumers and their relatives need to receive culture change training together with surveyors and nursing home staff. To maximize the success of these collaborations, they must also be part of the facility-level teams that identify regulatory barriers, work to minimize these hurdles, and ensure the achievement of cultural transformation." (Stone et al, 2009)

Kantor, in remarks to the Alliance for Health Reform and the Robert Wood Johnson Foundation, emphasizes the importance of state culture change coalitions in moving forward. She notes the important role of independent active groups with diverse stakeholder involvement, coordinating with other efforts to move culture change forward on the state level including effective partnerships with regulatory and technical consultation. She poses the fundamental question:

> "So, what's it going to take to make this resident-centered care the norm? What do we all have to do? First, it's important to know that this is no longer a question. We have gone from debates to conversation. We all agree, the question is how." (Kantor, 2007)

With the collaboration of researchers, academia and policy makers asking and answering the questions of "how" to the standards of their professions, pioneering states are demonstrating effective partnerships between regulatory and technical consultation. Pioneering providers are giving inspiration through a wide variety of approaches that successfully create home and resident-directed care. They are demonstrating that putting the person before the task and creating normalcy are indeed possible.

The Declaration of Interdependence, the Spirit of '06 from the Pioneer Network, can guide us all toward effective partnerships in the exploration of "how." The full document can be reviewed in Appendix G. In conclusion, it affirms:

> In declaring our interdependence, we recognize that when we are united, we have endless possibilities; when we are partners, we build community; when we are proactive together, we reduce our fear of change, and when we cultivate the common ground, we grow individually and collectively. (Pioneer Network, 2006)

THE DEEP SEATED ISSUE OF CHOICE
Advancing Resident Self-Determination

Working together to honor our residents' rights to autonomy and self-determination is clearly a good place to start in building community and making resident-centered care the norm. The basics: pro-active choice agenda for facilities, regulators, residents and families; best practice defined simply by the outcome of honored choice; professionals guided by ethics emphasizing the right to choice as a foundational value. But where does it stop? How do we know we are there? That resident-centered care is now the norm? That we have created home? The answer…it doesn't stop. It just keeps getting better. Shields shares his thoughts:

> *One of the hallmarks of the creation of home, self-led teams and high involvement is the respect staff gives residents--it is now standard. Yet we have to start at the beginning with every new staff person. We had a situation where a relatively new caregiver did not quite get the picture and had a temper outburst with a resident in public. The resident quietly listened to the staff person, then lifted her head and said, "You don't get to talk to us like that here, you'll be gone tomorrow." And she was. The beauty of the story for me is that the resident's assurance that "this is my home" was not damaged by the staff person's unacceptable outburst. The resident in no way cowered or felt her home or autonomy was threatened. She was confident in her place as driver in her home and she had quiet and absolute confidence the person would be gone the next day, and she was. So while I am embarrassed by the caregiver's actions, I am proud of how the culture of home, family, love and respect we worked so hard to create ultimately prevailed.* (Shields, 2010)

And Norton shares hers:

> Every resident should have home as he or she defines it. While this may seem impossible at first thought – to create home for each person with very different and even conflicting visions of home, an organization that makes this their challenge will find themselves working with great energy and pleasure. And together they will inspire and shape a true community – one which is home to all. (Norton, 2010)

Coming full circle on the deep seated issue of choice, recall the simple starting point of getting to know each resident and their choices: "*What does the resident want?*" "*How did they do it at home?*" Then act on the challenge: "*How can we do it here?*" Honor your residents' self-determination, and welcome everyone home.

Recommendation: While we work together to advance quality of life and quality of care for our residents, focus on one consideration first and foremost in our work – the legal rights of the residents of long term care facilities and individualized care practices that honor those rights.

APPENDIX A

Improving the Quality of Care in Nursing Homes. Institute of Medicine. Committee on Nursing Home Regulations. National Academy Press: Washington, D.C. 1986. Selected excerpts:

> The attributes of quality in nursing homes are very different from those in acute medical care settings such as hospitals. The differences stem from the characteristics of the residents of nursing homes, their care needs, the circumstances and settings in which the care is provided, the expected outcomes, and the fact that for many residents, the nursing home is their *home*, not merely a temporary abode in which they are being treated for a medical problem. Thus, quality of life is very important for its own sake (that is, as an outcome goal) and because it is intimately related to quality of care in nursing homes.

> Nursing home care is both a treatment and a living situation. It encompasses both the health care and social support services provided to individuals with chronic conditions or disabilities and the environment in which they live. Nursing homes are "total institutions" in which care-givers, particularly nurses/s aides represent a large part of the social world of nursing home residents and control their daily schedules and activities. This is the total environment for many nursing home residents for the duration of their stay, which may be several years. As a result, deficiencies in medical or nursing care or in housekeeping or dietary services, which could be tolerated during a brief hospital stay, become intolerable and harmful to well-being when they are part of an individual's day-to-day life over a longer period.

> The physical, psychosocial, and environmental circumstances and outcome expectations of nursing home residents distinguish the goals of nursing home care from those of acute medical care. In acute care, treatment goals are based on medical diagnosis. In nursing homes, the care goals are based on physical and psychosocial assessment. They focus on restoration, maintenance or slowing of the loss of function, and on alleviation of discomfort and pain.

> In sum, long-term care is directed primarily at relieving conditions that result from chronic physical or mental disorders or the chronic after-effects of acute disorders. Equally important is relief of pain and discomfort.

> Many aspects of nursing home life that affect a resident's perceptions of quality of life – and therefore sense of well-being – are intimately intertwined with quality of care.

> Conflicts of values and ethics are inherent in nursing home care – for example, conflicts between care requirements, as judged by professions, and the rights and preferences of the resident. Should a very old, perhaps mildly demented resident, who is not legally incompetent and who declines to eat, be fed by naso-gastric

tube even if he strongly objects to it? What about residents who decline to take medication or other treatments prescribed to manage their chronic disease? Should dietary preferences of a resident override adherence to a medically prescribed dietary regime? Should a frail, unsteady resident with osteoporosis, who insists on walking by herself, be permitted to walk around unescorted even though there is a substantial risk that she will fall and suffer a hip fracture?

For the very sick and disabled, the quality of the care and the way it is provided are probably the most significant contributors to well-being.

…residents who receive good personalized care and opportunities for choice have higher morale, greater life satisfaction, and better adjustment.

