The Power of Language to Create Culture

Carmen Bowman, MHS
Judah Ronch, PhD
Galina Madjaroff, MA

Dedication

To the beautiful people who live and work in long term care.
Let's create a beautiful language together.

Acknowledgements

Executive Summary

Language plays a crucial role in shaping the culture of aging and aging services in our society. The words we use when talking to and about older persons denote how they are valued, what is expected of them, and where they stand with respect to the speaker. Any serious and lasting attempt to change the culture of aging services organizations must include an analysis of what is said, to whom and what that communication both denotes (says) and connotes (means at multiple levels).

Learning from other fields, we have seen how words matter and can be sources of both good and harm. What a person is called creates expectations about their behavior and sets the limits on how much growth and individual identity is deemed possible by those who serve them. Our analysis of the traditional terms that have characterized speech in the aging services work place reveals culturally embedded ways of talking that infantilize, subordinate, marginalize and otherwise dishonor elders. We present many examples of changed vocabularies that reflect the values of some of the new cultures developed to combat these tendencies. These cultures reflect new assumptions about elders and their roles in society, and as such replace dehumanizing language with language that communicates honor, inclusion, partnership and equality of elders and those who serve them.

The impact of new language is seen as a way of interacting that goes deeper into the core of peoples' lived experience than mere changes in the words people speak. We argue that the new language will have a positive effect on how elders feel about themselves, how they think, and how functionally able they can be in daily life.

Words do indeed make worlds. We conclude that cultures of care that honor those who live and work in them will find that changing culture and changing language are complementary processes.

Judah Ronch, Galina Madjaroff

The greatest discovery of my generation is that human beings can alter their lives by altering their attitudes of mind.

William James

If thought corrupts language, language can also corrupt thought.
George Orwell

The difference between the right word and the almost right word
is the difference between lightning and the lightning bug.
Mark Twain

Languages differ essentially in what they "must" convey
and not what they "may" convey.
Roman Jakobson,
eminent linguist

Preface

Judah Ronch and Galina Madjaroff

Why Language?

The quotes on the front piece convey fundamental truths about how language has power. Language changes lives by changing minds, shaping thought, and making worlds of difference merely by what is said and not said. It embodies the rules of a culture and the aspirations of those who live in it. The language we speak, hear, and read, and with which our minds ponder our place in the world, shapes our reality.

Language is important both because of <u>what</u> it communicates and in <u>how</u> many ways it does it. It conveys the important rules about how we, and the others in our environment (seen and unseen), expect ourselves to go about our lives. The power and impact of language are really paradoxical in how language can influence behavior. Consider these examples of how language works and what language can do:

- it can inform in a desired way, both by what it says and doesn't say (i.e. "You really look good" vs. "You look good for your age"),
- it can exert power or control over someone else's actions and emotions even if they are not present (like when reading a history book or novel),

> *Culture change in nursing homes is incomplete without language change.*

- it allows us to contact another person when they are not physically present at the same time and place such as by phone and Internet (i.e. Skype and FaceTime) or in writing (on paper or through electrons, i.e. email and texting) and so create closeness, cooperation or affiliation with one another.

But,

- it can also create distance, opposition or isolation among people when they are physically together (like when someone uses jargon that marks identity in an in-group or someone who uses a different language which you don't understand),
- it can bring great emotional pain (i.e. name-calling or use of racial or sexual epithets),
- it can shatter a person's self-esteem, such as when someone personalizes the performance of another (i.e. "Your high error rate makes you totally useless"),
- it can do all these things, and more, both when we intend to and at times when we don't have the intention to because language can operate outside of our conscious awareness and contrary to our conscious intent (like so-called Freudian slips of the tongue).

So words really do matter. We can talk to, at, through, with, about, around and despite other people and events. The words we use, and how they convey our thoughts open our inner worlds of meaning to our audience, and so create our world and the worlds of those

around us. Through this dynamic process of reciprocal influence what we say affects others and vice versa.

Things can get very complex and confusing at times. We live immersed in a sea of language that, despite our best intentions and well-developed brains, can create either clear messages that say what we intend or can generate confusing noise. Because we produce speech at such a rapid rate, often without conscious thought, there are many times when we don't say what we mean, or wish we could take something harmful we said back because we didn't mean to say it, or say it quite that way. And sometimes, we think we are saying something that is not harmful but the listener feels injured nevertheless.

Historically, traditional nursing homes have been places where people use a great deal of language that might actually do harm. In their paper *Words Matter,* Ronch and Thomas (2009) examine the verbal and other communication we use, and point to where we can change the world of nursing homes. A core component of any culture, especially an organization's, is the language it relies on to create shared identity and communicate its values. The world being created by the common language of the institutional nursing home in particular is not a world people are clamoring to live in. It's our belief that the language of the traditional nursing home represents a culture that needs changing. So we advocate for changed language. An integral part of any cultural practice is the language used to communicate it.

A note to our readers:

Our research on language led us to discover that there were a number of terms used in the literature for the kind of speech used with people living in nursing homes that we want to replace with person first language.

Culture change: defined by the Pioneer Network, the leading national organization of the culture change movement is "a transformation anchored in values and beliefs that return control to elders and those who work closest with them. Its ultimate vision is to create a culture of aging that is 'life-affirming, satisfying, humane, and meaningful.' Culture change can transform a 'facility' into a 'home,' a 'resident' into a 'person,' and a 'schedule' into a 'choice.;'" These are changes not only in language but more importantly in practice – welcome, refreshing changes with profound impact on the lives of people living and working in what is commonly referred to as long term care.

Person first language. The disability community has developed what they call person first language encouraging our language to always speak about the person first. So instead of the Parkinson's resident we talk about Sam who has, or lives with, Parkinson's disease. Although you will read us report on what is called people first language, we have known it longer as person first language and feel it fits with the national culture change movement better. The movement advocates for *person* centered care and *person* directed care and putting the *person* before the tasks is one of the core values chosen by the Pioneer Network, the leading national organization of the culture change movement, to describe what needs to be done to change institutional culture. Thus we refer to person first language and we refer to the person or people doing the living in these institutional environments we are trying to change.

We want to clarify a few definitions we have seen used most often to give you an idea of the terms already in use. Researchers have been studying and classifying unintentional derogatory language for over 20 years. We present those used most often, to give you an idea of the terms already in use.

Baby talk speech: "Using a simplified speech register with special lexical items" (words, e.g. "blankie" instead of blanket, or "din din" instead of dinner) "and construction modified from adult speech, high pitch and exaggerated intonation contours. It is typically directed toward children learning language as well as toward pre-linguistic infants, animals, intimate friends, lovers, or hospital patients. In some instances it seems to communicate affection and nurturance; on the other hand, it seems to communicate a depreciatory message signaling *the powerlessness of the addressee"* (italics added). (Caporael, L., 1981; p. 877).

Accommodative Speech: "When adults are addressed in simplified vocabulary with high-pitched tone of voice and slowed speech." (Brown, A. and Draper, P., 2003; p.15).

Institution-Speak: "Words used when speaking to patients and staff" in institutions (e.g. nursing homes) and other large care settings (state institutions such as psychiatric

hospitals or developmental disabilities centers). For example, use of the word "we" instead of "you" in direct address suggests a patronizing tone, or terms such as "dear" which may suggest an inappropriate familiarity. (Schoeneman, Karen., 2003; p. 39-40).

Elderspeak: "An intergenerational communication style that is common in interactions between staff and residents in long term care settings……Elderspeak, (i.e. infantilization or secondary baby talk) features:

- Simplified vocabulary and grammar
- Shortened sentences (presuming that the elder can't process a sentence that is the length of regular adult speech)
- Slowed speech
- Elevated pitch and volume
- Inappropriately intimate terms of endearment
- Diminutives (nicknames or calling someone named William Bill or Billy), inappropriately intimate nominal reference *she's my baby* or *that's my girl* or calling an elder *sweetie* or *good girl*
- Collective (plural) nouns substitute the plural reference (*Are we ready for our bath?)* where a singular form is grammatically correct (*Do you want to take a bath now?)* which implies that the elder cannot act independently
- Tag questions or pseudo-questions that prompt the elders' response, suggesting his/her inability to choose (*You want to get up now, don't you?)*

(Adapted from: Williams, et. al., (2009). Elderspeak communication: Impact on dementia care. *American Journal of Alzheimer's Disease and other dementias.* 2009; 24, 1; 11-20.

Declinist language: Words or phrases that reinforce ageist stereotypes that suggest that ageing is the same thing as deterioration or failed adulthood such as "we let our residents," "that resident is so cute" and "my uncle still….". (Ronch, J and Thomas, W. , 2010).

Actually, many of these definitions describe ways of speaking that any English speaking person would recognize as reflecting how an adult might speak to an infant or young child. In that regard we especially want to bring to your attention the insightful observation in Caporael's definition that what she called "baby talk" *signals the powerlessness of the addressee.* In our opinion, that is the common factor in all of them, and where the heart of the problem lies.

We think that all of these definitions and examples present a good overview of the issue from just about every angle. But we thought very hard about which

Why do you think the staff insists on talking baby talk when speaking to me? I understand English. I have a degree in music and am a certified teacher. Now I hear a lot of words that end in "y." Is this how my kids felt? My hearing aid works fine. There is little need for anyone to position their face directly in front of mine and raise their voice with those "y" words.

My World Now: Life in a nursing home, from the inside. Anna Mae Halgrim Seaver, Newsweek, June 27, 1994

term we would use in this paper to refer to the language we are trying to replace. Each term had its virtues in the context of the scholarship that used it as a working definition, but at the same time each had connotations that may cause problems to some readers.

Regarding the term *elder*, some use it; some don't. Some older people like it; some don't. Sometimes it is also used with deep respect when referring to younger people who have lived with disabilities teaching others about surviving and thriving; and some younger people reject it. Thus, since there is no consensus on this word we do not advocate for or against using it. Regardless of our use of it, when used, it is always meant as a term of honor and respect. In this paper we interchangeably use *resident*, mostly *person*, and on occasion *elder* when referring to older persons, depending on the context.

We also use the term "traditional nursing home" to refer to care settings that are more like nursing home care of the past as opposed to settings on the road to change culture. We realize that many settings are in transition and we don't mean to dishonor or minimize the good they are doing.

Since we are writing about language in nursing homes and the need to change both language and culture are at work, we use ***institution-speak*** in this paper. In our view it is location specific, it encompasses all the problems detailed in all of the definitions we found and it speaks to the crux of the problem, the institution, its practices, and all its institutional ways including language.

