The Food and Dining Side
of the Culture Change Movement:
Identifying Barriers and Potential Solutions
to furthering Innovation in Nursing Homes

Pre-symposium Background Paper
to the February 11th, 2010
Creating Home in the Nursing Home II:
A National Symposium
on Culture Change
and the Food and Dining Requirements

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This pre-symposium background paper is intended to provide the history of the culture change movement as it pertains to food and dining, including current research regarding food and dining issues and innovations, and a review of relevant federal long term care regulations, the Food and Drug Administration Food Code and the Center for Disease Control and Prevention infection control guidelines affecting nursing homes' food service. It is part of contract number HHSM-500-2009-00057P between the Centers for Medicare & Medicaid Services and Edu-Catering, LLP and authored by Carmen Bowman. The content of this paper does not necessarily reflect the views or policies of the Centers for Medicare and Medicaid Services. For more information, contact Carmen Bowman at 303-981-7228 or carmen@edu-catering.com.

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Introduction

It has been said that living in the typical, traditional, institutional nursing home consists of three Rs – rules, routines and requirements. (Robinson and Gallagher, 2008) Could this be why so many dread the nursing home? Most realize it represents loss of so much if not everything: loss of home, loss of control, loss of choice, someone else's schedule, eventually loss of self.

In the year 2011 the first Baby Boomers turn 65. Baby Boomers comprise men and women who worked outside the home and depended more upon convenience foods. Who also traveled the country and the world, ate out more, are accustomed to a variety of foods and have acquired a broader taste for all kinds of food. This future long term care "…customer, savvy and well educated, will re-formulate long term care by demanding fine dining, and concierge services, and healthy fast foods from a food court with 'brand' named franchises open 24 hours per day" (Robinson and Gallagher, 2008).

Now imagine this new nursing home. No one wakes you up. You sleep until you naturally rouse. You decide if you want a cup of coffee, tea or your drink of choice (a caffeinated soda for many Baby Boomers) now or later. Maybe you have a coffee pot in your room. If you live in a neighborhood or household, coffee is brewing in the kitchenette or kitchen. You drink out of your own ceramic coffee cup. There is a coffee cart available or better yet, there is a coffee bar anyone can enjoy open early and open late. When you're ready, someone asks you what you're hungry for. Whether you eat breakfast early, late or not at all, but are hungry for lunch a little earlier than most, open dining times make it possible to eat when you are ready. You can order room service if you don't feel like getting up or wander down to the continental breakfast to see what's available today. Not only are you asked what you want every meal you are also involved in deciding the menus even making up the grocery list. You are welcome to cook what you're famous for. Or you contribute by setting the table and washing dishes, no one's offer is turned away. Some of the food comes from the garden in the backyard presenting the opportunity to eat fresh healthy foods you yourself may have tended to and harvested.

All these possibilities are becoming reality because of a growing movement called the culture change movement. In 1996 the National Citizens Coalition for Nursing Home Reform brought together pioneers from around the country who were transforming nursing home care independent of one another. This resulted in the formation of the Pioneer Network in 1997, a not-for-profit organization leading the movement nationally The Pioneer Network built its core values on the study of four pioneering models of care: Individualized Care at Providence Mount St. Vincent in Spokane, Washington under the leadership of Charlene Boyd; Bathing without a Battle under the leadership of Joanne Rader; the Regenerative Community led by Debby and Barry Barkan; and the Eden Alternative® led by Jude and Dr. Bill Thomas.

As of April 2009 there were 16,100 nursing homes in the United States (cdc.gov/nchs/fastats/nursingh.htm)The culture change movement is now 13 years old and the following statistics show its growth, slow progress but progress nonetheless.

According to Pioneer Network researcher Amy Elliot, there are 400+ nursing homes "in a sustained, long term culture change environment" (2009). According to the Pioneer Network website, there are over 30 State culture change coalitions with several in the process of organizing (pioneernetwork.net). According to the Eden Alternative® website, there are 199 Eden registered homes, homes that are committed to the 10 Eden Principles with the goal of building human habitats where staff and residents alike are assisted to grow and thrive (edenalt.com accessed 12/31/09). According to the Special Household Model Edition of the Action Pact magazine *Culture Change Now*, there were "almost 500" households in August of 2008. Households are home living environments in nursing homes with a full kitchen, living room, dining room with usually all private rooms led by self-directed work teams and a Town Center where residents gather for large events, often a coffee shop and sometimes a general store. According to the Green House Project® website, there are 50 Green House® homes on 17 campuses in 12 States (rwjf.org, accessed 12/31/09)Green Houses® are stand-alone houses where 10-12 elders live and are cared for by Shabazim who are specially cross-trained, self-directed staff teams, where nurses and other clinicians circulate among several co-located houses to provide needed care, where residents enjoy private rooms, a large dining room table where they can dine together and a hearth, often with a cozy fireplace

Many homes focused on providing individualized and personalized dining services are trading in the traditional tray line meal service for a variety of dining styles such as buffet, restaurant, family-style and others with increased choice and direct resident access to refrigerators and the kitchen throughout the day. These alternative dining arrangements, although common in society at large are new to the nursing home setting, have sometimes led to either real or imagined difficulties with surveyor interpretation of the federal requirements as applied to these innovations. New ideas bring about new questions. Must facility-developed menus be followed even if the person prefers something different? Must a facility serve a prescribed diet even if it means the person might not eat it, risking weight loss? A rising tension is that requirements are for facilities, nursing homes receiving Medicaid and Medicare reimbursement, not individuals who always have and always will have the right to live their life as they wish. These are but a few representative "awakenings" resulting from the new territory being cut by pioneering nursing homes all around the country.

In April of 2008, CMS and the Pioneer Network co-sponsored *Creating Home in the Nursing Home: A National Symposium on Culture Change and the Environment Requirements.* Almost 700 people attended, experts gave presentations and their own recommendations and anyone was invited to give public comment. It was followed by an invitational workshop of culture change experts and stakeholders who in workgroups studied and developed recommendations further. All recommendations were collected regarding the nursing home environment and many were acted upon (see Chapter Four for more details). All speakers' papers and presentations, the transcript from the entire symposium and the background paper written for it by this author are available at pioneernetwork.net.

Due to the many questions arising around food and dining, CMS and the Pioneer Network decided to again collaborate and co-sponsor a second symposium inviting another national

dialog to discuss them. The purpose of this paper is to set the stage for the upcoming Feb. 11, 2010 CMS/Pioneer Network ***Creating Home in the Nursing Home II: A National Symposium on Culture Change and the Food and Dining Requirements.***

Welcome to the table. Bon appétit.

Note to readers:
Because this paper predominantly discusses regulation, all italics used are always CMS regulation or interpretive guidance (unless a title of a book). Any emphasis of my own is made with an underline instead of italics in order to clearly identify direct regulatory language from anything else.

Lighting, use of color, plate and table color contrasting, music and more all affect the dining environment. However, because the physical environment was the focus of the 2008 symposium, many issues of the physical setting for the dining environment came to light then, and will not be covered in this paper or this 2010 symposium. Instead, the symposium planning team has set an agenda that focuses on some of the many clinical and quality of life issues regarding food and dining.

When referring to residents, all residents are meant, including those with dementia. The content of this paper is general to all residents and in particular each person's right to make their own choices and to receive superb individualized care. Persons with dementia are not singled out nor are they forgotten. Persons with dementia "tell" us everyday their preferences, sometimes with words, sometimes not. We must only observe and as Naomi Feil, the founder of Validation Therapy, says "exquisitely listen" (2003).

Chapter One
The Importance of Food and the Dining Experience in Creating Home

Food and the experience of dining happen every day, and are so important and unique to each of us. In fact, very often food and dining are spoken of, not separately, but together:

> "We should look for someone to eat and drink with before looking for something to eat and drink...." Epicurus
>
> "Good food ends with good talk." Geoffrey Neighor
>
> "One cannot think well, love well, sleep well, if one has not dined well."
> Virginia Woolf
>
> "Food is the most primitive form of comfort." Sheila Graham
>
> "When I walk into my kitchen today; I am not alone. Whether we know it or not, none of us is. We bring fathers and mothers and kitchen tables, and every meal we have ever eaten. Food is never just food. It's also a way of getting at something else; who we are, who we have been, and who we want to be."
> Molly Wizenburg from *A Home Made Life*
>
> "Food is the heart of the home and most often one of our life's daily pleasures."
> LaVrene Norton, from *Nourish the Body and Soul*

Food. Dining. Eating. "What's for dinner?" "Let's eat." "Let's go out for dinner." Favorite foods. Comfort foods. Potlucks. Cookie exchange. Out for coffee. Over for tea. "Come on over for a beer." Grilled. Sauted. Steamed. Carmelized. Cookies baking. Soup simmering. Tea steeping. Coffee brewing. Bread baking. Dishes clinking. Setting the table. Washing the dishes. Fresh fruit. Just picked veggies. Shucking corn. Snapping peas. Appetizers. Soup and salad. Chips and dip. Bread sticks and dipping oils. The main entree. Dessert. "I'm full." "That was sooo good."

This is the experience of food and dining. This is the experience of most people in the world, but is it the experience of those living in nursing homes. Unfortunately, "Institutions seem to have forgotten that 'food' and 'service' are at the heart of food service" (Frampton, 2003). Thankfully, many nursing homes have left behind the common institutional ways of providing food and dining which include so little of the rich experience eating and dining can be. We thank them and we are leaning on them to guide us here in this paper, in the upcoming Creating Home II Symposium, and into the future.

So what <u>should</u> food and dining look like even in a nursing home?

> "Like Mom's chicken noodle soup, the focus on food seems to hold an answer for just about every ailment of institutionalized living." Keith Schaeffer, *Nourish the Body and Soul*

"Comfort foods' – those familiar foods that evoke a caring, pleasant feeling <u>even before</u> (emphasis added) they are tasted." Frampton, Gilpin and Charmel, *Putting Patients First*

"Providing nourishment is more than just providing the right number of calories; it is taking care that the appearance, presentation, aromas, flavors, delivery and setting are optimal as well." Ibid

"We know that uneaten food provides no nourishment." *Ibid*

"The feeding of persons in health is of great importance, but when (one) succumbs to disease, then feeding becomes a question of extreme moment."
Fannie Farmer, *Food and Cookery for the Sick and Convalescent*.

"Food for the sick should be carefully prepared and attractively served at regular intervals. The person who is ill is frequently more difficult to please than when he is well. Individual tastes of the patient must be considered, as well as the suitability of foods to be served." Gorrell, McKay and Zuill, *Food and Family Living*

"Let food be your medicine." Hippocrates

"There may be four different causes, any one of which will produce the same result, viz., the patient slowly starving to death, from want of nutrition:

1. Defect in cooking;
2. Defect in choice of diet;
3. Defect in choice of hours for taking diet;
4. Defect of appetite in patient."

"Yet all these are generally comprehended in the one sweeping assertion that the patient has 'no appetite.'" Florence Nightingale

"Institutionalization itself produces feelings of loss of control and isolation which can lead to refusal to eat. Morley and Silver, "Nutritional issues in nursing home care." *Annals of Internal Medicine*

"Our goals are always two: increase our residents' intake and increase quality of life through celebrations around food." Linda Bump in *Nourish the Body and Soul*

<u>Food is the Heart of Home</u>

Linda Bump, a leader in the culture change movement, dietitian and licensed nursing home administrator has written one of the only books on changing the culture change dining called *Life Happens in the Kitchen…How to make the kitchen the heart of your home*. She says,

> Food is the heart of our home…and most often one of our life's daily pleasures. When we enhance the dining experience of our elders, we nourish their souls, as well as their bodies. As caregivers committed to maximizing the quality of life and quality of care (emphasis added) for the elders residing in our long term care facilities, we are called to best serve our elders' nutritional needs while best serving their psychological and psychosocial needs. When we honor our elders' preferences in dining, we honor their past and best serve their future (Bump, 2004-2005).

Bump says so much here. Home and daily pleasure, nutritional and psychological and psychosocial needs, quality of life and quality of care. All of that is precisely our focus for this paper as well as Creating Home II. Moving away from institution and toward home. Using food to nourish both body and soul. Using food to honor past and serve future. Food is one of the main mediums to reflect and build upon our past, and as psychologist Dr. Judah Ronch teaches: when our choices and preferences are not honored we have no "future self" (2009). Nothing to look forward to, nothing to decide, nothing to affect in our lives. And lastly the time has come to stop viewing quality of life and quality of care as separate. Perhaps we need to stop talking about them separately and come up with a new word for both together.

CMS, Karen Schoeneman in particular, has said over and over "Quality of life regulations go hand in hand with the quality of care regulations" (2007 yes is this a broadcast?). The famous Institute of Medicine study and precursor to OBRA '87 said the same thing in different words in 1986:

> 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…..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.

In 2006 and 2007 CMS aired a four part satellite broadcast series "From Institutional to Individualized Care." In Part I Barbara Frank , a regulatory reformer who was involved with studying the IOM findings and the writing of the Nursing Home Reform Act (OBRA '87), explains how well-being or individualized care may be what we are looking for:

> Here is it important to remember that OBRA doesn't pit Quality of Life against Quality of Care. It actually encompasses both Quality of Care and Quality of Life. The phrase physical, mental and psychosocial well-being combines Quality of Care and Quality of Life [emphasis added].
>
> When the Institute of Medicine Committee was conducting its study that provided the basis for OBRA '87, committee members attended a meeting in Florida convened by the National Citizens' Coalition for Nursing Home Reform. It was a gathering of researchers, practitioners, regulators, advocates, and residents called the National Symposium on Quality Care: The Residents' Point of View. The group was there to hear about and discuss what is quality care for residents.

When one committee member, a physician, said in her breakout group that the group needed to separate quality of life and quality of care, because it wasn't right to confuse the two, a resident named Janet Tulloch responded. She said, 'Excuse me doctor, but I am one person. If I don't get good care, I won't have a good quality of life, and if I don't have a good quality of life, your medical care won't help me.'

This shifted the conversation in the room as people began to acknowledge that quality of care is better when it is provided in the context of quality of life. You might perform clinically perfect treatments, but if you do them in the middle of the night so that people can't get good sleep, they won't work. Quality of care and quality of life have to go hand-in-hand to get the best possible, practicable quality of care. So the Institute of Medicine found, and so OBRA ['87] says, this is the public standard of care and it confirms the best in clinical practice.

The final words in OBRA are also transformative. OBRA requires that care be provided for the well-being of 'each resident.' This is where 'individualized care' comes in. It is consistent with basic medical and nursing practice -- that for care to be effective, it must be individualized (2006).

Pioneer and culture change leader Linda Bump encourages "**excellence in individualization"** and says in order to do that we must provide:

Choice – the choice of what to eat, when to eat, where to eat, who to eat with, and how leisurely to eat. <u>True</u> choice, not token choice. Choice of beverages, breads, desserts. Choice of service style, whether waited, self-selected, buffet or family style.

Accessibility – foods of choice available when hungry, or when just longing for a specific food. Food available 24/7, and someone available 24/7 to help prepare it. Refrigerator rights, perhaps even a refrigerator in their own room, and perhaps a microwave too!

Individualization – the elder's favorite foods, comfort foods, ethnic foods, foods prepared from their own favorite recipes, foods they choose to eat in their own home, foods that make them look forward to the day, foods that warm their heart and soul, as well as nourish their bodies.

Liberalized diets – The elder's right to follow a restrictive diet if they choose, and to not follow it if they choose. Clinical research repeatedly indicates that restricted diets do not lead to clinical improvement in the elderly, and may in fact lead to the harming effects of malnutrition and dehydration due to limited consumption. Some committed facilities have eliminated therapeutic diets altogether, offering only the traditional consistency modifications, choice in serving size, and choice of foods to avoid.

Food First – An expectation of OBRA since 1987, choosing food before supplements, and food before medication is a natural decision in culture change. With choice, accessibility and individualization, our residents eat foods of choice throughout the day, and even during the night if need be, eliminating the need for costly, and often refused, commercial supplements. Similarly, the need for laxatives is reduced and often eliminated with increased fluid intake and increased opportunities for fiber rich, bowel stimulating foods of choice. Even the need for medication for behavioral management can be reduced when foods of choice are available at times of choice and places of choice.

Quality Service – Relationships are the key to quality care giving; and relationships are the key to quality service in dining. Knowing the elder, their choices, their preferences, and their daily pleasures in dining results in service that encourages optimal intake. Relationship-based service is caregiving from the heart. Knowing what an elder ate, knowing what they need to eat, knowing what to tempt them with, all can make the difference between joy in dining and failure to thrive.

Responsiveness - Relationship-based service, refrigerator rights, 24/7 accessibility…the common theme is responsiveness, and just the right amount of attention – not hovering, just quiet attention to every need (2004-2005).

"Quiet attention to every need," now there is good food and dining service. Isn't that what gets servers good tips and prompts diners to give them? Isn't that what care for another is? CMS Region IX, agrees:

> Key is respect for resident-centered values, preferences and expressed needs, including an awareness of quality-life issues, involvement in dining related decision-making, dining with dignity and <u>attention to individual resident's needs and autonomy in food choices</u> (California Dining Project, 2008).

Quiet attention. Responsiveness. Quality of care and quality of life together. Individualized care. "Excellence in individualization." Good food. A warm and inviting dining experience. All contribute to a person's well-being.

Chapter Two
Progression of the Food and Dining Side of the Culture Change Movement

The Traditional Nursing Home Food and Dining Experience

Traditionally what most long-term care residents have experienced is a large main dining room where every resident must eat three meals a day at three meal times arbitrarily set by someone else, served what someone else decided. Homes have been required to offer an alternate, but leaders in the field have honestly identified that in many cases this has only provided "token choice." "Excuse me, excuse me, could someone please get me… oh never mind." Many residents need more assistance than has traditionally been made available to them and unfortunately have learned to not bother to ask for anything more or different. Unlike in our homes, food is often served in nursing homes with many small condiment packages too hard for arthritic hands to open. In some cases, food sits in front of people uneaten, assistance is lacking and by the end of the meal when the food is cold and still uneaten, it is treated as if, "Oh well, I guess you weren't hungry." This is by no means the case in every nursing home in America nor has it been. Staff of nursing homes that have always worked to offer better than this sometimes become offended when such a negative picture is portrayed. But unfortunately, this scenario has existed and still exists in some nursing homes. Thankfully it is becoming unacceptable and a part of the past. Leaders in this movement have modeled that by owning up to our shortcomings, and finding solutions to our problems, we move forward. That is the goal of this paper, the Creating Home II symposium and the culture change movement in general.

Moving from Traditional to Transformational

According to the *Stage Model of Culture Change in Nursing Facilities* developed by Leslie Grant and LaVrene Norton (2002) we are all quite familiar with what was just described as Stage I - Traditional. Stage II – Transformational is when there is a beginning awareness of the need for change and resident-centered care, consistent staff, engaging direct care givers and residents in decisions and increasing choices at meal times. In the Action Pact *Nourish the Body and Soul* DVD, Linda Bump advises us to "Think about the opportunities to have the coffee pot on all day, smell fresh cookies baking and enjoy a warm treat in the evenings. Even if we can't cook the hot food there, we can start simple hosting, offering choice of beverage, choice of white or wheat bread, a simple salad bar cart with just a few choices or a dessert cart" (2008). It can all start with toast:

> Transformational design can be as simple as - we brought our toasters to the table. We actually physically set the toasters in the middle of the dining room. When the core team met, they said, "We always cook it in the kitchen, stack it up, bring it out and by the time it gets to the dining room its cold and hard. And that's just the way we've always done it. Now a resident asks for a piece of toast, we put the bread in, butter it and we give it to them right there. Now, it was just an experiment and the whole building was talking about it for days afterwards, over toast. It was probably

> the very best thing we did, to start with that because everybody got excited about all the other things we could do." (*Nourish the Body and Soul* DVD, 2008)

Thus, it is within the transformational model where steam tables, open dining times, buffet style, waited table service and family style start to become possible.

Early Pioneers do Dining Differently

Sister Pauline Brecanier is considered a pioneer in the culture change movement leading transformation at Teresian House in Albany, New York as administrator since 1970. Sister Pauline's pioneering spirit began before then however. She tells of when she was at St. Joseph's nursing home in Connecticut in the 1960's and sent two men to Culinary Arts school, two brothers, who came back to serve residents as chefs. She explains that in order to provide good cooked food for the residents, Mother Bernadette, Teresian's administrator from 1964 to 1970, always had a chef and "never apologized for the cost of food as food was the most important part of a resident's day." She advises you're "going pay a little bit more [for a chef] but you're going to get better quality. Pre-prepared foods, anyone can put those together." In her matter of fact way, she says, "we've always had a chef" (2009).

After visiting Teresian House in 2001, I can attest to the fine work of the chefs on staff who treated me along with other outside guests to a lovely fine dining experience fully with wine, no different than how residents are treated. At Teresian House there is a cocktail lounge that serves drinks and food with hours of operation and a menu. What is most striking about it as Sister Pauline explained is it gives residents the opportunity to "treat their guests," something most nursing home residents no longer have.

Planetree is a patient-centered model of care begun in hospitals by Angelica Thieriot after a hospital experience that was worse than a life-threatening disease, she says. Already back in 1974 Planetree acknowledged "'the skeleton in the hospital closet' namely, mismanagement of patients' nutritional health, leaving the hospital more malnourished than when they entered." Since then, Planetree affiliates have focused on providing comfort foods, creating kitchens in patient care areas for families to prepare their relative's favorite foods and never turning down a request for food any time day or night (Frampton et al, 2003). The first nursing home to adopt the Planetree model was Wesley Village in Shelton, Connecticut under the leadership of Heidi Gil, now director of Planetree's expansion into nursing homes, or what Planetree calls continuing care communities. Not surprisingly, one of the Planetree Continuing Care Components is *Recognizing the Nutritional and Nurturing Aspects of Food* (Frampton and Charmel, 2009).

Restaurant Style Dining

As reported in the book *Person Centered Care: A Model for Nursing Homes*, Eric Haider as administrator of a nursing home in Kansas in1989 implemented a restaurant style dining service with waiters taking orders from a menu and longer/open dining times. He realized looking at a restaurant one day that a nursing home has everything a restaurant has – food, a kitchen and a dining room. In 1992 at Crestview nursing home in Missouri he added

buffet style dining, and by 1995 food was available upon request 24 hours a day (2003). Having had the pleasure of visiting Crestview in 2001 I witnessed something I had never witnessed before. At 11:45 a.m. a resident stood in the doorway of her room and said to Eric she just woke up and was ready for breakfast. I hate to admit I thought to myself, "She must be confused and surely she already had breakfast." A little while later we walked into the dining room and I heard Eric tell the staff standing behind the buffet line, "Edith is awake now and ready for breakfast." It was real. That was a turning point for me. Later, the director of nursing, Margie Haider told us ". . . and Edith has no behaviors anymore because of it."

Although nursing homes have food, kitchens, and dining rooms just like a restaurant, restaurants are able to offer a large menu offering instead of only one or two choices typical of traditional nursing homes. Restaurants are able to serve each customer what that person wants from their menu at the time the customer arrives. This has functioned "backwards" in the nursing home where traditionally the "customers" are made to be ready when the food is ready.

Buffet Style Dining

Although it began as a research study by Robin Remsburg and others, due to its success, buffet-style meal service was adopted by Johns Hopkins Geriatric Center in Baltimore for all meals (2001). Dr. Remsburg reports that buffet style dining advantages include the opportunity to bring tantalizing smells into the dining room to increase resident's appetites, and staff doesn't get "overtaxed" when there are typically just two main items and several side dishes (Roloff, 2006). And who doesn't like getting to pick exactly what they want?

Neighborhood Dining

From the Norton/Grant Stage Model, Stage III is the Neighborhood. Here is where self-led interdepartmental teams start to make greater changes to dining practices. Dining becomes decentralized, residents eat in smaller dining rooms on their neighborhoods and are supported to sleep until they wake and eat when they want. Med pass, housekeeping and activity schedules all change, therefore it must be done as Bump says, "in team." The need for kitchenettes and even full kitchens with shared decentralized production kitchens placed often between two neighborhoods begins to be realized (Bump, 2008).

In 1991 Teresian House remodeled into smaller neighborhoods of 40 residents from 60 (Ronch and Weiner, 2003). Each neighborhood has its own country kitchen and pantry. Meals are made in the main kitchen and brought to the steam tables in the neighborhood, bringing the point of service closer to the residents. A new staff position of neighborhood coordinator was developed to administer these small settings within the larger nursing home. Neighborhood coordinators were chosen for their leadership skills, and applicants were not restricted to nurses. When I was there in 2001 it was the first time I saw a social worker flipping eggs for a resident a little after 8:00 a.m. Not many residents were in the dining room either as most were still sleeping.

Interestingly enough, Providence Mount St. Vincent began its journey of neighborhoods with food served from steam tables in each neighborhood's kitchen also in 1991 after hiring Charlene Boyd as administrator in 1990. Charlene brought experience from the Mary Conrad Center in Anchorage, Alaska where a "neighborhood concept" gave residents access to a kitchen and snacks at all times where she had been administrator from 1986-1990 (Ronch and Weiner, 2003).

Family Style Dining

Another familiar dining style being implemented is family style which affords one the opportunity to serve themselves what they want and as much as they want just like at the table at home. "From bowls and baskets on their table, residents are able to serve themselves as much as they want of the foods they enjoy and none of the foods they dislike" (Roloff, 2006). Apple Health Care, a small for-profit nursing home chain implemented family style dining in 1997 beginning at Watrous Nursing Center in Madison, Connecticut under the leadership of dietitian Karen Morton. Sue Misiorski, former Apple nurse consultant shares that "family style dining was very successful. Food temperatures were great because the food came straight from the kitchen to the table and was served immediately. Plate waste decreased dramatically because residents took what they want. They also took lots of smaller first portions and then second helpings of things they particularly liked" (2009).

Choice Menus, Full Service Restaurant and Room Service

The Providence Benedictine Nursing Center in Marion County, Oregon underwent major dining transformations the fall of 2009 stemming from low satisfaction scores, an overly clinical atmosphere and an outdated dining environment. Choice Menus are offered within the long-term care units with staff assisting residents in choosing what they want to order for the following day. Room Service with 19 meal options and 12 sides is offered on the skilled unit where there are phones in each room. A grant and donations helped to acquire the computerized menu system which tracks preferences and allergies for each resident. Whereas most residents used to eat on their units making the main dining room underutilized, the full service updated restaurant is now filled to capacity, residents encourage and help each other get to the restaurant and many are "dressing for dinner." Through all three options residents are now "self-directing their lives" (Havens, 2009).

Household Dining

From the Stage Model, Stage IV is the Household Model and also includes the Green Houses®, small houses and the Scandinavian Service Houses. Home has been established again, living in houses with self-contained fully functioning kitchens, cross-trained staff reporting into the house and not to departments. Elders run their lives, get up when they want, eat what and when they want, choose snacks, have friends over for dinner or coffee and plan their lives (*Nourish the Body and Soul,* 2008). In some households there is a new staff role, homemaker, responsible for cooking meals and other homemaking duties. Many

households designate a food budget for the household for true resident choice. On a weekly basis, residents make their grocery list. They decide what kind of ice cream they would like or cereal, Captain Crunch anyone?