Modern management theory holds that excellent results are more likely to be achieved when the members of an organization are motivated not by fear of sanctions for inadequate performance, but by pride, accountability, cooperation and loyalty. The HCFA (now CMS) and state governments can apply this concept in their dealings with nursing homes. The current federal regulatory system is structured only to punish poor behavior. Good behavior goes unrecognized. Only a few states have developed systems for rewarding good or outstanding facilities. In part, it is attributable to the crudeness of the survey instruments. After the HCFA has implemented the new survey process recommended in Chapter 4, and after some statistically derived outcomes standards are developed, it should be possible to reliably distinguish the very good from the poor or merely acceptable performers. It will then be possible to reward facilities for excellent performance and thus to encourage continued excellent performance.

APPENDIX B

OBRA '87 Surveyor Training on *Quality of Life.* 1987. Selected excerpts.

<u>Autonomy: A Framework for Assessing Resident Rights and Quality of Life</u>

> All persons have autonomy, regardless of the range of their functional abilities.
> The concept of autonomy – the degree to which a person expresses his or her
> individuality – is useful to thinking about assessing a facility's compliance with
> resident rights and quality of life requirements. The new nursing facility
> requirements recognize that autonomy is a basic human need. Autonomy has
> three dimensions:
>> -Independence
>> -Self-control
>> -Competence

> Essential to reviewing resident rights and quality of life requirements is awareness
> of how the facility provides opportunities that enhance residents' "highest
> practicable" autonomy – the ability to exercise the independence, self-control, and
> competence that characterizes adulthood. There are three ways in which residents
> can be deficient in autonomy:
>> -By being incompetent
>> -By being procedurally dependent
>> -By lacking self-control

> Through your interviews with individual residents, organized resident groups, and
> family members, and observations in the Quality of Care and Environmental
> Quality Assessments, your task is to separate out factors that affect adversely a
> resident's autonomy.

<u>Autonomy and the Nursing Facility Environment</u>

> Your review of resident rights and quality of life reduces to one basic question –
> <u>how much control over their lives do residents living in a nursing facility have?</u>
> The new nursing facility requirements challenge the assumption that
> institutionalization limits personal autonomy more or less by definition. Rather,
> assume that the nursing facility and environment is <u>neutral </u>with respect to
> residents' autonomy. Everything depends on the way the facility sets up its
> institutionalized practices. Set up in one way, the facility is receptive to
> autonomy; set up in another way, it limits autonomy.

> That is why in the training videotapes, we show residents who are able to exercise
> a high degree of autonomy. Residents' interview responses indicate that the fit
> between what they want to do with their lives and what the institutional setting is
> designed for them to do is symbiotic.

In surveying resident rights and quality of life, you are evaluating the extent to which the nursing facility's social and physical environments advances resident autonomy. Think of your job as searching for organizational traits that assist residents' autonomous behavior – exercising independence, self-control, and competence. Assessing two characteristics are critical:
- -Flexibility
- -Controllability

Flexibility means that the facility provides opportunities for residents' autonomous participation. The resident may or may not seize these opportunities. Bringing flexibility into the nursing facility does not mean deinstitutionalizing it. It means organizing the facility in specific ways, like flexible seating arrangements that allow residents to sit alone, participate in small groups, large groups, and carry on private conversations, or serving a buffet breakfast on certain days encouraging residents to exercise their self-control, competence, and independence.

Controllability means that to some degree that facility allows residents to have an on-going role in shaping the institution – to have a say in how the facility functions. The group interview videotape shows a high degree of controllability – of a facility's response to residents influencing the life that institutional rules demand of them.

When thinking about flexibility consider how the facility is set up. When considering controllability, consider what residents can do to set up the facility differently.

Insofar as it is flexible and controllable, the nursing facility becomes an environment with opportunities for residents to live autonomously. What is beyond the control of the facility, and the regulatory process, is residents deciding to seize these opportunities.

APPENDIX C

OBRA '87 Surveyor Training on *Resident Rights*. 1987. Selected excerpts.

A New Perspective on Resident Rights

Dignity means more than door-knocking.

OBRA 87 gives us the opportunity and obligation to reexamine our attitudes, our routines, and personal assumptions regarding resident rights. We have the chance to re-focus our efforts and, in the process, social awareness and ethical practices that emphasize individuality will evolve.

When we reaffirm the dignity of each resident, we will also enrich the lives and values of our staff members. And, as we seek new ways of enhancing independence and offering new choices and opportunities to our residents, staff members will feel rewarded by those they empower.

Enriched lives means more productive lives for our staff. Pride and personal determination will improve the quality of life for our elders.

Busy care-givers are routinely required to make "on the spot" decisions. In the past, these decisions may have been made with the primary focus on efficiency and not on thoughtful consideration to individuality. To place appropriate emphasis on resident rights, we may need to sacrifice some efficiency for the sake of human pride.

Goals must be set that hold individual dignity in higher esteem than overall facility efficiency. It will not be easy. Years of caring practices and habits based on experience will need to be challenged. Ideas once believed to provide quality will need to be reexamined.

New ways to promote self-determination in a dignified fashion need to be identified. Communication and access both within and outside of each nursing facility needs to be fostered. Facilities can begin by creating and/or revising written policies and procedures that outline conflict resolution for staff and residents, as well as families, in areas pertaining to resident dignity and rights.

The following examples address areas in which quality care and resident rights should be examined.

Quality and the Dignity of Risk

The frail, elderly nursing home resident often must balance the dignity of risk,

which enables pride and independence, with the need to be kept safe…

The dignity of risk, individual pride, and the need for adult mastery and independence are valuable human options. We must carefully assess each resident before we even think about restraints. Exercising muscles and getting the maximum strength possible is the more important element in maintaining the potential to walk safely.

We may need to debate long-held beliefs about shining floors versus the pride of walking without assistance and feeling safe. Individual choice after full discussion of risk factors may be the most appropriate choice for many residents.

Quality and the Dignity of Privacy

Visitors, space and privacy are other important areas of concern. However, they may also be areas of conflict. For as many residents who prefer open visiting hours, there are often just as many who simply do not want visitors on their units before 9 or 10 a.m.

The key to the development of an effective policy that provides dignity and privacy is to remember that residents should make the final decision. In the process, they can learn to lobby and to take into consideration the wishes of the majority when making a decision…

Providing quality in areas of privacy may also extend to cleaning rooms by appointment and respecting the privacy of a resident's dresser drawers or closet space.

Privacy for families to meet must also be considered. Ideally, an administrator will foster family-like units that allow for readily-available private space, without a great deal of cost or effort.

Quality and the Right to Participate in Care Decisions

Although residents and their families are routinely invited to attend care conferences, we may need to explore other avenues that allow residents to participate in care and treatment decisions. Residents are empowered by being given the choice about their method of involvement.

The areas in which we must address resident rights continue to grow. Consider:
-the right of the life –long smoker versus the right to a smoke-free
 environment;
-the facility need to supply "optimal nutrition" versus the individual need
 to satisfy lifestyle or fast food habits;
-the facility need to document perfection in grooming versus the

individual right to grooming habits;
-the right to refuse treatment versus the nursing obligation to provide care;
-the right to refuse food versus the need to feed and offer supplements.