"Must say" versus "may say"

We have no desire to approve of or advocate for one set of alternative terms over another that are part of the varied person centered cultures under development, or to recommend that a standardized vocabulary list be established as a result of this paper. In fact, we recognize that the language change we are advocating for is a process that is still underway – as are all languages in the world – and that the process of how things are said will develop naturally. While standard varieties of languages are codified and taught in every culture, the non-standard varieties are the laboratories of language change that create the new forms that keep languages fresh when they ultimately get adopted by speakers from outside the originating subculture. Words that are not part of standard dictionaries or usage manuals enter the English language all the time, and may become part of common parlance if enough users use them, thus fueling the need for new editions of dictionaries. New words or phrases come from the worlds of adolescents, ethnic sub-cultures, the arts, and technical words that become everyday parts of the vocabulary of the least tech savvy among us. How many people use the word modem and have no idea that it is a shortened version of modulator-demodulator?

This process whereby language changes as a result of social influences will, we predict, also be at work in our world of culture change as well. As in the world at large, cultures that

share a philosophy (democracy, for example), use different words and even different languages to denote the same item. Despite a shared philosophy, many leaders and advocates for culture change have good reasons to use their preferred words unique to the culture they are crafting. This happens because each culture is striving to establish its own identity and so needs its own language to do that most efficiently and effectively.

We think that this is a positive thing, and that as we are early in the history of the culture change movement, we need these laboratories where language can develop and be tested every day to see how well the words convey the values and concepts of the specific culture, and evaluate how the language elements help realize the philosophy at the culture's roots. Language will stay current, vital and responsive as a result. The lesson of history is that any language needs speakers to use it in everyday life and modify it to respond to newly developed aspects of the culture as it matures.

Transitional Terms

Some of the words we are going to be including may sound awkward at first hearing but they represent what we would call transitional terminology. For example, the motor carriage became known as the motor car and then the automobile. How about the term telephone which became phone, and cell phone is now just a cell? Moving away from less respectful terms like front line staff, the transitional term became, for some, the direct care workers and now we refer to caregivers and care partners. The term permanent assignment has become softer with consistent staffing or dedicated staff. These transitional terms have one foot rooted in the past and one foot rooted in the future. Ultimately the foot in the past goes away and the term keeps progressing. The substitute terms are the transitional terms.

Introduction -Where we are with Language
Carmen Bowman

It is identified by leaders in the culture change movement that much of our long-term care nomenclature can be undignified to those who are served as well as to those doing the serving, the people working in the various long term care settings. Included in this arena of long term care settings are nursing homes either long term or short term/rehab, assisted living residences, adult day programs, rehabilitation centers, home health and acute care. Nancy Fox, in her book *The Journey of a Lifetime: Leadership Pathways to Culture Change in Long-Term Care,*(2007) wrote this about language,

> …our entire industry has developed a language that is demeaning and depersonalizing both of the Elders we serve and the hands-on staff who care for them. What we know is that language can and does influence us. Language is a powerful tool. When used in a positive way, it can inspire people. When used negatively, it can hurt. But when it becomes a part of a culture and is simply mindless, that is, when we speak the words without understanding their impact, it is dangerous…. When we awaken to the fact that this kind of language has seeped into our culture and is now actually driving our attitudes and beliefs, we can begin to change our language to shape a new culture (p. 82).

CMS is the Centers for Medicare and Medicaid Services and provides Medicare and Medicaid reimbursement to nursing homes that have been certified. To its credit, CMS has brought up language with its revised 2009 interpretive guidance at Tag 241 Dignity by stating that *language that labels people, such as "feeders," should be avoided*.

Additionally, within the CMS training to surveyors on the 2009 guidance for Tag 241 Dignity, author Karen Schoeneman states, "surveyors [nursing home inspectors] are expected to be good role models of dignified language." However, only one term is identified within the new guidelines and no training has been provided to surveyors regarding using better language. Thus, if they are to be good role models, which would be very a worthwhile goal given the authority and influence they hold in each state, they need the opportunity to learn about what makes the commonly used language undignified along with potential replacement language that honors people. And of course surveyors are not unique in needing training.

Other fields have changed their language. For example, prisons are now correctional centers and stewardesses are now flight attendants. One adjacent field to long-term care, the disability community, has developed what they call person first language. This will be explained in detail later in the paper but person first language simply and always puts the person first. So one is not a wheelchair bound person but instead a person, or Sue, who uses a wheelchair.

Leaders of the culture change movement have for many years identified the profound shortcomings of institutional language. However only a few publications regarding

language exist within the culture change community: some collected "old" and suggested "new" words, some articles, some sections of books and perhaps one book. You will see them referenced in this paper and listed in the references. Unfortunately, undignified language still exists in the majority of traditional nursing homes, mostly because it is accepted as common.

Before we delve into our thoughts about language we will share what Beth Baker learned and had to say as an outsider to the world of long term care. Beth is a Wall Street journalist who learned about the culture change movement and went about studying it. Regarding language, here are her observations:

> Other nursing homes use language in a way that distances, depersonalizes, or infantilizes those who live there. In fact, many companies no longer bother to use the word 'home.' The administrator where Gass [author of Nobody's Home: Candid Reflections of a Nursing Home Aide] worked insisted, 'It's not a home. It's a nursing facility.' Other [language] changes use terms such as "long-term hospitals.' (Can you imagine saying, 'It's time you go to the long-term hospital, Mom?' People don't 'move' to a nursing home, they are 'admitted.' Once there, they become patients of even 'beds,' as when aides are assigned beds or rooms rather than people. Administrators do not visit with residents; they 'work the floor.' You are labeled by your diagnosis, as the 'hip' or 'the Parkinson's' in room 278. You switch from living to 'having a care plan.' You are measured by the number of ADLs (activities of daily living) in which you are deficient or by your MDS (Minimum Data Set), a clinical assessment tool. If you have trouble swallowing and need help eating, you are a 'feeder.' You may wear a 'bib' at meal time or 'diapers' if you are incontinent. If the staff are benevolent, they will 'allow' you to make a few choices about your daily life, such as what to wear. But the primary emphasis is medical, custodial, and negative. Life revolves around what you can't do: walk, go to the bathroom by yourself, bathe, get dressed, go outside alone, shop, escape (Old Age in a New Age, 31).

When encouraged to think about language and what its messages are, long term care professionals get excited at the prospect of opportunities to change and improve it. What is still missing, however, is a language transformation of what is said to whom and how it is said, that conveys the values of a changed culture. Thus it is our hope that this Rothschild funded paper might make a significant contribution to improving language and the way it shapes the cultural experience for all living and working in what we call long term care, by suggesting some positive future directions of language and strategies to get there.

This paper describes the unintended and negative consequences of the traditional, institutional language of long term care as well as the good work being done by leaders to create a new vocabulary that honors those both living and working there. We also take a look at what can be learned from other fields regarding language. Lastly, we suggest strategies for all of us in how to shift to a different and better language. In setting out to write this work I realized early on it would have to have the insights from psychologist Dr. Judah Ronch who did his doctoral work in the psychology/sociology of language and behavior. Thus he was added to the project to share his very unique insights about

language, linguistics, and what we do to people psychologically with dishonoring language. As a Professor and Dean of the Erickson School of Aging Studies at the University of Maryland Baltimore County, he then invited a former student, now Lecturer and Undergraduate Program Director at the Erickson School and PhD candidate, Galina Madjaroff, who has now turned her doctoral focus to long term care. The Eden Alternative, a leading model of transformation of institutional culture, and its founder Dr. Bill Thomas identifies that leaders of homes where people live and work are "world makers" and that "words make worlds." So, what kind of world will we make with our words?

Learning from other Fields

Carmen Bowman

Why Words Matter

Language is important in every field of endeavor and every field of endeavor has the challenge of creating the right nomenclature to reflect that field's values and culture. The challenge has been undertaken in many other fields. Therefore, we illuminate this work and begin by learning what we can from these areas, outside of long term care.

What's in a name? Prisons are officially called correctional centers. A search on the Internet will show you the two terms are really used interchangeably. I hear both used by my police officer husband and his colleagues. In fact, they probably use prison more.   He agrees it is more "politically correct" to use the term corrections, explaining further that the dispatcher always refers to a former prisoner as a "corrections client." However, he says a prison is a prison and those within it are prisoners. "Political correctness" without values and goals, i.e. changing the term imprisonment to correction without true rehabilitation, is merely putting new paint on old rusty ships. Ronch, who years ago taught in a prison, observes that relationships and outcomes haven't changed in correctional centers despite the euphemistic "new-speak."

Learning from the Disability Community

According to Wikipedia (accessed 4/22/10), the terms "mentally challenged" or 'intellectual disability" have come about because of the negative and pejorative connotations with "mental retardation." "Developmental disability" and "developmental delay" for persons under 18 years of age are "generally considered more acceptable terms." Wikipedia also explains:

> Retarded comes from the Latin retardare, "to make slow, delay, keep back, or hinder." The term was recorded in 1426 as a "fact or action of making slower in movement or time." The first record of retarded in relation to being mentally slow was in 1895. The term retarded was used to replace terms like idiot, moron, and imbecile because it was not a derogatory term. By the 1960s, however, the term had taken on a partially derogatory meaning as well. The noun "retard" is particularly seen as pejorative; as of 2010, the Special Olympics, Best Buddies and over 100 other organizations are striving to help eliminate the use of the "r-word" (analogous to the "n-word") in everyday conversation.

> Perhaps the negative connotations associated with these numerous terms for mental retardation reflect society's attitude about the condition. There are competing desires among elements of society, some of whom seek neutral medical terms, and others who want to use such terms as weapons with which to abuse people.

Today, the term "retarded" is slowly being replaced by new words like "special" or "challenged." The term "developmental delay" is rapidly gaining popularity among caretakers and parents of individuals with mental retardation (fic). Using the word "delay" is preferred over "disability" by many people, because that term (delay) encapsulates the core deficit that creates mental retardation in the first place. Delay suggests that a person has been held back from their potential, rather than someone who has been disabled—self-fulfilling prophecy.

There is even a website called R-WORD: Spread the Word to End the Word (www.r-word.org accessed 9/11/11). It explains that the r-word retard or retarded are exclusive, offensive and derogatory. Although they were first used as a diagnostic term for profound intellectual disability, it has become a pejorative term for stupid or dumb as in "Don't be such a retard." On October 5, 2010, Senate Bill 2781 was signed into federal law. Called Rosa's Law, it removes the terms "mental retardation" and "mentally retarded" from federal health, education and labor policy and replaces them with people first language such as "individual with an intellectual disability" and "intellectual disability." Also observed at this website was an interesting advertisement for an event called Label Jars, Not People.

The American Association of Mental Retardation changed its name to American Association on Intellectual and Developmental Disabilities in the year 2006. In 2010, a big change in title occurred in the state of New York. Rather than just report it, look at the enthusiasm in this announcement about it:

June 18, 2010

Dear Friends and Colleagues:

WOW! Finally, some good news to tell you: Change is coming!