LaVrene Norton, Executive Leader of Action Pact often speaks of residents' "refrigerator rights." When one lives where there is a kitchen, they have the same "refrigerator rights" as any one of us has in our own home. That right to open up the fridge and ponder, "Hmm, what do I want to eat…." We might as well take it one step further and call them "kitchen rights." This is something the Household Model affords. It also affords limitless opportunities for hosting. Residents have hosted others in their homes all their lives, the household/house also makes this possible again. According to Linda Bump, "The systems that have held us back in the other stages are now transformed, and the entire household team can focus on resident preferences, their rhythm of the day and their choices" (2008).

Homes that have not progressed to the Household Model yet have come up with various ways of honoring "refrigerator rights" such as pantries, snack and beverage bars, coffee bars, the "general store" where residents can choose food items without paying extra, ice cream parlors and loaded snack carts taken to resident living areas.

Eden Alternative® and Green House Project®

The Eden Alternative® was born in the mid 1990's with the idea that is it better to live in a garden than an institution. The theme of the garden describes the Eden Alternative® in more ways than one. Eden has helped remind us that residents should flourish and thrive in their home. In addition, staff members, or "care partners" as Eden refers to them, also deserve to grow as individuals. As Nancy Fox, first Executive Director of the Eden Alternative says, "we've been managing for the worst in people instead of for the best" (2007). Dr. Bill Thomas, founder with his wife Jude of the Eden Alternative®, was one of the first to talk about giving back to residents the opportunity to till the garden and enjoy the bounty of fresh foods from it. He was the first person I heard articulate that the green grass which usually envelops most nursing homes is useless and boring.

After ten years of the Eden Alternative's existence, Dr. Thomas decided it was taking too long to transform nursing homes. He preaches that nursing homes shouldn't be changed, they should be abolished - calling himself a nursing home abolitionist (Baker, 2007). This led to the next level of creating home he called the "Green House Green House® communities have Culinary Arts, not dietary departments. In fact, the root word "diet" of Dietary has a negative connotation for most and is treated by many as a four letter word. All the more reason to move away from the medical model and offer dining and culinary services instead (McKorkell Worth, 2009). Ten to twelve elders live in a Green House® and lead their lives in a home where they can access the kitchen, dine together at the dining table and enjoy "convivium."

Convivium

Dr. Bill Thomas has resurrected the concept of "convivium," an old Roman word that describes the pleasure that accompanies the sharing of good food with people we know well. Instead of fast food, instant food and, for instance, soup from large cans warmed up as in most institutional nursing homes, soup is made from scratch and cooked slowly. It simmers on the stovetop all day for all to experience, from the preparation if they so choose, to the aromas, to enjoying it for the evening meal. Dr. Thomas says this about food:

> At its best food nourishes us – body and soul. A meal can embody powerful symbols of love and acceptance. The bond between comfort and food, which begins at the breast, is fortified throughout childhood and gains renewed strength in the late decades of life. Properly prepared, the meals we cook and serve to our elders should be drenched in memory, ritual and culture. … Fresh, local ingredients prepared according to authentic regional recipes are served to people eager to share. They use smell, taste and texture as a springboard to good conversation and vital relationships (2008).

Staff Dining with Residents – Convivium and Building Relationships

Staff dining with residents is a culture change practice which has been implemented to build relationships between staff and residents. It opens up the opportunity for friendships to form and grow between those living in a nursing home and those caring for them, something they both desire which has been traditionally forbidden in most nursing homes. I can still see a sign in a nursing home dining room, not that long ago really in 2003, that stated "STAFF MAY NOT EAT WITH RESIDENTS IN THE DINING ROOM." This caused confusion for me as realized staff are trusted to bathe residents and help them in the bathroom but why wouldn't they be trusted to eat with residents? Sharing food together is part of almost every kind of get together everywhere. Food is the mechanism over which we get to know one another. "Want to go out for coffee?" "Want to come over for a beer?" People are used to eating together and there is no reason to prohibit this normal human ritual. James Beard, the great gourmet and cookbook author says it this way, "Food is our common ground, a universal experience." Of course residents still need to receive any assistance they need, and good infection control needs to be practiced, and staff should interact with residents and not only with each other.

Dining Together Equalizes Everyone

"The extra socialization and encouragement, plus ready offers to get an alternate or to pour an extra cup of coffee makes all the difference between institutional food service and enhancing the residents dining experience" (Bump, 2004-2005). When I was still a surveyor I saw this "extra socialization" in action. Beth Irtz, then the administrator of Clear Creek Care Center in Colorado and now Quality of Life Lead for Sava Senior Care Colorado region and President of the Colorado Culture Change Coalition, implemented a Wednesday Buffet where staff were invited to eat (free of charge) with residents. The buzz of conversation was almost deafening and thrilling to see and hear (personal observation of

author, 2002). When people dine together, they are just people, no longer separated as "residents and staff." All people eat. Dining together serves as a well known experience that "equalizes everyone" a practice which serves to soften the common "us versus them" atmosphere common to institutional living (Krugh and Bowman, 2009).

<u>What Residents Really Hunger For</u>

Richard Taylor, retired psychologist and outspoken person diagnosed with dementia, was interviewed in a Leaders in Eldercare series. He said these powerful words about dining from an experience of his own in an institution:

> The staff would come in, and they were cheery-deary and loveable and well-intended human beings who really loved what they did, and they'd come in and start everybody eating, and then they would leave, and everybody would just sit there silently, eating. Not saying anything, not talking to each other. Eating wasn't an activity, it was barely an event. It was just something that they came and got me at five o'clock to do.
>
> And so I started talking to people. Now, it took me five minutes to get about half the room talking. It's not that I got everybody to talk or everybody wanted to talk or even could talk, but people who hadn't talked in a long time started to talk because I took the time to sit and listen to them. And I don't know if they were telling me the truth or not. They were telling me their version of it. And I found them to be very interesting and bright people (InsideElderCare.com, 2009).

The staff of a nursing home I work with reported to me after deciding to dine with residents that residents didn't eat. It sounds bad at first glance but it turns out the residents just wanted to talk. Residents now "fight over" which staff members they want to eat with them. They're showing us they are hungry for companionship.

Culture change leader and administrator of Rowan Community in Denver, Colorado, Maxine Roby eats with her residents every day, moving from table to table. Maxine often jokingly says, "I know what's going on in my building," an added bonus perhaps.

Psychologist Dr. Susan Wehry on Part II of the CMS From Institutionalized to Individualized Care DVD series relays the power of dining together in a story about a resident that staff were worried about. Staff identified signs of depression including not eating, although the resident, Helen, had always seemed to enjoy meals. Helen had Alzheimer's disease and agnosia, meaning she didn't know what to do with her meal. When Dr. Wehry put Helen's fork in her hand, pointed to her potatoes and said, "This looks good- do you want to try some?" Helen would smile, nod her head yes, but take no action. "When I demonstrated what I wanted her to do, she mimed me very well. She wanted to eat. She had the physical capability to eat. My intervention was then to have lunch with her. I asked staff to bring me a tray. I would say, "That looks good," take a bite, and she would do the same. She ate the whole meal independently by watching to see what I would do next. I suggested to the CNA that she do the same" (2007).

Probably every staff member in a nursing home has been asked by a resident somewhere along the way to "Sit and eat with me." Yet staff members admit they have been programmed to reply with something like "Oh no, I can't" even though they say they would love to. In a nursing home in Colorado after discussing this, the administrator said, "I'm embarrassed to say this but I was invited by residents to eat with them the other day and I went and asked the dining supervisor if I could and I still didn't eat with my residents." That is a bold and brave administrator to admit what to him was embarrassing. Culture change pioneer Eric Haider has said over the years that the culture change movement could be called the common sense movement. Dr. Thomas and his focus on convivium and experiences such as these are making the case that dining together makes good common sense.

Staff Members Get to Know Residents' Preferences

On Part II of the CMS From Institutional to Individualized Care series, staff from featured home Salmon Family Services of Westborough and Northbridge, Massachusetts reported that residents eat better when staff look residents in the eye to connect and get a response directly from them. "One of the big things in my opinion is the Dietary staff. The people who were always on the serving line, always making up trays now get into the dining room and actually meet people. Some of them don't speak English very well. It's amazing that they can communicate. They figure out exactly what the residents want, and they have come to know the resident" said Mike Salmon, Food Service Director (2007).

Many homes have experimented with all sorts of ways to serve residents with great results. At Littleton Manor in Littleton, Colorado, department managers have taken turns serving residents at mealtimes since 2003. The former director of nursing always remarked that when it came time for quarterly re-assessment, she knew firsthand what each resident ate or didn't eat. Brookside Inn in Castle Rock, Colorado, had all department managers become trained dining assistants. They rotate serving as the dining room host or hostess and are available to assist residents to eat if needed. Many homes have brought the kitchen staff out of the kitchen with many stories of relationships forming and staff members realizing things like, "Why would we serve that to Mary, she doesn't like it, never has."

Other Welcomed Dining Practices

As part of a dignified dining experience, forward thinking pioneers questioned and then simply stopped using bibs, serving food on trays, and got rid of what used to be called "feeder tables" - tables designed in a horseshoe shape in order to feed four residents at a time. What is also becoming a former long term care practice is referring to those needing assistance or to be fed as "feeders." Harm was not meant by these ideas, but they have contributed to putting the task and the goal of efficiency before the person. Many have replaced the language "feed," "fed," and "feeder" with "dining," "dine," "assist with dining," and even more personal, some encourage the normal practice of using the person's name instead of any sort of label.

Lastly, some homes have had fun shopping with residents for real glassware and real coffee cups, no longer serving coffee in plastic mugs. Plate, glass and silverware that came from Pier 1 Imports places like Pier 1 and other dinnerware stores fits what Rose Marie Fagan, founding executive director of the Pioneer Network, teaches wherever she goes that the goal of the culture change movement is “rampant normalcy.”

Chapter Three
Food and Dining Research and Outcomes Realized by Pioneering Homes

According to a 2005 American Dietetic Association *Report of the Task Force on Aging* as many as 65% of long term care residents experience unintended weight loss and under nutrition, and there is concern that the incidence of malnutrition is underreported.

Ph.D. prepared nurse and researcher Robin Remsburg has discovered that the causes of malnutrition fall into the following categories:

1) Inadequate assistance for those dependent upon it to eat
2) Poor food quality (attractiveness and temperature)
3) Lack of sensitivity to individual needs and food preferences
4) Lack of food choices
5) Suboptimal dining room environment (2001).

Perhaps this is actually good news as these causes are, as Remsburg points out, reversible and the very areas the culture change movement and CMS guidelines revisions are changing. Formal research studies and anecdotal evidence coming from homes focusing on individualizing food and dining services show some promising results.

In a Scandinavian study, food was served family style, and residents helped themselves. Residents experienced a 25% increase in protein and energy intake (Elmstahl et al, 1987). In a study of thirty Veteran's Administration homes where choice was increased, dining environment improved and restricted diets liberalized, 50% of the residents gained weight (Abassi and Rudman, 1994).

One family style dining study which also focused on staff giving encouragement and praise to persons with dementia resulted in higher participation in eating and even improvement in appropriate communication (Altus et al, 2002). And a family style dining study including persons without cognitive impairment resulted in improvements in quality of life measures, fine motor functioning and body weight (Nijs et al, 2006).

A study done in Canada found that "bulk" or steam table/buffet food service and a homelike dining environment optimized energy intake in individuals at high risk for malnutrition, particularly those with low body mass index and cognitive impairment (Desai et al, 2007).

According to the *Person Centered Care* study and resulting book about Crestview under Haider's leadership, "As the residents were able to eat food they desired, weight loss declined. In September 1998, 38 residents were suffering from significant weight loss, as documented by the Quality Assurance Committee minutes. By July 2000, only 10 residents were exhibiting significant weight loss"(2004).

The Tupelo, Mississippi Green House Project®, the very first, after two years of operation discovered there was no unexplained weight loss and almost no use of nutritional supplements (The Green House Project® Guide Book, 2009).

Rolling Fields of Conneautville, Pennsylvania, an Eden registered home and winner of the OPTIMA Long Term Living 2009 Award, offers 24 hour dining. Residents can choose food they want to eat around the clock. As a result, pressure ulcers have healed, many residents at risk for weight loss have gained weight, supplements have decreased and even pain and behavioral issues have improved. Staff attributes this to being able to serve actual meals [rather than minimal snacks] for those who are awake and hungry, especially at night. Additionally, resident satisfaction has improved, care plan meetings and Resident Council meetings no longer revolve around food issues but instead are filled with compliments. During the last State surveys, not only were there no resident complaints about food, there were instead "many glowing reviews about the food service not only from our Elders but also from the state surveyors, who ordered lunch each day of the survey" (Ltlmagazine.com, 2009).

After being reminded personally of the feelings that foods like soup and bread evoke for him, Franco Diamond, administrator of Idylwood Care Center in Sunnyvale, California, embarked on a journey focusing on foods and their aromas. A Soup of the Day contest led his whole community into forty some food activities and events. "Diamond's soup-aroma theory was validated when a woman fed through a gastric tube for seven years began eating again. 'I smell the food and I want to start eating,'" she said. With her doctor's guidance she began with a puree diet and slowly transitioned to solid food. Ironically, she gained 20 pounds and now wants to go on a diet and become more active in order to lose weight. In all, half a dozen residents have traded in their g-tubes for a place at the table" (Schaeffer, 2008).

Schaeffer writes, "Anyone could participate in that experience by merely inhaling and letting memories arise with the aroma. For people with advanced dementia, food may be the last thing they lose interest in" (2008). One resident, Mrs. C, was not "so easily enticed," still complained about the "lousy" food, and her eating habits declined. Staff decided to use food as an ice-breaker when they discovered her love for cooking Italian food with fava beans. [No need to capitalize a bean]Caregivers planted some, but because they "didn't know beans" about fava beans, they got her to show them how to pick, shell and cook the gourmet bean which ultimately led to Mrs. C leading a cooking class. Not only did she flourish socially, but nutritionally as well. "Mrs. C's magical transformation confirmed for Diamond that residents would become involved if offered familiar and meaningful activities. It also fed staff's gastronomical approach to culture change: If Mrs. C could change so dramatically, maybe they should put more stock into how meals were presented and the ingredients in them" (Schaeffer, 2009). Perhaps Ildylwood's experience makes the case for care planning "familiar and meaningful food and aromas" for each resident.

Good food and nutrition becomes the focus when people are sick and what we are all encouraged to focus on in order to be healthy. When there is good food, good nutrition and good hydration, as Linda Bump relays:

> Clinical outcomes will improve, and all conditions with a nutrition and hydration related outcome will decline in frequency and severity. From pressure ulcers to

> urinary tract infections, expect a decline in the costs of clinical treatments due to the preventive therapy of good nutrition and good hydration (2004-2005).

Dietitian Sharon Leppert makes a great case for creating "a social atmosphere and culture for resident dining" that is participatory with choice and independence as well as socially rich "as a treatment modality" (2007). Although the term "treatment modality" sounds a bit medical, Leppert is onto something. She invites us to consider how the dining atmosphere contributes or takes away from an individual's health by asking:

> When residents are given the opportunity to express preferences on food selection and portion size at the time of service, are they not also provided with an opportunity to contribute to their sense of self-esteem by exercising control over their environment in a small yet positive way? Adequate energy intake to prevent weight loss is an important factor in managing the health risk in populations with advancing age, but the value of food may impact more than nutrition when mealtime contributes to social interaction, self-esteem, and enjoyment for the aging individual (2007).

Outcome of Outcomes

Dr. Bill Thomas' development of the Green Houses® to create true homes where people flourish has resulted in just that. As this author commented in the background paper for the first Creating Home symposium regarding the environment:

> The Green House Project ® captured move-in day on a DVD for those residents who moved from the traditional nursing home to the first Green Houses in 2005. On it, a resident named Mildred Adams, who has dementia, is observed in the large nursing home before moving to be fed by others, non-responsive, and in a wheelchair. Upon moving into her new Green House home, staff and family are astonished, as is anyone viewing this DVD, to see Mildred take a fork from her family member's hand and feed herself at the very first meal! (2008).

Mildred shows us that the institution contributed to her decline, [word seems odd here, very medical and is a duplicate of the phrase you just said, dump phrase, and to her not reaching her highest practicable level of well-being

After Initial Increases, Budget Neutrality and Cost Savings

Linda Bump explains that initial food costs may increase with new enhancements, but as staff learn resident preferences and plan for them, those costs "reestablish within budget" (2004-2005). Eric Haider, similarly says staff learn what residents prefer and how much of each item to prepare, minimizing waste. He attributed a savings of $20,000 per year to this process (personal visit 2001 and Rantz and Flesner, 2004). This is also the experience of the facility identified in Linda Handy's book *Surveyor M.O. for Nutritional Care (F325)* that there are "budget increases at first until you figure out who is going where," "less prep," residents "usually eat what they take which means we are not feeding the garbage can as

much as we used to" and budget is now "actually more efficient and more effective" (2009). Also by avoiding the pre-plating of food, unused food may be used as leftovers following guidelines at Tag 371 or even as "planned overs" which both reduce costs according to Linda Bump (2004-2005).

There may be initial costs for a steam table and other equipment as it is added, but there can be a coinciding decrease in main kitchen equipment replacement and repair according to Bump. She also teaches that labor costs can be held budget-neutral following the initial confusion of transitioning to new serving styles. She encourages teams to be creative, to tap underutilized staff minutes and to "take the plunge many homes have without increasing staff" (2004-2005).

What the culture change movement has learned is that although thought to be more efficient, the institutional schedule and shift-driven way of working is actually inefficient. To wake someone who does not want to be awakened, to take them to a meal they do not want to eat, to serve food they do not eat, only to take them back to their room to sleep in most cases, is not efficient. Instead time and money are wasted, thus making self-directed, individualized care a win-win for residents, for staff, even for the bottom line.

Real Food instead of Commercial Supplements

Margie Haider, director of nursing at Crestview in 2001, espoused that by giving people foods they like to eat, you can minimize the use of supplements. Margie and Eric shared that Crestview saved $1,164.00 per month by serving real foods residents wanted to eat (personal visit 2001). In *Person Centered Care* it is recorded that supplements went from 72 in 1998 to only 14 by July 2000 (2004). Bump explains that having foods of choice available 24/7 virtually eliminates the need for supplements. She adds, "There are not many residents who will choose a canned commercial supplement over real food or personal preference." Bump points out that snack and "hydration" carts can also be eliminated with the addition of pantries and snack bars (2004-2005). Eliminating carts is also what many homes have done to lessen the institutional feel and to create home.

In his article on malnutrition in the older individual, Webster states that "Oral supplements are also not very beneficial and often go wasted or conflict with medications" (2008). Oral liquid nutrition supplements have been shown to be only moderately successful in increasing energy intake, which has also been shown to be related to the limited time staff can devote to getting the supplements delivered and giving verbal encouragement to consume them (Schlettwein-Gsell, 1992). Webster says that, "Improving taste is one of the best and simplest ways of improving nutrition" (2008). And not surprising, the "elderly have the same taste preferences as they have had all of their life, and thus low sodium, low fat meals are not always as appetizing as the normal version of a food with naturally high fat and sodium content (Calverley, 2007).

Real Foods, Less Meds and Cost Savings

When nutrients are offered in the form of yummy foods, medication usage will decline especially for laxatives, appetite stimulants and even multivitamins. Neighborhood and household kitchens virtually eliminate laxatives, using food instead to support normal bowel function (Bump, 2004-2005). Charlene Boyd of Providence Mount St. Vincent reports that "the number of special diets is reduced to a few, as homes learn it is more important for elders to eat appetizing food than to have meals medicalized into inedible ordeals," leading to less food waste and reduced use of dietary supplements, all while residents gain weight (Baker, 2007).

Common Sense Ideas and Results

Debi Majo the director of nursing at the Northwood Health Care Center in Marble Falls, Texas shared some common sense ideas that more homes are trying on Part III of the CMS From Insitutional to Individualized Care series:

> We work diligently on reducing sugar in all of our menus because in reality, no one needs a lot of sugar in their diet. We sweeten our cakes with applesauce and sometimes add carrot juice or even prune puree to chocolate cupcake batter instead of sugar. So our reduced concentrated sweet diet is actually closer to sugar free. For all diets we do not add salt to any item that we cook. Some of the 'pre-made' breads contain salt so we call our reduced sodium diet 'no added salt' and I can tell you that corn bread tastes a little flat without salt, but you get used to it. And mechanically altered diets, these are just regular food that has been blended in the blender or hand chopped (2007).

Lastly, some really good news is shared by Connie McDonald Administrative Director for Maine General Rehabilitation and Nursing Care, Augusta, Maine who CMS featured in Part II of the From Institutional to Individualized Care series in 2007, "When you have residents who are sleeping better and eating better and feeling better, you naturally have positive outcomes. The survey findings reflect that."

Chapter Four
CMS – A Partner in the Culture Change Movement

As the brochure for the upcoming February 2010 Creating Home II Symposium co-sponsored by CMS and the Pioneer Network states,

> CMS has become a partner in the culture change movement, and wishes to encourage meaningful changes in food and dining service that provide greater quality of life for residents.

It is no secret that CMS supports culture change. In 2002 Karen Schoeneman, now CMS Deputy Director of the Division of Nursing Homes developed and moderated a satellite webcast for all survey agencies called "Innovations in Quality of Life: The Pioneer Network. Surveyors were exposed to what culture change is, its positive outcomes and how facilities are making culture changes and remaining compliant.

Culture change became a pilot project with twenty-one states in the 8th scope of work for the CMS Quality Improvement Organizations (QIOs) between 8/04-10/05. Karen Schoeneman as CMS' culture change lead and Thomas Hamilton, the CMS Director of the Survey and Certification Group, recorded an interview in June 2005 stating CMS's support for culture change and the QIO project. In it Mr. Hamilton said, "Facilities that are moving to resident -directed care are actually fulfilling the mandates of the OBRA '87 law."

CMS took part in the famous St. Louis Accord in 2005. This was a gathering of all types of long term care stakeholders interested in culture change. There were over 400 participants including ombudsmen, advocate groups, regulators, providers, state and national trade associations, culture change experts and QIO representatives. All 50 States were represented and State teams created action plans to promote transformation of institutional culture in their respective State (qualitypartnersriqio.org/cfmodules/objmgr.cfm accessed 1-11-10).

In December of 2006, CMS issued a Survey and Certification letter with answers to culture change questions from the culture change community (Appendix B) which is available at http://www.cms.hhs.gov/SurveyCertificationGenInfo/downloads/SCletter07-07.pdf.

In April 2006, CMS contracted with Edu-Catering and this author to co-develop the Artifacts of Culture Change measurement tool with Karen Schoeneman of the Division of Nursing Homes. The tool is designed to capture tangible changes that come from a changed culture and includes several dining items under the domain of Care Practices. In 2009 the Pioneer Network developed a data base that automates the completion of the tool. The site, which is in the test stage at this writing, will enable a nursing home to fill out the Artifacts tool and receive a report comparing them to others in the data base.

In April of 2008 CMS and the Pioneer Network co-sponsored the historic *Creating Home in the Nursing Home: A National Symposium on Culture Change and the Environment Requirements* a Recommendations from the symposium were taken seriously. The Hulda B.

and Maurice L. Rothschild Foundation funded the Pioneer Network to convene the National Long Term Care Life Safety Task Force. After many months of volunteer service by architect and Life Safety Code experts five proposals were submitted to the National Fire Protection Association regarding the Life Safety Code® in August of 2009 for the 2012 Edition. CMS Division of Nursing Homes issued new interpretive guidance effective July 12, 2009 for ten regulations regarding the environment and quality of life, directly stemming from the symposium recommendations.

CMS funded the writing of the background paper for the first symposium as well as this background paper in preparation for *Creating Home II.* Culture change has even found a place on CMS' annual Action Plan supporting the continuation of culture change projects. CMS Central Office now has its very own culture change team. In addition, the 2009 version of the CMS "Guide to Choosing a Nursing Home," which goes to all Medicare beneficiaries, contains for the first time a section describing culture change and person-directed practices.

The Pioneer Network has asked AHFSA – the Association of Health Facility Survey Agencies – and AHFSA in turn has invited each State survey agency, to name a culture change contact person within their survey agency. In addition, the leadership of AHFSA has created an Individualized Care Committee or, in other words, its very own culture change committee.

There are regulatory leaders across the country from CMS Central Office, CMS Regional Offices, CMS Consortiums, AHFSA and individual States who support the changes they see that are bringing improved quality of life and individualized care to residents. Dr. Randy Ferris, CMS Consortiums Director, has stated publically that he wants State agencies to support any culture change initiatives in their respective States (as reported by CMS Western Consortium Director Captain Steven Chickering at the April 3, 2008 *Creating Home* Symposium).

Thomas Hamilton, commented at the beginning of the CMS From Institutional to Individualized Care broadcast series,

> Nothing is more important than being responsive to the whole person, understanding the person and tailoring supports to their individual preferences. William Moser the physician said it better when he advised other physicians to 'Ask not what a disease a person has, ask what person a disease has.' The very word health itself is derived from the old English meaning the state of being whole. Other members of this linguistic family include hail, heal and holy. So much of our healthcare system separates workers from people through severe division of labor and such specialization of labor that we end up treating people as not whole human beings but as an amalgam of disconnected parts, disease processes, and problem behaviors. Long term care is THE part of the healthcare system with the best opportunity to be truly person-centered (Part I, 2006).

Lastly, Mr. Hamilton in that 2005 interview for the QIOs encouraged CMS and State agencies to "work together to handle any regulatory issues that arise as facilities begin to change."

Recommendation: To take Mr. Hamilton up on his offer for CMS and State agencies to work together to handle any regulatory issues that arise around culture change ideas. Some State survey agencies are more forward thinking than others. They too see what CMS sees that person-centered practices embody OBRA '87 and improve quality of life. However, in other State agencies this is not understood as evidenced by surveyors having said, "In our state, regulations first, culture change second." CMS' influence on State agencies is needed to help them see the correlation between CMS requirements and transforming cultures away from institution to self-direction.

Chapter Five
The Issues and the Regs:
Food and Dining Issues and the CMS Food and Dining Regulations

The issues surrounding new and innovative ways of serving food in the nursing home weave in and out of regulatory requirements. Thus, both the issues as well as the regulations are presented here together intertwined along with highlighting what is missing and recommending what might be helpful. CMS is to be commended for already having identified many culture change practices in newer interpretive guidance. As well, new ideas bump up against some requirements causing a healthy friction, the driving force for the upcoming symposium and this paper. Having first served residents proudly as an activity professional, having also been a state surveyor and member of the CMS Division of Nursing Homes and now consultant and educator, I work with both surveyors and providers to synthesize compliance and culture change and views expressed try to take into account both roles.