The list goes on.

This new perspective on approaching resident rights is appropriate as we enter a new decade of providing health care services. It is an opportunity to affirm that quality goes beyond hot meals and clean sheets. It is the chance to acknowledge that quality perhaps has more to do with meeting, to the best of our abilities, each resident's right to maintain his or her dignity, pride, and self-esteem while in our care.

APPENDIX D

Recommendations for Regulatory Guidance Changes to Support Resident Rights, including the Right of Self-Determination

F151
483.10
Interpretive Guidelines:
Expand the examples with the inclusion of "right to refuse treatment" and "right to make choices about all aspects of his or her life in the facility that are significant to the resident."

F152
Interpretive Guidelines:
Procedures 483.10(a)(3) and (4)
Add a procedure to determine if the "resident can understand the situation and express a preference, the resident has been informed and his/her wishes respected to the degree practicable."

F154
483.10(d)(2)
Interpretive Guidelines
Add a protocol to clarify the best practice process risk benefit education and determination of reasonable available alternatives.

F155
483.10(b)(4)
Interpretive Guidelines
Strengthen the guidance on honoring advanced directives to assist care team members in advocacy for resident expressed choice.

Consider wording to reflect the positive nature of choice instead of the negative of refusal.

Expand the guidelines and add a procedure and protocol to clarify the best practice process regarding a resident choice of treatment option, positioning the right to choose no treatment as a viable option. Include best practice guidance on assessing the reasons for the resident's refusal, clarifying and educating the resident as to the consequences of refusal, offering of alternative treatments.

F156
483.10(b)(8)
Interpretive Guidelines
Expand the guidelines and add a procedure and protocol to clarify the best practice process regarding providing care that conflicts with a resident's living will and/or advanced directive, including the guidance of an established ethics committee, ombudsman, or other specified resident advocate.

F163
Interpretive Guidelines
Add guidance in paragraph 2 to detail the physician's failure to support resident self-determination in treatment options as an example of appropriate cause for requesting an alternate physician.

F241
483.15(a)
Interpretive Guidelines
Expand examples to include promoting resident self-determination in treatment options with risk/benefit education and offering of alternative treatments in a manner that promotes resident dignity.

F242
483.15(b)
Intent
Expand to state respect the right of the resident to choose and refuse a treatment option.

F250
483.15(g)
Interpretive Guidelines
Expand the examples to which a facility should respond with social services to include resident choice of refusing a treatment option, situations potentially regarding opposing resident advanced directives, and to assist residents in consistently making meaning choices about aspects of their life significant to them.

F280
483.10(d)(3)
Interpretive Guidelines
Add guidance to address the right of the resident to choose and refuse a treatment option after a thorough exploration of care alternatives.

483.20(k)(2)
Interpretive Guidelines
Add guidance to address the right of the resident to refuse treatment options that the facility deems appropriate in light of the statutory requirement that hold the facility ultimately accountable for the resident's care and safety, including clinical decisions.

F281
F483.20(k)(3)
Interpretive Guidelines
Add specific reference to accommodation of guidelines to respect resident right self-determination, including the right to refuse treatment.

F309
483.25
Interpretive Guidelines
Clarify the facility responsibility to honor the resident right to self-determination in decision of avoidable or unavoidable decline or failure to reach the highest practicable wellbeing.

Resident/Representative Interview
Add probes to determine if resident self-determination was respected.

Care Plan Revision
Detail the resident right to self-determination and treatment refusal as one of the conditions determining compliance.

Interpretive Guidelines for Selected Specific Quality of Care Issues at 483.24
Add review of a resident regarding self-determination, similar to guidance on pain.

F325
483.25(i)(2)
Intent
Expand first bulleted intent to include consistent with the resident's right to self-determination in addition to comprehensive assessment.

Expand third bulleted intent to include resident's right to self-determination in addition to clinical condition and preferences.

Definitions
Expand avoidable/unavoidable to include resident right to self-determination in addition to needs, goals and recognized standards of practice.

Overview
Change implement to offer in the sentence allow the IDT to develop and implement interventions to stabilize…

Care Planning and Interventions
Remove the qualifier "to the extent possible".

End of Life
Expand the guidance to unseat the long standing expectation that the facility must continue to monitor weight and intake and to adjust care plan approaches continually until the resident is unwilling/unable to swallow.

Investigative Protocol – Objectives
Change the third bulleted point to read offered instead of received a therapeutic diet.

Criteria for Compliance
Change the third bulleted point to read offered instead of received a therapeutic diet.

Deficiency Categorization
Change the fourth bulleted point to read offered instead of received a therapeutic diet.

Severity Level 3 (or 2) Considerations:
Add bulleted example of failure to honor resident self-determination regarding nutritional care.

F361
483.35(a)
Intent
Add to assure that the residents are offered adequate nutrition and receive adequate nutrition within their rights to self-determination.

Interpretive guidelines
Add experience or training in individualizing approaches to nutritional care based on resident self-determination.

F363
483.35(c)(1)
Intent
Change to assure that the meals offered, not served, meet the nutritional needs.

Change nutritionally adequate meals have been planned for the resident and offered, not followed.

Add "Residents may choose to follow a menu pattern of personal choice."

Procedure
Add consistent with resident choice to observation guidelines.

Add interview with resident and/or family regarding resident choice for reason for deviation.

Probes
Change the first probe to ascertain that residents are offered (or receive within their rights to self-determination) food in the amount, type, consistency and frequency to maintain normal body weight and acceptable nutritional values.

F364
483.35(d)(1)(2)
Probes
Add "and acceptable to the resident" regarding appearance and texture.

F366
483.35(d)(3)(4)
Probes
Add probe guidance to affirm the resident right to refuse substitutions of equal nutritional value and instead receive foods of personal preference.

F367
483.35(e)
Intent
Change receives and consumes to offered foods in the appropriate form and/or the appropriate nutritive content…

F368
Intent – Interpretive Guidelines - Procedures
Clarify that the availability 24/7 of foods of resident choice, including high quality protein, offered and served by staff according to care plan preference for alternative meal times is an acceptable accommodation of frequency of meals.

F371
483.35(i)(2)
Factors Implicated in Food Borne Illnesses
Food Handling and Preparation
Expand guidance to clarify reasonable expectations and identify acceptable procedures regarding food service by non-food service staff in decentralized kitchens and dignified resident assistance in dining. Consider the standard of compliance with standard precautions as appropriate in all circumstances.