I am extremely pleased to let you know that both the State Senate and the Assembly have now passed our name change bills – as soon as the Governor signs them into law, OMRDD [Office of Mental Retardation and Developmental Disabilities] officially becomes the **New York State Office For People With Developmental Disabilities (OPWDD)!**

This vital legislation not only removes the words "Mental Retardation" from the name of the State agency, but also from State statute and regulations, excluding clinical references.

Since the beginning of my administration, I have wanted to make this change in support of the individuals with developmental disabilities and their families. This is the culmination of all the work individuals, families, and providers have done to advocate for the dignity and respect for all people with developmental disabilities.

I am incredibly delighted about this vital milestone that greatly supports our mission of helping people with developmental disabilities live richer lives.

We will be making a more formal announcement in the very near future! Stay tuned!

Sincerely,
Diana Jones Ritter, Commissioner of the OPWDD (at the time)

People/Person First Language
People with disabilities have for many years stood up for more dignified and respectful language. We have much to learn from them and namely what they call *people first language* or *person first language.* One of the best articles found succinctly explains it all. It is written by Kathie Snow, a mother of a son with many characteristics she explains, only one of which is cerebral palsy. Her article, *To ensure Inclusion, Freedom and Respect for all, we must use People First Language* is so helpful we cite much of it here. Her thoughts can also be found with a whole host of other helpful materials at her website which is www.disabilityisnatural.com.

Kathie Snow (2011) also says that attitude and language changed in the civil rights and women's rights movements. As an obvious example, she says we no longer use what she called the "n" word and men no longer get to call women "honey" or "sweetie" or worse. She also wisely points out that "the majority impose language but the minority has to take control of the language and identify how they want to be described, words to use and words not to use".

Snow points out that we typically label the "handicapped" or "disabled" with these disrespectful descriptor terms and proceed to further describe them with more disrespectful descriptions and stereotypical perceptions such as *retarded, autistic, blind deaf, learning disabled;* people who *suffer* from the *tragedy* of *birth defects*; *paraplegic heroes* who *struggle* to become *normal* again; and v*ictims* who *fight* to *overcome* their *challenges.*

Instead, Snow points out who these people really are:

> Moms and Dads – Sons and Daughters – Employees and Employers – Friends and Neighbors – Students and Teachers – Leaders and Followers – Scientists, Doctors, Actors, Presidents, and More. They are people. *They are people, <u>first</u>.*

Snow has learned what she too calls *The Power of Language and Labels* and states,

> Words are powerful. Old and inaccurate descriptors, and the inappropriate *use* of these descriptors, perpetuate negative stereotypes and reinforce an incredibly powerful attitudinal barrier. And this invisible, but potent, attitudinal barrier is the greatest obstacle facing individuals who have disability diagnoses. When we describe people by their medical diagnoses, we devalue and disrespect them as individuals. Do you want to be known primarily by your psoriasis, gynecological history, the warts on your behind, or any other condition?

Worse, medical diagnoses are frequently used to define a person's potential and value! In the process, we crush people's hopes and dreams and relegate them to the margins of society.

Snow calls the term "handicapped" archaic and reports it can no longer be found in any federal regulation. She explains its origin is from an Old English bartering game in which the loser was left with his "hand in his cap," in other words at a disadvantage. Another origin refers to one with a disability begging with his "cap in his hand." Snow says this "antiquated, derogatory term perpetuates the stereotypical perception that people with disability diagnoses make up one homogenous group of pitiful, needy people!" She wisely points out that other people who share some characteristic are not all alike nor are people with disability. She teaches that people labeled "disabled"- which implies broken down like a disabled car – are not broken.

Snow shows how attitude shapes language:

A change in attitude can change everything. If educators believed children with disability diagnoses are boys and girls who have the potential to learn, who need the same quality of education as their brothers and sisters, and who have a future in the adult world of work, we wouldn't have millions of children being segregated and undereducated in special ed. rooms.

If employers believed adults with disability diagnoses have (or could learn) valuable job skills, we wouldn't have an estimated 75% unemployment rate of people with disabilities! If merchants saw people with disabilities as customers with money to spend, we wouldn't have so many inaccessible stores, theaters, restrooms and more. If the service system saw people with disabilities as 'customers,' instead of 'clients,' 'consumers,' or 'recipients,' perhaps it would focus on meeting a person's real needs (like inclusion, friendship, etc.) instead of trying to remediate a person's 'problems.'

Kathie Snow's points are "spot on" regarding putting the person before the disability and the only labels needed are peoples' names:

People First Language puts the person before the disability, and it describes what a person *has*, not who a person *is*. Are you 'myopic' or are you a person who wears glasses? Are you cancerous or are you a person who has cancer? Are you freckled, or are you a person who has freckles? Are you 'handicapped/disabled' or are you a person with a disability?

Children with disability diagnoses are children, first. The only label they need are their names! Parents must not talk about their children in the clinical terms used by professionals. The parent of a child who wears glasses (diagnosis: myopia) doesn't say, 'My daughter is myopic'" so why does the parent of a child who has the diagnosis of autism say, 'My daughter is autistic?'

Adults with disability diagnoses are adults, first. The only labels they need are their names! They must not talk about themselves the way professionals talk about them. An adult with a medical diagnosis of cancer doesn't say, 'I'm cancerous,' so why does an adult with a diagnosis of cerebral palsy say, 'I'm disabled.'?

A person's self-image is strongly tied to the words used to describe him. For generations, people with disabilities have been described by negative, stereotypical words which have created harmful, mythical portrayals. We must stop believing (and perpetuating) the myths – *the lies* – of labels. We must believe children and adults who have been diagnosed with conditions we call disabilities are unique individuals with unlimited potential to achieve their dreams, just like all Americans.

People First Language doesn't end up being 'politically correct.' It is, instead, about good manners and respect (and it was begun by individuals who said, 'We are not our disabilities!') We have the power to create a new paradigm of disability. In doing so, we'll change lives of children and adults who have disability diagnoses – and we'll also change our world and ourselves!

Worse yet, we sometimes refer to sufferers or victims of dementia. With *The Best Friends Approach to Alzheimer's Care*, David Troxel and Virginia Bell (2002), suggest approaching a person with Alzheimer's disease as a close friend. If you approached Sarah as your close friend you would know oh so many other things about her; living with dementia would be only one of them. And it follows that instead of any label we would always use Sarah's name. So she becomes Sarah, the new person moving in who needs assistance with eating instead of Sarah the new admit who is a feeder.

As we explore the power of language to create culture, we will attempt in this paper to apply the premise of people first/person first language to nomenclature used in the various long term care settings.

> The great danger is that you might undergo that radically devaluing and dehumanizing transformation from being a person to being an illness.
>
> Patricia Deegan, Recovering our Sense of Value after Being Labeled 1993.

The People First Language Pledge

Lastly, in her work to promote People First Language, Kathie Snow also developed a pledge for communities and individuals to consider using:

Words Matter! For too long, hurtful words have been used about people who have disabilities. So I pledge to make changes in how I think and talk, and will use People First Language, to put the person first, not the disability. The examples below will be my guide. Using People First Language is about having respect and following the Golden Rule.

I will say:	Instead of:
People with disabilities	Handicapped/disabled
Cognitive disability	Mental Retardation
Mike has autism	Mike is autistic
JoAnn uses a wheelchair.	JoAnn is wheelchair-bound.
Steve has a physical disability.	Steve is crippled.
Maria has a mental health condition.	Maria is mentally ill.
Tyrone communicates with…	Tyrone is non-verbal.
Accessible Parking	Handicapped Parking

I also pledge not to use the "R-word" (retard) or terms like idiot, imbecile, moron, psycho, lame, sped kid, special needs, and other disability labels that are used as insults or that may be hurtful. I will treat others as I want to be treated.

I make this pledge on _____ 20_.   Signed _____

(www.spsk12.net/documents/peoplefirstpledge.pdf).

Developmental disabilities and language reform

Dr. Wolf Wolfensberger founded a reform movement, expanded the theory of normalization (1972) and later formulated the theory of social role valorization (1995) to address what he saw as the systematic deprivation of socially valued roles for people with mental illness and developmental disabilities. He wrote that if a person holds socially valued roles, they are more likely to receive the good things in life among which are home, family, friendship, dignity, respect, acceptance, and the development and exercise of one's capacities. He identified that people with socially devalued roles are at heightened risk of not having the opportunities to strive for these good things in life and are likely to be treated badly.

Wolfensberger realized that in order to communicate new concepts, new terms are often needed (Osburn, 2011). He deliberately chose terms that were uncommon but carried the essence of what he meant to say. Wolfensberger was a pioneer in addressing the role of language in carrying negative images of socially devalued people. If we look at his list of negative experiences that devalued individuals and groups contend with, the lives of too many elders in traditional nursing homes come to mind.

He observed that over their lifetimes, devalued individuals and groups are far more likely to be subjected to a series of negative experiences such as the following:

1. Being perceived as deviant due to physical or functional impairments.
2. Being rejected by community or society and even family or services.
3. Being cast into negative social roles.
4. Being put and kept at a social or physical distance, the latter most commonly by segregation.
5. Having negative images, **including language**, attached to them (emphasis added).
6. Being objects of abuse.

The Foster Care System

An article entitled "Creating the Everyday Magic of a GHC: Language" by Eheart and Power (2009), speaks to the institutional language of the foster system and how an intentional experiment shows, again the premise of this paper, that language has power for either good or bad. GHC is Generations of Hope Corporation, an intentional community bringing together an interesting combination of children in the foster system, adoptive parents and older adults. Eheart and Power bring the terms script and stories into the discussion explaining that scripts are "linguistic recipes for social interaction" guiding "what people say and do in a particular role in a specific situation." While "stories are the way through which individuals, families, and communities draw upon the past in order to understand themselves and each other in the present." They challenge us to think about what kinds of scripts we are writing and stories we are telling in terms of the language used in long term care.

Confirming our premise that language has the power to create culture, they state, "Language, from words and labels to scripts and stories, has the power to be transformative for good or ill."

According to Ehart and Power the term *foster child* all by itself suggests to others the child is damaged or at fault for his or her foster child status, or comes from a family that is "abnormal, irresponsible, abusive and perhaps criminal" without knowing the "rest of the story."

This labeling language has a profound effect on the person. Although a child did nothing to earn this stigma that comes with foster status, the tendency to internalize labels is strong. Youth from foster care speak of the "hurtful effects of the foster care label" such as being teased and made fun of.