483.35(i) F325 Nutrition

Based on a resident's comprehensive assessment, the facility must ensure that a resident –
483.35(i)(1) Maintains acceptable parameters of nutritional status such as body weight and protein levels, unless the resident's clinical condition demonstrates that this is not possible: and
483.35(i)(2) Receives a therapeutic diet when there is a nutritional problem.

Receives a Therapeutic Diet
Therapeutic diet refers to two kinds of diets: restricted such as no concentrated sweets and low or no salt and altered texture diets such as mechanical soft or pureed. Restricted diets seem to be the kind of diet causing the most problems, as most people just do not want to nor do they follow them. Sometimes a person on a modified texture diet also does not want to follow it, risking choking and ultimately death.

Receives a therapeutic diet is causing all sorts of problems nowadays. The way this is worded pressures a facility to feel they must; they must serve a therapeutic diet as long as an order for it exists. So, even if the person prefers not to follow a restricted diet, the facility fears being cited for the deficient practice of not serving it. Thus the facility errs on the side of following the regulation in the strictest sense, ignoring the person and what they want but then actually being non-compliant with Tag 242 Self-determination and participation, the requirement to honor a resident's right to make choices about what is significant to him or her.

It is becoming well known that there is no evidence-based research to show that restricted diets even do what they are intended to do (more below under Liberalized Diets). Thus less focus on ensuring provision of restricted diets is needed and more focus on investigating negative outcome. A surveyor is to investigate negative outcome to a

resident. This would include all kinds of negative outcome. We are used to looking at what might happen if a certain diet is not followed. In fact most deficiencies are written at the potential for harm severity level. Research is showing there is no potential for harm since there is no medical reasoning for these kinds of restricted diets. Instead it is time the person becomes the focus; the person, not the prescribed diet. And instead of talking about potential negative outcome that does not exist empirically, what is needed is to talk about the negative outcome of being told you cannot eat this or you must eat that. Being told what to do or what to eat is denial of choice. Denial of choice is deficient practice according to several CMS regulations: F151 Exercise of rights, F155 Right to refuse medical treatment and Tag F242. The negative outcome needs to be determined to the person's physical health as well as to their emotional health when denied the right of choice.

Recommendation: CMS give greater guidance on the negative outcomes that result from being denied the right to make choice. Researchers show us the research, what happens to us when we're denied choice and what further research is needed.

The Intent statement in the interpretive guidance for this requirement already states that care and services be *consistent with the resident's comprehensive assessment* and that *the therapeutic diet takes into account the resident's clinical condition and preferences.* CMS deserves much credit for recognizing a person's personal wishes with the following: *Goals and prognosis refer to a resident's projected personal and clinical outcomes. These are influenced by the resident's preferences (e.g., willingness to participate in weight management interventions or desire for nutritional support at end-of-life)….* This is well laid out and explained here. However, it is in the field, when surveyors are in a nursing home where this guidance emphasis on the person and their *preferences*, *goals* and *projected personal and clinical outcomes* is typically not the focus.

Recommendation: CMS create more focus on the person and less focus on the physician diet order. CMS' guidance does give focus to the person. However, the language of this regulatory text is what remains problematic for surveyors and providers who fear them. Thus it is the regulatory text of this tag, *receives a therapeutic diet* that needs to be considered to incorporate resident choice. Increased training as well as holding surveyors accountable to the good new guidance that already exists here is also recommended.

Kudos to CMS here in Tag F325 Nutrition guidance for identifying that a person has *dislikes, preferences* and *preferred portion sizes.* It seems that facilities are in the habit of inquiring about likes and dislikes on every dietary form imaginable. However, from my experience as a surveyor, likes and dislikes are not always honored. A resident who was a former nurse claimed to be allergic to eggs only because she hated them. It's too bad a resident had to elevate a dislike to an allergy in order to ensure she did not receive it. What if we asked what someone hates to eat and what they love to eat? Sometimes these kinds of extremes tell us a lot about a person. And the culture change community tells us over and over again that it is often via smaller living environments and always with consistent staff who know a resident well that these preferences are learned and remembered.

Preferences not Problems

Preferences is an excellent concept that CMS has included here at Tag F325 Nutrition. In long-term care the focus has always been problems. Most people working in long-term care have been led to believe that they must create what are called "problem statements" for each identified MDS "deficit" area on every person's care plan. When in fact the traditional style of Problem/Goal/Approaches is not required by any Federal regulation (nor State regulation, that I have ever heard of). It is a nursing style care plan which makes sense when you think of caring for a person's medical problems which are problems for which the person and the nurses have goals and approaches to meet those goals. However, most of what a person wants really are preferences, not problems. For instance, we used to write: "Difficult Behavior – resident wanders at night." That is not a problem unless it is a problem for that person, not a problem for staff. In many cases it is a person's preference and often a lifelong routine of working a night shift for instance. In a workshop once when inviting my participants to write their own care plan, one nurse wrote:

> Problem: Staff's idea of what's important.
> Goal: Staff will realize what is important to me and align themselves with me
> As Evidenced By:: my happiness.
> Interventions: Forget all the 'rules' when it comes to me because I don't care.

Recommendation: Providers focus more on preferences and distinguish between true medical problems and personal preferences. CMS has taken the lead here. Even in the CMS' newly revised guidance to Tag 242 Self-determination and Participation, CMS states that the facility must be *actively seeking preferences*.

Resident Goals

Also well identified by CMS here is that *resident goals and resident specific interventions should be care planned.* The culture change community has begun I-format care planning which has redirected staff to the person. I-format care planning is the resident's care plan in their own voice such as "I have diabetes and my goal is for my blood sugars to be stable." Approaches are also in the voice of the person stating to care givers what works best for them. Providers who have committed to I-format care planning state that it is "powerful" and helps staff see the resident as a person.

Some homes are slowly starting to ask the residents what their goals are. I remember once my career when I was an activity director thinking to myself, "I should probably go ask the resident what she thinks of this goal that I set for her" but then deciding I didn't have time. Professionals all over the country admit they have done the same. I commend pioneers who have decided to ask residents what they think. It is their life. It is exciting to see resident goals actually stated and even quoted in a resident's own words on a resident's care plan and here CMS is calling for it.

Recommendation: Clinicians/providers and academicians who teach new professionals within each discipline, begin asking residents what their goals are for their life. When one

is unable to say, ask the responsible party what they think the resident would state as their goals. State and Federal surveyors also need to be trained in this new way and provide oversight to ensure it. If surveyors started to look for some of these profoundly personal things, such as the resident's preferences and goals, surveyors could contribute to this new culture of honoring residents' wishes and goals and preferences <u>which CMS is requiring</u>. Also stated now by CMS in Tag F325 Nutrition: The *assessment also provides information that helps to define meaningful interventions to address any nutrition-related problems.* Kudos once again to CMS - *meaningful interventions* is another way to say individualized care which is very meaningful to the person and is sometimes missing in the rote systematic, computerized process of producing care plans.

<u>Resident Choice</u>

Congratulations to CMS for a whole section on *Resident Choice* here at F325 Nutrition. Some of which states:

> *The resident or resident representative has the right to make informed choices about accepting or declining care and treatment. The facility can help the resident exercise those rights effectively by discussion with the resident (or the resident's representative) the resident's condition, treatment options (including related risks and benefits, and expected outcomes), personal preferences, and any potential consequences of accepting or refusing treatment. If the resident declines specific interventions, the facility must address the resident's concerns and offer relevant alternatives.*

There is so much recognition here of *the right to informed choice*, about the fact that one *may decline care and treatment*, that the facility can even *help* the resident *exercise those rights*. It begs the question whether providers and surveyors have read them as the focus is still on following the physician order instead of what the resident wants. These are new guidelines and I myself did not know all that was within them until taking the time to study them. CMS is to be commended, they have set the course.

More from the *Resident Choice* section of Tag F325:

> *The facility's care reflects a resident's choices, either as offered by the resident directly or via a valid advance directive, or based on a decision based on a resident's surrogate or representative in accordance with state law. The presence of care instructions, such as an advance directive declining some interventions does not necessarily imply that other support and care was declined or is not pertinent. When preferences are not specified beforehand, decisions related to the possible provision of supplemental or artificial nutrition should be made in conjunction with the resident or resident's representative in accordance with State law, taking into account relevant considerations such as condition, prognosis, and a resident's known values and choices.*

Care is to reflect a resident's choices, not work against them. Even 13 years into the culture change movement people are still being told what they can or cannot eat. CMS goes

so far to point out that if a representative makes decisions for the resident, the decisions should reflect the *resident's known values and choices*. Again, CMS has covered so many of the bases.

Advance Directives and Food Choices

Notice advance directives are mentioned here by CMS, not waivers. Not knowing why, I am hearing all over the country that attorneys are telling providers that waivers do not hold up in court. This led me to wonder what does hold up in court. Will it come to residents needing to specify in an advance directive their desire to not follow a restricted diet that their physician has ordered? [I think you are off beam here, an AD doesn't kick in till you are terminal] let's go over this part, may need to be thrown out or rethought This is very possible if physicians do not work with the person to change or liberalize the diet order. A lawyer in Texas, Kelly McDonald, guides clients to create what she has termed an "alternate treatment agreement." In it possible risks and possible benefits, and protocols to follow are all specified. It is signed by the resident or responsible party and witnesses. Asking family to sign as witnesses reduces the likelihood of legal action later knowing full well the resident's decision (2009). The agreement reflects a resident's decision even against medical advice and can also be used later if needed. McDonald also suggests trying to find less risky alternatives like the gentleman who agreed to eat his mechanical soft diet as long as he could have regular thin coffee. She also advises to develop and ensure staff is fully aware of specific protocols to follow and complications to observe for individual residents.

In a way it seems unnecessary that the right to choice issue is culminating with more advance directive planning. Then again it may be a blessing. Providers want some back up to be able to honor resident choice. Providers are also fearful of being cited for not following prescribed diets as the regulatory text of this tag requires even though honoring choice is also required within the very same tag's guidance. CMS needs to know from the field that although its guidance is good it does not always "play out" and the regulatory text is what surveyors are taught to cite. And even though CMS' guidance is good right here, it also seems that residents, providers and surveyors alike would benefit from further education and exposure to this concept of alternative consent agreements. [we shouldn't need these agreements, let's talk

Recommendation: CMS ease the tension between its own regulatory language *receives a therapeutic diet* and its interpretive guidance. It would be an extremely beneficial contribution for CMS and/or the Pioneer Network to convene a national workgroup to look at the practice of alternative consent agreements I disagree, too cumbersome to need to have an agreement, we just need to guide surveyors to take it easy and educate residents, staff and surveyors about them. Having all stakeholders knowledgeable of this option could ease the rising tension for providers, residents and families, and clinicians serving as a welcome catalyst in helping all of us honor residents' rights.

Diet Liberalization

Kudos to CMS on a whole section here at F325 Nutrition on *Diet Liberalization*:

> *Research suggests that a liberalized diet can enhance the quality of life and nutritional status of older adults in long-term care facilities. Thus, it is often beneficial to minimize restrictions, consistent with a resident's condition, prognosis and choices before using supplementation. It may also be helpful to provide the residents their food preferences, before using supplementation. This pertains to newly developed meal plans as well as to the review of existing diets. Dietary restrictions, therapeutic (e.g., low fat or sodium restricted) diets, and mechanically altered diets may help in select situations. At other times, they may impair adequate nutrition and lead to further decline in nutritional status, especially in already undernourished or at-risk individuals. When a resident is not eating well or is losing weight, the interdisciplinary team may temporarily abate dietary restrictions and liberalize the diet to improve the resident's food intake to try to stabilize their weight. Sometimes, a resident or resident's representative decides to decline medically relevant dietary restrictions. In such circumstances, the resident, facility and practitioner collaborate to identify pertinent alternatives.*

Collaborate to identify alternatives. This is great advice and guidance. However, from what I see as a consultant and hear in workshops around the country and am told by consultant dietitians is that this collaboration with *the resident, facility and practitioner* to *identify pertinent alternatives* is not happening to this degree and surveyors are not looking for it. Instead the resident continues to be pointed at as the problem labeling him "non-compliant" and telling him he "must" follow the diet order.

Recommendation: CMS ensure surveyors know about and survey for this guidance to collaborate, find alternatives, and consider diet liberalization as many have identified a disconnect between the new guidance which thoroughly reflects current standards of practice and it being upheld in the field through the survey process.

Diet Liberalization – A New Standard of Practice

Some health care facilities have as many as 44 therapeutic diets (Puckett, 2005). The American Dietetic Association (ADA) already in 2002 came out with a position on diet liberalization and a paper explaining it called "Liberalized Diets for Older Adults in Long-term Care." In it the ADA states, "It is the position of the ADA that the quality of life and the nutritional status of older residents in long-term care facilities may be enhanced by a liberalized diet." Nutrition in long term care settings must meet two goals, the paper states: maintenance of health through medical care and maintenance of quality of life. Good health, good medical care and quality of life, these are things we all want, these are goals of the ADA and CMS requirements. But liberalized diets are still few in many nursing homes.

The ADA points out that research calls for liberalization of restricted diets: "Research supports that many diets for the elderly should be liberalized, including diets for diabetes, cardiac disease, hypertension and renal disease." The ADA, the dietitians themselves, have gone beyond just looking at quality of care to consider quality of life as well: "To meet the needs of every resident, dietetic professionals must consider each person holistically, including personal goals, overall prognoses, benefits and risks of treatment, and perhaps most important, quality of life" (2002). These terms sound familiar as many of them are now included in CMS guidance.

Linda Handy, retired dietary specialty surveyor from California and author and speaker on these very subjects, points out in all her publications that diet liberalization is "a standard of practice" (2009). The ADA has contributed greatly to this new standard with their position in support of it. The ADA updated their position in 2005 and is working on a third rendition in 2010 as the "ADA is a very, very evidence based organization and insists members are kept up-to-date" according to Linda Roberts, ADA government relations representative (2009). Kudos again to CMS for not only recognizing this new standard of practice but actually requiring it in its guidance to Tag 325 Nutrition.

In the CMS Individualized Care series, a CMS Central Office dietitian from the Division of Nursing Homes, Alisa Overgaard, made the following profound statements:

> Liberalized diets should be the norm, restricted diets should be the exception.
>
> No research shows restricted diets have any benefit.
>
> Some homes have made liberalized diet the standard with monitoring of edema, high blood pressure, blood sugars and then make changes as necessary.
>
> Research shows that quality of life may be enhanced by a liberalized diet.
>
> Facilities should review existing diets to minimize unnecessary restrictions.
>
> There is broad consensus that dietary restrictions, the so-called therapeutic diets such as low fat, sodium restricted and modified textured diets are only sometimes helpful and may actually inhibit adequate nutrition especially in undernourished or at risk individuals. Generally weight stabilization and adequate nutrition are promoted by serving residents regular or minimally restricted diets (Part III, 2007).

It begs the question, what everyone is waiting for. Why is there such a lag time of liberalizing diets in facilities? CMS has paved the way but we need your help CMS to get us all on the same path.

<u>CMS "Gets" Culture Change</u>

From the *Environmental Factors* section of these F325 guidelines:

> *Appetite is often enhanced by the appealing aroma, flavor, form and appearance of food. Resident-specific facility practices that may help improve intake include providing a pleasant dining experience (e.g., flexible dining environments, styles and schedules), providing meals that are palatable, attractive and nutritious (e.g., prepare food with seasonings, serve food at proper temperatures, etc.), and making sure that the environment where residents eat (e.g., dining room and/or resident's room) is conducive to dining.*

Flexible dining environments, styles and schedules to *help improve intake.* In other words, open, 24 hour, buffet, restaurant and family style dining, the culture change dining practices designed to honor self-directed living which have resulted in weight gain instead of weight loss and have contributed both to both quality of care and quality of life.

Pleasant dining experience - much could be said about this. Research shows us socializing with others improves appetite (Simmons et al 2001, Simmons and Schnelle, 2004). Most have heard that certain aromas such as chocolate improve appetite. Music, lighting, ambiance, basically a pleasant dining experience improves everything. CMS states it here but what if CMS more strongly required it.

<u>Facility Policies honored more than Resident Choice</u>

Not only has a quagmire with treating the physician order as "the end all be all" been created. On top of that many homes have developed policies that state physician orders <u>must</u> be followed. Dietitians have told me they are frustrated when a facility lets its policy trump a resident's right to choice. Even when residents would like to downgrade a diet themselves, facilities don't let them. Say a person wants a soft texture diet because their dentures caused a sore in their mouth, which is precisely what we would all naturally do living at home. Instead it becomes a "policy example of not allowing a downgrade of texture per resident request because it is an 'order' and staff have to follow policy" (Moldono, 2009). This example shows how "too far" this has come. When the issue is a facility policy that is where there is freedom, freedom to change the policy to do what is right by people. Surveyors could be looking more at the instances in which the policies are trumping resident rights as potential instances of noncompliance with resident rights and quality of life requirements.

In the fictional story throughout the Handy handbook *Surveyor M.O. for Nutritional Status (F325)*, Reverend Hal says, "No one should be on a diet at my age. Let me have my last few pleasures. What – am I going to live a few months longer if you make me eat heart healthy? Sometimes it is just nice to have a little fried food. Besides, our food is pretty healthy. Right, Victoria?" The dietitian then answers, "Our 'house' regular diet is low in sodium and low in fat, with a few exceptions. Joe is working hard to make the food taste good and still be quite healthy" (2009). This is an example of a facility policy and practice that serves people well.

Real Food over Supplements

CMS states that most people prefer real food to supplements: *With any nutrition program, improving intake via wholesome foods is generally preferable to adding nutritional supplements*. Again, CMS gets it and is stating the truth.

Recommendation: There is research, there is anecdotal evidence, there is cost savings, there is common sense and now even CMS is saying it, people in general prefer real foods to the "fake food" supplement drinks. Providers, you might ask yourself what is holding you back from offering real foods before supplements

Avoidable and Unavoidable

Providers react so often out of fear of citations yet it seems like we might be forgetting the definition of "unavoidable" in regards to nutrition here at F325:

> *"Unavoidable" means that the resident did not maintain acceptable parameters of nutritional status even though the facility had evaluated the resident's clinical condition and nutritional risk factors; defined and implemented interventions that are consistent with resident needs, goals and recognized standards of practice; monitored and evaluated the impact of the interventions; and revised the approaches as appropriate.*

Thus a weight loss is not automatically a deficiency. Surveyors will investigate whether it was avoidable in light of poor care practice or unavoidable in light of good care practices. Only the avoidable weight loss will become a deficiency. When investigating whether any sort of nutritional decline was unavoidable, is all of the above taken into consideration? Are surveyors investigating whether the facility identified the *resident's needs* and *goals* and is everyone considering *recognized standards of practice*? And are surveyors investigating whether the home was finding out and honoring food preferences? That is part of providing good care and now a part of the new guidance for Tag F242 Self-determination and Participation. The ADA position paper about liberalizing diets was published in 2002. This new F325 CMS guidance was issued September of 2008 and yet most facilities, most physicians and most surveyors continue to treat restricted diets as the norm. According to this definition, when the resident's needs or goals, such as to eat whatever foods they want, led to some unacceptable parameter of nutritional status, it is to be considered unavoidable.

Recommendation: Better training for surveyors and providers on the concept of "unavoidable" and all that plays into it including resident needs and goals, in other words preferences.

Investigative Protocol

> *Review of Facility Practices, If the interventions defined, or the care provided, appear to be inconsistent with recognized standards of practice, interview one or more health*

care practitioners as necessary (e.g., physician, hospice nurse, dietitian, charge nurse, director of nursing or medical director).

Recommendation: CMS, your guidance is so good, so thorough, so in line with current standards of practice and with OBRA '87 mandates, yet there are many disconnects with surveyors and providers alike. What if you mandated training or even testing to ensure all your surveyors in every State knew and could then be expected to survey according to your good interpretive guidance? Something more is needed. Surveyors could help promote a world where residents' wishes were incorporated. Surveyors could inquire as to why there is still a physician's order for a restricted diet when the resident won't follow it and cite deficient practice when the resident's choices and the standard of practice to liberalize diets is *not* being followed.

CMS shows it is "up-to-speed" with person-centered, self-directed living ideas by stating under Observations in the Investigative Protocol for Tag F325 Nutrition:

> During observations, surveyors may see non-traditional or alternate approaches to dining services such as buffet, restaurant style of or family style dining. These alternate dining approaches may include more choices in meal options, preparations, dining areas and meal times. Such alternate dining approaches are acceptable and encouraged.

Heavy Hitters

F325 Deficiency Categorization is where CMS has made a strong statement regarding the importance of resident choice and preferences.

The first is an example of Severity Level 4 - Immediate Jeopardy:

> *Substantial and ongoing decline in food intake resulting in significant unplanned weight loss due to dietary restrictions or downgraded diet textures (e.g., mechanic soft, pureed) provided by the facility against the resident's expressed preferences.*

The following are examples given at Severity Level 3 - Actual Harm:

> *Unplanned weight change and declining food and/or fluid intake due to the facility's failure to assess the relative benefits and risks of restricting or downgrading diet and food consistency or to obtain or accommodate resident preferences in accepting related risks;*
>
> *Decline in function related to poor food/fluid intake due to the facility's failure to accommodate documented resident food dislikes and provide appropriate substitutes*.

Against the resident's expressed preference happens every day in many nursing homes yet here is an example of Immediate Jeopardy and one for Actual Harm. I have never heard of it being cited at either level. *Failure to accommodate resident preferences* and/or *provide*

appropriate substitutes also takes place commonly but I wonder how common it is for it to be cited at all let alone at the harm level.

And under the section Potential Tags for Additional Investigation, the very first tag mentioned is Tag 150 Resident Rights and stated is, "Determine if the resident's preferences related to nutrition and food intake were considered."

On the CMS Individualized Care series Part III, medical director Matt Wayne who incorporated liberalized diets and personalized med passes at an Ohio home advises that it takes a change in philosophy. He says, "We begin with liberalized diets unless there is a strong reason not to, and monitor outcomes. If there are bad outcomes, such as high blood pressure or blood sugars out of normal range, maybe then a restrictive diet is needed" (2007).

F360 483.35 Dietary Services

The facility must provide each resident with a nourishing, palatable, well-balanced diet that meets the daily nutritional and special dietary needs of each resident.

Nourishing, palatable, well-balanced diet. In talking with a friend about this paper she said, "I couldn't even recognize what they served my Grandma in the nursing home where she lived." At the 2006 Pioneer Network conference, several culture change leaders from Illinois did a skit depicting stereotypical traditional nursing home food. In it, the dietary manager offers a resident some "mystery protein, chopped green things, and a scoop of starch."

When I was a surveyor I heard from residents practically every week during every survey, "Just give us more fresh fruits and vegetables." Ombudsman say residents tell them the same thing. And why aren't fresh foods, fresh produce offered to residents? They are better, healthier and nourishing. It has been commonly accepted to barely have any. Eric Haider has said this over the years too and he did, along with many others now, offer residents a salad bar every day.

Recommendation: CMS consider a requirement for fresh fruits and vegetables because they are *nourishing, palatable and well-balanced*. And the Food and Drug Administration consider adding to the Food Code or the ADA consider a position paper to that effect creating another needed standard of practice that is not being encouraged or enforced by any entity at this time.

F361 483.35(a) Staffing, Qualified Dietician

It is certainly reasonable that CMS require a qualified dietitian. What we are seeing in the culture change movement is that many dietitians, along with professionals from every discipline, are having to "unlearn" what they've learned to some degree. I have heard leading dietitians say about their own profession that many dietitians have put themselves in a policing position of "we keep resident's safe," "we have rules that enforce good nutrition and infection control," "you can't do that" and "you must do this." Regulation and

enforcement is to blame for some of this, nursing homes legitimately want no citations. Unfortunately though, especially in the field of long term care, regulation breeds more and more rules.

What then is the role of the dietitian? CMS at Tag F325 Nutrition identifies that *qualified dieticians help identify nutritional risk factors and recommend nutritional interventions, based on each resident's medical condition, needs, desires and goals*. Once again, this is person-centered but is not always how it plays out; the focus usually ends at based on each resident's medical condition leaving needs, desires, and goals out. This focus on medical care is why a major premise of the Eden Alternative® is "Medical treatment should never be the master of genuine human caring" (Eden Principal #7).

Linda Roberts, RD and consultant in long term care, shares some insight into the role of the dietitian. She says the dietitian "has been trained to treat certain diseases with food" citing the extensive education an RD receives, much with pre-med students, in chemistry, biochemistry, microbiology and anatomy. The dietitian understands the body's workings at the cellular level and how the components of food (carbohydrates, fats, proteins, vitamins/minerals, phytochemicals) affect the health and wellness of the individual. And dietitians want to help people (2010).

The other part of the equation, Roberts advises, is the patient's lifelong habits:

> Dietitians need further education and training in the psychology of eating, in my opinion. Did you know that only 4% - 5% of people are successful at maintaining changed eating patterns and keeping weight off? I would venture to assume you could extrapolate those figures for any therapeutic diet.
>
> The question becomes, how can we assume to change the diet of an 80year old? There will be some that are very interested in prolonging their life and others will say, who cares if I live another 2 months or not- I'm 80 years old. But remember the dietitian has been trained to help people with food. She/he will continue to want to provide a 'therapeutic diet' in the hopes of helping the resident. So when does therapeutic become too therapeutic? The ADA position paper is supposed to help the practitioner answer these questions and support their actions in case of litigation. Yes, we are getting sued . . . Mom, an 80 year old with end stage Alzheimer's, refuses to eat (therefore does not have adequate protein/calories in the diet), develops a pressure ulcer, and dies" (2010).

As you can see, everyone needs more education and a better understanding of what is happening here. Dietitians and other clinicians also need to be supported in supporting the person and their individualized care even when it goes against all their training and desire to help people with what they know. Helping should be reframed from preventing someone from eating something that is "bad" for them to helping them live their life their way. This may include educating residents on the consequences of food and drink choices and using the clinicians' expert knowledge to help find ways that accommodate and compromise. Compromises may take the form of special cooking/flavoring techniques,

experimentation with sweeteners instead of sugar, "making a deal" to have the regular dessert after eating the low sugar dessert so many meals, etc. The goal should always be to individualize according to what each person wants, needs, will put up with, will concede to. To truly individualize means to figure out what works for a person, we're all different and usually willing to make some sort of "deal" even with ourselves.

Staffing to Complement the Dietitian

In order to create less rules, focus on resident *needs, desires and goals*, and "unlearn" old ways, some nursing homes are hiring chefs and restaurant managers to complement the role of the required qualified dietician. Because chefs, restaurant managers and wait staff are used to serving people what they want when they want it, no "unlearning" as far as service goes is necessary. Solid training in the facility's practice of encouraging and reminding residents of any food related recommendations is needed by all staff. And not to leave the dietary manager out, perhaps they need to be invited, given permission, and/or new expectations that the focus is to be on the person, that individualizing care is what it's all about.