Food Receiving and Storage
Include the clarified guidance from Memorandums clarifying the acceptance of food from outside sources. Address the expectations for maintaining safe refrigerated storage in resident rooms, as well as safe storage of residents personal food in facility refrigerators.

F373
483.35(h)
Expand paid feeding assistants to all states through federal guidance.

F385
483.40
Interpretive Guidelines
Expand definition of supervising medical care to include education of residents on the risks and benefits of treatment options and honoring resident right to self-determination in treatment choice.

F441
483.65
Preventing the Spread of Infection
Expand the list of some situations to clarify reasonable expectations and identify acceptable procedures regarding food service by non-food service staff in decentralized kitchens and dignified resident assistance in dining. Consider the standard of compliance with standard precautions as appropriate in all circumstances.

F464
483.70(g)(3)
Acknowledge that an adequately furnished dining area may include the option for a resident to dine in their room with an appropriate chair and table to accommodate in-room out-of-bed dignified dining.

F501
483.75
Intent
Detail the expectation that the medical director helps the facility identify, evaluate, and address/resolve medical and clinical concerns and issues that affect resident care, medical care or quality of life, including the resident right to self-determination of treatment options.

Overview
Add facilitating resident self-determination to the list of areas for medical director input to the facility.

F520
483.75(o)
Investigative Protocol
Add to staff in various department interview to determine if they know what type of issues are appropriate to bring to the QAA committee, including issues relating to resident self-determination.

APPENDIX E

Principles of Pioneer Network
Principles of Eden Alternative
Essential Elements of Households

The Pioneer Network - Mission, Vision and Values

OUR VISION

A Culture of Aging that is Life-Affirming, Satisfying, Humane and Meaningful   We recognize our need to create ways of living and working together different from the traditional models. The Pioneer Network supports models where elders live in open, diverse, caring communities. Pioneers are working for deep system change by both evolutionary and revolutionary means, using Pioneer values and principles as the foundations for change. In-depth change in systems requires change in governmental policy and regulation; change in the individual's and society's attitudes toward aging and elders; change in elders' attitudes towards themselves and their aging; and change in the attitudes and behavior of caregivers toward those for whom they care. We refer to this work as culture change. Our aim is nothing less than transforming the culture of aging in America.

OUR MISSION   The Pioneer Network advocates and facilitates deep system change and transformation in our culture of aging. To achieve this, we:
    Create communication, networking and learning opportunities
    Build and support relationships and community
    Identify and promote transformations in practice, services, public policy and research
    Develop and provide access to resources and leadership

VALUES AND PRINCIPLES
- Know each person
- Each person can and does make a difference
- Relationship is the fundamental building block of a transformed culture
- Respond to spirit, as well as mind and body
- Risk taking is a normal part of life
- Put person before task
- All elders are entitled to self-determination wherever they live
- Community is the antidote to institutionalization
- Do unto others as you would have them do unto you
- Promote the growth and development of all
- Shape and use the potential of the environment in all its aspects: physical, organizational, psycho/social/spiritual
- Practice self-examination, searching for new creativity and opportunities for doing better
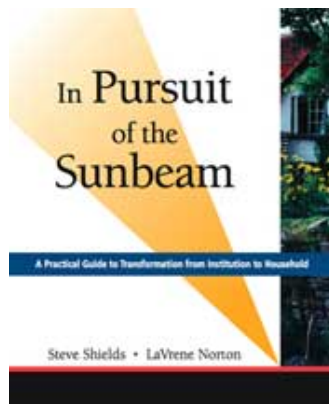- Recognize that culture change and transformation are not destinations but a journey, always a work in progress

The Ten Principles of the Eden Alternative

1. The three plagues of loneliness, helplessness, and boredom account for the bulk of suffering among our Elders.

2.   An Elder-centered community commits to creating a human habitat where life revolves around close and continuing contact with plants, animals, and children. It is these relationships that provide the young and old alike with a pathway to a life worth living.

3.   Loving companionship is the antidote to loneliness. Elders deserve easy access to human and animal companionship.

4.   An Elder-centered community creates opportunity to give as well as receive care. This is the antidote to helplessness.

5.   An Elder-centered community imbues daily life with variety and spontaneity by creating an environment in which unexpected and unpredictable interactions and happenings can take place. This is the antidote to boredom.

6.   Meaningless activity corrodes the human spirit. The opportunity to do things that we find meaningful is essential to human health.

7.   Medical treatment should be the servant of genuine human caring, never its master.

8.   An Elder-centered community honors its Elders by de-emphasizing top-down bureaucratic authority, seeking instead to place the maximum possible decision-making authority into the hands of the Elders or into the hands of those closest to them

9. Creating an Elder-centered community is a never-ending process. Human growth must never be separated from human life.

10. Wise leadership is the lifeblood of any struggle against the three plagues. For it, there can be no substitute.

ESSENTIAL ELEMENTS
To create Households

Excerpt from

In Pursuit of the Sunbeam, *A Practicial Guide to Transformation from Institution to Household*

by Steve Shields and LaVrene Norton,
Chapter 4, pp 34 - 38.
Available from
www.culturechangenow.com

The Essential Elements of the Household Model

1. The household is each resident's home and sanctuary.

2. The people who live here direct their own lives, individually and collectively.

3. The boundaries of the person and his/her home are clear and respected as a matter of course.

4. Grace, a shared sense of what is sacred about the house and its people, is deeply valued, consciously created and preserved. Ritual, spontaneity, friendship, spirituality, celebration, recreation, choice, interdependence, art and humor are all manifestations of a culture of grace.

5. The people who live here are loved and served by a responsive, highly valued, decentralized, self-led service team that has responsibility and authority.

6. Leadership is a characteristic, not a position. Leaders support and are supported by values-driven, resource bearing principles and practices as a way for each person to actualize his or her full potential.

7. All systems, including treatments, exist to support and serve the person, within the context of his or her life pursuits.

8. We build strong community with one another, our family, our neighbors and our town. Each household is part of a neighborhood of houses, dedicated to continuous learning.

9. The physical building and all its amenities are designed to be a true home.   Institutional creep in design and culture is treated as a wolf at the door.

APPENDIX F

Issue Brief, Stone et al

Supporting Culture Change: Working Toward Smarter State Nursing Home Regulation

Robyn I. Stone, Natasha Bryant, and Linda Barbarotta

ABSTRACT: The traditional nursing home regulatory approach, which uses survey and enforcement to achieve performance improvement, has created tensions between providers and surveyors. It has had limited success in improving quality overall and not necessarily allowed innovation to flourish. This has been the perception of many homes wanting to undergo transformative "culture change" reforms. To move toward a new model of nursing home regulation, the states and federal government must strike a balance between the traditional regulatory approach to weed out substandard facilities and a partnership model aimed at promoting high performance. This issue brief highlights the importance of how such a model is structured, as well as the need to adequately train and educate regulatory staff and providers about culture change. Regulators, providers, consumer groups, residents, and their families also will need to commit to the principles of person-centered care to ensure the success of the new collaborative approach.