Part of the Generations of Hope Corporation is Hope Meadows, a successful living experiment focused on use of normal language and connection. Hope Meadows was designed to normalize life for everyone in its community where "children can be free to be children without the burdens of a foster care label or any of the other labels that would serve to exclude them from full family and community life." At Hope Meadows, community members and staff avoid the use of any unnecessary and stigmatizing jargon that sets

children and families apart as different or not "one of us." "Words that denote difference, or attempt to label or categorize, are abandoned in favor of more neutral terms: for example, the word *person* or *individual* is used instead of *ward, client, patient, and case*. Better yet, the actual names of people are used." No one is referred to as foster or adoptive; children are not placed but instead live with; adoptive parents are never asked if the children are "their own" or if they are the child's "real" parents. This serves to equalize everyone, as no one knows who is a foster child or who is adopted.

> Given every attempt to de-stigmatize language at Hope Meadows, language related to place is also normalized. Not used are traditional social service terms such as placement, beds, slots, and campus which, like the label foster, impose hierarchy, assign blame, create shame, and by doing so, reinforce existing power inequities. At Hope Meadows, families live in homes in a neighborhood, not in cottages on a campus. These homes are indistinguishable from adjacent houses that are not part of the program, and there are no physical markers to indicate that the neighborhood or the residents are any different from their neighbors. This deliberate effort to normalize the physical setting of Hope Meadows has resulted in a special place. The results are in and they're good. New scripts are being written with the absence of hurtful labels, inclusion is felt instead of exclusion, friendship instead of isolation, belonging instead of loneliness and being cared for, not rejected (ibid).

Eheart and Power address older adults as well. "Much less recognized, but equally important, is the need to change our perceptions of aging and learn positive language to create new scripts and tell new stories about the nature and importance of later life."

Eheart and Power refer to sociologist Dr. Hagestad's keynote address at the United Nations (ibid, p. 3) in which she suggests we need more c-words such as care, choice, compassion, competence, connectedness, continuity, and contribution and less d-words, such as decline, dementia, dependency, disease, disability. Hope Meadows adds to the c-word list: *completing the circle of care*.

The seniors at Hope Meadows (the term the older adults chose) say that although they certainly have disabilities, the disabilities do not define them, much like Kathie Snow explains above. Those that live at Hope Meadows are "both givers and recipients of care" – something to which the Eden Alternative has also given attention identifying helplessness as one of the three plagues of institutionalization and teaching that the opportunity to give care is the antidote for it (www.edenalt.com, Eden Principles).

"It often takes serious effort to change habits of speech" say Eheart and Power in the same article. They also cite Heap who suggests that styles and patterns of language, used by mental health professionals are often pejorative. Pejorative language is observed in long term care as well.

> To integrate the philosophy of a non-derogatory or non-depreciating view of children and youth, families, and older adults into a GHC, staff must be exemplary in their exclusive use of positive, respectful, normative language. Building upon the

work of Richardson, 1997, we suggest that the use of this language can create discourse that allows for the emergence of a 'sacred space' where four things happen:

1) people feel 'safe' within it, and safe to be and experiment with who they are and who they are becoming,
2) people feel 'connected' – perhaps to each other, or to a community...,
3) people feel passionate about what they are doing, believing that their activity 'makes a difference'; and
4) people recognize, honor, and are grateful for the safe communion (Eheart and Power, 2009; p. 184-185).

GHC feels they have created this sacred space for community and relationship, communion and connectedness enabling "the people of Hope Meadows to shift the focus of problem-solving from intervention in community to community *as* intervention" enabling new scripts and new stories to change lives.

Language, Customer Service and the Culture of the Nursing Home Workplace

Judah Ronch and Galina Madjaroff

People who live in nursing homes are customers in that they use the services the organization is in business to provide. But nursing homes are unusual business settings because unlike other establishments, where dissatisfied customers are free to take their business to a competitor, the person living in a nursing home cannot easily leave and go to live elsewhere. Because they can't "vote with their feet" like you and I do, people in nursing homes often are at a disadvantage when it comes to experiencing excellent customer service such as what we seek when we patronize providers in the community such as stores, restaurants, hotels or medical providers.

The current business literature emphasizes that customer loyalty is critical to running a successful business, and most writers in this area advise that the way to build customer loyalty is through customer service excellence. We agree that excellent customer service is a hallmark of the most successful organizations, but have seen this philosophy incompletely realized in most traditional nursing homes perhaps, because the customer has few if any options. Excellent service should lead to high customer satisfaction, which in turn would be expected to be associated with customer feedback attesting to the high quality of their lives. This would be the desired outcome and would logically drive organizational practices designed to achieve such goals.

Most authors on the topic of service excellence emphasize that the way customers are spoken to - that is the language and communication behavior they experience from employees - is a key factor in customer satisfaction and business success. Successful communication requires that each party in a conversation not only speak clearly and respectfully, but that each listens to and understands what the other person is saying. The communication style that characterizes excellent customer service requires that each person's point of view is to be respected so that each feels comfortable enough to speak openly and honestly and so that all speakers feel empowered in the conversation. In addition to the words used in the conversation, aspects of language that convey respect and openness to hearing the other's ideas and opinions include tone of voice, speed of speaking, gestures and other body language (eye contact, posture, and facial expressions) and comfort with each person's physical position relative to the other. Our view is that the language of traditional nursing homes illustrates one aspect of customer service excellence that is lacking in many if not most of them.

Communication, that is words, gestures and body language, that promotes customer service excellence and thus optimizes the customer's pleasure carefully avoids signaling that one speaker in the conversation has higher status. Also avoided usually is presenting oneself so that one speaker's needs are dominant in the conversation. These are usually avoided so that neither participant feels that the conversation has been imposed on them against their will or without their permission. We have unfortunately observed many instances of such poor customer service and its characteristic communication style in

traditional nursing homes. The scenarios presented below are all too common and each illustrates how the initiator of the conversation (the staff member) has presented the listener (the person living in the traditional nursing home) with a situation that leaves no room for a customer friendly conversation that signals equality and invites openness between conversants. Each scenario illustrates that:

- the staff initiator has not taken into account the listener's point of view or readiness to have a conversation,
- the patterns, by virtue of how common they are, represent traditional institutional culture where tasks are more important than people and where customer satisfaction is not a priority.

In each instance, the staff person initiates a conversation that signals his/her needs, and not the resident's, are what is most important, and that their expectations are that the patterns of communication they initiated are not likely to be negotiable.

Examples:

- When persons in nursing homes are addressed primarily only when the staff have a need to "do business" and provide care (this indicates conversations are only about tasks, not relationships)
- When a staff member who is standing towers over a seated person when talking (this indicates that the staff person has no sensitivity to the impact of their physical domination of the conversation)
- Talking while walking briskly past a person (more like a "drive by" conversation)
- Standing far away, like in the doorway, when speaking to a person who is in bed (this indicates staff prefers to converse at a distance or "I don't want to be near you")
- When a staff member starts a conversation with a person in a noisy setting, such as a hallway or when the radio or TV is blaring in the background (this communicates "I expect you to hear me no matter what; I have no responsibility to make myself audible")
- When a staff member knocks on the door, saying "Hi, can I come in?" while walking in before being granted permission to enter (this communicates that the staff member considers the question to be an announcement, not a choice; it says "I want to talk to you now and that's all that matters)

An interesting contrast to this communication, and an illustration of how else it could play out, occurs in Sonia Gruen's wonderful novel, *Water for Elephants*. The hero, Jacob, is living in a nursing home at age 93 and protests this kind of insensitive, controlling and depersonalizing communication by his nurse aide. She responds by exiting the room after his outburst and then quickly returns after apparently contemplating his words to finally initiate a person-centered conversation with him that beautifully depicts excellent customer service.

One clear indicator of person centered cultural values is whether conversations that occur use terms of address that support the self-esteem of all speakers by honoring each person. Throughout their lives, both the people living and working in a nursing home are motivated to satisfy a universal set of human needs that drives them to pursue the highest possible quality of life they can imagine. The language heard in each environment they have been in, including the nursing home, will satisfy or frustrate their freedom to pursue these strivings. Does language in the nursing home setting honor those needs, or denigrate them? Consider the following actual examples:

Person: Nurse, I don't like this food. Can I have something else?

Nurse: Honey, that's what we have. Your doctor said you have to eat this, and anyway, the kitchen is closed.

OR

Person: I have to go to the bathroom.

Aide: I just took you. Just wet the bed and I'll clean it up later.

(Aside to another employee: Remind me to clean up Room 320 later.)

OR

Scenario: It is time for the mid-day meal at a nationally renowned nursing home. At one table, three people are in a semi-reclined position, each being fed by a staff member. Each is facing up at a bright, translucent skylight, while the employees talk only to each other and spoon mouthful after mouthful of pureed food into the elders' mouths.

OR

Scenario: A person living in a nursing home who has significant cognitive impairment and is hard of hearing is being questioned in a public place about her preferences for end of life care. Two staff members are holding her in a standing position while one speaks to her in a voice that can be heard throughout the adjacent area and says: "We need to know your preferences about how you want to be cared for at the end of your life. You don't want a feeding tube or artificial hydration do you?"

The examples illustrate in many ways how dignity is *not* honored. Language is uniquely able to honor or destroy the dignity of the listener merely by how the speaker addresses or does not address (speaks over) him/her. Terms of address for persons living in nursing homes should recognize that they have lived long and productive lives even though they are not presently "productive" in the traditional sense of work-oriented productivity. Their dignity and value as human beings are *not* situational or relative.

For employees of institutions, the manner in which they address those they serve and the terms they use must reflect the employees' status as human beings who occupy important roles at work, in their homes, and communities. It must communicate that their needs as human beings matter regardless of where they are on the organizational chart. Language is the key channel through which the culture says what it thinks about whose needs are valid, when they may be pursued, and whether a person has the authority to pursue their needs for the highest attainable quality of life goals they desire. The employees in the vignettes above need to be shown how their behavior dishonors themselves and frustrates their pursuit of self-esteem, as it does to those in their care.

Language and the Maintenance of "Self"

Judah Ronch and Galina Madjaroff

"Who am I?" Over a lifetime, we develop an identity or self-concept that is rooted in a fundamental sense of who we are as an individual, distinct from others. This identity is constantly modified according to how we organize and derive meaning from our experiences. The outcome of this process has been described as producing a self with two complementary aspects; the "I" (my internal messages about my experience) and the "Me" (the messages I get about how others experience me). Messages about the "I" emanate in words generated in our minds, and the words communicated by others about us create the "me".