"Healthcare: Chefs Needed"

Ryan Krebs is Executive Chef/Director of Dietary Services at Victoria Special Care Center in El Cajon, California. A former executive chef from the restaurant world, Krebs is passionate about inviting executive chefs into the meaningful business of long term care. According to Krebs, a culinary education focus is service plus a passion and enthusiasm for food. What many suppose is that chefs cost more. Krebs says this is true initially but to "keep in mind that many chefs are also held to the highest of standards, especially from larger corporations and privately owned restaurants. They manage money, large staffs, and control costs and are held accountable to numbers in so many ways. And, their management experience could immediately impact overhead labor and purchasing costs, possibly allowing their salary requirements to be met. Having an executive chef is also a great marketing tool for organizations, stating that your business has made an investment in bringing in the best the industry has to offer…." (2009).

Johnson & Wales University, Krebs' alma mater in Providence, Rhode Island, offers a degree in Culinary Nutrition, the first of its kind, blending the healthcare focus of nutrition with the culinary arts. Krebs says that as our economy suffers and restaurants and hotels are closing or making cut-backs, there are eager chefs awaiting the chance to enter the field of healthcare (2009).

F362 483.35(b) Sufficient Staff

If research shows that residents are not receiving sufficient assistance for meals (Amella, 1999; Kayser-Jones, 1996; Simmons, Babineau, Garcia & Schnelle, 2002; Simmons, Garcia, Cadogan et.al., 2003), I wonder if this tag should be cited more than it is.

F363 483.35(c) Menus and Nutritional Adequacy

Menus must: Meet the nutritional needs of residents in accordance with the recommended dietary allowances of the Food and Nutrition Board of the National Research Council, National Academy of Sciences.
483.35 (c) (2) *Be prepared in advance*
483.35 (c) (3) *Be followed*.

Menus – Whose are they?

This requirement for menus that reflect recommended daily allowances has kept registered dietitians very busy over the years. The conflict between what has been planned on paper and what the person wants to eat has come to a head. Providers seeking to honor resident choice like never before have bumped into the strict enforcement of this regulation, serving what is on that menu, period.

The Intent section of the guidance for this regulation states: *This regulation also assures that there is a prepared menu by which nutritionally adequate meals have been planned for the resident and followed.*

Planned for the resident is problematic. It seems the time has come in our quest to create home, which is also a CMS requirement, that menus should be planned by residents and at the very least with residents. In Colorado there are two State requirements that could lend a hand. The Colorado State Assisted Living Residences licensure regulations include residents in the following menu requirement:

> *Residents shall be encouraged to **participate in planning and making suggestions as to menus** and the facility shall make reasonable efforts to accommodate such suggestions. (1.109 4c)*

In 2008 the Colorado Department of Healthcare Policy and Finance developed the Colorado Nursing Facilities Pay for Performance (P4P) Medicaid reimbursement program which also includes resident participation in menu planning. One of the minimum requirements is:

> Menus that include numerous options, menus developed **with resident input**. Menu options must be more than the entree and alternate selection. These options should **include input from a resident/family advisory group** such as resident council or a dining advisory committee. **The residents have input** into the appearance of the dining atmosphere.

Recommendation: CMS consider rewording regulatory text and guidance to include resident involvement in menu planning as this reflects choice and home which are also required by CMS regulations.

483.35 (c) (3) *Be followed* – Menus placed above Resident Choice

The next problem becomes the menu on paper compared to a person's personal choice. Unfortunately, in some states this tag is being cited even when a resident indicates they do not want the items stated on the menu. OBRA '87 throughout the regulations requires individualization, yet we do not see it upheld when deficiencies such as this are given. Speaking as a former surveyor, often it is easiest for a surveyor to treat issues in a very black and white manner, i.e., cite that the menu was not followed.

Review of, and exploration into, several deficiencies regarding this issue have revealed the following. First, staff who know the situation and resident involved explain "the rest of the story" to be that the resident did not want the milk, for instance, that was listed on the menu. Second, even if it became a "he said, she said" situation with the surveyor and facility staff, the 2567s (Statements of Deficiencies) that I'm reviewing online do not include any resident interviews nor do they state that the resident was non-interviewable. If not receiving what was on the menu was a problem to the resident, wouldn't surveyors include the resident's interview? And if it was not a problem to the resident, why is it being written? Third, consultant dietitians involved have revealed that the facility or corporate decision "behind the scenes" becomes "just put milk on every resident's tray when the state is in the building." Is that the goal? Consultant dietitians are quick to point out that there was also no deficit in the resident's health by not taking the milk, that milk substitutes were/are offered and call this a "knee jerk" reaction by facilities and companies.

From the Procedures section of the interpretive guidelines for this tag, F363:

> *For sampled residents…observe if meals served are consistent with the planned menu and care plan in the amounts, types and consistency of foods served*.
> *If the survey team observes deviation from the planned menu, review appropriate documentation from diet card, record review, and interviews with food service manager or dietician to support reason(s) for deviation from the written menu.*

Notice, it does <u>not</u> state that deviation from the menu is deficient practice but rather surveyors are guided to investigate the <u>reasons</u> for the deviation. It seems that many surveyors get stuck at the first sentence to observe if meals are consistent with the menu, period. Again, that is easy to check, it is black and white. More investigation is required when one looks into <u>why</u> there was deviation. CMS guides the surveyor to conduct a *record review*. Therefore if the facility has explained "the story" in assessments and the plan of care, according to this guidance it should be a non-issue. What is missing above as part of the review is interviewing the resident or her/his representative regarding the deviation and how they feel about it.

Recommendation: This guidance regarding deviation from the menu also requires a resident interview to be a part of the investigation. The wording *be followed*, is problematic as the focus by surveyors on the menu being followed is in conflict with CMS' requirement for facilities to honor the residents' right to choice at Tag F242. CMS clarify guidance to surveyors that resident choice "trumps" any planned menu by indicating that a planned

menu is *not intended to restrict resident choice* such as CMS has stated at tag F371 regarding food being brought in by visitors. Also following suit with guidance at other tags, CMS guide surveyors to cite Tag F242 when choice is not being honored. The guidance for this tag F363 has not been updated since 1987 and may be in need of so doing. In future guidance, both providers and surveyors could be refocused onto what has been done to encourage good nutrition per individual needs and <u>with</u> the individual.

<u>Scoop and Portion Sizes versus Individual Preference</u>

Scoop and ladle sizes are listed on the very bottom of the traditional survey Kitchen Observation form. There are no instructions regarding them anywhere on this form or anywhere in any guidance. It is understandable that the appropriate scoop size pertains to the recommended allowances of protein, carbohydrates, etc. However, many residents have made it very clear that too much food on their plate overwhelms them Both common sense and CMS guidance would tell us that what the resident wants would trump some arbitrary protein scoop size. But every surveyor approaches this differently. As CMS Western Consortium Captain Steven Chickering stated at the California Culture Change Coalition kick off events in 2007, "Scoop sizes should not be the end all be all."

It seems that many issues are boiling down to this one issue – whether the resident's voice trumps the requirements put upon the facility. One of the Pioneer Network's core values is "Put the person before the task." In this case, we need to "Put the person before the facility's requirement." And certainly, as with anything else, wouldn't the resident's choice especially "trump" when it has been assessed, shown to be the resident's preference and identified in her care plan? Perhaps even in her own voice quoting her stating her wishes right on her care plan?

Recommendation: CMS to clarify and train that resident choice trumps any planned menu or any facility requirement in the end. CMS could also clarify use of scoop sizes compared to resident portion size preference. In fact, CMS has a great example of *interventions to improve food/fluid intake* in the guidance for F325 that mentions portion sizes: *Increasing the portion sizes of a resident's favorite foods and meals*.

<u>483.35 (d) F364 Food</u>

Each resident receives and the facility provides:

(1) Food prepared by methods that conserve nutritive value, flavor and appearance;

(2) Food that is palatable, attractive and at the proper temperature;

When talking with a friend who doesn't work in long-term care about this paper she blurted out, "Give the residents fresh foods, don't even <u>let</u> canned food be served, there is <u>no</u> nutritive value in canned foods." What if canned foods started to be considered a method of serving food that does not conserve nutritive value? That would be a big change. And if we're serious about conserving nutritive value my friend might be onto something.

483.35 (d) (3) F365 *Food prepared in a form and designed to meet individual needs.*

This tag is interesting. When you think back to the example of a person not even being able to downgrade his diet texture for a sore mouth because his physician order would not be followed, that also contradicts this requirement.

483.35 (d) (4) F366 *Substitutes offered of similar nutritive value to residents who refuse food served.*

It seems to me that CMS has already covered much of our issues with resident choice right here by identifying that residents <u>do</u> *refuse food served.*

From CMS' Dining and Food Service Investigative Protocol, surveyors are to observe if an equivalent substitute is offered within 15 minutes. 15 minutes that's quick. All the more reason for smaller living environments and for consistent staff caring for residents in order for a care giver to even observe that a resident might need a substitute, let alone to ensure it is offered in 15 minutes. And are surveyors really watching for this?

In a two year research study in two nursing homes 12 months after implementing paid feeding or dining assistant programs, researchers found that "both types of staff (the paid feeding/dining assistants and nurse aides) did a poor job of offering residents alternatives to the served meal, even when the residents' oral intake was low." Additionally, "the majority of both groups of staff who completed an interview reported that they were responsible for the retrieval of alternatives if the resident did not like the served meal" (Bertrand et al, 2009). Such a detailed study reveals there is much work to be done. Staff need to be trained and held accountable to observe resident eating patterns every meal and be quick, 15 minutes quick, to provide substitutes.

<u>F367 483.35(e) Therapeutic diets</u>

Therapeutic diets must be prescribed by the attending physician.

"Low-salt, low-cholesterol diets are unpalatable and are often associated with protein energy malnutrition and postural hypotension in older persons… studies have shown that weight loss, low albumin levels, and orthostatism are associated with therapeutic diets. **In the nursing home, special diets should therefore be avoided whenever possible**" (Morley and Silver, 1995). According to these two physician researchers, therapeutic diets in and of themselves could actually be considered a deficient practice regarding weight loss and other nutritional deficits. That is new thinking.

This tag falls under Dietary services which basically means that dietary service staff is to provide what the physician has ordered thus making it an easy black and white issue for surveyors to cite when it doesn't happen. Handy points out, "This is the tag that I think is often written and is most at risk when culture change concept opportunities 'allow' residents to make choices and decisions for food texture or therapeutics NOT on their ordered therapeutic diets" (2009).

Recommendation: It seems the case is being made that CMS requirements around therapeutic diets, both here at F367 and at F325 should be reconsidered. Perhaps besides dietitians, CMS should engage psychologists in looking at the matter of choice and what happens when one's choices are not honored such as depression and other psychosocial harm as well as weight loss as indicated by the researchers above. (More on this follows later in this paper.)

Therapeutic Diets, "Non-compliant" and Choice

"Non-compliant" – a term we've heard often in our business of long term care. In having done some work and writing around this issue, here are some of my thoughts on this undignified label we give residents:

> A connotation comes with the term, with the label, doesn't it? This particular word goes beyond just "dignifying" our language, there's more to it, much more comes with it and unfortunately none of it positive.
>
> Now let me ask you, we all know we *should* eat right and exercise, and we *should not* drink too much caffeine and smoke. How many of us are … "non-compliant?" But we certainly don't call it non-compliant now do we? Instead, what are we doing? *Making choices?* What are we exerting? *Our rights?* What are we living? *Our life?* Don't we have the right to make bad choices? Don't people have the right to make poor choices?
> Who are we to tell anyone what to do or not to do? Who are we to wake someone up in the morning? Who are we to tell someone they *can't* eat this or they *have to* eat that?
>
> Have you thought about this issue? Have you struggled with it? Are you tired of calling someone "non-compliant" when in your heart of hearts you know that what they're doing you would probably do too?
>
> Haven't we dealt with a person who chooses not to follow her no concentrated sweets diet all along? Hasn't there been such a person in most every nursing home you've served in? Are you ready for a new day? One that honors people instead of pigeonholing them to be considered a bad person?
>
> Well, the new day is here and we invite you to join it. The movers and shakers and adopters of the culture change movement say move over "non-compliant," hello choices! (LTC Leader 10/6/09)."

Recommendation to all of us: We can all stop using this derogatory word that puts people down. We can each choose to call it what it is, a person making choice, choosing to not follow the physician order. We can stop saying it, we can stop using it in our documentation, and we can stop using it on a person's care plan. Speaking of choice, we can choose to eliminate this label from our long-term care language and instead create a beautiful language we are proud to speak.

The Physician Order

So what is the role of the physician order? Is it that, "A physician order is just a recommendation." Medical director, Dr. Bobbie Livingston, said this at a culture change committee meeting in a Colorado nursing home in 2005 and I've been quoting her ever since. Aren't we all guilty of not following a physician order to the nth degree? Aren't we all privileged to make that choice? We take this for granted on the outside of a nursing home but what happens inside the walls of a nursing home? Isn't the physician order treated in a nursing home almost as if God wrote it? Why is this? And is that its proper place?

I'm curious what defines the power physicians have or do not have. As far as their power within the long term care facility, the CMS guidance at Tag 325 Nutrition states that health care practitioners, e.g., physicians and nurse practitioners help *define the nature of the problem* and *tailor interventions to the resident's specific causes and situation and monitor the continued relevance of those interventions*. *Tailor*, that is definitely person-centered, however, it seems to be missing in many cases.

The California Department of Public Health (CDPH) Licensure and Certification office, the State survey agency, points out in the Dining Project package (explained in more detail later), "Physicians are typically responsive to their patient's wishes and requests. Care for the elderly population supports liberalized therapeutic diets as ordered by the resident's physician and have been successfully incorporated in skilled nursing facilities" (2008). However, CDPH also stated "… there may be the rare instance when resident's choices **cannot** [emphasis added] be integrated" (2008). But no examples or further explanation was given by the State survey agency and it sure leaves "a wrong taste," doesn't it? Does this mean physicians have the right to order, to make, to force someone to do something? That would be in direct conflict with Tag F155 Right to refuse medical treatment.

It seems the trickiest scenario is when a person at high risk for choking has an order for thickened liquids but does not want to follow it, wanting instead to drink regular thin liquid beverages. Linda Handy relays that "administrators become concerned about two areas: First, being cited for F367 Resident to receive and consume the ordered physician's diet order and second, some liabilities. If the facility contributed to a 'death', heaven forbid, would the duty or expected stewardship of care supersede resident rights?" (2009). Once again, and this will come up again and again in this paper and in the symposium, which trumps the physician or the person's right to choice? It seems obvious.

Recommendation: CMS develop new guidance and steps for 155 Right to Refuse Medical Treatment. Guidance for this important tag has never been updated since 1987.

When a Person Chooses to Not follow a Physician Order

It is my understanding and when I ask nurses across the country they agree, that when a person does not follow a prescribed physician order, the nurse is to call the physician to get

an order that will work. When there is a side effect from a medication, the nurse naturally calls the physician to explain the order is not working for the person. What about an order for a restricted diet the person will not follow? Are physicians being called or is this step being missed? Most nurses admit in trainings around the country this step is not usually being taken. And most staff agree we keep pointing at the resident saying "you should," "you must," "you have to" follow that order and treat them as if they are "bad" for not doing so… when it is *their* life. What about going "against medical advice?" Isn't this something a nurse has a duty to report?

CMS Region IX also identified this issue in their answers to culture change questions n the Dining Pilot:

> Staff participants may need to be flexible in allowing certain foods prohibited on any resident's dietary restrictions and focus on the role of nutrition in maintaining health in the nursing home's residents. While the facility is required to follow the doctor's orders for a resident's diet, ***staff participants may need to clarify information to the doctor*** [emphasis added] regarding the resident rights and the role of nutrition in maintaining the resident's health and quality of life (2008).

Attorney Kelly McDonald advises to not only inform the physician but to also verify that the physician is fully aware of a resident's decisions. She states that if the physician isn't fully aware of the circumstances and there is an adverse outcome relating to the resident's choice to not follow a diet order, issues with the family and survey team can become far more difficult to resolve (2009).

In CMS' own requirements at Tag F309 Quality of Care, the physician is required to be *notified regarding significant changes in the resident's condition or a need to alter treatment significantly*. Also the *facility is expected to address the resident's concerns and offer relevant alternatives* when a resident refuses services. In the article, Preventing Malnutrition in the Elderly, author Clint Weber says, "Registered nurses are key in the fight against elderly malnutrition because they give the most direct care to elderly populations" (2008).

And what about the physician's duty? I am hearing about physicians who won't change or liberalize a diet. What about the duty to "do no harm?"

Dr. Brechtelsbauer, the current President of the American Medical Directors Association (AMDA), did a study where nurses were interviewed and completed questionnaires in 26 nursing homes in Connecticut. He found barriers to good nurse-physician communication to be that nurses feel hurried by the physician, that she/he is bothering the physician, that the physician does not want to deal with the problem, and anticipates that the physician will be rude or unpleasant (2009). The nurse is the life line to the physician, if s/he feels this way, there is no life line.

In the California Dining Project, CMS Region IX encourages thinking about "partnership":

> Nursing facilities need to establish a partnership among the health care practitioners including consistently assigned direct care staff, the long term and short stay residents and his/her families (when appropriate) to ensure that food and fluid decisions respect all these residents' wants, needs and preferences and that the capable residents, care givers and involved families are satisfied with their care, as well as their clinical outcomes. Coordination and integration of the nutrition and hydration services should involve and include clinical, ancillary, and support services staff. Capable residents should be encouraged to give on-going input about the program (2008).

The Role of the Physician Order

Why it is that we even have physician orders for diets at all? A physician's oversight for a special/therapeutic diet makes sense when a person is in a very compromised situation. But then how did this practice morph into needing a physician order for everything? For a pass to go out for activities? To volunteer in the facility? I do not see in the regulations or anywhere where this level of oversight (interference?) is required.

Along these lines, I remember once during a survey watching my nurse surveyor colleagues get a little bent out of shape with a Rum and Coke event planned for later that day, "but what about medications?" When I asked then administrator and nurse Beth Irtz she said, "Carmen, it's this much rum (holding her fingers maybe a half inch apart)." So this raises another issue, must physician approval be gained for any bit of alcohol any resident has or wants to have. I think what must have happened is that of course when someone is on a drug with contraindications to alcohol we need to be aware of the risk but then it became rote to check with the physician for every resident whether or not they even took medication. It has always seemed like overkill to me but that is the mark of an institution, making a rule that applies to everyone.

Recommendation: That CMS or AMDA, the American Medical Directors Association, clarify what kinds of orders are really necessary and in the physician's purview to make. Also clarify what is meant by the term "order." If it is really a recommendation, perhaps the word itself is in need of replacing.

Recommendation: CMS, nursing associations and programs, and facilities clarify that when restricted diets are refused the resident's physician should be informed, and that a diet should be found that works for, not against, the person. CMS has already led the way by giving guidance at Tag F325 that *the resident, facility and practitioner collaborate to identify pertinent alternatives.*

F368 483.35(f) Frequency of Meals – "The 14 Hour Rule"

1) *Each resident receives and the facility provides at least three meals daily, at regular times comparable to normal mealtimes in the community.*
2) *There must be no more than 14 hours between a substantial evening meal and breakfast the following day, except as provided in (4) below.*

3) *The facility must offer snacks at bedtime daily.*
4) *When a nourishing snack is provided at bedtime, up to 16 hours may elapse between a substantial evening meal and breakfast the following day if a resident group agrees to this meal span, and a nourishing snack is served.*

Unfortunately, this regulation has become known as "the 14 hour rule" by providers and surveyors and has become problematic with "operators interpreting that it is the only way to schedule meal services and not allow dining programs to be flexible and defined by the elders" (Moldono, 2009). This is what is often referred to as using regulations as excuses. Looking closely at this requirement, 14 hours can easily be turned into 16 hours. Plus anyone can see that when dining times are expanded, certainly three meals a day are provided while a facility is also more compliant with Tag 242 Self-determination and participation than ever before. Are time frames needed anymore as we look at accommodating residents' preferences? Here is an example of a regulation that does not specify time frames from the Colorado Assisted Living Residences State licensure regulations : "At least three nutritionally balanced meals … shall be made available (CO ALR 1.109 3i)."

It would be good for CMS to answer some of the questions that arise regarding this requirement such as how often the Resident Council needs to approve mealtimes going beyond the 14 hour timeframe. Many more questions arise surrounding the part of this requirement that the *facility must offer snacks at bedtime daily.* This statement has led to many questions over the years for both surveyors and providers. Does staff have to go to resident rooms to offer the snack or can they just inform residents that snacks are available for whenever they want one? What if the resident is sleeping when the snacks are delivered? Do staff need to document when the resident did not get a snack?

CMS could borrow from the following two States' requirements:

> Frequency of Meal Requirements for the State of Texas:
> c) The facility must offer snacks at bedtime daily. Routine snacks that are not ordered by the physician and are not part of the plan of care do not need to be documented as accepted or rejected.
>
> Frequency of Meal Requirements for the State of Minnesota
> 4658.0620 FREQUENCY OF MEALS.
> Subp. 2. Snacks. The nursing home must offer evening snacks daily. "Offer" means having snacks available and making the resident aware of that availability (http://www.hpm.umn.edu/NHRegsPlus/index.htm).

Recommendations: CMS clarify that the intent for this regulation is met and facilities are compliant with this tag as long as three meals a day are made available to residents. Or CMS write new regulatory language that simply three meals be available and delete the language regarding hours between evening and supper meals altogether. CMS refer surveyors to Tag F242 Self-determination and participation, when choice in dining times is not offered. Additionally, the Intent that currently states, *times consistent with the*

community, could go further to state something like "times consistent with resident preferences."

CMS already gave some good guidance in the S&C-07-07 letter (Appendix B) answering culture change questions including "the 14 hour rule" and the resident right to choice:

> Question 1: Tag F368 (Frequency of Meals): You request a clarification that the regulation language at this Tag that "each resident receives and the facility provides at least three meals daily" does not require the resident to actually eat the food for the facility to be in compliance. You also ask for clarification about the regulatory language specifying that there must be no more than 14 hours between supper and breakfast (or 16 hours if a resident group agrees and a nourishing snack is provided). You state that some believe this language means all of the residents must actually eat promptly by the 14th hour, which makes it difficult for the facility to honor a specific resident's request to refuse a night snack and then sleep late.
>
> Response 1: The regulation language is in place to prevent facilities from offering less than 3 meals per day and to prevent facilities from serving supper so early in the afternoon that a significant period of time elapses until residents receive their next meal. The language was not intended to diminish the right of any resident to refuse any particular meal or snack, nor to diminish the right of a resident over their sleeping and waking time. These rights are described at Tag F242, Self-determination and participation. You are correct in assuming that the regulation language at F368 means that the facility must be offering meals and snacks as specified, but that each resident maintains the right to refuse the food offered. If surveyors encounter a situation in which a resident or residents are refusing snacks routinely, they would ask the resident(s) the reason for their customary refusal and would continue to investigate this issue only if the resident(s) complain about the food items provided. If a resident is sleeping late and misses breakfast, surveyors would want to know if the facility has anything for the resident to eat when they awaken (such as continental breakfast items) if they desire any food before lunch time begins.

<u>F369 483.35(g) Assistive devices</u>

Assistive devices are so helpful to certain individuals needing them, contributing greatly to independence. This tag plays an important role in helping residents reach their highest practicable level of well-being.

The next regulation, F371 closes the Dietary services section. Other than F371 Kitchen sanitation, the rest of the Tags under Dietary services have not had any updated guidance or investigative protocols written since 1987. Many ideas for updating them have been suggested in order to keep up with the new standards of individualized care which CMS has shown great commitment in doing.

Recommendation: CMS consider convening a panel of experts to develop up-to-date guidance for the Dietary services Tags that have not been recently updated.

<u>F371 483.35(i) Sanitary conditions</u>

The facility must: 1) Procure food from sources approved or considered satisfactory by Federal, State or local authorities: and 2) Store, prepare, distribute and serve food under sanitary conditions.

Much is covered in the newly revised guidance to this Tag F371 which was issued June 20, 2008 with an effective date of Sept. 1, 2008. Many questions have already been raised within the context of culture change and rightfully so as new ideas keep pushing what we will accept as common practice.

First off, kudos to CMS for recognizing new approaches within this tag:

> *Approaches to create a homelike environment or to provide accessible nourishments may include a variety of unconventional and non-institutional food services. Meals or snacks may be served at times other than scheduled meal times and convenience foods, ready-to-eat foods, and pre-packaged foods may be stored and microwave heated on the nursing units. Whatever the approach, it is important that staff follow safe food handling practices.*

Unsafe Food Sources

Unsafe food sources are not approved or considered satisfactory by Federal, State or local authorities. Nursing homes are not permitted to use home-prepared or home preserved (e.g. canned, pickled) foods for service to residents. This topic and statement have received a great deal of attention since the new guidance was issued. CMS was bombarded with questions and responded with this clarification added to the guidance May, 29 2009: *NOTE: The food procurement requirements for facilities are not intended to restrict resident choice. All residents have the right to accept food brought to the facility by any visitor(s) for any resident.*

This clarification was issued in a June 12, 2009 CMS Survey and Certification letter SC 09_39 (Appendix A) in which CMS also indicated to facilities:

> The facility does have a responsibility under the food and safety regulatory language at F371 to help visitors understand safe food handling practices (such as not holding or transporting foods containing perishable ingredients at temperatures above 41 degrees F) and to ensure that if they are assisting visitors with reheating or other preparation activities, that facility staff use safe food handling practices and encourage visitors and residents who are contributing to food preparation in the facility to use these safe practices as well.

As Linda Handy points out, there are three messages within this memo:

1. There is an EXPECTATION that the facility assist visitors/families with safe handling. She suggests guidelines for safe food handling practices include reminders that persons needing long term care are often the most vulnerable and susceptible to food borne illnesses.
2. Once food is in the building, safe handling now becomes the facility's responsibility, so what is the procedure and does all staff know it?
3. Surveyors should now be citing facilities at Tag 242 if their right to accept foods brought to the facility is not honored! There's a switch. Handy has a great "note" of her own pointing out that surveyors have been taught for years that potlucks were <u>not</u> allowed and now potlucks <u>are</u> allowed. She suggests giving safe food handling guidelines to staff and families regarding preparing foods at home and transporting them to the facility (2009).

So, yes food can be brought in but the facility still has responsibilities to keep it safe once it's there and try to have it come in as safe as possible. I often try to put myself in the shoes of an administrator and think about what I would do. And, of course nobody wants anybody to get sick. So, I have come up with the suggestion of inviting people who bring foods into the nursing home to bring only baked or cooked items. This would add an extra level of safeguard baking off any poor infection control practices used at someone's home and burning off any pathogens that inadvertently got into some dish. I would then have my kitchen staff members prepare any dips/sauces/dressings that include sour cream or mayonnaise that are more problematic. And of course facility staff would take the responsibility over of ensuring the potluck foods are cold and hot enough. A facility gets to decide on their own policies and practices to uphold resident rights as well as keep food safe.