★　★　★　★　★

OVERVIEW

The Pioneer Network—an advocate for person-directed care in the long-term care community—defines culture change as: "a transformation anchored in values and beliefs that returns control to elders and those who work closest with them. Its ultimate vision is to create a culture of aging that is life-affirming, satisfying, humane, and meaningful. Culture change can transform a 'facility' into a 'home,' a 'resident' into a 'person,' and a 'schedule' into a 'choice.'"[1] Over the past decade, the culture change movement has begun to attract many nursing home providers, beyond those who were among the early adopters of the reforms. As more nursing homes engage in culture change efforts, providers have raised concerns about federal and state regulations and practices that they view as barriers to successful implementation. Some argue that the regulatory approach, which they view as primarily legalistic and enforcement-based, creates an environment in

Figure 1. Policymakers Cite Adequate Workforce and Improving Quality as Most Urgent Challenges Facing Long-Term Care

"In your opinion, how urgent are the following challenges facing long-term care for policymakers and health care leaders to address?"

■ Very urgent   □ Urgent

Challenge	Very urgent	Urgent	Total
Developing sufficient workforce	48	34	82
Improving quality of care	46	34	80
Securing adequate financing of long-term care	54	26	80
Forming a sufficient supply of home- and community-based services	39	37	76
Adequate information on facilities for consumers	24	43	67
Establishing sufficient regulations and enforcement	13	38	51
Adopting information technology systems	15	33	48

Source: The Commonwealth Fund Health Care Opinion Leaders Survey, June 2008.

which administrators and staff are afraid to pursue culture change activities that they believe may put them in jeopardy. Others indicate that specific regulations actually get in the way of culture change, particularly those that prevent necessary changes to the physical environment, staffing patterns, and training requirements.

A recent study of state culture change initiatives funded by The Commonwealth Fund found substantial evidence of perceptions by providers that regulations can impede culture change. It also identified several states that have developed a more collaborative relationship between regulators and nursing home providers to facilitate successful culture change efforts. This issue brief highlights issues related to the real and perceived tensions between regulation and culture change and examines how the federal government and states could move toward a relationship that combines a traditional regulatory role with a complementary technical assistance and partnership role. The brief begins with an overview of various regulatory approaches, how nursing home regulation fits within these different approaches, and the evolution toward resident-centeredness and quality of life, as well as quality of care. This is followed by a discussion of federal and state efforts to create a more responsive regulatory system, highlighting the experiences of

Kansas and Oregon. It concludes with a review of the key issues that must be addressed as states attempt to develop a collaborative approach to regulation that supports culture change and maximizes the potential for success.

NURSING HOME REGULATION: BACKGROUND

During the early 1960s, a wave of nursing home scandals attracted the attention of politicians, the media, and advocacy groups. In the decades since then, concerns about the quality of nursing homes have been periodically debated and addressed. The most significant response to nursing home quality problems was the passage of the Omnibus Budget Reconciliation Act of 1987 (OBRA 87) that required nursing homes to "attain or maintain the highest practicable physical, mental, and psychosocial well-being of each resident." To achieve this goal, standards were developed, enforcement mechanisms were expanded, and nursing homes were required to fill out a resident assessment instrument for each resident at admission and at specified times afterward. In response to this new regulatory approach, many nursing homes adopted a "quality assurance" orientation, which focused primarily on paper compliance with government regulations rather than on the actual quality of care and life experienced by residents.

Today, nursing home quality oversight is focused on deterrence. The federal government (and many states) relies on a rigorous survey and

North Carolina's survey agency is trying to balance regulations and culture change to help facilities create a more "homelike" environment, yet comply with regulations for safety. For example, when nursing homes want to place plants and other decorations in the facility, these changes can violate regulations because they can obscure exits. The department tries to work with facilities to help them be code-compliant and still create environments for residents that are as much like home as possible.

certification process to set and enforce standards regarding every aspect of nursing home care. It is a model that combines two regulatory paradigms—deterrence and compliance.[2] In an attempt to eliminate chronic bad performers that flout the rules, deterrence takes a formal, legalistic, and sanction-oriented approach. The compliance approach, on the other hand, is generally less formal and more supportive, measuring improvement in developmental terms and using sanctions only as a last resort. Although nursing home providers, regulators, and advocates may disagree on where nursing home regulation falls on the deterrence–compliance continuum, most agree that deterrence alone is a blunt instrument that has had limited effects on the organizational performance of nursing homes or on resident outcomes.[3]

As the culture change movement has gained momentum among providers, consumers, and policymakers, there has been increasing concern about the extent to which implementing physical redesign of nursing facilities—that is, putting the "home" (including plants and animals) back into the concept of the nursing homes—and changing the organizational structure and staffing patterns violates existing regulations.[4] Some regulatory theorists have argued in recent years for a more contingent or adaptive approach to regulation. This "responsive" or "smart" regulation would seek to combine the benefits of both deterrence and compliance regulation.[5] The main principle of responsive regulation is that regulatory methods and approaches should be adapted in response to the behavior of individual organizations.[6] This paradigm encourages cooperation, information-sharing, and negotiated agreement between regulators and providers while retaining the powerful incentives and sanctions of deterrence regulation.

NURSING HOME REGULATION: THE SMART MODEL

A growing number of advocates, providers, and regulatory officials have recognized the need to shift the regulatory paradigm toward a more collaborative and cooperative model.[7] Initiatives at the federal and state
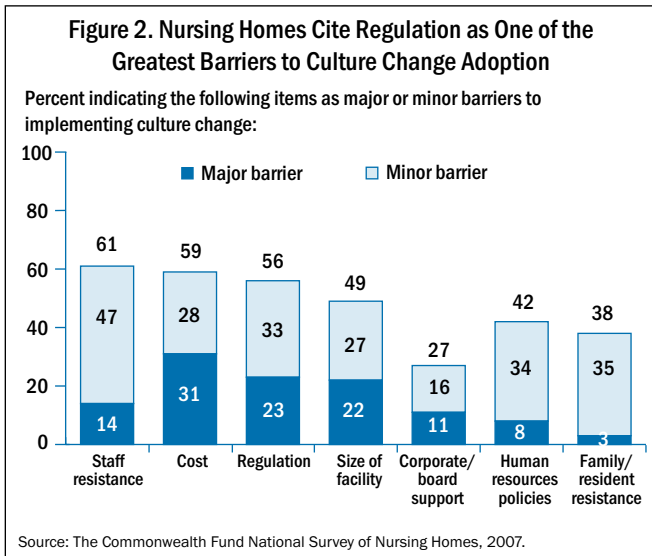
levels indicate a growing interest in developing more responsive regulation to help facilitate successful culture change efforts.