This distinction becomes important when an "other" sees us very differently than we see ourselves. That's when words can create emotional discomfort because they challenge our self-concept by opening a gap between the "I" and the "Me." As we proceed through life we harvest all our experiences into a subjective record of events that is our autobiography, the story we tell ourselves about our lives (Thomas, 2009). Atchley (2003) says that in later life the person uses an adaptive process he calls continuity with adaptation that allows the individual to maintain his/her basic identity despite the various challenges to adaptation found as we age. Atchley's research demonstrates that the general patterns of life choices and traits that characterize an individual persist (continuity), but the choices are modified in response to life's realities according to the resources available to use (adaptation). Here is the root of why words really matter for people living in nursing homes and other environments. The most important thing to bear in mind is that for people living in such settings, personal continuity is the most important fact of their lives and any experiences that serve to undermine personal continuity are destructive to identity.

The previous discussion about the labels we use amply illustrates how the language used in nursing homes can so easily create discomfort for the people who live there. They may even cause psychological harm, like other stigmatizing language does (e.g. using the "n" word or saying to an outstanding female science student "You are really good in science for a girl"). All of the examples are evidence of how the words we use can undermine a person's sense of self, the self-concept. The self-concept has taken a lifetime to develop and can so easily be undermined by the many issues that can come with dependency in old age. Having to experience the impact of ageist language in addition to having to worry whether those we depend on will actually be dependable is too high a price to pay for care. Imagine you're walking along and fall down. Somebody offers their hand to help and says, "Could I help you up you clumsy idiot?"

The words we use to talk to and about older persons communicate more than the informational content we want them to know about; they convey how we see them. The many examples of ageist, institution-speak in this paper are sad evidence that our words can have the impact of assaults on the self when we use language that communicates that

we don't see them as the same person they know they are (see the discussion of Bruner's three narratives, below).

Ageist institution-speak language can create a disorienting sense of personal incongruity when messages deliver the news that "I am not as others see Me." Since there is evidence that older persons may themselves harbor negative views of aging persons (Levy, 2010), having grown old is an extreme irony as it turns that person into an object of his own bigotry because he has joined this negatively stereotyped group. In a traditional nursing home elders may experience profound feelings of disempowerment, when spoken to in institution-speak. A struggle may erupt over which view of the self, the "I" (continuity) or the "Me" (discontinuity), is being addressed in the conversation and which should respond. ("Whom are you talking to; are you talking to the me I know or the me you see?") The resulting decision may have a negative impact on self-esteem, as the older person is at risk of confirming the negative view of himself if he responds without protesting this way of speaking to him.

The potentially destructive impact of such a disconnect between the "I" and the "Me" aspects of the self has been brilliantly described by social psychologist and Columbia University professor and provost Claude Steele (2010). He points our attention to the fact that there are "things you have to deal with in a situation" because you have a given social identity" to get what you want or need (identity contingencies)(p.3). Among the social identities he lists is "old." Steele describes how important group membership is to people's vulnerability to being stigmatized in social settings, and cites research that demonstrates how social identities can affect important things like performance in the classroom or on standardized tests, athletic performance, and memory capacity.

His analysis focuses on one kind of identity contingency called stereotype threat, which happens when we are "in a situation where a bad stereotype of our identities could be applied to us, such as being old, poor, rich, female – and we know it" (p.5). In these situations, we know that "anything we do that fits the stereotype can be taken as confirming it. And we know that, for that reason, we could be judged and treated accordingly" (p.5). In such situations, says Steele, the person must multitask, that is divide their mental energy and focus between task demands and defending themselves, i.e. dealing with the threat posed by how to cope with the stereotype that hangs over their heads.

Stereotype threat can result in involuntary stress reactions, such as increased physiological signs of anxiety (e.g. heart rate, blood pressure) that interfere with performance in younger persons (Steele, 2010). We assume that this would be the case in older persons as well. While people are unaware of these physiological changes, they do report that they are aware of an increase in rumination (thinking about something over and over), cognitive distraction and coping responses like thought suppression and attempts at regulating negative emotions that distract them from a task.   The long term consequences of stereotype threat show links between threats to social identity and poor mental health (e.g. depression and anxiety), poor physical health (obesity and hypertension), and unhealthy

behaviors (ignoring medical advice, drug use, etc.) (Inzlicht, Kang, 2010).

An equally important findings at the core of what we are advocating when we talk about changing language, culture and the harmful effects of perpetuating stereotype threat for the aging in nursing homes. Steele and others have found that stereotype threat can be reversed (see Levy's study cited below), though a recent analysis by Meisner (2011) found that negative stereotyping has much stronger and longer lasting influence than positive stereotyping does.

Nursing home staff can experience stereotype threat as well. When elders use language that indicates that the employee is seen as uneducated, subservient, of low status or ignorant because of their job status, race, ethnicity, gender or age, a stereotype threat can hover in the mind of the staff member. The result is that a dueling threat scenario arises, because both parties are engaged in multitasking as they deal with the feelings and thoughts the threat stimulates as well as the surface content of the conversation. This causes neither to be fully present nor to be at their best in the care partner relationship, at least at those times resulting in guardedness, fear or even anger.

There are many stereotypes about aging persons that hang over their heads (and the heads of those nearing their aging years ("senior moments" anyone?) especially when they are with younger people. Hess, et. al. (2002) looked at stereotypes about aging and memory, and found that older people who had read an article claiming that age impairs memory did worse on a memory test than did a matched group who read an article claiming that age had little effect on memory. In the group who read the article that claimed aging impairs memory, "the more aware the participants were of the aging stereotype the worse they performed" (Steele, p. 97). On the positive side, Hess also found that if subjects heard something positive about aging and memory, their scores improved. Levy (2002) found the same two-way effect in a memory test with older adults. Hearing positive words about aging, such as *wise, alert, sage and learned*, improved the memory performance of older subjects while hearing negative words, such as *decline*, *senile, decrepit, dementia and confused,* made subjects' tested memory worse.

This effect is called <u>priming</u>, and means when a message is planted in a person's mind (for example "Things go better with Coke"). Priming has been shown to influence behavior even when people were not aware of the effect that the words had on them. Priming can trigger stereotype threat when especially loaded words are used. In a study by Bargh, Chen and Burrows (1996), two matched groups of equally healthy undergraduate college students were asked to unscramble a series of words to form sentences. One group got a list of words that included terms associated with a stereotypical view of older persons, such as Florida, bingo, ancient, retired, lonely and wrinkle. The second group got a list of words unrelated to aging, like thirsty, clean, and private. After each group was finished with the sentence formation task, they were thanked and were unobtrusively timed as they walked down a long hallway toward the exit. The group that worked with the list of words that reinforced the ageist stereotype walked significantly slower than did the group that was exposed to the neutral words. Participants in the stereotype words group were asked if the words they saw affected them in any way, or if they were aware of the stereotypic

associations of the words they saw. Most were unaware of the nature of the words, and all claimed that the words would have had no negative effect on their behavior.

Given the nature of these findings, we are concerned about the possible negative impact of ageist talk on older people living in traditional nursing homes, and wonder if priming and stereotype threat work in tandem to create negative pressure on how they perform everyday functions. Stereotype threat and the ensuing adverse involuntary responses like anxiety and elevated blood pressure stimulate multi-tasking and so add more mental work and the chance of confusion or misinterpretation to an older person's cognitive burden. The ability to multi-task has been found to decline with age, possibly because the older brain has difficulty not responding to competing environmental stimuli like background noise or other thoughts or emotions that demand attention (Clapp, et. al., 2011; Stevens, et. al., 2008). The result is that short term, working memory is less efficient and negative priming messages such as those delivered by institution-speak, could be expected to suppress elders' abilities to problem solve and remember as well as when they feel more comfortable.

Stereotype threat is associated with a state of compromised reserves of self-control, of having little mental energy to overcome environmental temptations and override urges, emotions and automatic responses. This response sounds very similar to some of the emotional outbursts that those living in nursing homes may display when frustrated (and which are typically documented in the medical record as "inappropriate verbal outbursts.")

It is possible that hearing institution-speak or other negative primes trigger stereotype threat and initiates the multi-tasking cognitive style in older persons. We can imagine that the individual's sense of personal adequacy would be undermined because of the additional emotional and cognitive burdens imposed by having to cope with the distraction and anxiety these terms may generate while dealing with the actual task demands (e.g., answering a question, performing an act of daily living). These kinds of words and related communication behaviors initiate a self-fulfilling prophecy that helps to validate the negative stereotype about aging that the very words used carry, even when the speaker may not intend to do so. Merely using this language positions an elder to have his/her current level of self-esteem undermined and personal adequacy threatened by even an innocent question or request if it is phrased using ageist language.

Transforming institutional culture is so crucially important in combating stereotype threat because, while the effects of stereotype threat can linger it is possible to reverse the harm of stereotype threat by offering people who experience it the opportunity to do things that immerse them in a new, more hopeful frame of mind (Steele, 2010; Levy, 2010; Hess. et.al, 2002). These experiences change the "priming words" to positive or neutral ones, and allow people to tell a different story about their lives; to make their autobiographies become more self-affirming in their elderhood, despite any challenges in function or cognition.

Changed environments use new language to restore the self by creating a world of language and meaning that "embraces past, present and future dimensions" (p.36). Environments that have been structured to enhance social relationships through more engagement and

non-stigmatizing language, like households and small house nursing homes, appear to have produced positive results according to Sharkey, et al. (2010), who conducted a study of the Green House Project homes and found them, along with their characteristic language, to be associated with improved positive social relationships.

Why do Good People use Labels, or Categories, in their Speech?

It's worthwhile to take a moment and ask why do people who mean well use disempowering words in their conversations? (Carmen addresses this issue further below). At the risk of oversimplifying a very complex issue we name things to facilitate knowing the world around us, and that helps us remember (Yoon, 2009). Instead of remembering each separate item we encounter, it's more efficient for our energy hungry brains to remember categories of things and then search the categories for the discrete and the individual items in the category that have been stored there. We humans seem to use this quick brain response (Gladwell, 2009) to help us overcome the heavy demand and often confusing effects on our brains of too much information, which Schwartz (2004) characterized as the paradox of too many choices in daily life.

One result of this tendency to rely on concepts we use to embody categories is that they "govern our everyday functioning, down to the most mundane details. Our concepts structure what we perceive, how we get around in the world, and *how we relate to other people* (Lakoff and Johnson, 1980, p. 3, italics added)". Culture is really a system of concepts. Our conceptual system is not something we are normally aware of. We are immersed in it but not aware of it. Listening to and understanding the meaning of its language is how to know it. Culture is the sum total of concepts that characterize the behaviors in an organization. So what we call something or someone is how we will treat it, him or her in a particular culture.