CMS actually gave guidance on this issue in the Survey and Certification S&C -07-07 December 21, 2006 answering culture change questions (Appendix B):

> Question 2: (370) Approved Food Sources: You ask if the regulatory language at this Tag that the facility must procure food from approved food sources prohibits residents from any of the following: 1) growing their own garden produce and eating it; 2) eating fish they have caught o a fishing trip; or 3) eating food brought to them by their own family or friends.
>
> Response 2: The regulatory language at this Tag is in place to prohibit a facility from procuring their food supply from questionable food sources, in order to keep residents safe. It would be problematic if the facility is serving food to <u>all</u> residents from the sources you list, since the facility would not be able to verify that the food they are providing is safe. The regulation is not intended to diminish the rights of specific residents to eat food in any of the circumstances you mention. In those cases, the facility is not procuring food. The residents are making their own choices to eat what they desire to eat. This would also be the case if a resident ordered a pizza, attended a ball game and bought a hot dog, or any similar circumstance. The

right to make these choices is also part of the regulatory language at F242, that the resident has the right to, "make choices about aspects of his or her life that are important to the resident." This is a key right that we believe is also an important contributing factor to a resident's quality of life.

CMS articulates in this memo the difference between the facility procuring food from approved sources and the right of residents to make choice, an important distinction.

Gardens

Already in 2006 in the S&C -07-07 letter (Appendix B), CMS honored the resident right to choose to eat foods they grew in a garden under the umbrella of involvement in activities, not food procured by the facility for all residents. Since that time CMS has received many questions as to whether gardens planted by the facility to serve the whole population is acceptable. For a while the FDA advised CMS to tell nursing homes their gardens must be approved by the FDA. However, it didn't take long for the FDA to realize they did not have the manpower to inspect potentially 16,100 gardens, and with CMS is now working with the FDA on a solution and Glenda Lewis from the FDA will address this issue at the Creating Home II symposium. Homes are eagerly awaiting the regulatory "green light" to be able to serve the whole population delicious, fresh vegetables, not just in an activity.

No bare hand contact

In the Employee Health section of this guidance it is stated: *Bare hand contact with foods is prohibited*. This requirement stems from the Food and Drug Administration's (FDA) Food Code and this issue has raised many questions and concerns.

The Food Code's Intent at 1-102.10 is stated as, "The purpose of this Code is to safeguard public health and provide to consumers food that is safe, unadulterated, and honestly presented."

In Chapter 3 of the Food Code at 3-301.11 is where no bare hand contact is found:
(B) "….Food employees may not contact exposed, ready-to-eat food with their bare hands and shall use suitable utensils such as deli tissue, tongs, single use gloves or dispensing equipment."

(D) "Food employees not serving a highly susceptible population may contact, exposed, ready-to-eat food with their bare hands if…" (many points follow).

At 3-801.11 (D) Special requirements for Highly Susceptible Populations it is stated, "Food employees may not contact ready-to-eat food" and "'Food employee' means an individual working with unpackaged food, food equipment or utensils, or food-contact surfaces" according to Chapter 1 – Purpose and Definitions.

It does seem this definition would apply to any of us working with food whether in a neighborhood or household or in what we call the main kitchen.

"Highly susceptible population" means persons who are more likely than other people in the general population to experience foodborne disease because they are:
(1) Immunocompromised; preschool aged children, or older adults; and
(2) Obtaining food at a facility that provides services such as custodial care, health care, or assisted living, such as a child or adult day care center, kidney dialysis center, hospital or nursing home, or nutritional or socialization services such as a senior center.

The FDA Food Code can be accessed at http://www.fda.gov/Food/FoodSafety/RetailFoodProtection/FoodCode/FoodCode2009/ucm186464.htm (as of Dec. 2009).

The nursing home, older adults and immunocompromised individuals no matter their age are identified as a highly susceptible population thus meaning we must have "no bare hand contact" with food in the nursing home. Our struggle, however, is to assist a fellow human being eat within a pleasant and dignified dining experience three times a day plus snacks. To assist a person to eat literally means to feed them and to feed someone handling food items that need to be touched such as breads sandwiches with gloved hands does not fit the warm environment we're trying to create. Many residents are responding to this practice with "What is wrong with me that you have to use gloves around me?" Once again, this is certainly not the outcome we want.

What if staff members washed their hands prior to touching the bread? That would seem more normal to the residents. Proper hand washing gets lots of attention at Tag 441, so why the jump to "no bare hand contact?" Washing hands is by far the best strategy to prevent the spread of infection. Why don't we focus on hand washing instead of "no bare hand contact?" In a discussion with epidemiologist Dr. Nimalie Stone of the CDC, she too agrees that if a person was to wash his/her hands and then sit and assist/feed a resident, that should be safe (2009). I personally get feelings of being offended when I am told I would need to glove my hands in order to feed someone. Some people are diligent in washing their hands and that is what we want, isn't it? The use of tongs and tissues and even a fork and knife to butter bread makes sense but gloves when feeding someone needs discussion, and maybe needs some definitive research.

And this requirement, "no bare hand contact" is in direct conflict with brand new July 2009 CMS guidance at Tag F441 Infection control where this situation is identified as requiring hand hygiene (washing with soap and water):

Hand Hygiene continues to be the primary means of preventing the transmission of infection. The following is a list of some situations that require hand hygiene:

- *Before and after direct resident contact (for which hand hygiene is indicated by acceptable professional practice);*
- *Before and after eating or handling food (hand washing with soap and water);*
- *Before and after assisting a resident with meals (hand washing with soap and water):*

- *After removing gloves or aprons.*

Gloves – More Harm than Good?

Gloves are not the answer. They are often part of the problem. You can watch poor, make that bad, infection control practice by people wearing gloves all over America. I watched a person take my money with a gloved hand and then handle my bagel at a bagel shop. I watched a person open the walk-in cooler handle with her gloved hand, get something then come back and touch the meats and cheeses at a deli with the same gloved hand. As a surveyor and consultant for most of my career, I've watched staff of nursing homes do the same thing From the staff members in the kitchen to the CNAs and even nurses I've seen all staff, guilty of poor infection control practice. And what were they all wearing? Gloves. And, interestingly enough, aren't we all trained to know better? Apparently CMS agrees and has given tighter guidance regarding gloves here at F371:

> *Gloved hands are considered a food contact surface that can get contaminated or soiled. Failure to change gloves between tasks can contribute to cross-contamination….. NOTE: The use of disposable gloves is not a substitute for proper hand washing with soap and water.*

Recommendation: CMS reconsider the *no bare hand contact* at all times and instead lean on its own F441 guidance as to when washing hands is necessary. CMS will perpetuate the use of gloves with this guidance instead of good hand hygiene.

Invite Community Members to Prevent Infections

In my days as a surveyor in Colorado, we called this The Magic Glove Syndrome when one would don gloves and appear to not think about what they were touching with their gloved hands. I contend that when one does not wear gloves our chances of the person realizing they just scratched their head and should now wash their hands is increased. The glove seems to make people feel they can do anything. Certainly they are protected themselves but good practice more often than not seems to be forgotten. Debra Swinton-Spears, nurse consultant with CMS Division of Nursing Homes who was the lead in developing the 371 and 325 guidance revisions, in a conversation explained it best. She pointed out that when we just tell staff to wear gloves we just create a rule for them to follow. On the contrary, she wisely points out that when we invite staff and everyone in a community for that matter to help prevent infections, to not get any, to watch the data, we invite them to think about it instead of just follow an arbitrary rule. She also points out, "we use volumes of gloves but residents are still getting MRSA" (2009).

The California Dining Project highlighted issues that arose in their pilot project. This exact issue came up as one of their Thinking Points: "Requiring gloves seems to be a conflict between the intent to protect highly susceptible residents and 'home-like' dining; and the case probably could be made that gloves should not be required for staff who dine with residents (2008). Interesting point California makes that staff wearing gloves while dining with or feeding residents should be considered a dignity issue and potentially cited as

deficient practice under Tag F241 Dignity. That is precisely for what much of the culture change community is advocating.

Storage of Food Brought into the Nursing Home – New Rules

Some State survey agencies have decided that food brought into the nursing home cannot be kept with facility food. Some are requiring the facility to log in all foods brought into the home. Others are requiring the facility to interview the person who made the food to inquire about safe food practices and whether ingredients used were obtained from approved food sources. Can you imagine? CMS, a little more guidance please.

Resident Refrigerators

This is an area needing discussion. Who has the responsibility of maintaining them, resident or facility? The Environment task in the QIS survey directs surveyors to look at "snack/nourishment refrigerators on the units." Some surveyors have taken this to mean looking at resident's personal refrigerators, but should they? Should facilities have oversight for something that belongs personally to a resident? This is what a Thinking Point in the California Dining Project directs: "Refrigerators: In pantry & resident rooms need temperature monitoring, food labeling & dating, and throw away oversight" (2008).

Will CMS take the similar stand as it has with food brought into the facility by visitors that residents certainly have the right to have a personal refrigerator but that the facility has responsibility to educate residents on food safety, storage and handling? What if the resident chooses to disregard food safety instruction? Does the facility need to keep documentation that the resident was educated (including given risk) and chose to disregard? These may be good discussion points for a panel or national workgroup to discuss perhaps. No one wants anyone to get sick so regardless of what CMS requires or does not require, nursing homes may wisely design dignified ways to have staff inquire with residents about their food storage and come to some mutual agreements for food safety.

Take-out and Delivered Foods

Again, per the new CMS clarification, take-out and home delivery foods are the right of residents. And again, per the 5/29/09 Survey and Certification letter (Appendix B), the facility does end up with the responsibility to keep foods safe. I suppose someone could ask what if staff is unaware that a resident brought food to the nursing home. This could certainly happen and probably has many times. It reinforces the benefits of consistent staffing where relationship can form and staff is aware of each resident's comings and goings, habits and routines. This issue also reinforces the reason to be educating and reminding residents, staff and families about safe food handling practices continually. Getting sick from contaminated food can be life-threatening and must be treated with the utmost importance.

Getting Creative

We are seeing consistent recommendations from CMS to educate everyone on safe food handling practices. We can't go wrong in following this good advice. So, how about getting creative? According to dietary consultant Lori Maldono, chemical vendors have "cool" and inventive stuff from glow gels to black lights that show microorganisms we can't see, Serve Safe education encourages practical applications, scavenger hunts can be fun, staff members can be identified with names of bacterium during trainings, art can be made to demonstrate bacterium with yarn, noodles, Cheerios, etc. and Petri dishes can always be used to grow actual bugs increasing an awareness of good food handling practices (2009).

Alcohol-based Hand Rubs

In the section Hand Washing, Gloves and Antimicrobial Gel, CMS has stated: *Antimicrobial gel cannot be used in place of proper hand washing techniques in a food service setting*. This should be no problem for any of us. In our homes we use soap and water to wash our hands before preparing meals, not gels. Epidemiologists and others say the antimicrobial gels, more currently being called alcohol-based hand rubs, should be used "between assisting residents." Is this just an arbitrary rule? If I wipe one resident's mouth does it suffice to use this antimicrobial gel before helping someone else to eat? Does this mean the rubs are strong enough to kill any pathogens obtained? Or should hands be washed again is my question. And if the rubs are strong enough to kill microorganisms why does there have to be *no bare hand contact* with foods? The question needing clarification is what can rubs be used for in comparison to hand washing?

Eggs

Guidance here calls for any unpasteurized eggs to be cooked to a 145 degrees Fahrenheit internal temperature, and under the section called Pooled Eggs, CMS has made the statement: *Waivers to allow undercooked unpasteurized eggs for resident preference are not acceptable. Pasteurized shell eggs are available and allow for safe consumption of undercooked eggs*.

Regarding eggs laid by chickens, a question was answered by CMS in response to the Pioneer Network webinar "New Quality of Life Revisions to LTC Surveyor Guidance" June 10 and 11, 2009 which is posted on the PN website at http://pioneernetwork.net/Events/Webinars/LTCGuidance/Session1QA/:

> Q: A resident desires yard eggs from home to be cooked for him at breakfast. Is the facility allowed to prepare those brought in yard eggs for this resident?
>
> A: If by 'Yard eggs' you mean chickens in the yard that are laying eggs. NO, this is NOT allowed, under no circumstances should a facility accept eggs from an unapproved source and prepare them for residents' consumption. ALL EGGS prepared by the facility for residents' consumption should come from an approved source!

Although these are certainly the safest decisions, it does raise issues for some regarding choice and some point out that pasteurized eggs cost more money and are not typical in the community-at-large. Thankfully, a facility would only need to purchase pasteurized eggs for those few residents who want a runny egg, which is not most people, and other good news is that apparently they "look, cook and taste just like other shell eggs" (safeeggs.com/eggs/how-eggs-are-pasteurized.html). It is a well known fact that salmonella in an older and sicker population poses higher risk than in other populations. CMS' goal is to simply prevent unnecessary sickness and death.

<u>Hairnets</u>

In the Action Pact DVD *Nourish the Body and Soul*, a video shot of staff caring for, serving and actually sitting and dining with residents is ruined, in my opinion, by the fact that they are wearing hairnets. To make it worse, what is being said by the narrator is that "just like at home a special or holiday meal, the food keeps coming, the coffee keeps coming and the fellowship keeps coming." Well, you don't see anyone wearing hairnets at home. I also don't see hairnets worn in restaurants. The writers of the video were probably worried about showing infection control compliance and thought they best wear them as they were serving food, however, it is not normal. I think we all agree and "get" that hair nets need to be worn by anyone cooking or preparing food in a main food establishment kitchen. As we come out of an institutional kitchen however and look at societal norms, we don't wear hairnets in our homes even when we are preparing foods for others, and restaurant servers don't wear them either. I think we can all appreciate long hair needing to be restrained but to make the jump that all staff must wear hairnets at all times around food and in all dining areas is something that should be discussed and settled. It would be helpful for the long term care community to define who needs to wear what hair restraint and when. And to clarify, CMS has <u>not</u> said that all staff must wear hairnets.

CMS only requires hair restraints of dietary staff here at F371: *Dietary staff must wear hair restraints (e.g. hairnet, hat, and/or beard restraint) to prevent their hair from contacting exposed food.* In all fairness it makes sense that hair restraints should be worn by any staff *contacting exposed food* especially if there is hair to restrain. It is when this requirement gets stretched to mean in all dining situations, it becomes unhomelike and undignified.

The issue here is that the guidance is written with the assumption of the roles and duties of staff by department. In innovative homes with households or little houses, there is no departmental division of labor, and there is no large, main preparation kitchen that is off limits to residents. Instead, roles become blended. A person who is a certified nursing assistant may be cooking, a person who is a social worker may be dishing out food from large bowls at a table, the administrator or family member or resident may be taking cookies out of the oven, washing dishes, etc. We need clarity on what duties and situations, not what positions or departments, need hair restraints. We need to clarify exactly for what reason in what setting they are required.

And while we are at it, if a particular setting does require hair to be restrained, how exactly should it be restrained? Does a baseball cap suffice? Is it okay for long hair in a pony tail to stick out from the cap? If a person is nearly bald with a fringe of hair, must they wear anything? Does a hairnet need to completely cover every strand of hair? Isn't the goal to prevent hair from ending up in food?

Recommendation: Clarification of the use of hair restraints when serving and dining with residents in CMS guidance.

Scrubs and Uniforms

Some pioneering homes have taken the unfriendliness of gloves and hairnets one step further. Seeing staff mingle, care for, and practically live as family with residents while wearing scrubs and uniforms is also beginning to stand out as institutional and unhomelike. The more we move toward home, the more the medical model practices stand out like a sore thumb. It was in the Almost Home PBS documentary where staff of Saint John's nursing home said, "Why would we wear uniforms, we don't wear them at home" (2006). This return to normalcy in staff clothing was accomplished in large developmental disability facilities and small group homes already decades ago yet nursing "homes" continue to lag behind and look like little hospitals.

Buffets and Steam Tables

There are standards of good infection control practice that naturally come with buffets such as sneeze guards, serving utensils, tongs, tissues and ensuring proper food temperatures.

Food Holding Times

"Danger Zone" refers to temperatures above 41 degrees Fahrenheit (F) and below 135 degrees F that allow the rapid growth of pathogenic microorganisms that can cause foodborne illness. Potentially Hazardous Foods (PHF) or Time/Temperature Control for Safety (TCS) Foods held in the danger zone for more than 4 hours (if being prepared from ingredients at ambient temperature) or 6 hours (if cooked and cooled) may cause foodborne illness outbreak if consumed. CMS specifically mentions the time frame food can be on a steam table following this 4 hour rule: *The maximum length of time that foods can be held on a steam table is a total of 4 hours*.

In Appendix P, the Traditional Survey Process Sub-Task 5B Kitchen/Food Service Observation, it is mentioned that food can be on the steam table for only thirty minutes prior to serving. It might be helpful for CMS to clarify if the four hours would include that 30 minutes.

Food Temperature Questions

It remains a question for some whether the required 135 degrees F is point of service or temperature of food on the plate. Apparently some surveyors are citing Tag 364 Palatability if each hot item is not 135 degrees on the plate.

Recommendations: CMS clarify point of service and plate temperatures. My understanding as a former surveyor was that only point of service was regulated, not plate temperatures which instead depended upon resident opinion of palatability. But this needs to be clarified for all of us.

Family Style Dining

When foods are served in serving bowls like in our homes, good infection control practice needs to be followed and food temperature is important. Point of service now becomes interesting, is point of service considered when foods are taken out of the oven or stove, or is the temperature supposed to be in the serving dishes, or even at the point when the last person takes food onto their plate from the bowl?

Recommendation: CMS is striving to keep up with changes, as evidenced by the very clear statement that food cannot be on a steam table more than 4 hours. Keeping in line with this it would be helpful if CMS continued to create clear guidance for other dining styles such as the food temperature requirements and what is considered point of service for family style dining.

Salt, Pepper, Sugar, and Condiments on Dining Room Tables

Condiments on the table – something very normal, something we do at home and at restaurants. So, can't people living in nursing homes have access to them too? In at least one case in one state the survey agency made the case in a deficiency that was upheld in the informal dispute resolution process that staff was not observed reminding or encouraging the residents of good choices nor were they trained in doing so. However, on Part III of the Individualized Care CMS broadcast series, a home is highlighted that has put condiments on the table, including salt and pepper and even hot sauce. CMS personnel on the show did not have a problem with it. This level of educating staff is important, and really is the only thing a facility can do since none of us can force a person to follow a physician order.

Recommendation: It might be good for CMS to very clearly define what the facility's responsibility is in encouraging residents to make healthy choices but ultimately to be able to support a person in their decisions. CMS uses the term *informed choice* frequently in Tag F325 which probably needs to be clearly defined for everyone.

Resident involvement with Food Preparation

Eric Haider frequently shows a picture of a resident who lived at Crestview when he was the administrator there in the late 90's and early 2000's standing in the kitchen, the main

nursing home kitchen, peeling potatoes…with a knife… a real knife. Most homes typically decide "no way, too dangerous." Eric always points out the natural ability of most residents to do life tasks they have always done safely. In the book *Person Centered Care*, the researchers point out "Because they are so familiar with their residents, Crestview staff are able to take risks with them that other homes would probably avoid. Pushing the envelope is encouraged at the home if it benefits the residents" (2004, 53). In fact, the researchers identified this as "a common theme of the desire to participate in the work of the nursing home. All the residents interviewed participated in some manner at the facility, from gardening to kitchen tasks. There was the desire to participate and still contribute, and they wore their facility name pins proudly throughout the day" (60). There is no reason for facilities to make blanket decisions that no resident can be involved with food preparation. Thankfully, CMS never prevents this nor the Food Code. Of course good infection control practices must be used and one determined to be safe in conducting the task.

Staff Dining with Residents

All over the country staff and residents are demolishing the old unwritten and sometimes written rule that staff may not eat with residents. Why did we create such a rule? Most people's answer is infection control. However, we trust staff to use good infection control with residents no matter what they do. Nothing in CMS regulation or guidance is holding us back, and CMS answered this question already in 2006 in that S&C-07-07 letter (Appendix B):

> Question 11 (Dining Together): Is it permissible for staff and residents to dine together?
>
> Answer 11: There is no federal requirement that prohibits this. We applaud efforts of facilities to make the dining experience less institutional and more like home. Our concern would be for the facility to make sure that residents who need assistance receive it in a timely fashion (not making residents wait to be assisted until staff finish their meals).

So CMS makes it clear from their standpoint that dining together is welcome as long as residents always receive assistance needed.

Many pioneering homes have realized that key to changing an institutional culture is relationship. Some homes' commitment runs so deep they invite staff to dine with residents for all the right reasons - the opportunity to create friendships, assist residents, cue residents and just allow the normalcy of dining together - and then take their lunch break. Remember the residents who didn't eat when staff began to dine with them? What so many really hunger for is companionship. Dr. Thomas and the Eden Alternative® have also well established this (edenalt.com).

F323 Accidents – Dining Safety Issues

Does a Nurse have to be in the Dining Room for Meals?

At Tag F373 regarding paid feeding/dining assistants CMS has stated:

> *Adequate supervision by a supervising nurse does not necessarily mean constant visual contact or being physically present during the meal/snack time, especially if a feeding assistant is assisting a resident to eat in his or her room. However, whatever the location, the feeding assistant must be aware of and know how to access the supervisory nurse immediately in the event that an emergency should occur. Should an emergency arise, a paid feeding assistant must immediately call a supervisory nurse for help on the resident call system.*

This more recent guidance for a newer regulation sheds some light on this age-old question. And even before this regulation and guidance came to be, it was never a Federal requirement that a nurse must be in the dining room, instead it has been facility or company policy that has become a common standard of practice. Certainly we don't want any resident to have an accident in the dining room but anything could happen even with a nurse in the room. Certainly having a nurse in the dining room is not a bad thing if that is what a facility does and has always done. However, as Linda Handy points out, "with the culture change of resident rights for their own normalized patterns of dining, with the wider spread dining hours and many more opportunities to eat, it would be almost impossible to have a policy for a licensed nurse to be in all dining areas all the time" (2009).

Choking is usually the accident we are trying to prevent which requires knowledge of the Heimlich maneuver, not necessarily a nursing degree. Since the Heimlich maneuver can be done by anyone trained to use it, some homes utilize CNAs in the dining room and other homes are training more and more staff members to know how to use it.

Hot Coffee

Hot coffee has become an issue during surveys in the last several years often being cited at the Immediate Jeopardy (IJ) level. This raises some very "hot topics." In an IJ case in Texas the four residents who spilled hot coffee on themselves did not complain, knew that it was a risk of drinking hot coffee and are up in arms with the fact that now the facility has to serve lukewarm coffee in order to be compliant with preventing accidents. The lawyer is making the case that all people who drink coffee burn their lips or mouth at some point but still drink it and learn to approach hot coffee with small sips, pursed lips, and some blowing almost like a learned response. No one likes lukewarm coffee. In fact attorney McDonald explains the facility had lowered the temperature to 140 degrees Fahrenheit (F) but due to an outpouring of complaints had increased the temperature to 160 degrees F (2009).

This brings us right back to the person's choice to drink hot coffee and the facility's requirement to keep people safe. The failure facilities are being cited for is not having assessed residents for their ability to drink hot coffee safely. Isn't there something crazy about this? When a person eats soup and burns him or herself, will there be failure to assess ability to eat soup? What about hot cheese on pizza or lasagna, will there need to be

a cheese on the roof of the mouth assessment too? If this is what CMS wants then perhaps it needs to be spelled out so facilities can start assessing for everything. And at the same time, out of the other side of its mouth so-to-speak CMS requires facilities to honor residents' choice. Thus here is another example of the need to study and deal with how to meld safety and choice.

Recommendation: CMS give much clearer guidance on hot coffee. For instance, are assessments required, really? And guidance on melding the facility's responsibility to prevent accidents and the resident's right to choice is much needed.

F373 483.35(h) Paid Feeding Assistants – Dining Assistants

CMS published a Federal Register rule September of 2003 creating the regulatory language that was then placed at Tag F373, making it possible for long -term care facilities to use Paid Feeding Assistants to help residents eat *who have no complicated eating problems*.

"Paid Feeding Assistant" or "Dining Assistant?"

First of all the language being used here needs to be addressed. Continuing to look at this through culture change eyes, perhaps CMS could consider changing the name to "dining assistants." CMS does have a statement in the guidance at Tag F373 that other titles such as dining assistant may certainly be used. And why was the word "paid" put into the title? We don't call nurses "paid nurses," or any other staff members, "paid" anything. CMS could do better. The term "dining assistant" is better, it flows both with the movement's quest to change undignified language to dignified and would actually be "more compliant" with CMS's *own* change to guidance at Tag F241 Dignity. New Dignity guidance actually identifies the term "feeder" (a sister word to feeding) as an example of undignified, labeling language. CMS is credited with many moves to support quality of life, culture change and dignity, thus making a regulatory title change would be fitting and welcomed. (The term dining assistant (DA) will be used instead of paid feeding assistant in the rest of this paper.)

Recommendation: CMS change Paid Feeding Assistants to Dining Assistants.

Dining Assistant Research

Now that DAs have been in existence for six years, several studies have been completed to investigate the impact of DA programs co-sponsored by CMS and the Agency for Healthcare Research and Quality (AHRQ). Common sense would probably tell us that with increased assistance, one would probably eat better. And now research is showing it to be true. The primary researchers for these studies Drs. Sandra Simmons of Vanderbilt University and Rosanna Bertrand of Abt Associates will share their findings as featured speakers at the upcoming Creating Home II symposium.

A *Manual for Dining Assistant Programs in Nursing Homes: Guidelines for Implementation* has been developed by Abt Associates and Vanderbilt University with funding and input from both CMS and AHRQ. It is available at www.VanderbiltCQA.org. Interestingly , in a

footnote in the Introduction, a comment is made that “we believe that the term ‘dining assistant’ is more sensitive to residents’ sense of dignity.” Also stated is, “the DA program can be the nursing home’s first step toward culture change” (2009). I think they are onto something, changing institutional culture includes making all staff available to meet all needs of all residents all the time (other than licensed-only work of course).

Dining Assistants play a large part in the 24-hour dining that is offered by Rolling Fields of Conneautville, Pennsylvania. Rolling Fields explains that in order to “pull off” 24 hour dining, staff roles had to be changed, every staff member stepped out of their traditional role and became a caregiver including, “all Staff in our home are certified feeding assistants; therefore, anyone can sit down and assist an Elder with his/her meal” (ltlmagazine.com 9/11/09).

Dining Assistants Enhance Quality of Care and Quality of Life

Rolling Fields says that because of their increased selection of food available and because there is more time for one on one interaction with dining, partly due to the DAs, they only have seven residents remaining on a pureed diet from the 20-30 they used to have. They also state, “quality of life for our Elders has been improved greatly because they now may choose exactly what and when they want to eat” (2009).