Federal Level Initiatives

At the federal level, the Centers for Medicare and Medicaid Services (CMS) has signaled its interest in moving toward more responsive regulation through a number of discrete initiatives. In 2002, the agency sponsored a satellite broadcast to all surveyors entitled "Innovations in Quality of Life—the Pioneer Network." This program taught state surveyors about common culture change innovations and how compliance with federal requirements might be maintained within nursing homes that are at various stages of transforming their culture. In addition, CMS staff

In a Kansas nursing home, a surveyor saw a resident sitting alone in the hallway. A nursing assistant came by periodically to talk to the resident, but essentially, the surveyor saw no activity and perceived a "red flag." However, the nursing assistant knew—through consistent staffing that had helped her get to know the resident well—that the resident was okay and was happy where she was and did not want to listen to the piano, the current activity.

The surveyor may have asked the nursing assistant about the resident to learn more about the situation, but nursing assistants can be intimidated by surveyors and are not usually taught how to communicate with them. As such, the nursing assistant did not fully explain the situation. The surveyor only saw an unattended resident—not a resident whose needs were being met. The problem was not the regulations, per se, but the interpretation of the regulations. This example illustrates the importance of surveyors learning how to survey for person-centered care, even though some of the benefits of person-centered care are hard to capture.

Figure 2. Nursing Homes Cite Regulation as One of the Greatest Barriers to Culture Change Adoption

Percent indicating the following items as major or minor barriers to implementing culture change:

Source: The Commonwealth Fund National Survey of Nursing Homes, 2007.

funded, coauthored, and publicly disseminated a measurement tool, called the Artifacts of Culture Change, designed to help providers measure their success in achieving concrete changes. More recently, CMS and the Pioneer Network cosponsored "Creating Home in the Nursing Home: The National Symposium on Culture Change and the Environment Requirements." The one-day conference brought together key stakeholders to review the range of environmental innovations (e.g., private rooms, higher quality and quantity of appropriate lighting, use of color for contrast, access to outdoor spaces, etc.) being implemented in nursing homes and how these changes relate to federal and state regulations and the life-safety code, a regulatory code. The following day a workshop for stakeholder organizational leaders, culture change experts, researchers, and regulators was also convened by CMS and the Pioneer Network to review findings and make recommendations concerning how the regulatory process can best support culture change efforts.

State Level Initiatives

In addition to federal regulations, each state has its own set of nursing home licensure regulations. There is significant variation in the nature and extent of these state regulations, which may affect how culture change efforts are implemented. For example, although the federal regulations do not require facilities to have nurses' stations, some state regulations require this type

of structure while others do not.[8] Given the intent of the culture change movement to make nursing homes more like homes, the nurses' station has become a strong symbol of the institutional model that mimics a hospital. The surveyors' interpretation of the regulation, therefore, has important implications for the implementation of culture change initiatives.

In interviews with stakeholders, state agency staff and providers talked about the perception that regulations were barriers to culture change.[9] Some believe that while the director and upper level managers of a particular regulatory agency may be committed to culture change efforts, the frontline supervisors and, often, middle managers have not been educated about culture change and how to interpret and enforce the regulations in light of these activities. Several interviewees in Kansas, for example, noted that a subset of nursing homes would never apply for the Promoting Excellent Alternatives in Kansas (PEAK) culture change award because of their perception that if they are identified as a culture change provider, surveyors will target them for more intensive scrutiny.[10]

States have begun to explore a more collaborative model of smart regulation in which the surveyors and providers are viewed as partners in creating culture change in nursing homes. The following two examples illustrate significant efforts to shift the paradigm:[11]

Promoting Excellent Alternatives in Kansas (PEAK), which began in 2002, is a culture change program initiated by the state. There are two components: recognition and education. The award component recognizes nursing homes that have initiated significant culture change in their organizations. The award program criteria are based on culture change measures of resident control, staff empowerment, home environment, and community involvement. Civil monetary penalty funds are used to provide cash awards of $300 to each winning facility. The Kansas Department on Aging contracts with Kansas State University to develop and deliver the education component of the PEAK program.

Kansas. The multiple responsibilities of funding and regulating services to older Kansans are located in one department—the Kansas Department on Aging (KDOA). The KDOA administers Older Americans Act funds and Medicaid reimbursement for nursing homes and other long-term care settings, and has regulatory oversight of all long-term care settings. Prior to 2003, the state survey agency was housed in the Department of Health and the Environment. In 2003, the state legislature mandated that the survey agency be moved to KDOA to create more efficiency and to support KDOA's efforts to improve nursing home care. One Kansas legislator noted that the movement of the survey agency to KDOA helped the survey team focus on outcomes rather than solely on compliance. This integration has allowed KDOA to recognize and eliminate regulatory barriers to culture change and to reward providers who have engaged in culture change efforts by giving the Secretary of Aging the ability to use nursing home payments and the regulatory process to promote culture change.

In addition, KDOA created a technical assistance program (the long-term care division) within the department that helps providers navigate the regulatory process in their attempts to implement culture change. This division is separate from the survey function and has four professional staff—two registered nurses, a licensed dietician, and an environmental specialist. According to the Secretary of Aging, the inclusion of the state survey agency within the KDOA umbrella and the creation of the long-term care division have enabled her to take a more unified approach to culture change. According to the current U.S. Assistant Secretary on Aging and Secretary of KDOA at the time of the study, Kathy Greenlee, "Regulations are not a barrier to culture change, more like a speed bump. The state does not have the power to demand providers do culture change but it can offer advice through this unit."

Oregon. The Office of Licensure and Quality Care began training surveyors about culture change and their role in the process in the early 1990s. Continuing complaints from providers about surveyors "getting in the way" of culture change catalyzed a more serious effort by the survey agency to develop a partnership model. In 2005, the agency partnered with Oregon nursing home members of the Pioneer Network to create culture change teams—one surveyor and one provider representative—that would jointly attend a culture change institute in Portland sponsored by the Pioneer Network. Following the conference, each team would work on a culture change initiative to ensure that the changes were in sync with specific regulations that might hinder successful implementation. With resources from the Civil Monetary Penalties fund, the state supported six teams in the program and awarded a $2,500 matching grant to each nursing home to engage in a specific culture change activity. In 2008, six more teams were added and the state hired a part-time consultant to provide team support.

> Civil monetary penalties are fines the Center for Medicare and Medicaid Services can impose on Medicare and Medicaid-certified nursing facilities that are found to be noncompliant with federal safety and quality-of-care standards. Some states use the fines to support a broad range of culture change activities.