We understand that changed culture cannot eliminate entirely the human tendency to use categories and concepts. Important change occurs when we use new words to frame new concepts. This is a way to re-categorize the people we work with, and ourselves. The most fundamental change occurs when we change the labels or names we use for people in our everyday language. "Names matter because they prime us to respond in specific ways", wrote James Geary in his book on metaphor titled, *I is an other* (Geary, 2010, p.120). That is, referring to Mary as a "wetter" puts her in the "object" concept where the pronoun "it" is correct, and removes her from the concept of "person," where the pronoun "she" or "you" would be correct. A person has feelings and a sense of self; an object doesn't. Mary is a member of the same category we are in, people, and that allows for empathy. We can ask the question: "How would I feel if I were referred to as a 'falling stars', a 'pooper' or a 'walker'?" These labels are also metaphors. These metaphors that shape our experience are powerful ways of making meaning (Lakoff and Johnson, 1980; Geary, 2011) sometimes positive; sometimes negative.

So, why do we label? Perhaps because it organizes our experience in some way and so provides the illusion of control and that we have "done something." Thus, labeling is

actually doing something, maybe just not the right thing or the most helpful thing in all cases. Labels help to organize experience, and the mental act of categorizing a stimulus provides organization and deeper meaning to it in our mind. For example, when we see an animal, our minds immediately start to scan its properties to see which category it belongs in, e.g. dangerous or not. That way we can start deciding if we should start to run in the opposite direction or pet it. (Children have the categories for "cat" and "doggie" very early in life, and get the difference pretty quickly.) Mistakes can be dangerous, as when a youngster sees a skunk and says, "Look at the pretty kitty Mommy." Here, the categorization is not yet fully developed.

By changing the labels we use to organize our experience we will be able to rid our speech of labels that do harm.

In sum, words create experiences that shape our external and internal realities. The words we use with others have an impact on more than their ears; words may influence the emotions of the listener, and even how they perceive themselves and their capabilities. Which words we use, and how we use them, are a personal characteristic by which people recognize us - like a style of clothes. By the same token, the words people use when speaking to us can, like a sculptor's hands, shape our internal image of ourselves. This effect can be temporary, or if the words/messages are consistently of one kind, they are able to have a permanent impact on our self-images and even our abilities.

The Status of Language in Long Term Care

Carmen Bowman

Early adopters of culture change who have been doing the hard work to change culture for a good while have also changed much of their language, making it a new norm in their communities. However, in probably the majority of homes, language used is old, derogatory, and demeaning. This section will spell out what is happening in long term care communities, identifying old as well as new replacement language that early adopters and leaders have chosen or created to lead the way.

Have you noticed the undignified language within the world of long term care? Many have shared the experience of some word grating the inside of their brain or wishing someone didn't talk "that way" to residents.

The Centers for Medicare & Medicaid Services, has noticed undignified language "as evidenced by" (isn't that funny language we use every day in our medical way of talking and writing in institutions?) its new interpretive guidance issued July of 2009 at Tag 241 Dignity where CMS has now added: *avoiding labels such as feeders*. I wonder how one feels to be called a "feeder?" When I was a surveyor, a resident once said to me, "I'm what you call a feeder around here." He knew. He knew he was being labeled.

Do you know what a *feeder* really is? If you looked it up in a dictionary you would find bird feeder, trough, bottom fish feeder, and young cows and pigs referred to as feeders. An Internet search similarly resulted in bird and deer feeders and "one that supplies food." So, who really is "the feeder?" Think of whose arm is moving - the person doing the "feeding." Thus this term is not only derogatory and undignified, it is also grammatically incorrect. Something else to consider is cows and pigs feed; people eat.

Actually, the terms feeding, feed and fed all seem to have a negative connotation to them. I once heard that California focused on replacing all the variations of the word *feed* with instead all the delineations of *dining,* such as someone needs assistance with dining or is independent with dining. Personally I do think the term dining is lovely in comparison to any word having to do with feeding. I mistakenly proceeded to think that the best replacement for "feeder" might then be "dependent diner." However, I was wrong and challenged once by someone while speaking about this. The person rightly pointed out that what should always be used is the person's name; "dependent diner" is just another label.

Cultures moving away from institution-speak and toward person first language no longer refer to "the stroke," but to the person by name who had a stroke; not the Alzheimer's patient or Alzheimer's resident but to the person by name who happens to also have Alzheimer's disease. LaVrene Norton, executive lead for Action Pact a national culture change consulting company encourages referring to the person who *lives with* Alzheimer's disease. I have even decided to stop referring to one as diabetic even though it is quite common to say. Instead it would be the person by name who has, or lives with, diabetes.

So I wonder what it does to a person to know they are referred to as "the TIA" (trans ischemic attack or heart attack) or "the quad" (for quadriplegic) or "the amputee." And in fact, co-authors Judah Ronch and Galina Madjaroff tell us exactly what it does later in this paper. How would you like to be known by your diagnosis? I'm sure we all have a diagnosis of something. I have chronic nasal drip, so am I a chronic nasal dripper?

And the labeling goes on: the complainer, the screamer, the isolator, the difficult resident. Institutions are pretty famous for turning just about anything into a label. The cows and pigs don't know they are referred to as feeders but like the gentleman I mentioned above, sometimes people do know how they are being labeled. Patricia Deegan, Ph.D. was labeled as a schizophrenic early in her adult years and encourages all of us to not label anyone and encourages those who have been labeled to not succumb to it. Look at the title she uses for an article she had published in the Journal of Psychosocial Nursing, "Recovering our Sense of Value after Being Labeled." Labels strip people of their value, she teaches out of her personal experience. Rather than labeling a person as "combative, "we suggest using the analyzing the situation or situations. Was the person startled? Did they prefer to do it, whatever it was, differently? Oftentimes a person who cannot express themselves verbally might strike out. Rather than labeling one as combative and going down the route of more labeling "behaviors" and the negative connotations that come with them, investigate the root cause. Founding Executive Director of the Pioneer Network Rose Marie Fagan is known for saying, "Behaviors are not problems behaviors are messages."

Although a person living in a traditional nursing home may not want to get up when staff make them, and they get a little upset about it, even potentially hurting someone, they are the one that gets labeled *combative* or *aggressive*. But whose fault was it? The fault of upsetting the person can be laid to the system of care that requires caregivers to wake people up on a fixed schedule as opposed to a care system where care givers know an individual's preferred time to awaken and where caregivers check with the person at the time of their awaking to see if he or she needs assistance. Labeling the person combative or aggressive unfairly blames the victim.

So why do we label? Perhaps it is because it is an institutional value that tasks should come first. What is required of staff is to get all their tasks done within their shift, and "no overtime." Nurses have to get so many pills passed; housekeepers so many rooms cleaned; and bath aides so many baths completed. Leaders in the culture change movement have identified that in order for the human beings doing the care (the staff members) to feel less guilty about the lack of time to build a normal relationship with the human beings they are caring for they have to objectify those fellow human beings in order to not feel so guilty.

I once heard a team member of an innovative nursing home in North Dakota say that she and her fellow staff would get in trouble if they *didn't* stop to visit with the residents or be concerned if something was the matter. I usually hear the opposite; that staff members are *still* getting in trouble for interrupting their tasks in order to be with a resident who needs them. The focus has traditionally been on the tasks so much that the Pioneer Network has identified as a core value: *Put the person before the task*. Another example of this task

oriented work and objectification is the list of "get ups." The "get ups" is the label given to those people on a list deemed by the institution to be gotten up; some by night shift, some by day shift. Andyes there are also the "put downs" –the label describing the people on a list who need to be "put" to bed.

Sitting down in the two seated side of an airplane, I once met an accountant who worked at a nursing home. All of a sudden I could talk nursing home "lingo" like MDS (Minimum Data Set, a federally required assessment) and CMS and we understood each other. Not a common occurrence on an airplane. When I mentioned that a practice of culture change was to give residents the freedom to sleep until they wake up she retorted, "Oh yeah, 'free sleep' we do that." Later she referred to their residents' "free living" which I believe similarly meant free to live as you want. Odd new language? Another example of us always having to label and title everything? And yet no one would disagree with being supported to be free to live as a person wants.

Changing Language
This section of the paper attempts to identify common institutional language, or institution-speak, still spoken in the majority of nursing homes and to then suggest potential replacement person first language.

*The Alzheimer's patient/resident, the tube feed, the new admit→***person's name***
Person first language teaches us to put the person first. So we might say this is Sarah and maybe somewhere later in the conversation you learn that she has or lives with dementia.

*Alzheimer unit, dementia care, memory care →***instead the residents might select a name representative of their culture, geography or interests, such as Aspen Neighborhood***
Think about the term memory care. What is being cared for? Memory? So if the memories of those we serve continue to fail, does that say we are not providing good care? Or, is care for the whole person being provided in the presence of a memory deficit? Some homes have decided to no longer label in any way and instead focus on living normal life - on the Aspen Neighborhood, for instance - where people with cognitive loss may live but the deficit is not the focus of the living area's title.

Dr. Al Power, MD and Eden Alternative Mentor and Educator, tells us in his enlightening book *Dementia Beyond Drugs*, "Regardless of how enlightened it may look and sound, naming any living area after a disease reveals an institutional mindset that reduces people to their deficits. It also perpetuates the notion that all people with the disease are alike, should be treated alike, and have no personal identity in our eyes. Let's stop doing 'memory care,' 'Alzheimer's care,' or even 'dementia care.' Let's care for people who happen to have dementia" (131).

*Hoarder →***person's name, describe what the person does and find out why***
Did you know we label people living in nursing homes hoarders for all sorts of various reasons? First of all, we all know how small a half of a shared nursing home room is. So, if we have even a small number of personal belongings, we are going to at least look like

something of a hoarder and then think of the amount of stuff most of us have. Second of all, perhaps there are some things you have more of than others. I already keep salt packets in my purse just in case there isn't any wherever I am eating. When I am older, I may keep salt packets and salt shakers, who knows? So am I a hoarder or just making sure I'll have salt when I need or want it like I've always done? Those who know me well know that I've kept salt in my purse much of my adult life. So if I just continue to be me and keep salt around, is that a problem? Am I still a hoarder? Additionally, for those who like to watch their pennies, it may be thought of as a way to save. Some folks take the sugar or a spare dinner roll at a restaurant. Seeking to know those we serve well will help us stop the inappropriate and unnecessary labeling.

One of Dr. Ronch's former students called him in great distress to tell him that her father who lived in a traditional nursing home and had memory problems was recently diagnosed with "kleptomania" by a psychiatrist. She told the story of her 91 year old father referred for a psychiatric evaluation because he was looking through trash baskets and taking broken objects back to his room. He would try to repair the found objects, but his memory problems prevented him from being successful. When asked if this was a new behavior, Dr. Ronch's student said that to the contrary, her father had done this in his old neighborhood for years. He would find broken radios, toasters, and other objects, take them home, fix them, and then give them to people who needed them.