Pioneer, dietitian, administrator and household culture change leader, Linda Bump says she is “a huge supporter” of DAs “if they can form a relationship with the elder that transcends the task of feeding.” She explains that ”business office professionals, maintenance guys, assisted living and independent housing residents are all ‘great dining assistants’ who form fabulous relationships with their elder friend whom they assist daily, and after the meal, they do a ‘documentable’ 1:1 meaningful activity with their elder friend, always consistently scheduled, and perhaps the highlight of the resident’s day” (2009).

Apparently some culture change leaders have criticized CMS for allowing for DAs. They make the case instead there should be a requirement for more CNAs so that the whole person can be cared for by more people. Although there is certainly merit to this line of thinking, it does seem that some kudos should be given to CMS for creating this option for homes to give more attention to residents at meal time. We now have evidence that specialized training to assist residents in a specific way such as with dining does enhance both quality of life and nutritional care.

More Dining Assistants or More CNAs?

The rationale for more CNAs instead of DAs to be able to assist residents with any daily living need, not just dining, does have great relevance to this discussion.

What if every person working in a nursing home was a CNA? What if “in the beginning” of nursing home time there had been a requirement that every staff member had to be a certified nursing assistant as of 1987? It makes you wonder. What would nursing homes have looked like in comparison to what they look like today? I don’t know how anyone

could argue with the fact that it is simply not good customer service for the many of us who are not CNAs to have to tell a resident they have to wait for help while we go hunt down a CNA. When we do find a CNA, and tell them yet another resident needs them, this does not make friends. We are putting CNAs and the rest of us at odds all the time.

Yes some people can't lift due to bad backs, but residents are rarely lifted by staff anymore thanks to mechanical lifts. So many needs of our dear residents could be met. Providers could do this. Providers could decide that as of next Monday or next month only people who are either already a CNA (or nurse) or willing to become one will be hired. CMS has made many rules and requirements, perhaps a requirement that every staff member be or become a CNA would go even further in bringing about the quality of care and quality of life CMS wants for residents served by Medicare and Medicaid certified nursing homes. But should it have to be a requirement by the government?

Recommendation: Leading nursing homes begin to require all hired staff to be willing to be trained to help residents in every way, including as certified nursing assistants.

483.15 F240 Quality of Life

It is fitting for our discussion about food, dining, and self-directed living to think about the requirements of this Tag that states: *A facility must care for its residents in a manner and in an environment that promotes maintenance or enhancement of each resident's quality of life*.

Quality of life is personal to each person as are food preferences and facilities are required by CMS here to maintain it or even better, enhance it for each resident. The facilities' requirement to promote quality of life only begins here at this Tag which leads the regulatory section of Quality of Life and continues throughout the entire section, 483.15 (a) – (h).

In Handy's *Surveyor MO for Nutritional Status (F325),* she warns, "While self determination/resident rights/homelike environment have always been intended by the OBRA regs, surveyors have really NOT cited many of these tags UNLESS there were obvious abuses and resident complaints, etc. But the new revisions (to Tag F325) will have surveyor probes and expectations with MUCH MORE FOCUS and FORCE to CITE. THE IMPACT WILL BE SIGNIFICANT" (2009). The day is coming when surveyors will cite Tag 242 when choice is not honored. CMS has paved the way.

Depression and Weight Loss

The results of the study conducted by Simmons et al "Prevention of Unintentional Weight Loss in Nursing Home Residents: A Controlled Trial of Feeding Assistance" showed that residents with a diagnosis of depression lost more weight than those without the depression diagnosis. In fact, studies by Morley and Kraenzle, Morley and Silver and Simmons, Cadogen and Carbonnera have shown what is not surprising, that depression is a major cause of unintentional weight loss and yet something that sort of surprises me is that

"depressive symptoms often are undetected and thus untreated in NH residents" (2008). I thought we were good at detecting and treating depression, at the least with medications.

Now, if depression has a high likelihood to <u>cause</u> weight loss, and the depressed person is on a restricted diet they <u>do not want to follow,</u> and the ability to control what they eat is <u>taken away</u> from them, it makes you wonder what we are doing to <u>cause</u> even more depression and subsequent weight loss.

In 2006 CMS released the Psychosocial Outcome Severity Guide, which guides surveyors on how to select the level of severity for any deficiency with a psychosocial outcome or potential outcome to residents (State Operations Manual for Long-term Care Facilities, Appendix P). CMS deserves much credit for developing this guide, for bringing attention to psychosocial severity that could occur as a result of any deficient practice. And even though this attention to psychosocial harm is somewhat new and many surveyors and providers alike are still becoming educated about it, the momentum of the culture change movement is moving everyone toward talking, thinking about and discovering what harm and negative outcome results from <u>the denial of choice</u>.

Recommendation: Researchers and psychologists educate the long term care community on the potential negative outcomes/psychological harm that takes place when choice is not honored that we all can benefit from, ultimately residents.

<u>F241 483.15(a) Dignity</u>

The facility must promote care for residents in a manner and in an environment that maintains or enhances each resident's dignity and respect in full recognition of his or her individuality.

Kudos to the writers of OBRA '87 and this requirement of utmost importance. Note the last part, I think the best part, *in full recognition of his or her individuality*. This is where the whole intent of OBRA is spelled out.

CMS issued new guidance to ten tags in July of 2009, Dignity being one of them. CMS is to be commended for having identified many institutional practices and asking facilities to now avoid them including several dining practices. Food served on trays has been identified as institutional, a remnant of the old hospital-type institution. Staff standing while assisting residents to eat has been earmarked as undignified as well. Surveyors are now guided to watch for staff conversing with residents rather than only with each other and to provide any needed bathroom assistance during meals. And, thankfully bibs have again been identified as undignfied: *Promoting dignity in dining by eliminating such practices as: bibs (also known as clothing protectors) and instead offering cloth napkins.*

<u>Bibs</u>

What would happen if surveyors actually started dialoging with residents about them? I did that as a surveyor. Sure enough, at first residents said there was nothing wrong with

the bib, something many of us have heard residents say. However, when we really discussed bibs, who wears them and when, the residents ended up saying, “Bibs are for babies.”

All around the country I hear caring staff concur that they cannot use the word diaper, too undignified. I know I could just not bring myself to refer to a person’s diaper that is my elder or even younger than me. And so we use other words, avoiding the word diaper. We have tried to apply this thinking to bibs by calling them “shirt savers” or “clothing protectors.” However, it just isn’t the same. A bib is a bib no matter what you call it. Thankfully there is a true replacement that is used in society at large, the linen napkin. Many have shared that their residents say they want their bibs. What residents really want is their clothes to remain clean, they really are not saying they want an undignified, abnormal thing they never even considered using at home even though it has come to seem normal in the institution.

There is an excellent 20 minute training video called Dining with Friends recently made available by the Alzheimer’s Resource Center of Connecticut (alzheimersresourcecenter.org). In it, Dr. Harry Morgan states, “It is sad when I attend some institutions where there is a room called the feed room and that means where we go shovel food into patients with bibs that are white terry cloth bibs…. in a sense, nothing is wrong with a bib, except the message it conveys to a person is that they're now infant like, that they're no longer able to manage… I’m in my baby high chair with a bib on with food being pushed at me” (2010).

We are positioned to finally change what has been accepted as common practice better than ever before. Bibs were identified by CMS in the early 1990’s in the guidance to this same Tag F241 Dignity. They have always been mentioned as undignified practice, but seemingly no one listened and no deficiencies got cited. Now with CMS’ new guidance with emphasis again on bibs being considered an example of what is undignified, updated and placed in the midst of a set of other undignified practices, perhaps surveyors will discuss them with residents and cite Dignity when residents agree they are undignified. A few deficiencies around the country will serve to motivate many to do what residents deserve to give them back what is a norm in the life lived outside of institution.

Recommendation: CMS give more in depth training to surveyors on how to discuss institutional practices with residents. Many residents will say they want bibs and many providers and surveyors alike will jump to the matter of choice that residents have the choice of course to choose bibs and then bibs will never be avoided although avoidance is the goal. Instead, what culture change leaders have taught us is that residents need to be invited into a dialogue about what is normal. They did not wear bibs at home but instead used aprons, paper napkins, linen napkins, the kitchen towel and washed their clothes (another option that rarely is talked about). Residents also need to be invited into the facility’s culture change journey of creating home and what is normal. Providers, residents and surveyors, especially, if they are to be taking the lead on investigating this issue, need more training.

Vendors

Vendors are interested in selling their products. Providers could be telling them they want different products, i.e. no more bibs but instead nice, oversized, absorbent linen napkins. Vendors could lead the way in demolishing undignified practices and items such as terry cloth adult sized baby bibs by no longer selling them. Vendors could play an important part in moving away from the institutional status quo to a new dignified norm. Vendors could still sell products by offering products that enhance dignity. Soon these will be the only kind of products providers will be interested in on behalf of resident dignity (and compliance with new CMS Dignity guidance).

Language

As a fellow advocate for more dignified language in this business of caring for people called long-term care, I commend and thank CMS for some attention to language in their new guidance at F241 Dignity. CMS calls for *avoiding labels such as "feeders*." Thank you CMS. Unfortunately, there is much more labeling language that gets said in our long-term care world that needs to be dealt with. In fact, in the surveyor training that CMS created and made public to go with the new guidance to F241, CMS calls for surveyors to be role models of good language. However, in order for surveyors to be good role models which would be very welcomed, they need in-depth training on language, what is considered undignified and why, and what dignified replacement language could be used instead.

Recommendation: CMS provide training to surveyors on Dignity, a Tag and topic that has never been developed or offered to surveyors as a broadcast. CMS provide training on dignity in general, on dignified practices and especially on dignified language. As Karen Schoeneman of CMS has always said, "Language drives practice." And of course if training developed for surveyors is made available to anyone working in long-term care as CMS usually does, we can all learn together making CMS' good work go even further.

F242 483.15(b) Self-determination and participation

The resident has the right to:
1) ***Choose*** *activities, schedules, and health care consistent with his/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 that are significant to the resident.*

Kudos to the writers of this regulation, and to the writers of the Nursing Home Reform Act of 1987. This requirement has been in existence for a long time. However, everyone has been walking right by it. No choice. Residents in most homes are awakened to fit the facility schedule; no choice. The facility sets arbitrary meal times all must follow; no choice. Bath times are told to residents; no choice. Even though this has been considered the right of the resident, the institutional way was all everyone knew. Now we know better, thanks to many pioneers and early adopters of changed and transformed homes.

CMS deserves praise again for giving choice more prominence. Facilities now must be *actively seeking preferences, choice over schedules important to the resident, i.e., waking, eating, bathing, and retiring* per CMS' new guidance. *Actively seeking preferences* that is the new guidance. Typically it is the "squeaky wheel that gets the oil." Most every nursing home has one or two residents who just *won't* get up for breakfast at the arbitrarily set time. Staff of this home say, "Oh we let people sleep." But typically what is done for the one who demands it is not what is done for each resident.

But what about the person with dementia? Even if a person can't tell us their preferences, caregivers can still *actively seek* them. Take sleeping for instance. The best way to know a person's preference is to <u>not wake them</u>. When we don't wake someone, their body will tell us when it has had enough sleep by waking up. And when it pertains to some other preference CMS has covered its bases with this: *If resident is unaware of the right to make such choices determine if the home has actively sought resident preference info and if shared with caregivers.* CMS' requirement is that the facility go deeper in finding out resident preferences <u>even if</u> a resident did not tell staff, <u>even if</u> a resident does not realize they have this right to choice and their preferences should be honored. Culture change advocates are thrilled with this new guidance and aren't we all when we consider ourselves as the resident?

In a study where twenty nursing home residents were interviewed, residents stated that choice and ensuring that food preferences were honored was part of quality dining (Evans et al, 2003). This is not surprising. And to conclude, CMS Region IX believes "Food offers the perfect vehicle for nursing home residents to make choices… "(Person Directed Dining Pilot Project Practice Package, 2008).

<u>Decaf Coffee</u>

How many of you drink coffee? Caffeinated coffee? How many of you would be offended if it was decided <u>for you</u> that you will drink decaf coffee <u>only</u>? Personally I thought this was a thing of the 1980's and 1990's but was shocked and incensed when I met a woman on a plane, a very committed-to-her-mother daughter told me nothing positive about a nursing home experience they were going through. She said something about coffee and then backed up to say, "Well, it's really decaf." I said, "They have no caffeinated coffee in the whole place?" She said, "Well, I happen to know there is some in the break room for the staff…." Something is wrong with this picture. When I asked a crowd of long term care professionals why we do this, the only rationale anyone could think of was that it came from thinking caffeine would cause people with dementia to "go off the wall." So what happened? This worry got assumed and transferred to every single person living in long-term care. That's institution, that's generic, that's <u>not</u> person-centered or self-directed living. Surveyors, this is where a citing deficient practice at Tag F242 if residents also are outraged or at least wanting caffeinated coffee would be fitting. Surveyors could actually guide the transformation of institutional culture when they look into these kinds of issues.

<u>Sneaking and Pretending</u>

Here is another way to think about it. Where did this practice come from of sneaking decaffeinated coffee into the cups and pretending nothing happened? It is a terrible shock to a new resident who is used to several cups of real coffee perhaps producing a bad headache, sleepiness, and maybe a bad temper too. And it is equally a shock to a family member drinking the same coffee who can't understand what happened to them and why they are so tired and why their head hurts. Let's get a handle on this practice of sneaking around, changing things and hoping it won't be noticed. It is a matter of trust, of dignity, of rights.

<u>Good Coffee</u>

Good coffee is something that many of us surely have opinions about. Some like it from Starbucks, some from Dunkin Donuts, from McDonalds, or from their own kitchen where the brand is one they chose. Along with giving residents more choice over foods, and times to dine, how about coffee choices too? This is not a regulatory issue but an issue of facility purchase practices. A friend told me she went to a nursing home on the West Coast that had a coffee bar in the lobby where you could get real cappuccino, espresso, and a variety of flavored coffees. Yum. Doesn't that sound good to have such choice? Even if a home doesn't go that far, are the residents getting a chance to have some choice over their coffee, creamer, sweetener or syrups?

Recommendation: Long term care, let's stop sneaking decaf and pretending no one knows and instead give the choice, caffeinated or decaffeinated? And how about offering more choice over types of coffees, creamers, sweeteners and syrups? The convenience store does.

<u>Choice and Survey Stories</u>

Here are two encouraging stories from an Eden registered home that answered a call for stories regarding choice and dining:

> We were in annual survey – the state surveyor came to me around 6:00 pm and told me that one of our elders, a lady with significant cognitive loss, had left the supper table and had not received or eaten a hot entree – a main course. No one had stopped her. It probably goes without saying that my stomach fell to my toes as I calmly related – "Let's go see what she ordered." We went to the dining room, found a CNA and said that Mrs. Green had left the table without receiving the main entree or any other hot item – what had she ordered? The CNA took us to the table, grabbed the menu showing the circled items that Mrs. Green had chosen. They were indeed what she had received and eaten. No tag.

Moral of this story? Perhaps we should stop assuming a "hot entree" or "main course" is norm for all. And having residents circle a menu in order to order their meal certainly comes in handy. Next story:

> Complaint Allegation: Failed to provide services as outlined in plan of care. Resident's medical durable power of attorney informed facility at admission that the cognitively impaired resident required assistance in choosing nutritious meals. It was care planned that staff would choose meals – not the elder. Allegedly this didn't happen because resident repeatedly ate the same thing – macaroni and cheese or something similar. The surveyor DID NOT cite us for several reasons. The first thing she said is that she sided with the elder – she said, "I have a few favorite things and notice that I eat them repeatedly." Additionally, the meal intake record showed fairly poor intake – she agreed that it was important to serve the elder what she liked so that she would have SOME nutrition. Also, she saw that when elders weren't eating their meals, staff offered alternatives (2009).

These stories bring a sigh of relief and facilities will hope for this surveyor to come. It is nice to see surveyors bringing a little common sense into the picture. It doesn't make sense to cite menus not followed when the resident did not want what was on the menu. People will not want to live in the home that says the menu must be followed regardless of what you want or like or hate. People will want to live in the homes that honor a person's choices. Surveyors, what a grand opportunity you have. Providers, what do you want to be famous for? Honoring or dishonoring choice? I predict we will see more and more deficient practice for choice not being honored thanks to CMS' new guidance.

Informed Consent

Is a facility supposed to just let people eat what they want and when they want with no oversight or care about it? No and this is what needs to be clarified more than anything else for all interested parties. What exactly are the responsibilities the facility bears?

Waivers not only do not hold up in court but Handy points out that a waiver gives a facility a "false sense of security that their responsibility ends there" (2009). Remember the collaboration and the right to make informed choice required now in Tag F325: *Sometimes, a resident or resident's representative decides to decline medically relevant dietary restrictions. In such circumstances, the resident, facility and practitioner collaborate to identify pertinent alternatives.* And stated is that the resident or representative *has the right to make informed choices about accepting or declining care and treatment*.

Informed choice implies that someone informed the person, this is the facility's responsibility: risks of certain choices, benefits of certain choices, education. However, it now sounds like what we've been teaching to be the risks of choosing not following a certain restricted diet may not be true after all. If there is no evidence that restricted diets actually bring about the outcomes we thought they did, then we really do not know. Better yet would be basing probability on what the individual's baseline and history shows risk for that person to be.

Facility Responsibility and Surveyor Investigation

Handy points out that Tag 325 essentially tells a surveyor to now "investigate the cause of decline in nutritional status related to resident choice." Handy shows her expertise with this analysis of what surveyors are to now to be doing:

> Surveyors are to examine if the facility failed to 'liberalize' the diet with less restriction which would have benefitted the resident's food intakes. Why isn't the resident allowed to sleep in and have a late breakfast, which was a normal pattern of living at home or a request for that resident? Why didn't the facility change the traditional 'three square and a snack' pattern, when it was not working for a vulnerable resident with a diminished appetite? Why didn't that facility offer an alternative meal pattern such as 5 or 6 fortified small meals when the resident would only eat small amounts, but the nutritional needs were great? Why weren't the residents' food and dining preferences honored? (2009).

These are investigative steps that surveyors are probably not accustomed to taking.

Here is an excellent scenario in which staff members think through how to help residents from Linda Handy's *Surveyor M.O. For Nutritional Status (F325)*:

> ---Say Resident A was an elderly diabetic lady. If Resident A has many choices of sugar free or low carbohydrate offerings that look and taste like the regular diets, wouldn't it be MORE LIKELY that 'following' a modified diabetic diet would be easier? Maybe.
> ---If Resident A was informed and educated on her health condition and maybe attended one of our diabetic support groups where she heard about the consequences of making a lot of poor food choices, wouldn't she be MORE LIKELY to make wiser choices and not see it as an imposed restriction? Maybe.
> ---And if Resident A went hog wild and ate a lot of high sugar or high carbohydrate items, and then Resident A's blood sugars followed and went hog wild high, she would be informed and more discussion would occur. Wouldn't she be MORE LIKELY to reconsider? Maybe.
> ---The point is that there is choice and self-determination. It is Resident A's life. It is our responsibility to support and help Resident A (or her decision makers) by being diligent at our end in every way we are able (2009).

A new way of thinking is being presented here, how to make good healthy decisions more likely for people. By making good food choices available, by equipping residents with good education and staff members with good training to use in caring for these residents, and by using good communication with each person regarding their own health status and understanding it, we could create what might be called principles of excellence in informed choice.

F279 483.20(d) Comprehensive Care Plans including Highest Practicable

The facility must develop a comprehensive care plan for each resident that includes measurable objectives and timetables to meet a resident's medical, physical, mental and psychosocial needs that are identified in the comprehensive assessment.

CMS calls for care plans to be *comprehensive*. Most care plans could be much more comprehensive because most care plans tend to simply follow the MDS and stay in the MDS box, if you will. To truly be comprehensive and comprehensively reflect a person, a care plan will go outside the MDS box. If our care plans for individuals we serve were comprehensive, they would precisely describe what happens with and what works best for the person. This would detail food preferences and choice, food passions and pet peeves, what someone loves to eat and hates to eat. Sometimes even if this gets "assessed" it does not get carried over to the care plan or more importantly to practice when serving the individual.

Highest Practicable Well-being

F279 continued - The care plan must describe the following:
The services that are to be furnished to attain or maintain the resident's highest practicable physical, mental and psychosocial well-being.

Highest practicable means innate capability, based solely on the individual's abilities, limitations, and potential, independent of external limitations (CMS Individualized Care series, 2006). If someone is capable of feeding him or herself, a facility is to do all it can to assist the person in maintaining this highest practicable level of well-being.
Charlie was a sample resident of mine one survey many years ago. His care plan identified that he could feed himself at times. After watching two meals where no caregiver encouraged him or had him try to feed himself, I asked. The caregiver said he could not. I asked her to hand the cinnamon roll to Charlie who, sure enough, did not take it with his hand. I then asked the care giver to hand him a glass of juice and wouldn't you know he drank it all up. He then drank his milk and his water too. We all know it's easier and quicker to do for residents and often time is an issue. Staff report that when times for dining are expanded and residents are supported to follow their own routine, time is also opened up for staff to not be as rushed.

When we take over and do for we actually contribute to a residents' decline. Barbara Frank explains the opposite of highest practicable is a Greek word iatrogenesis which means "we caused it – it was caused by the medical actions taken." Think back to Mildred Adams who lived in the institutional nursing home at Traceway in Mississippi. She didn't talk or feed herself, was totally dependent and no one really thought twice about it. The day she moved into a Green House, a home with no traces of the institution, a home with a normal dining room table, a normal room of her own, a home where food cooking in the kitchen is seen and smelled, what does she do but grab the fork from her son's hand and feeds herself, something also very normal. Looking backwards this is a story of iatrogenesis. Although the institutional way has become normal to all of us, Mildred Adams shows that it, the

institution, all by itself is causing people to diminish, iatrogenesis again and to <u>not</u> maintain or attain their highest practicable level of well-being.

Perhaps there needs to be more research. Perhaps research that exists needs to be used to teach all of us more about iatrogenesis including surveyors who then are trained to look for it and cite it which will help lead everyone forward in identifying and preventing it.

Maybe we need to ask ourselves if we are contributing to inability and iatrogenesis by always serving residents. Sure some simply cannot serve themselves, and we all know of people who love being served but dietitian and Eden Educator Ann Evans just raises the issue. In the language of Eden, she asks, "Are we making residents helpless?" (2009). How many residents in your home do any kind of serving themselves? What might you be able to do to encourage and make it possible for a few more and then a few more to help themselves? How many self-service areas do you have? Are we contributing to iatrogenesis by serving everyone all the time? This becomes an area to work on to prevent iatrogenesis and improve highest practicable while honoring choice, all which are <u>required</u> by federal regulations.

Recommendation: CMS and provider associations and educators provide more training on iatrogenesis and disability the institution is actually causing individuals and give more focus on highest practicable, identifying it and thereby contributing to better compliance with this important requirement.

<u>483.10(d)(3) F280 Participate in Planning Care and Treatment</u>

The resident has the right to –- unless adjudged incompetent or otherwise found to be incapacitated under the laws of the State, participate in planning care and treatment or changes in care and treatment.

Participate in planning care – When looked at honestly most agree that "lip service" is given to this requirement. What is meant is yes residents and their representatives are invited to care conferences but what typically happens there is that a report about them is given to them. Residents are often not asked what they think, what they want, or their opinion of how well staff is doing to support them. Residents have lived long productive lives, sitting in the driver's seat of their lives. Some homes have decided to ensure they continue to sit there. A gift that can easily be given yet goes against the traditional institutional way. It is exciting when you hear others saying the same thing in a movement such as how Steve Shields and LaVrene Norton say in their book *In Pursuit of the Sunbeam*, "The elders in households must be in the driver's seat as they create their own home. We have a responsibility to be their partners in this pursuit"(2006.) Another leader in this field, Christine Krugh co-author of the workbook *Changing the Culture of Care Planning: a person-directed approach* makes the case that the resident should sit in a place of honor much like a father sits at the head of the table (2008).

Recommendation: CMS has not updated the interpretive guidance to this requirement since 1987. It would be very fitting for new guidance regarding *participate in planning*

care. Doing so would continue to meet its OBRA '87 mandates, match its new guidance at F242 Self-determination and participation, and to continue to support the premises of the culture change movement. Another of the Pioneer Network's core values is "Each person is entitled to self-determination wherever they live" (pioneernetwork.net). CMS could take it one step further with an emphasis on supporting residents in "driving" their own care, let alone planning it, and more importantly planning and driving their own life which is more than care.

483.20(k)(3) F281 Professional Standards

The services provided or arranged for by the facility must meet professional standards of quality. According to leading dietitians, the only issue ever seen cited at F281 is unqualified dietitian issues. However, that issue is covered and should be cited at Tag F361 Staffing, Qualified dietitian. Apparently, Tags F325 and F371 have incorporated current standards of practice to such a degree, it has not been necessary to cite any here.

According to Linda Roberts, RD consultant in long term care and also Chair 2008-2009 for the Dietetics in Health Communities, a dietetic practice group of the ADA, the ADA has Standards of Practice and Standards of Professional Performance for the Registered Dietitian. This workgroup developed standards of practice specific to the dietitian in extended care settings which will be released in 2010. What has been developed thus far is available at
http://eatright.org/ada/files/2008_Sept-SOP_Nutrition_Care_SOPP_RD_and_DTR.pdf.

The Dietary Managers Association has Practice Standards for the Certified Dietary Manager (CDM) available at
http://www.dmaonline.org/search_results.php?search_string=practice+standards&x=0&y=0
<http://www.dmaonline.org/search_results.php?search_string=practice+standards&x=0&y=0>.

Not all dietary managers are CDMs. As of November 2009, HR Bill 1636 presented before Congress in the spring of 2009 had been attached as an amendment to HR 3200 the healthcare reform bill which would mandate that if a director of food services is not a qualified dietitian then he or she must be a CDM or a Registered Dietetic Technician.

483.65 F441 Infection Control

CMS released new guidance for this requirement and made effective the same day July 17, 2009. Many infection control guidelines having to do with food and dining are included in Tags F325 and F371. The following statement in the new guidance for F441 is in my opinion confusing:

> *Note: It is important that all infection prevention and control practices reflect current Centers for Disease Control (CDC) guidelines.*

Does this mean that all CDC guidelines must be followed or that following CDC guidelines is just good practice? Will surveyors be surveying for some of CDC guidelines? If so which ones? (More about CDC and infection control guidelines in Chapter Seven). These things make providers nervous. Most providers make a good faith attempt to know what they are to know. What exactly is being said in this note?

Recommendation: CMS make a clarification in regards to this statement and whether it means all facilities must follow all CDC guidelines or certain CDC guidelines. Please make clear which guidelines, where they are located, etc.