The state survey office also has created a surveyor and provider forum that meets every other month to discuss regulatory issues and build relationships and trust among the stakeholders. Participants include representatives from the state agency, provider associations, nursing home and home care agency administrators and management staff, surveyor managers, and surveyors. Forum members develop an annual action plan with one concrete deliverable per year. One year, their work centered on the informal dispute resolution (IDR) that occurs when surveyors give facilities 10 days to respond to a deficiency or sanction. Forum members reviewed the process, determined it was fair and did not need to be changed. They did, however, choose to hold a series of trainings around the state to help providers learn how to prepare for an IDR.

In 2007, forum members developed an Innovative Practice Award that recognizes providers who have implemented successful culture change efforts.

MOVING TOWARD SMART REGULATION: ISSUES

There are a number of issues that must be addressed as states and the federal government move from a more traditional regulatory model to smart regulation that combines the best of deterrence and compliance through collaboration and coordination.

Striking the Balance Between Regulatory Models

Given the history of nursing home regulation, and in particular, the important role that consumer advocacy groups played in the development and ongoing implementation of OBRA 87, it is essential that policymakers strive to achieve a delicate balance between a traditional regulatory approach and a partnership model. Some surveyors and consumer advocacy groups are concerned that providers use the regulatory barrier argument as a smokescreen to relieve them of the responsibility for engaging in culture change activities in a meaningful way. Others worry that in the shift toward more responsive regulation, the federal and state governments will abrogate their responsibility to enforce OBRA 87—which is seen as the embodiment of resident-centeredness. Federal and state policymakers, therefore, must recognize that in their zeal to support culture change, they do not send a message to various stakeholders—including providers and consumers—that they have become soft on regulation. Kathy Greenlee, the Secretary of KDOA at the time, noted that Kansas has retained its reputation as a state with strict regulatory policies.[12] The technical assistance arm of the department provides assistance to high-performing organizations that are in a position to pursue culture change initiatives. This does not lessen the responsibility for ensuring that poor performers are scrutinized and penalized if they fail to comply with regulations.

Organizational Issues

One key issue is how to structure a partnership model. In Kansas, the traditional regulatory and technical assistance functions are both housed in the same agency (KDOA), albeit in separate divisions. State employees are hired specifically to perform the survey and technical assistance activities. State policy officials believe this organizational structure has sufficient firewalls to ensure that regulatory oversight and enforcement continues at the same time as technical assistance is provided to nursing homes interested in culture change. In Oregon, the culture change teams comprise both state-employed surveyors and nursing home staff. The state contracts with an independent consultant to provide technical assistance to the teams. Hiring an outside specialist may provide greater separation between the regulatory and technical assistance functions than in Kansas, where all functions are housed internally.

In recent testimony before the U.S. House of Representatives Committee on Energy and Commerce, Mary Jane Koren of The Commonwealth Fund argued that "the Quality Improvement Organization (QIO) be designated as the appropriate locus for technical assistance to providers rather than the survey agency."[13] She cited the Rhode Island Department of Health's Individualized Care Pilot—supported by a grant from The Commonwealth Fund—as a collaborative model in which the state's QIO provides technical assistance to nursing homes that have been identified by surveyors as having quality-of-life problems. Dr. Koren noted that this model warrants further examination since it "removes the surveyors from the role of consultant yet offers assistance to providers anxious to address problems."[14]

There are some concerns about relying on the QIOs to provide technical assistance on culture change implementation to providers. First, although a number of QIOs are beginning to recognize the importance of culture change in helping to support and enhance quality improvement in nursing homes, most have focused primarily on clinical quality problems. Similar to most surveyors, QIOs face a steep learning curve in assisting

nursing homes in culture change activities. Perhaps more problematic, however, is the fact that CMS contracts with QIOs to do this technical assistance. Up until a few years ago, only a minority of these organizations worked on nursing home issues. The focus of the QIO contracts is highly dependent on the interests of the particular CMS administrator and political environment, in contrast to the ongoing role that survey agencies play at the state level. It may be risky, therefore, to assign the responsibility for culture change technical assistance to QIOs. It is clear that additional exploration and more rigorous research is needed to help federal and state regulatory officials decide how best to structure these types of partnerships.

Training Issues

In moving toward a partnership model, stakeholders from the public and private sectors need to have a better understanding of the training that will be required to prepare surveyors and other regulatory staff and providers to jointly support culture change. In conducting case studies of culture change at the state level, Bryant and colleagues found that having surveyors and nursing home staff attend conferences, workshops, or Webinars on culture change was not sufficient to expose them to the various viewpoints and challenges and to help them learn strategies to working together more effectively.[15] The Oregon model, in which surveyors and nursing home staff are paired and receive more intensive team training, may be a promising approach. The curriculum should focus on culture change principles, how they are implemented in real-world settings, the identification of real or perceived regulatory barriers, and overcoming such obstacles. Regulatory and nursing home staff also must learn about each other's culture and how trust can be established to encourage partnerships. Finally, the training must occur in real-world settings where regulators and nursing home staff, residents, and families can problem-solve and achieve and sustain culture change. To the extent that QIOs are involved in the partnership, they also must be trained in a similar manner.

Stakeholder Responsibilities

The success of the partnership approach will depend, in a large part, on the extent to which the stakeholders buy into the process and assume responsibility for successful implementation. The regulatory agency staff at all levels—particularly midlevel managers and frontline surveyors—must be committed to this new paradigm and integrate their training in both culture change and new ways of communicating with providers into daily practice. The same holds true for all levels of nursing home staff—they must shift their mistrust of the survey process to a collaborative approach in which they share failures as well as successes. In many cases, organizations that have established rigid policies and procedures will need to move toward a more organic process that focuses on embedding culture change principles into policies and practice. Federal and state policymakers, as well as nursing home corporations and individual facilities, will need to establish incentives to hold the regulators and providers accountable and to reward successful partnerships.

Given the pivotal role that consumer advocates played in the creation of OBRA 87 and their ongoing efforts to ensure consistent oversight and enforcement, this group's buy-in of smarter regulation is essential. While some members of the advocacy community have recognized the importance of greater collaboration between regulators and providers in facilitating culture change, others have been resistant to shifting from the traditional regulatory paradigm. Continued evidence of poor quality among a subset of facilities and the failure of most nursing homes to engage in culture change undoubtedly creates skepticism among many consumer advocates. At the same time, a partnership model between regulators and providers will not work if consumer groups are not supportive and positively engaged.

It is also essential that the most important stakeholders—nursing home residents and their families—assume responsibility for the success of this approach. Resident and family councils must weigh in on how partnerships should be structured and implemented. Consumers and their relatives need to receive culture

change training together with surveyors and nursing home staff. To maximize the success of this collaboration, they must also be part of the facility-level teams that identify regulatory barriers, work to minimize these hurdles, and ensure the achievement of cultural transformation.