This man was referred for a psychiatric evaluation, and his family was upset because his behavior was labeled as antisocial in intent. A simple inquiry into who this man was and his history would have completely explained that what was considered a concerning "behavior" was actually a lifelong constructive pursuit.

Wanderer, wandering → **"that's Mary, she loves to walk, always has;" or "that's George, he is probably looking for his cows"**
If we get to know the person; get to know what they might be doing; looking for; needing; then the answer is often readily apparent. Is he or she restless, bored, wanting to move and get some exercise? Work to get to the bottom of "the behavior;" take it on as a challenge to figure it out. Labeling it wandering and the person a wanderer gives it a negative connotation. Often, meaningless approaches or interventions are automatically attached to this labeling as when a computer program assigns generic pre-programmed interventions to one's care plan. And just because we don't necessarily know the goal of the action doesn't' mean it has no purpose. Have you ever seen the t-shirt that says, "All who wander are not lost?"

*Therapy → pet therapy →***enjoys his or her pet; fond of animals**
Rose Marie Fagan since 2002 has been reminding us that we don't use this word in our everyday life. We take a walk; we don't say I'm going to go get some ambulation therapy. She points out that we have and enjoy a pet; we don't give ourselves pet therapy. Yet, pet therapy is still prevalent in many traditional nursing homes. What is it really? Pet therapy typically consists of specially trained dogs that come to visit. We must ask ourselves if that that is really therapy. The Eden Alternative has taught us that companionship is the antidote to loneliness. It is hard to be lonely with a dog on your lap or a bird living with

you as a companion. In other words the animal lives with me, it doesn't visit once a month. This is in no way intended to diminish the many well-meaning people who train their dogs to assist individuals and bring joy periodically to those living in institutions. Dr. Bill Thomas explains it further by saying while a pet visitation program is better than doing nothing, this type of intervention medicalizes the joys we associate with the human-animal bond (Thomas, 2004).

Therapy or treatment is typically understood to mean an attempt to remedy a health problem or illness. Not everything that can be significantly helpful has to be a therapy. Karen Schoeneman of CMS' Division of Nursing Homes says this in an article she wrote for the Pioneer Network and is posted on their website called *MayDay!*,

> Look at the word "therapy," for instance. Why does everything have to be therapy once you live in a nursing home? If I liked to paint before I moved into the nursing home and I paint now that I'm there, why is my hobby now "art therapy?" I mean no insult to the wonderful folks who call themselves therapists and their work, their special training, or their skills. In fact, I'm a massage therapist myself. But in this context, "therapy" is another of those separating words.

Power (2010) cites the Dementia Care Australia blog statement: "Often the best therapy is to provide opportunities for happiness and increased meaning in the lives of residents". This really gets back to "normalization" as referred to above. Perhaps the best therapeutic opportunity is to provide the chance to do something that everybody else does. Sometimes just restoring access to opportunities that exist for people in the world has a "therapeutic benefit" in that people become better.

*Activities →***community life, living life, engagement, a meaningful day, vibrant living, "what are you going to do today?"**
When I ask people what they associate with the word "activities," most reply with something like being busy or busywork. Indeed, the definition according to the Random House dictionary is "the state of being active; doing." Additionally, when a resident is exhibiting a "behavior problem" staff might say, "Take her to activities." What does this mean? What do the activity and recreation professionals hear? "So they can babysit." No harm is meant by anyone but it naturally puts the disciplines and departments unnecessarily at odds.

The term activities has also become synonymous with groups. Most people presume that activities means only group activities when, in fact, activities can be done alone, with another person, with an animal, or in a group. I also do not hear people in the general public ask "What activities did you do on the weekend?" or "What recreation therapy are you planning for this week?" or "What will you be doing with your leisure time next weekend?" Some are trying to get at this issue by using other terms like Community Life, Life Enrichment, Life Enhancement and Lifestyle Services. The Lifestyle Services team members explain that a person comes with their own lifestyle and they are simply there to support it. I love the concept of "continuing life experiences." And although I don't know the exact words to use yet, what I do know is that meaningful engagement is what it should be

all about. On the list of Language of Change put out by the Wisconsin Coalition for Person Directed Care they suggest instead of activities, "meaningful things to do."

In writing a book on this very issue with LaVrene Norton, Executive Leader of Action Pact, we have chosen to call our book Vibrant Living to focus on living, whatever that means for each person; not so much on the group activities on a calendar. With the goal to assist people to live out their lives on their own terms, it was actually written *to those living there,* and published in a scrapbook, coffee-table style, designed to be paged through with *inspirations to energize daily life* ideas offered for pondering.

Barry Barkan, an original pioneer and Pioneer Network board member, says something similar when he refers to one's "pre-admission lifestyle" and to the need for "participation in present time activity that provides life's continuity, connection to the events of the world beyond one's illness, connection to the shared reality of the community" (*The Renewal of our Culture, Dementia in Community and the Liberation of the True Self,* undated).

Another group, which has also refocused on building community life, is the Institute for Caregiver Education. Here is their explanation of community life from their website:

> Community Life is a relatively new area of interest in Culture Change. This area focuses on what we historically have thought of as "Activities" or "Therapeutic Recreation."
>
> The Community Life approach asks nursing home professionals to stop thinking of activities in the terms of large scale group offerings at rigid times during the day. Rather, Community Life asks us to break down activity offerings into smaller, more manageable and more spontaneous "happenings."
>
> Larger scale activities may still be offered, but in a truly culturally-changed home, primary care nursing assistants are offered the opportunity to sit down with the 'neighbors' that they care for and share a cup of coffee, play with the neighborhood cat, or just share stories about children. In this aspect, Community Life becomes everyone's responsibility (Institute for Caregiver Education, 2011).

The term *therapeutic* is sometimes used to describe activities, but again begs the question, what does that mean? In the institution we feel the need to medicalize terms such as this; the culture change movement and real life show us it is unnecessary. And perhaps the day has come to use our language to emphasize what "activities" has always meant to stand for: living life, being engaged, experiencing meaningful days, being in community, connected and vibrant living.

Activity/recreation therapy director →community life coordinator/developer life wellness coordinator, life enrichment coordinator, community development guide/advocate
LaVrene Norton teaches that the word director is problematic in home environments where we are trying to reverse what institution does to people and instead support the

person to direct their own life. This removes the need for managers/directors in the old context. Those individuals take on the new and more expanded roles of guides, teachers, coordinators, and facilitators. The new CMS interpretive guidance for Tag F248 Activities, issued in 2006, identified this issue as well in the section entitled *Non-traditional approaches to activities*:

> Surveyors need to be aware that some facilities may take a non-traditional approach toward activities. In neighborhoods/households all staff may be trained as nurse aides and are responsible to provide activities and activities may resemble those of a private home (Thomas, 2003). Residents, staff and families may interact in ways that reflect daily life instead of in formal activities programs. Residents may be more involved in the ongoing activities in their living area, such as care-planned approaches including chores, preparing foods, meeting with other residents to choose spontaneous activities, and leading an activity. It has been reported that, 'some culture change homes might not have a traditional activities calendar, and instead focus on community life to include activities. Instead of an 'activities director,' some homes have a Community Life Coordinator, a Community Developer or other title for the individual directing the activities program (Bowman, 2003).

The Eden Alternative suggests use of any of these other titles: Life Wellness Coordinator, Life Enrichment, Household Coordinator, Community Development Guide/Advocate, Care Partner (2012).

Activity calendar community **calendar, social calendar**
The Eden Alternative suggests using the term community calendar or social calendar emphasizing that such a calendar represents "Where people in the community come together to spend time in meaning-filled events" and that an individual can choose to include these events in their rhythm of daily life, or not (Eden Alternative, 2012).

Behaviors, belligerent, difficult, behavior problems/symptoms →**reactions, unmet needs, coping, communication**
"She has behaviors." Worse yet, "she *is* a behavior problem." Earlier we shared Rose Marie Fagan's famous insight, "Behaviors are not problems, they are messages." She tells of her first week on the job as an ombudsman, barely knowing what one is and she has to go visit Ed, a resident in a nursing home who has been peeing in the plants. She goes to meet him, chit chats for a while to build rapport and eventually asks, "So Ed, what's this about peeing in the plants?" His response? "Well, it got you here, didn't it?" Sure enough, behaviors are messages. In the Language of Change by the Wisconsin Coalition for Person Directed Care "communicating distress" is suggested instead of "agitated."

Dr. Al Powers has created the new word "calmatose" referring to the practice of sedating residents in order to keep them quiet (p. 30). Dr. Ronch says something similar, that typical institutions want residents to not complain and be compliant with what we want them to do when we want them to do it (CMS 2006 satellite broadcast on the CMS Psychosocial Severity Outcome Guide and Psychosocial Well-being). "Calmatose" helps to make that happen.

"Help me, help me." Many people who have worked in a nursing home have cared for a person who repeats this over and over, making us feel helpless to help her, but what is she really asking for? What is her message? Someone come to me, someone come love me, someone come, someone. We often explain that this person is "seeking attention" but that portrays her need as negative. She is lonely and needing what she can only articulate as "help." Being able to repeat, "Help me, help me" also indicates that there is a person in there fighting to stay connected. We can no longer afford to see this as a negative "behavior" but instead we must embrace the person fighting to stay alive and engaged with life.

Cohen-Mansfield and Mintzer have said it this way: "Thus many 'problematic behaviors' represent a cry for help, a result of unmet needs, or an inadequate attempt to fulfill those needs (Power, 2005, p. 37). Dr. Power has studied this phenomenon and altered his way of describing it to *behavioral expressions* (p. xxii). When one is irritable or grouchy, it usually is an expression of hunger or pain or lack of sleep. We need to challenge ourselves to figure out what one's need is and meet it, thus truly caring for one another.

CMS, in its 2006 interpretive guidance for Tag F248 Activities, refers to *behavior symptoms* instead of problems, which was an attempt to move away from labeling them behaviors so strongly. However, Dr. Power points out that the word symptom still "puts us squarely in the realm of disease" (p. 82).

Behavior indeed implies problem and Joanne Rader, pioneer in the culture change movement and original board member of the Pioneer Network, teaches that "one of the first questions we need to ask is, 'Whose problem is it?'" Joanne also teaches that when one screams in the shower that too is not a behavior but a coping mechanism and the message is simply, "This is not working for me."

The Eden Alternative wisely says about this issue: "When care partners cannot define the need behind the action, it is termed a behavior as though it is something to be corrected. When the unmet need is defined and met, relationships deepen and the individual experiences better quality of life."

"Non-compliant" →***a person making their own choices, i.e. "She chooses to not take a recommended medication and has articulated understanding of the pros and cons."*** What comes with the label "non-compliant?" Usually it is the negative connotation of trouble maker, difficult or bad person.