Residents can be exposed to potentially pathogenic organisms in different ways, including but not limited to the following:

- *Improper hand hygiene*
- *Improper glove use (e.g. utilizing a single pair of gloves for multiple tasks or multiple residents) and*
- *Improper food handling.*

Under *Hand Hygiene* the following are examples relating most to food and dining:

> *Hand Hygiene continues to be the primary means of preventing the transmission of infection. The following is a list of some situations that require hand hygiene:*
>
> - *Before and after direct resident contact (for which hand hygiene is indicated by acceptable professional practice);*
> - *Before and after eating or handling food (hand washing with soap and water);*
> - *Before and after assisting a resident with meals (hand washing with soap and water):*
> - *After removing gloves or aprons.*

These guidelines beg the same question identified above. Must hand hygiene or washing hands, take place between helping two residents to eat? I pick up a spoon and feed one resident set it down and pick up a fork to assist another resident. This guidance indicates hands must be washed in between. Did anything really happen to warrant hand washing? Does this become more of a burden on staff? Epidemiologist Dr. Stone, referenced above, gave her opinion that an alcohol-based hand rub may be appropriate in this scenario barring any other obvious reason for hand washing such as gross contamination of the care giver's hands with saliva or other secretions (for example, wiping a person's nose) (2009).

Recommendation: CMS to clarify if hand washing or hand sanitizer should be used in between residents or if facilities can just be held to good infection control practice all around thus teaching and expecting each staff member to think about what they are doing and prevent the spread of infection. If hand washing is required as stated above between residents this will be logistically challenging and may again promote the use of gloves giving the false impression staff do not then need to go wash their hands. Perhaps this is an issue that needs more research, not only into what germs are found on caregivers' hands but also what outcomes come from them, how often and how seriously.

Resident Hand Hygiene

A good practice mentioned in the California Dining Project is what Recreation Therapy Consultant Michelle Nolta calls sensory wash cloths, warm washcloths in a towel warmer with appropriate essential oils for residents to use both coming in and out of the dining room. Resident hand hygiene is equally important and CMS, clinicians and providers alike may want to make practices such as this into standard of practice.

F 492 Other Federal, State, local laws

As the CDC's infection control guidelines are not law, they should not ever be cited here (aside from the above request to CMS whether they must be followed or not). As the FDA's Food Code is not considered law and since CMS makes no statement about it having to be followed, it should never be cited here either. However, some States do require the FDA Food Code to be followed. If the Food Code was not followed by a facility to such a degree surveyors deemed it necessary to cite a deficient practice, it may cited at that State's licensure requirement and/or here where "other" laws, a State law in this example, are to be followed. Although a search on 1/1/2010 on the NHRegsPlus searchable website revealed that only Iowa, Nebraska and Wyoming require the FDA Food Code be followed, some State licensure regulations require a nursing home to follow their State's restaurant regulations which sometimes require the FDA Food Code be followed.

483.75 (i) Tag F 501 Medical Director

"The secret and underutilized weapon – the medical director." In this 2003 *Provider* article author Lorraine Tarnove, Executive Director of the American Medical Directors Association (AMDA) rightly points out that medical directors should address administrative and managerial issues, not clinical issues which is exactly what most facilities engage them in. Clinical care of individual patients falls to the attending physician, not the medical director. Instead he or she should be used to improve "patient care processes through management of the systems and caregivers in the facility." AMDA repeatedly identifies that the medical director should be "participating in administrative decision making and the development of policies and procedures related to patient care" (Levenson, 2002).

AMDA takes it a step further calling medical directors to promote "a learning culture …. for physicians, patients and families" (Levenson, 2002). Tarnove says they should be knowledgeable of "changing social, regulatory, political and economic factors" affecting long term care (2003).

CMS issued new interpretive guidance to this requirement regarding medical director several years ago. The guidance repeatedly mentions keeping up with standards of practice. Thus, the question for facilities is if their medical director is "up-to-speed" on "the latest." Are medical directors familiar with CMS' many sets of newly issued interpretive guidance that do reflect current standards of practice such as liberalizing restrictive diets not only for improved quality of life but because people actually eat better?

Do medical directors guide their physicians in understanding the intent of OBRA '87 that the nursing home is to be home to residents where they have the right to choice. Are medical directors keeping up and, in turn, educating their physicians? Do physicians know AMDA's Clinical Practice Guideline for Altered Nutritional Status which "recognizes that nutrition management must be individualized, not to just follow a 'cook book' approach" (Levenson, 2002)? Do physicians know that they are being called to work in *collaboration* with the resident and care givers as Tag F325 now requires? CMS has done a nice job of identifying the role of the medical director, only leadership of each facility can answer these questions.

Recommendation: Every person who cares for residents needs to be educated on our role in supporting resident choice and designing individualized care from academia to professional ongoing continuing education to facility in-services.

483. 75(o) Tag 520 Quality Assessment and Assurance (QAA)

This tag seems to be somewhat of a well kept secret. Linda Handy says QAA is "very misunderstood" and that facilities "miss the boat on what a powerful tool it can be" (2009). She wisely points out there is a difference between "reporting data" and truly working on improvement. The guidance actually states if there has been *good faith efforts to identify quality deficiencies and to develop action plans to correct quality deficiencies, this requirement (520) should not be cited*.

I remember well on one survey we surveyors detected a potential deficient practice in the area of activities during the second phase of the standard survey. When brought to the activity director's attention she explained how the staff was aware of it and the administrator showed evidence of it being evaluated in their QAA process. They fully knew about the problem, they were evaluating it and moving toward fixing it. No tag. Why? Because this is precisely what CMS wants, for facilities to find and fix their own problems. This is a gift and gifts don't come all that often from the federal government so providers should take advantage of this great gift.

483.15(h) Environment: Safe, Clean, Comfortable and Homelike – The Short Stay Experience and Food and Dining

In a facility in which most residents come for a short-term stay, the "good practices" listed in this section are just as important as in a facility with a majority of long-term care residents.

CMS also states in a Note, under Procedures:

Many residents who are residing in the facility for a short-term stay may not wish to personalize their rooms nor bring in many belongings

We're all coming to the same realization, including CMS, that persons needing a short rehab stay in a nursing home do not want to be called residents, they are not moving in and they do expect a medical treatment atmosphere. However, as CMS points out the "good

practices"/institutional features to eliminate listed in the new guidance are still important. Additionally, all people appreciate choice and the clientele for a short stays are quite accustomed to exerting choice. Choice in foods and meal times, choice in whether to go to a dining area or stay and eat in the room, all are choices most people want to make and are used to making every day.

In a *Provider* article about individuals who stay for a short time, author Meg Laport reports that the short-stay customer wants "more choices in dining such as buffet, family-style, on-demand, and fine-dining" (2006). Not surprising. I believe Providence Mount St. Vincent is the first nursing home to open a coffee shop (it is in Seattle, Washington). Continuing care retirement community Covenant Village in Westminster, Colorado recently turned their kitchen into a pizza place where residents can now order a delicious pizza for ten dollars. The co-administrator Audrey DiGiorgio noticed her residents were paying over twenty dollars every time they called the neighboring pizza place. Now residents are saving money while helping their community make some. There is a nurse who says she chose to work at a Planetree affiliate hospital in Glenwood Springs, Colorado because it had a coffee shop. CMS is to be commended for stating that the less institutional practices should be offered even to persons experiencing a short stay only. Offering exciting and contemporary food and dining options as well as a transformed, less institutional atmosphere not only draws potential patients/residents but staff as well, as many pioneers have attested to throughout the years.

Taking Med Pass Out of the Dining Room

Medications have traditionally been "passed" (administered) in the dining room during meals. However, not all medications need to be given with food and those that need to be "given with food" or "on an empty stomach" do not mean a person must be in the dining room at a certain time. My stomach is just as empty if not more when I skip breakfast and eat lunch at 11:00 a.m. The majority of medications do not have to be administered at set times either. Set times is just what the whole of long-term care is used to.

Perham Memorial in Perham, Minnesota diminished medications as possible for each resident, then took med pass out of the dining room and then designed locked medication storage in each resident's room. Director of nursing Denise Ellis shares that with less distraction and noise, appetite and dining improved for their residents (2009). The CMS guidance at Tag 235 Nutrition even identifies *level of disruption in the dining environment* as a potential indicator of poor intake.

The Role of the Consultant Pharmacist

Much more could be said about medications: how they can alter taste, cause dry mouth, lethargy, nausea, confusion, etc. which can all affect a person's eating patterns. Pharmacists enter into a resident's food and dining experience in several ways besides their typical role of reviewing medications and identifying side effects. Pharmacists can affect appetite stimulation with medications and timing of medications, as well as identify contraindications of foods with medications. They are charged with reducing number of

medications wherever possible. They affect whether a "fake" food nutritional supplement might be used or real food. There is still plenty of work to do towards putting self-directed living, choice and preferences before medications.

Recommendations: CMS requires nursing homes to always try real food first before oral liquid nutrition commercial supplements and appetite stimulants and as pharmacist Denise Hyde with the Eden Alternative says, to treat these approaches much like restraints (Tags F221 and F222) in that least restrictive or least medical be tried first (2009).

<u>483.10 (b)(4) Tag 155 Refusal of treatment</u>

The resident has the right to refuse treatment, to refuse to participate in experimental research, and to formulate an advance directive.

"Treatment" is defined as care provided for purposes of maintaining /restoring health, improving functional level, or relieving symptoms.

From the interpretive guidelines: *The facility should determine exactly what the resident is refusing and why. To the extent the facility is able, it should address the resident's concern. For example, a resident requires physical therapy to learn to walk again to after sustaining a fractured hip. The resident refuses therapy. The facility is expected to assess the reasons for this resident's refusal, clarify and educate the resident as to the consequences of the refusal, offer alternative treatments, and continue to provide all other services.*

If a resident's refusal of treatment brings about significant change, the facility should reassess the resident and institute care planning changes. A resident's refusal of treatment does not absolve a facility from providing a resident with care that allows him/her to attain or maintain his/her highest practicable physical, mental and psychosocial well-being in the context of making that refusal.

Not much else needs to be said. CMS has addressed and recognized the rights of a person, has these rights in place within its State Operations Manual for Long-term Care Facilities <u>and yet resident refusals of treatment are being refused.</u> Unfortunately the institutional way is driving this but so is the legitimate fear facilities have of being cited by surveyors for not following the physician order. CMS your help is needed. It is as if the CMS regulations, requirements and guidance are giving two messages: cite a facility for not following a therapeutic order and cite for not honoring a resident's right to choose whatever is important to them. And if this requirement wasn't strong enough all by itself, this is CMS' very first requirement of all the nursing home requirements:

<u>483.10 (a)(1) Tag 151 Exercise of Rights</u>

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.

From the interpretive guidelines: *The facility must not hamper, compel, treat differentially, or retaliate against a resident for exercising his/her rights.*

This makes it clear. A person living in a nursing home has the very same rights as anyone living in the United States and no resident should be *hampered* ("you can't eat that") or compel ("you must eat this") or treat differentially ("oh, she's non-compliant") for exercising the very rights you and I exercise every day, the very rights they exercised before they lived in the nursing home. This is good news worthy of being embraced and figured out together.

Recommendation: CMS take under its wings the clarification of this issue that must be clarified, the facility's duty to encourage good health and good decisions while also honoring a person's right to choice and in the end, supporting resident decision <u>above and over what anyone views as "safety</u>."

In one state it is being said by surveyors, "In our state, preventing accidents trumps resident rights." This is <u>not</u> what OBRA '87 intended. No requirement trumps another in the sense of priority. As I study the CMS regulations if anything trumps anything it seems it would be that rights trump "safety" or preventing accidents. Three Tags, <u>three</u> CMS requirements - Tag F151, Tag F155 and Tag F242 - all speak to the right to choice and to refuse medical treatment.

Recommendation: Again, perhaps what CMS could do is convene another expert panel to look at making clarifications throughout the regulations especially at the regulations that state we have these rights. The make-up of this panel might include members of the interdisciplinary team who each representing their respective body of knowledge and profession, as well as psychologists, attorneys and residents themselves.

We all need to shift our focus away from the "medicalness" of it all; the diagnoses, the diets, following the physician orders, etc. and instead make the person the focus. That is what OBRA '87 intended and we have missed the mark. What a great opportunity for CMS to take the lead to clarify the biggest question out there for all of us.

In the words of culture change leader, Nancy Fox, Chief Life Enhancement Officer Pinon Management and former and first executive director of the Eden Alternative,

> Beneficence, the need to do good or "do no harm" vs. autonomy, the right to risk and the right to pursue happiness: In my mind this is probably the single greatest challenge we will have with bringing person-directed care into the current system. We fought and won the battle to remove restraints, the right to fall. The next great battle ground with institutional mindset will be the right to eat what we want even when we are at risk of choking or aspirating (2009).

Chapter Six
Current Survey Processes as they Pertain to Food and Dining

Traditional Survey

The traditional survey process is slowly being replaced by the Quality Indicator Survey (QIS). If CMS were to make any further changes to the traditional survey process it might be to each of the three Quality of Life interviews (Resident, Group and Family) to ask residents if they get to eat what they want to eat when they want to eat along with other choices to be in sync with CMS' new guidance at Tag 242 Self-determination and Participation regarding *actively seeking* resident preferences. Plus, CMS' new guidance at Tags F325 Nutrition and F371 Kitchen sanitation provides updated guidance to surveyors regardless of the survey process.

QIS

Within the new QIS process the following Pathways, Critical Elements and Interviews touch on food and dining.

Dining Observation Pathway
On the QIS Dining Observation Pathway (20053 9/09), #9 is problematic in regards to the goals of culture change as well as with CMS' own new guidance for F241 Dignity:

> 9. Are resident's desires considered when using clothing protectors

The new revised Dining Observation Pathway (20053 revised 7/31/09) slated to be released June 2010 does bring up the use of napkins but also still clothing protectors:

> Provide napkins and non-disposable cutlery and dishware (including cups and glasses).
> Consider resident's desires when using clothing protectors.

Recommendation: As CMS' new guidance at Tag F241 identifies bibs, also called clothing protectors, as an undignified practice, CMS could draw attention to that perhaps by stating something like, "If clothing protectors are still being used, inquire as to why and ask residents if they would prefer a linen napkin." CMS could utilize this item better to guide facilities in replacing the undignified use of bibs with the dignified and societal norm of using linen napkins.

The Nutrition-Hydration-Tube Feeding Critical Element (20075 6/07) under the Resident/Representative Interview on page 7 guides surveyors to ask "Whether there are any concerns regarding…" many things. However, resident food preferences are not inquired about, although they are under Care Planning. This would be more in sync with CMS' new F325 guidance that includes knowing resident food preferences.

The Resident Interview and Resident Observation (20050 6/07) includes this question at

B Choices: Are you able to participate in making decisions regarding food choices/preferences?
What is missing is inquiring with the resident about their preferred times to eat. Time to go to bed, get up and bathing schedule are reflected.

The Family Interview (20049 9/08) includes these questions at B Choices:

> Does the facility honor [resident's] preferences and previous life routines, such as when to get up, and go to sleep or when to take a bath?
> Does the facility honor [resident's name] preferences on what he/she eats or drinks?

Again, there is no question regarding preferred times to eat.

Recommendation: CMS add to the Resident/Representative Interview on page 7 of the Nutrition-Hydration-Tube Feeding Critical Element, questions regarding the resident's food preferences which would be more in sync with guidance at Tag F325. CMS add to Resident Interview and Family Interview inquiry into whether resident is able to choose times to eat. This would be more reflective of CMS' new guidance at Tag F242 Self-determination and participation.

On both the current (20053 9/09) and newly revised (20053 revised 7/31/09) Dining Observation Pathway, the following question is asked:

> 16. Does the facility provide meals with no greater than a 14 hour lapse between the evening meal and breakfast (or 16 hours) with approval of a resident group and provision of a substantial evening snack?

Recommendation: In keeping with recommendations given earlier it would soften things if the focus was on <u>meals being available</u> rather than provided within 14 or 16 hours. The focus on 14/16 hours puts surveyors in the position of focusing on the exact mealtimes thus perpetuating the focus of providers and surveyors on "the 14 hour rule" rather than meal availability. Meal availability refocuses everyone to individualized care and resident choice. Perhaps CMS could instead have an item something to the effect of, "Does the facility provide meals three times a day that are available to all residents and that meet resident preferences?"

The new Dining Observation Pathway (20053 revised 7/13/09) slated to be issued June 2010 identifies and recognizes neighborhoods, households and expanded meal hours:

> Meal times and dining room locations should be identified while the team coordinator is conducting the entrance conference. Some nursing homes have "households" or "neighborhoods" that contain a kitchen and dining room and provide expanded meal service hours, such as 7-10 a.m. for breakfast, or food services on a 24-hour basis, seven days a week. Meals may be prepared in the

household/neighborhood or catered in, such as occasionally ordering pizza or take-out food. The purpose of meal services in these settings is to provide the residents choices for times to eat and sleep, to offer food choices/preferences, and to provide a more home-like setting.

Recommendation: When a next round of changes are considered, CMS may consider rewording this to reflect that any home may offer these expanded meal service hours, not only homes with neighborhoods and households.

MDS 2.0

Within the federally required Minimum Data Set assessment in its current 2.0 version, food and dining are mostly reflected in Section K. Oral/Nutritional Status. The most problematic item for nursing homes desiring to be less institutional is:

K.4.c. Resident leaves 25% or More of Food Uneaten at Most Meals

Directions for this item are to consult varying records including "dietary/fluid intake flow sheets." Many nursing homes across the country are interested in recording meal intake for only those residents at nutritional risk. It would be a great time savings to not record meal intake for every single resident. Recording food intake is technically not required by regulation. Recording food intake is mentioned by CMS in the guidance for Tag F325 Nutrition, in regards to when there is insidious or sudden weight loss, in particular by "intensifying observation of intake and eating patterns." Additionally, as the MDS requires a 7 day look back period, perhaps facilities could take advantage and only assess for 7 days during the assessment period at a minimum especially for those residents not at any risk.

Recommendation: CMS clarify if homes need to get a baseline of food intake only during the assessment period, for everyone or only for those at risk.

According to the MDS Active Resident Information Report: Third Quarter 2009, 34.5% of all residents nationally leave 25% or more of their food uneaten (http://www.cms.hhs.gov/MDSPubQIandResRep/04_activeresreport.asp?isSubmitted=res3&var=K4c&date=28). First, if that many residents are leaving that much food uneaten, it raises questions about the palatability of the food. This statistic also supports the point that it is not every resident that has this problem and freeing up staff to focus on those that do could be a welcome relief. Each facility would obviously need to have tight systems and policies in place to ensure recording intake is completed when needed. When intake is recorded, a good practice identified by Handy is to use printed menus first to mark resident choice and then to record percentage intake for each item eaten (2009).

MDS 2.0 items can be tracked at MDS Active Resident Information Report at: http://www.cms.hhs.gov/MDSPubQIandResRep/04_activeresreport.asp.

MDS 3.0

An MDS 3.0 version is scheduled by CMS to be implemented in October 2010. The K.4.c. item is not included in it. In looking at the new MDS 3.0 through a food and dining lens, the only question about food posed to the resident is: "While you are at this facility how important to you is…have snacks available between meals?" Although bedtime preference is asked about, preferences regarding times to eat and what to eat are not.

Recommendation: Because CMS has asked how important snacks are to a resident right in the MDS 3.0, it seems that questions regarding a person's preferences for dining times and food preferences would be just as important. Thankfully CMS has required that facilities discover food preferences per Tag 325 Nutrition and also actively seek preferences per Tag F242 Self-determination.

Chapter Seven
Other Food and Dining Standards

Food and Drug Administration (FDA)

The U.S. Public Health Service (PHS) began its food protection activities at the turn of the 20th century with studies of the role of milk in the spread of disease. These studies found that effective disease prevention called for comprehensive food sanitation measures from production to consumption. Model codes began to be developed, the first of which was the *Grade A Pasteurized Milk Ordinance – Recommendations of the PHS/FDA* published in 1924. Today the FDA maintains many model food codes for various retail sectors of the food industry. The FDA explains the use of "model food codes" and reveals the following about the Food Code:

> The model Food Code is neither federal law nor federal regulation and is not preemptive. Rather it represents the FDA's best advice for a uniform system of regulation to ensure that food at retail is safe and properly protected and presented…. Through the years all states, hundreds of local jurisdictions, and many federal agencies have adopted some edition of model food codes recommended by the PHS.

A new edition of the Food code is developed every 4 years by the FDA. During each 4 year cycle the FDA may issue supplements to the code if necessary and those supplements are incorporated into the next edition. The FDA accepts recommendations for Food Code modification from any individual or organization with specific forms and time frames for submission. The Conference for Food Protection covers retail food issues while there are conferences specific to milk and shellfish production. The 2005 edition of the Food Code reflects recommendations made at the 2002 and 2004 Conference for Food Protection. The FDA has an open and democratic process of state by state delegate votes. And the FDA "encourages interested individuals to consider raising issues and suggesting solutions involving the federal-state cooperative programs based on FDA's model food codes through these organizations."

The FDA has 75 state and territorial agencies and more than 3,000 local departments whose primary responsibility is prevention of foodborne illness and licensure and inspections of retail food establishments.

Information and history about the FDA were found at the following website: http://www.fda.gov/downloads/Food/FoodSafety/RetailFoodProtection/FoodCode/FoodCode2005/ucm123930.pdf.

The Food Code itself can be found at: http://www.fda.gov/Food/FoodSafety/RetailFoodProtection/FoodCode/FoodCode2005/default.htm.

CMS does not state that the Food Code must be followed but CMS has purposefully made sure that its guidance at Tags F371 Kitchen Sanitation and F441 Infection Control do not conflict with it according to Debra Swinton-Spears of CMS Division of Nursing Homes who led the projects to revise these tags (2009). Food Code issues that have surfaced for nursing homes are garden inspection and approval and "no bare hand contact" with food which have been addressed above.

Centers for Disease Control and Prevention (CDC)

In its beginning CDC actually stood for the Communicable Disease Center which came into being in 1946. Descending from the wartime agency Malaria Control in War Areas, the CDC initially focused on fighting malaria by killing mosquitoes. Fewer than 400 original employees, the majority were entomologists and engineers with only seven medical officers on staff. The CDC celebrated its 60th anniversary in 2006, and is now called the Centers for Disease Control and Prevention.

Today, the CDC is a global leader in public health and leads our nation in health promotion, prevention, and preparedness. Its public health efforts include prevention and control of infectious and chronic diseases, injuries, workplace hazards, disabilities, and environmental health threats. The CDC is globally recognized for conducting research and investigations and for an action-oriented approach. It works with states and other partners to provide a health surveillance system to monitor and prevent disease outbreaks including bioterrorism, implement disease prevention strategies, and maintain national health statistics. The CDC also guards against international disease transmission with personnel stationed in more than 25 foreign countries. CDC is one of the 13 agencies of the Department of Health and Human Services (HHS).

The CDC is comprised of seven coordinating offices, one of which is the Coordinating Center for Infectious Diseases. The Division of Healthcare Quality Promotion (DHQP) is part of the National Center for Infectious Diseases, within CDC's Coordinating Center for Infectious Diseases. The mission of DHQP is to protect patients, protect healthcare personnel, and promote safety, quality, and value in the healthcare delivery system by providing national leadership for nine key areas:

- Healthcare outcomes,
- Outbreaks in healthcare settings,
- Emerging antimicrobial-resistant infections,
- Efficacy of new interventions for patient safety,
- Clinical microbiology laboratory quality,
- Water quality in healthcare settings,
- Cost effectiveness of prevention interventions,
- Promotion of implementation and evaluation of prevention interventions, and
- **Development of infection control guidelines and policies**.

CMS does not directly state that nursing homes must follow CDC guidelines but does make this statement in its guidance to F441 Infection Control:

Note: It is important that all infection prevention and control practices reflect current Centers for Disease Control (CDC) guidelines.

As stated earlier, this statement may be misleading and warrant clarification whether a nursing home must know and follow all CDC guidelines and if so which ones and where they can be obtained.

For a provider trying to find out anything about CDC infection control guidelines for a nursing home, a search of the cdc.gov website might be frustrating as there is no clear cut link to nursing home infection control guidelines. An Internet search of CDC infection control guidelines brings one to this website: http://www.cdc.gov/ncidod/dhqp/guidelines.html which gives a page full of 20 some guidelines: everything from surgical site infections to isolation to catheters, to hand hygiene. At the very end there is a long term care line/link.

Clicking on Long-term Care takes you to a separate page with many position papers and other links and two "Guidelines:" 1) Prevention and control of TB in LTC among elderly, and 2) Prevention of Healthcare –Associated Infections. When you click on this last one it takes one back to the first long page again which will tell you to click on Long-term care again, making it a bit of a confusing and frustrating circle.

CDC guidelines are developed with the help of federal advisory committees. The Federal Advisory Committee Act (Public Law 92-463) provides a mechanism for experts and stakeholders to participate in the decision-making process by offering advice and recommendations to the Federal government as members of advisory committees. Twenty-four federal advisory committees provide advice and recommendations on a broad range of public health issues including an advisory committee on healthcare infection control. That federal advisory committee is called the Healthcare Infection Control Practices Advisory Committee (HICPAC) and its function is described as follows: "The Committee shall advise the Centers for Disease Control and Prevention on periodic updating of existing guidelines, development of new guidelines, guideline evaluation; and other policy statements regarding the prevention of healthcare-associated infections and healthcare-related conditions" (cdc.gov/hicpac/).

According to its charter, the committee is comprised of 14 public voting members, selected by the Secretary of Health and Human Services (or her designee). In addition to the 14 public voting members, there are several non- voting members who serve as liaisons to other federal agency partners including CMS and FDA and other infection control organizations. All HICPAC meetings are posted in advance and open to the public. Transcripts of past meetings are available on the website as well. When new guidelines are being developed, they are always made open for public comment as well. HICPAC has a detailed process by which guidelines are developed in terms of key questions, grading of research evidence, and formulating priorities.

As an example, The Guideline for Hand Hygiene in Healthcare Settings – 2002, was developed by the CDC's Healthcare Infection Control Practices Advisory Committee (HICPAC), in collaboration with the Society for Healthcare Epidemiology of America (SHEA), the Association of Professionals in Infection Control and Epidemiology (APIC), the Infectious Disease Society of America (IDSA).

The next HICPAC meetings are scheduled Feburary 11-12, 2010 in Atlanta, GA; June 17-18, 2010 in Atlanta, GA and November 4-5, 2010 in Washington, D.C.
Guidelines currently being developed are: Guidelines for Infection Prevention and Control in Healthcare Personnel; Guidelines for the Prevention of Intravascular Catheter-Related Infections; Guideline for the Prevention and Management of Norovirus Gastroenteritis Outbreaks in Healthcare Settings; and Pediatric Infection Prevention: Gap Summary.
More information regarding the posting of guidelines in development open public comment periods will be discussed at the HICPAC meetings and posted on the website.

And as is with the FDA Food Code, CMS' guidance at F371 and F441 also does not conflict with CDC guidelines per Swinton-Spears (2009).

Information and history about the CDC was obtained from http://www.cdc.gov/about/history/ourstory.htm.