NOTES

1   C. S. Bowman, *The Environmental Side of the Culture Change Movement: Identifying Barriers and Potential Solutions to Furthering Innovation in Nursing Homes*, background paper to the symposium, "Creating Home in the Nursing Home: A National Symposium on Culture Change and the Environment Requirements" (Washington, D.C.: Centers for Medicare & Medicaid Services, Apr. 2008), available at: http://www.pioneernetwork.net/Data/Documents/Creating-Home-Bkgrnd-Paper.pdf.

2   R. A. Kagan and L. Axelrad, *Regulatory Encounters: Multinational Corporations and American Adversarial Legalism* (Berkeley, Calif.: University of California Press, 2000); and K. Walshe, "Regulating U.S. Nursing Homes: Are We Learning from Experience?" *Health Affairs,* Nov./Dec. 2001 20(6):128–44.

3   M. B. Kapp, "Quality of Care and Quality of Life in Nursing Facilities: What's Regulation Got to Do with It?" *McGeorge Law Review*, 2000 31(3):707–31; Walshe, "Regulating U.S. Nursing Homes," 2001; and J. M. Wiener, "An Assessment of Strategies for Improving Quality of Care in Nursing Homes," *The Gerontologist,* Apr. 2003 43(Spec. no. 2):19–27.

4   Bowman, *Environmental Side of Culture Change,* 2008.

5   I. Ayres and J. Braithwaite, *Responsive Regulation: Transcending the Deregulation Debate* (New York: Oxford University Press, 1992).

6   Walshe, "Regulating U.S. Nursing Homes," 2001.

7   Bowman, *Environmental Side of Culture Change,* 2008; M. J. Koren, *Moving to a Higher Level: How Collaboration and Cooperation Can Improve Nursing Home Quality,* testimony before the U.S. House of Representatives Committee on Energy and Commerce, Subcommittee in Oversight and Investigations, May 15, 2008.

8   Bowman, *Environmental Side of Culture Change,* 2008.

9   N. Bryant, L. Barbarotta, and R. Stone, *Assessing State Investments in Culture Change,* unpublished final report to The Commonwealth Fund, (Washington, D.C.: Institute for the Future of Aging Services, 2008).

10 Ibid.

11 Ibid.

12 Ibid.

13 Koren, *Moving to a Higher Level*, 2008.

14 Ibid.

15 Bryant, Barbarotta, and Stone, *Assessing State Investments,* 2008.

About the Authors

Robyn I. Stone, Dr.P.H., executive director of the Institute for the Future of Aging Services (IFAS) and senior vice president for research at the American Association of Homes and Services for the Aging (AAHSA) in Washington, D.C., is an internationally recognized expert in the field of long-term care policy and aging services workforce development with over 30 years of experience in applied research, policy analysis, and policy development. After serving as Deputy Assistant Secretary for Disability, Aging, and Long-Term Care Policy and Assistant Secretary on Aging at the U.S. Department of Health and Human Services in the 1990s, she created IFAS at AAHSA to bridge the worlds of research, policy, and practice. Over the past 10 years, she has led several national initiatives, including the Better Jobs Better Care program. Dr. Stone is a distinguished speaker and has been published widely in the areas of the financing and delivery of long-term care, family caregiving, long-term care workforce development, affordable senior housing, managed care for the chronically ill elderly, nursing home quality improvement, and consumer direction in home and community-based care. She serves on numerous provider and nonprofit boards that focus on aging issues. She has a doctorate in public health from the University of California, Berkeley.

Natasha Bryant, M.A., is senior research associate at the Institute for the Future of Aging Services at the American Association of Homes and Services for the Aging. She manages and conducts research projects on workforce and quality improvement. Ms. Bryant was the managing director of the Better Jobs Better Care program, a four-year, $15.5 million initiative to improve the recruitment and retention of direct care workers. Ms. Bryant has a master's degree in experimental psychology from DePaul University.

Linda Barbarotta is the senior communications associate at the Institute for the Future of Aging Services at the American Association of Homes and Services for the Aging. She is responsible for managing and implementing communication and marketing strategies for relevant projects. Ms. Barbarotta previously contributed to the communication efforts of Advancing Excellence for America's Nursing Homes, a coalition-based campaign made up of 32 organizations committed to improving the quality of life for residents and staff. She is the author of several training manuals, publications, and articles for print and the Web on Medicare and long-term care.

Acknowledgments

APPENDIX G

DECLARATION OF INTERDEPENDENCE

DECLARATION OF
Interdependence

The Spirit of '06

W E BEGAN YEARS AGO AS A MOVEMENT TO AFFIRM THE FUNDAMENTAL RIGHTS OF THOSE LIVING AND WORKING IN LONG-TERM CARE SETTINGS. WE LEARNED THAT WHERE INDIVIDUALS ARE EMPOWERED AND HONORING OF RELATIONSHIPS, THE PROCESS OF *creating home and community* REKINDLES THE HUMAN SPIRIT AND MENDS OUR FRAYED SOCIAL FABRIC.

Our collective journey of transformational change is inspired by a spirit of openness.

- It is an openness *to see* those who live and work with us with an honest reckoning of the present, and a progressive vision of the future.

- It is an openness *to hear* the voices of those who have been too often silenced in the decision-making process, and *to listen* to their self-directed preferences.

- It is an openness *to speak* from the heart and *to act* through a respectful awareness of community life and teamwork.

Openness to change and new possibility sustains us through inevitable periods of conflict and disruption. It helps us overcome the real world hurdles on our path toward de-institutionalized services and individualized care. It creates the energy for us to realize our leadership potential in our organizations and in our broader communities.

Today we invoke a spirit of openness to usher in a new era of aging in community. We declare our *interdependence*, and we invite each other into a dialogue about how to make interdependence our true way of being and living in community.

INTERDEPENDENCE: Reliance on one another for mutual support or sustenance

Each of us has our own unique passions, capacities and strengths. We recognize these gifts as self-evident. And yet interdependence is not self-evident — it requires acts of intention.

As human beings, we live by and through cooperation with others — it is our destiny. In spite of the emphasis placed on being independent, in reality we are all interdependent. The nature of our cooperation with and relationship to others changes as we grow, mature, and age. These relationships form the basis of all true communities. Therefore, we seek to understand and possess the skills necessary to be interdependent in healthy, productive ways.

In declaring our interdependence, we recognize that when we are united, we have endless possibilities; when we are partners, we build community; when we are proactive together, we reduce our fear of change, and when we cultivate the common ground, we grow individually and collectively.

Pioneer
Network

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