American Dietetic Association (ADA) Standards

The ADA is a leader in keeping up with current standards of practice as well as in creating them as evidenced by their stand on liberalizing diets. The ADA is to be commended for raising awareness of the resident rights issue as well as the lack of evidence supporting the prescribing of restricted diets. The ADA's position on this topic was first stated in 2002 and then updated again in 2005:

> "Liberalized Diets for Older Adults in Long Term Care." Position Paper of American Dietetic Association, Journal of American Dietetic Association, September 2002. www.eatright.org/imagesjournal/0902/adar2.pdf www.eatright.org/Member/policyInitiatives/index_21039.cfm.
>
> Position of the American Dietetic Association: Liberalization of the Diet Prescription Improves Quality of Life for Older Adults in Long-Term Care. ADA Reports. *Journal of the American Dietetic Association*, 2005.

The ADA also has standards of practice for the various dietetics professionals all available at adajournal.org:

- Standards of Practice for Registered Dietitians in Nutrition Care
- Standards of Professional Performance for Registered Dietitians
- Standards of Practice for Dietetic Technicians, Registered, in Nutrition Care
- Standards of Professional Performance for Dietetic Technicians, Registered

State Licensure Regulations

When innovative ideas have bumped up against State-specific requirements, providers and others have taken it upon themselves to change them. State requirements can be changed with a willing group of stakeholders to investigate how and then present their case before that State's board of health and/or legislature. Many such State success stories now exist in the annals of the young culture change movement's history.

Colorado P4P

The Colorado Department of Health Care Policy and Finance (HCPF) underwent its own "culture change" in the way it reimburses long-term care facilities for Medicaid services in 2009. HCPF adopted a pay-for-performance program offering financial incentives to providers that provide high levels of quality of life and quality of care to their residents. The P4P program has 27 performance measures in the two domains of Quality of Life and Quality of Care. Reimbursement for these measures is based upon points. A total of up to 100 points are possible to be earned. Reimbursement begins with scores of 21 or higher. 49 points are possible within the Quality of Life domain and 51 in Quality of Care. A facility chooses which and how many of these measures it applies for. The one dining feature included in the P4P is the following:

> Definition/Minimum Requirement(s)/Required Documentation:
> Menus that include numerous options, menus developed with resident input. The dining atmosphere reflects the community. Residents have access to food 24 hours/day, and staff are empowered to provide food when resident desires it. Dining atmosphere is defined as the table settings, table cloths, lighting, music, servers and dining style (restaurant, salad bar, menu, buffet).
>
> Minimum requirement(s) with supporting documentation:
> Menu options must be more than the entree and alternate selection. These options should include input from a resident/family advisory group such as resident council or a dining advisory committee. The residents have input into the appearance of the dining atmosphere. Residents have access to food at any time and staff are empowered to provide it. Supporting documentation can be resident signed testimonials, resident council minutes, minutes from another advisory group or a narrative and photographs of changes in the dining atmosphere.

For more information about the Colorado P4P program go to: http://www.colorado.gov/cs/Satellite?c=Document_C&childpagename=HCPF%2FDocument_C%2FHCPFAddLink&cid=1251568645486&pagename=HCPFWrapper.

HCPF contracted with Public Consulting Group to do a thorough review and evaluation of the P4P program. One recommendation was: "The Department has made significant

strides with the implementation of the P4P program and should continue to fund and support the program for the improvement of resident care and outcomes for many years to come" (PCG, 2009).

For the report *Nursing Facility Pay-for-Performance Application Review* go to: http://www.colorado.gov/cs/Satellite?c=Document_C&childpagename=HCPF%2FDocument_C%2FHCPFAddLink&cid=1251568133906&pagename=HCPFWrapper

Other State Medicaid agencies may be interested in looking at Colorado's program and their success story revealed through this thorough report and consider it for their State.

The California Person Directed Dining Pilot Project

An exciting collaborative effort between CMS Region IX, the California State survey agency, the California Association of Health Facilities and the California Culture Change Coalition (CCCC) began in 2007. The CCCC presented a proposal for the project to the CMS Regional Office and the State agency. Both agreed to participate and offered letters of support, staff contacts and written responses to practice-related questions. Eleven nursing homes voluntarily agreed to explore one of three new practices that would expand dining choices for the people living in their facilities: restaurant style, buffet style, and an expanded snack program. The project began in January 2008 with an orientation for participating facilities and concluded in October 2008. The experiences of these providers including their "lessons learned" were collected and made into the Person Directed Dining Package available at http://www.calculturechange.org/services-dining.html. The package includes identification of critical elements, Decision Making Tools and Sample Action Plans for each dining practice.

California is to be commended. In their words shared in the project package, this project "offered the Coalition and a small group of facilities a chance to 'just do it' so we could learn from the experience and provide useful guidance to others interested in taking a 'first step.'" Such projects where facilities agree to "dive in," try new practices and share the bumps and successes is a smart idea for coalitions looking for ways to promote culture change in their state. Inviting all the stakeholders to the table including the CMS regional office as well as the State survey agency is also smart. This project design provides neutral ground for all to work together on a worthwhile endeavor to benefit residents during the project and into the future. The support of CMS Region IX and the California Department of Public Health is exemplary and a model for other States.

Here is a glimpse into the future from the Thinking Points of the California Dining Project: "Preventing or denying residents on restrictive diets from participating in dining programs and snacks may be a dignity/rights issue" and "educate/guide residents (***not control***) (emphasis added)." California has learned much. Notice this is what happens when you take on a project and sink your teeth into it (no pun intended, okay pun intended).

The Stage Model

The Stages Tool developed by Les Grant and LaVrene Norton is a stage model of culture change in nursing facilities. This tool assesses the degree of culture change from an organizational development perspective in four stages: Stage I - Institutional model, Stage II - Transformational model, Stage III - Neighborhood model and Stage IV - Household model. It describes the organizational status of Decision Making, Staff Roles, Physical Environment, Organizational Design and Leadership Practices in each. The tool speaks to the respective dining practices to each stage also explained in Chapter Two. The tool is available at culturechangenow.com. The **Culture Change Staging Tool** is a web-based questionnaire that assesses 12 key culture change domains. It determines for a facility based on the facility's responses, what its highest model stage is of the four stages identified in the Grant and Norton Stages Tool. This tool is available at myinnerview.com.

Artifacts of Culture Change

The **Artifacts of Culture Change** tool was co-developed by this author and Karen Schoeneman of CMS in 2006. It is a tool designed to capture the concrete changes homes make that reflect a changed culture, changes in attitude, policies and practices to be more resident-directed. A full report called **Development of the Artifacts of Culture Change Tool** explains the rationale for developing the tool, the point scale and has a large Source Information table. The Source Information gives backup for each item, where it exists around the country, as well as any research found which supports it. The Development report and the Artifacts tool itself are both available at pioneernetwork.net.

The tool is comprised of the following six domains with a point structure that gives the following potential totals for each:

Care Practices	70
Environment	320
Family and Community	30
Leadership	25
Workplace Practice	70
Outcomes	65
Total points	580

Food and dining items in the tool follow. From the Care Practices section:

1. Percentage of residents who are offered any of the following styles of dining: ▪ **restaurant style where staff take resident orders;**	____ 100 – 81 % (5 points) ____ 80 – 61% (4 points)

▪ **buffet style where residents help themselves or tell staff what they want;** ▪ **family style where food is served in bowls on dining tables where residents help themselves or staff assist them:** ▪ **open dining where meal is available for at least 2 hour time period and residents can come when they choose; and** ▪ **24 hour dining where residents can order food from the kitchen 24 hours a day.**	____ 60 – 41% (3 points) ____ 40 – 21% (2 points) ____ 20 – 1% (1 point) ____ 0 (0 points)
2. Snacks/drinks available at all times to all residents at no additional cost, i.e., in a stocked pantry, refrigerator or snack bar.	____ All residents (5 points) ____ Some (3 points) ____ None (0 points)
3. Baked goods are baked on resident living areas.	____ All days of the week (5 points) ____ 2-5 days/week (3 points) ____ < 2 days/week (0 points)
4. Home celebrates residents' individual birthdays rather than, or in addition to, celebrating resident birthdays in a group each month.	____Yes (5 points) ____ No (0 points)

From the Environment section:

45. Home has café/restaurant/tavern/canteen available to residents, families, and visitors at which residents and family can purchase food and drinks daily.	____Yes (5 points) ____ No (0 points)
46. Home has special dining room available for family use/gatherings which excludes regular dining areas.	____Yes (5 points) ____ No (0 points)
47. Kitchenette or kitchen area with at least a refrigerator and stove is available to families, residents, and staff where cooking and baking are welcomed.	____Yes (5 points) ____ No (0 points)

Amy Elliot, Policy Analyst with the Pioneer Network explains an exciting brand new interactive version of the Artifacts tool and soon to be developed data base:

> In January 2010, Pioneer Network will release a web-based, interactive version of the Artifacts of Culture Change tool. This online version includes several value added components to assist providers and to enhance the analysis, benchmarking and scoring of Artifacts data. To aid providers in completing the Artifacts, the online design includes practical "How to Use" instructions and "Tips" for completing the tool. To enhance the analysis of the Artifacts, the web-based version includes functionality to augment the parameters of data collection. For example, the online version of the Artifacts requests that providers enter interval level data for certain

questions including responses requiring percentage estimates. With this interval level data, Pioneer Network and providers will be able to better analyze timelines for implementation, efficacy of change (correlating responses to outcomes), and to perform benchmarking analyses for more detailed comparisons between homes. In addition, the online Artifacts survey allows homes to enter in comments and anecdotal examples of implementation practice that can be compiled into a best practice document for future use (2010)

NHRegsPlus

The Hulda B. and Maurice L. Rothschild Foundation provides funding for the NHRegsPlus searchable website which contains a repository of State nursing home regulations for each of the 50 States. It allows the user to search through all 50 States' requirements per sections such as dietary services. Most States' licensure regulations and waiver/variance process (if there is one), can be accessed directly from the site. The website, housed at the University of Minnesota, is a wealth of information at your fingertips and can be accessed at http://www.hpm.umn.edu/NHRegsPlus.

Chapter Ten
Negative Outcome

No Negative Outcomes

> 'Watching your residents dining brought tears to my eyes. This is the first time in my career that I have observed a meal the way OBRA intended it to be' – the words of a surveyor at the exit of the first survey visit after culture change in a pioneering facility. Another surveyor stated 'You aren't doing anything 'by the book' but OBRA is an outcome-based survey process and I can't find a single negative outcome.'
> Linda Bump, Life Happens in the Kitchen, 2004-2005.

> When you have residents who are sleeping better and eating better and feeling better, you naturally have positive outcomes. And the surveyors see that. Connie McDonald administrator featured on Part II of the CMS Individualized Care series, 2007.

A Refocus on Health and Nutrition

If nursing homes truly are healthcare facilities and about promoting good health, why don't they promote sleep, offer healthy foods and fresh produce and encourage people to eat the foods they love? Sleep is like medicine, my mother always said. Why don't nursing homes let people sleep? The benefits are many to being well rested: people are more awake and alert, eat better, feel better, enjoy better mood, and fall less. Preventing falls - another reason to support what most people love, to sleep.

> Clinical benefits, just by going by the resident's schedule, have resulted in better sleep, nutrition, moods and other outcomes.
> CMS Individualized Care Series, Part II, 2007.

Individualized Care

> Individualized care is better care. Individualized care creates a greater capacity to respond to clinical needs. For example, if we know we need to maintain good nutrition then having a broader array of ways to meet a resident's individual food preference will make it easier for us to make sure our residents eat well.
> CMS Individualized Care Series, Part III, 2007.

> Individualized, person-centered care, in my opinion, is where the best long term care and the best medical care, for that matter, is to be found.
> Thomas Hamilton, CMS Survey and Certification Group Director at the Creating Home Symposium April 3, 2008.

Feeling Unsafe

In a New York Times article, "Rethinking Old Age," the author writes about an 89 year old friend shortly after moving into a nursing home of her own choosing:

> She's glad to be in a safe place -- if there's anything a decent nursing home is built for, it is safety. But she is struggling. The trouble is -- and it's a possibility we've mostly ignored for the very old -- she expects more from life than safety. 'I know I can't do what I used to,' she said, 'but this feels like a hospital, not a home.' And that is in fact the near-universal reality. Nursing home priorities are matters like avoiding bedsores and maintaining weight -- important goals, but they are means, not ends (Gawande, 2007).

Typically we think of being safe in terms of safety from fire, from intruders, from accidents and injury. We worry it is not safe when one eats what "they are not supposed to." But what else does safety encompass? If I am told over and over I cannot have something I want, something I've always had, we now know this lack of control over my life contributes to feeling helpless and unable to affect my life. Might this lead to feeling unsafe in a way we have not thought of? Isn't it supposed to be my home where I am free to, safe to, make my own decisions?

The Right to Folly

And what about the right to make poor decisions? Isn't that ours to make too? Dr. Thomas says it this way:

> I'm a firm believer in the rights of elders to do whatever the hell they want. If you only have the right to make the 'good, wise' decisions that your grown daughter agrees with, then you're not running your own life anymore. I've taken care of lots of people who didn't even know their own children. Sure, they probably shouldn't be making decisions about their 401(k) plans, but they can decide what to wear and what to eat and whether to go outside on a daily basis. People think that if old people cannot make the big decisions, they cannot make any decisions—and that is just wrong. They have the right to folly (Brown, 2008).

The Smoking Analogy

Most of the world has accepted the fact that some people choose to smoke *against medical advice*. We all have come to understand that is the person's choice to make bad choices, their life to live and their life to give up if that is what comes of their choice. Why isn't this applied to people living in long-term care? Basically because a facility is held to two standards, keeping residents safe at all times, preventing accidents, and honoring their choices. Safety has won over.

The Dawning of a New Negative Outcome

Although this reference is dated, it surely still applies and captures the essence of the issue:

In my experience, no one is talking about this work in the field of long-term care that has been around since 1976. Ellen Langer and Judith Rodin are psychologists, continuing their work in their respective fields, who early in their careers were interested in choice, or the lack thereof, in nursing homes. In Ellen Langer's own words:

> I had recently completed research on the illusion of control, which showed me how important it was for people to control their own lives. It was so important that even in chance-determined situations, people would not relinquish their control. Therefore, with the slightest provocation, they engaged in illusory control behavior. Around this same time, I was visiting my grandmother in a nursing home. I was struck by how little control she and the other residents were permitted. I thought this was outrageous. How could 'they' be so sure they know better than these people? I thought all facts were probabilistic statements so their certainty bothered me.
>
> Let me give you an example to make this clearer. Should an elderly diabetic be allowed to have ice cream? The relationship between diabetes and sugar is probabalistic 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 findings, however, 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.
>
> I approached Judy Rodin at Yale, who was also working in the area of control at this time. She too felt that this population was characteristically denied the opportunity to exercise control. Together we visited local nursing homes.… The experiment we conducted was successful. Psychologically, control proved to be a potent variable. The follow-up showed us that control was also important physiologically. Half as many people given our control intervention had died 18 months later than those given a comparison treatment. Because the longevity findings were so dramatic, I've spent a good deal of time trying to understand how such a simple treatment (a pep talk encouraging decision making, a few decisions, and a plant to take care of) could have such a profound effect on people (1985).

The experimental group also showed "a significant improvement over the control group in alertness, active participation, and general sense of well-being" (Langer, 1985). This is really no surprise. At the first Creating Home Symposium quality of life researcher Dr. Rosalie Kane exasperatedly said about people's desire for private rooms, "But I hope we won't have any more studies about whether it's a good idea." Could it be we don't need any

more research to prove what we all know innately to be true that making choice improves our quality of life and our health too?

Learned Helplessness, Learned Dependency and Psychosocial Well-being

Seligman taught that learned helplessness means a person has learned to behave helplessly even when the opportunity is restored to exert control. Learned helplessness theory is the view that clinical depression and related mental illnesses can result from even a perceived absence of control (1975). Dr. Judah Ronch, psychologist and Interim Dean of Erickson School of Aging at the University of Maryland, takes it one step further. He points out that many who've become depressed tend to believe they are not capable of influencing the results of events in their environment or, worse yet, believe they themselves are the source of bad outcomes and if they act, will affect things for the worse (2006). Eric Haider teaches that we teach residents learned helplessness and the Eden Alternative® recognizes helplessness as one of the three plagues of institutionalization (edenalt.com).

On the CMS 2006 satellite broadcast regarding the CMS Psychosocial Severity Outcome Guide Ronch taught that psychosocial well-being boils down to having the ability to make choices and decisions about important factors in daily life. He explains that our basic human needs are either served or frustrated by the care giving setting.

Ronch said on the CMS broadcast that staff working in long-term care are highly nurturing people. In the institutional setting staff learn that if residents cooperate with their ability to help them, it is a more efficient use of their time. The price paid is for the resident to learn to wait to be helped. This squelches autonomy, skills atrophy, residents become even more dependent on care givers, and have even less control over their lives. Staff's style of speech encourages learned dependency. Intonation is often similar to what is used with children which causes an adult to feel devalued. Research shows the person loses faith in their ability to affect outcomes in their own world. Ronch said he doesn't mean to give the impression a resident can do anything regardless of safety, but part of good care is learning what a person can do for themselves and supporting it. It leads to better health and clinical outcomes. The good news? Learned dependency is entirely preventable and reversible.

In 1986 the Institute of Medicine identified a nursing home as "… both a treatment and a living situation. 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." Also "… residents who receive good personalized care and opportunities for choice have higher morale, greater life satisfaction, and better adjustment" (IOM, 1986).

Do No Harm

Harm was not intended with restraints but we discovered they harm people. Harm was not intended trying to get people clean even when battles ensued but we discovered people were being harmed. Now we look at food. Harm is certainly not intended when we want residents to eat what is good for them.

It's hard to describe how it hit me when I heard about decaf coffee only still being served to residents. I felt as if my body had been transported back in time. I knew of this happening in the early 1990's but have not encountered, heard of, or even thought about it since. It took the wind out of my sails. Whoever makes these decisions, they mean no harm but at some level it is harming people. All it takes is to think of ourselves being denied something we prefer and given something we dislike instead.

And now we know better. Not supporting individualized care and a person's choice, not supporting "the right to folly," causes learned helplessness, depression, learned dependency, even bringing death earlier. We have not intended harm with our good intentions, but we are creating it.

Weight loss is attributable to adverse effects of medications in 8 percent of nursing home residents (Cicero, 2001). I wonder what percent of weight loss is attributable to the side effects or "life effects" of not being able to lead one's own life, make one's own decisions and eat what one wants to eat.

The Hippocratic Oath has become known as "Do no Harm." Frank, Forbes-Thompson and Shields explored this issue and came up with:

> It is as difficult as staring straight at the sun, but if we as a profession are to initiate radical change, then <u>we must be conscious of and focus on the harm that we do</u>. <u>Harm – not just to the body, but to the very person – is systematically embedded in bureaucratic institutions that strip elders of their personhood</u> (2004).

The harm, the potential harm, we overly identify and worry about is to the body. When a person will not follow recommended medical advice, aka the physician's order, we worry about the physical harm it might cause their body. Notice too how it is called "against medical advice" as if the person is somehow wrong to go against the physician's advice, again a bad person, "non-complaint." We haven't contemplated much the harm to the person that results from denying them this right, the right to go against medical advice, the right to their personhood, their life, their schedule, their wishes.

No one should have to fight for, cry for or be told ever again, "You can't come in the dining room until the doors are open" or "You can't have this because it's not on your diet." We decide <u>for</u> people they will only drink decaf coffee. We decide <u>for</u> people they can only eat this food and not eat that food. If you were denied your rights to this extent, would it feel like abuse, neglect? Part of the culture change movement is to call things as they are and not longer sugar coat.

<u>Reasonable Person Concept</u>

Even if a resident doesn't try to exert their choice, doesn't complain, but "goes with the flow," and makes no "waves" (which is quite common in institutional living) there is another aspect of harm to be considered, the "reasonable person concept." According to

CMS' Psychosocial Severity Outcome Guide, this is used "When the resident's reaction to a deficient practice is markedly incongruent with the level of reaction the reasonable person would have to the deficient practice." Let's apply this concept to our discussion. Even if a resident's reaction is that it is "fine" for her/his choice not to be honored this is "markedly incongruent" with a reasonable person like you and I living in the community at large. If someone gave us decaf coffee when we wanted caffeinated or woke us up according to when they thought we should get up, we would not be happy about it … to say the least.

I ask people all over the country how many of them do not even eat breakfast. Inevitably half the crowd raises their hands whether there are 8 or 800. Half of us do not eat breakfast. What is the number one driving force in every nursing home every day for getting people up? Breakfast. Why do we even wake people up at all? Breakfast. I ask my half a crowd how they would feel about being awakened from sleep to eat a meal they didn't want. They say "mad" and "angry." Someone inevitably says they would be "non-compliant" and administered a psychotropic drug in order to be compliant. Unfortunately, this is the norm, according to my audiences. This is Unnecessary Drugs. This is restraining a person for the convenience of staff, for honoring what a CNA once called the "almighty schedule" not the person. This is non-compliance with the federal requirements. It is the dawning of a new day to realize there are negative outcomes we are not considering and people's health and well-being are in the balance.

Chapter Eleven
Moving into New Territory

Many issues have been set forth in this paper. Many issues exist when it comes to food and dining and serving the individual. The table has now been set for the *Creating Home II* national symposium February 11, 2010. We invite you to join us and share what you think. Experts have been invited to share their experiences and recommendations. Anyone is invited to come and share their own wisdom on these subjects at this once-in-a-lifetime event. Together we will create a welcomed and needed national dialog about what needs to happen next by CMS, the Pioneer Network, providers, clinicians, professions, academia, researchers, grant makers and really each of us.

I would like to thank CMS personally and on behalf of the culture change and long term care community as it is not every field where the federal government branch with authority invites all players to the table to express their view points while the government staff sits and listens. In fact, when I tell people about this project, whatever walk of life they come from they say they wish the government would listen and gather ideas for what needs to be changed in their respective fields. Other entities are sitting up and noticing as evidenced by an upcoming symposium with similar format by the National Fire Protection Association. I would like to thank CMS for this unique opportunity to point out gaps and give ideas straight to CMS Division of Nursing Homes. You deserve an award of some kind. Providers and surveyors alike are struggling through issues and CMS you are taking the lead. Thanks to you and the Pioneer Network, this national symposium, dialog and gathering of ideas and solutions shows that we are all in this together. And together we're stronger.

As Linda Roberts, registered dietitian and long term care consultant said at her 2009 Pioneer Network session on dining, "we are in new territory." You said it well, Linda.

We invite you to pull up a chair to the table with these thoughts in mind, thoughts from Alexander Hamilton that Steve Shields and LaVrene Norton bring to our attention even in the title of their landmark book *In Pursuit of the Sunbeam*,

> 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 (2006).

This is the "menu item" of most interest to all of us, transforming our thinking and our systems to where the person and her/his individualized preferences take precedence over any prescribed diet. We now know that the potential for bodily harm from not following restricted diets is miniscule and has been assumed, not proven. We have entered new territory where we are realizing that dishonoring choice given "as with sunbeam…by the hand of Divinity itself," is causing harm, both clinically when one does not eat at all as well as psychologically. New territory indeed.

What will your role be in cutting the paths in this new territory? We all have a part to play. Certainly CMS needs to look at its dueling requirements for facilities to prevent accidents while also honoring residents' right to choice. Even if CMS does come to some decision regarding this conflict, there is also the issue of litigation. However, more and more long-term care professionals and corporations are realizing, in the words of a Colorado nurse, "you're damned if you do, damned if you don't" and are deciding to take a stand for supporting people in directing their lives.

What will you stand for? What are you willing to "take on?" Will it be volunteering to speak at a nursing course in your community? Will it be developing a research study? Will it be taking it on personally to educate just one physician? Will it be leading a committee in your facility? Thank you for what you have done, for what you are doing and what you will do.

We are each being called to take a stand. What do you want to be known for? Isn't it time we back each other for backing the resident? I dream of a day there is no need to "take a stand" or "back each other" for doing so because we've changed it. We've created the world we want to live in, even in a nursing home.

Let this be what we <u>stand against</u>:

> The food provides nothing that anyone is likely to object to, a consideration which more than anything leaves the <u>flavor of sadness in the mouth</u>. What we value all our life, <u>what fires us and sparks us</u>, <u>the sense of our individuality, dampened down, crushed, deprived of oxygen</u> (the experience of Faye Weldon living in a nursing home in *Rhode Island Blues*).

And let this be what we <u>stand for</u>:

> Bonnie Kantor, (then) director of geriatrics and gerontology at Ohio State University, shared a personal story that exemplified what families want. Her mother had suffered from dementia for years and lived in a nursing home in New York, hundreds of miles away. She didn't speak, got around in a wheelchair, and ate only pureed food. One day, two aides were chatting together about going to Wendy's for lunch.
>
>> All of a sudden my mother uttered the first sentence she had said since she'd been there in five years – "Can I go too?" Everything stopped. They said, "Where do you want to go, Miriam?" And she said, "Wendy's." They said to her, "What would you have?" And she said, "Chicken nuggets." Somebody ran over to the head nurse and said, "Can we take Miriam to Wendy's?" This is a woman who hasn't been out of the nursing home, can't walk without incredible assistance – and the nurse said yes.

> They got her all dolled up and put her in the car and took her to Wendy's and got carryout. They weren't sure what kind of sauce she wanted, so they got all of them. Meanwhile they called me on a speakerphone in her room, so that I could be part of the party. As her daughter and as a professional, I knew she could die – she was eating chicken nuggets and she's been on a pureed diet. Did they know in twenty minutes she'd have no memory of it? Sure. Did that matter? No. It provided them with a connection, so for the next long time they could say, "Miriam, remember when we went to Wendy's?" (Baker, 2007).

I find it fascinating that Bonnie Kantor is now the Executive Director of the Pioneer Network a bold leader who personally has "put the person before the task" or in the case of her mother, "put the person before the physician order." Bonnie Kantor's mother did not die from eating her chicken nuggets. She did not taste the "flavor of sadness" but instead tasted that which "fired and sparked" her thanks to caring staff who took a stand to support her individuality, her well-being, and supported her to live and breathe and thrive.

> "The life of a nursing home resident…should be as similar as possible
> to the life he or she would choose to lead at home"
> (Pearson, Hocking, Mott and Riggs, *Journal of Advanced Nursing,* 1993).

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Carmen is a Certified Validation Worker, Certified Validation Group Practitioner, Certified Eden Associate and Eden Mentor. In 2002, she co-founded the Colorado Culture Change Coalition and she has authored seven culture change workbooks for Action Pact, Inc. available at culturechangenow.com:
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Quality of Life: The Difference between Deficient, Common and Culture Change Practice
Building Culture Change Coalitions
Regulatory Support and Considerations for Culture Change
Changing the Culture of Care Planning: A Person-Directed Approach
You Hold the Key to a Vibrant Daily Home Life
SOFTEN the Assessment Process (and training DVD).