We all know we *should* eat right and exercise, and we *should not* drink too much caffeine and smoke. If we don't, are we … "non-compliant?" But we certainly don't call it non-compliant. Instead, we are simply m*aking choices, e*xerting o*ur rights and* living o*ur life. We also* have the right to make what are considered "bad" choices.

Within the federal long term care regulations there is a requirement to honor resident choices - Tag F242 Self-Determination and participation. The resident has the right to:

1) **Choose** activities, schedules and health care consistent with interests, assessments and plan of care;
2) Interact with members of the community both inside and outside the community; and
3) **Make choices** about aspects of his or her life that are significant to the resident.

Perhaps you can see why some of us lovingly call this regulation, or tag, "choices." Most nursing homes have served a person who chooses not to follow a restricted diet order and we've learned she will do as she wishes as it is her life. Looking through an institutional, controlling lens she is called "non-compliant;" but she is just living life on her terms and making choice.   Thankfully, more and more homes are working with the physician who works with the person to eliminate "orders" that do not work for a person so that there is no reason to label the person "non-compliant" and more importantly to honor their choices.

*Difficult family member →**a care partner who cares***
Besides behaviors and problems we also label residents who typically complain as "difficult." Not surprising this label has also been applied to family members who complain, as well.

Dr. Ronch published a chapter in the book Cultures of Caregiving (Levine and Murray, 2004) and wrote that the typical institutional nursing home automatically puts families and residents onto the "problem team" when the family and resident are actually trying desperately to be part of the "solution team." Unfortunately, he wrote, the staff often believe and give strong signals to family members that membership on the "solution team" is reserved only for the staff.

Thankfully, some pioneer homes have eliminated this institutional practice. As a leader in Colorado, administrator Beth Irtz has always said, "Family members care just as much about your home as you do." She meant it too, as she invited family members to serve on her home's quality assurance committee. Karen Schoeneman of CMS Division of Nursing Homes and I under contract with CMS developed the Artifacts of Culture Change measurement tool in 2006. In the 79 items that represent culture change practices and outcomes, we included this idea. Number 49 is *Residents or family members serve on home quality assessment and assurance (QAA, QI, CQI, QA) committee.* Uptown Care Center in Denver invited a resident to serve on their QA committee during a grant project using the Artifacts tool. It went so well the administrator said that they soon needed a resident from each neighborhood represented.

*High functioning or low functioning →**no label, no description, none necessary***
According to Patricia Deegan, PhD and author of Recovering our Sense of Value after Being Labeled, an article published in the Journal of Psychosocial Nursing, "'high functioning' and 'low functioning' are not attributes that exist inside a person. They are value judgments that are put on a person. There are no high-functioning or low-functioning people. There are people whose contribution we are able to see and value and there are those whose gifts we have failed to see and have failed to value" (1993, p.11). In addition, how well a person

functions is highly dependent on the environment they are in. Function is a relative state – it is an outcome of person–environment interaction. For example, someone who is blind will function better in a dark room than a sighted person will.

*Physician order→**physician recommendation, prescription***
One time a favorite medical director of mine in the Denver area, Dr. Bobbie Livingston, said in a culture change committee meeting, "A physician's order is really just a recommendation" but it is not treated that way in a traditional nursing home. In a typical institution, it is truly treated as an order. Who gives orders in real life? Maybe a commander in the army. In our personal lives, the physician really just recommends to us, as he or she certainly can't make use at right, exercise, take our meds, take our vitamins, etc. And we either do or we don't. We know we can choose to follow the advice or not. It is our choice and our life. In fact, when you visit a physician, he or she doesn't give you an order. Rather, you get advice, recommended course of treatment and prescriptions for meds or therapies.

On my Action Pact web talk show, *Conversations with Carmen* on 3/18/11, I interviewed Dr. William Thomas about Surplus Safety a concept he has developed with Dr. Ronch. I asked him about this issue of physician orders, where it came from, etc. and he had this to say, "In the outpatient world, it is a prescription. Once one is an inmate of any institution, it is not a prescription but an order."

*"Against medical advice" →**making choices, living my life, living life on my terms***
Notice how it is called "against medical advice" as if the person is somehow wrong to go against the physician's advice or order, again implying they are somehow a bad person and "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, and their wishes. Another form of language similar to this is when we state, she "denies having depression." Certainly one may not be aware of having something like depression but the way we say "she denies it" just carries that hint of "medical advice rules."

Nursing homes are becoming better and better at what some call negotiated risk; what CMS calls informed choice. The concepts of negotiated risk or informed choice are pretty self-explanatory. The nursing home/interdisciplinary team informs or explains to the person the pros and cons of basically two choices but the choice is ultimately up to the person receiving care. For example, "We have explained that his doctor recommended this exercise, but he says it is too uncomfortable and prefers not to do it. He also understands that his joint will most likely be less flexible as a result." And then this should not be cited as a deficient practice as it shows the home is compliant with honoring the resident right to choice at Tag 242 and to refuse medical treatment at Tag 155.

*Assessment, assessment process →**getting to know you, becoming well known, "Tell us about yourself"***
The term assessment is also very medical and institutional. When you get to know a new person, do you "do an assessment?" Do you grab your clipboard and take your assessment

forms over to meet your new neighbor? Maybe you actually wish you did… but what do we call just getting to know someone? What could we call it if we didn't call it "assessment?" Getting to know you? All about me? All about you? The Eden Alternative talks a lot about becoming well known and being well known.

*Medicalized diets → liberalized diets →***regular diet, regular food***
Forward thinking physicians Drs. Karyn Leible and Matthew Wayne who were expert speakers at the CMS and Pioneer Network Creating Home II national symposium on culture change and the food and dining requirements, call restricted, based-upon-diagnosis-only diets, medicalized. Notice, the physicians are making a point. Something is medicalized when it is made to be more medical than is necessary, such as the term therapeutic mentioned earlier. The term liberalized diet seems to indicate that people should be free from, liberalized from, restrictions placed upon them by others. Also an expert speaker at the Creating Home II symposium pioneer administrator and dietitian Linda Bump, advocates for no special terminology, not even regular diet; just regular food.

Dr. Al Power, another physician, also talks about the "medicalization of care," stating "thus the lives of people in nursing homes have become medicalized … the amount of reimbursement for their care depends on the diagnoses that they carry and the medical procedures that are carried out on their behalf. This puts the emphasis on medical treatment …" which "… leads to a backward system of financial incentives for care" and asks what if the system rewarded "wellness instead of illness?" (2010, p. 43). (Ronch and Madjaroff discuss this in the section below called Language and What Matters at Work.)

*Care plan →***Life Plan, Living Plan, is it a plan?, All About Me, My Care Plan, My Goals, My Day, Growth Plan***
If we use the same rationale, what might we call a care plan instead to ensure the person retains control over their life? Life Plan? What I Need From You? All About Me? My Day Whatever we may call it, I am encouraging providers to ask residents their goals and then refer to them on the care plan as My Goals. I'm not sure anyone has come up with a great replacement title but it is absolutely true a redesign is needed to put the person is in charge of their life and their care. Another way to say it is, is the person in the driver's seat of their life like they always have been and always should be? In fact, this is why I Care planning has come about because even care planning can be extremely medicalized. In the workbook I co-authored with culture change leader and social worker Christine Krugh *Changing the Culture of Care Planning: a person-directed approach*, (Bowman and Krugh, 2006), we speak to many of these issues:

> In the state of Oregon, an innovative nurse was working on a project she called, 'I' care plans. Using this method her care team began to rewrite traditional medical care plans into a 'first person' format. Instead of problems, goals, and approaches being written in nursing diagnosis language such as 'Alteration in thought process,' the 'I' Care Plan would provide information as if the elder were sharing it himself: 'I have a problem with my memory.' To create these new care plans, teams had to really get to know how an individual elder thought. Suddenly one of the basic beliefs of providing medical care was being challenged. Could we provide good

medical care without any investment into knowing who we were caring for?   As more and more teams began to use 'I' care plans, they questioned that paradigm. They began to put into practice an idea which they had known in their hearts all along. In order to heal the physical body we must also nurture the spirit. If we care for a body without also caring for the spirit, elders in our care will quickly fail (2006; p. 7)

In the Picker/Planetree Long-term Care Improvement Guide, the idea of Life Plan or Living Plan is given, bringing back the focus on living (2010). And then of course when we are talking about caring about someone, that doesn't need a plan, just a relationship. In the world of developmental disabilities people write their own vision statement for themselves. Even just adding the simple word "my" to make it My Care Plan changes it a lot, especially if care partners truly honor the idea and support the person to create their very own care plan. Simply changing the tense of a care plan can become just another task, a change in semantics only. Or the culture change practice of I care planning can be a tool to assist in hearing directly from the person what they need from caregivers, a tool to support self-directed living. The Eden Alternative suggests instead growth plan and defines it as "a person-first story of what is important in the individual's life, their life goals and how they intend to accomplish those goals" (Creating a New Language for the Eden Alternative Journey, updated April 2012; p. 2).

*Problems →**needs, challenges, preferences***
We used to write: "Problem: Difficult Behavior – resident wanders at night." Demeaning language indicating the person is at fault and a bad person. Could the whole problem really be around the fact that staff prefer the person to be in bed sleeping? In many cases a resident is awake at night because it is their preference or routine to be up at night. Most likely they worked at night or have always been a night owl or have some need such as hunger. This again fits with the question Joanne Rader asks, "Whose problem is it?"

I once heard a speaker who was a nurse state that she was a night owl. She predicted that when the nursing home staff came to tell her it was "bedtime" she would probably be sweet about it for a few nights, but when she realized this was her new home she would be less forgiving about it and demand to stay up. She then described how in this world of "problems" she would be diagnosed with insomnia and prescribed medication to "help" her sleep. What was equally sad was that this speaker then asked her audience, "Now what was my problem?" Her answer was "she didn't want to go to bed when the staff wanted her to." However, that is not a problem that is her preference.

The typical care plan format in most traditional nursing homes across the country is Problem/Goals/Approaches. Did you know that the traditional style of Problem/Goal/Approaches is required neither by any federal nor state regulation? This style of care plan was adopted in long term care from nursing school where you are taught to care for a person's medical problems for which there are goals and then approaches to meet the goals. Most people working in long-term care have been led to believe

somewhere along the way that they must create what we call "problem statements." We've been led to believe that we must create a problem statement for each "deficit" identified on the MDS. Deficits and problems… these are actually part of the problem. The only federal tag about the care plan is Tag F279 Comprehensive Care Plan and it only requires this:

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

There is no mention of the word problem; no requirement for a problem statement as many have been led to believe; nothing about how the care plan must be written i.e. in the third person. This is why we have freedom to do care plans differently; why it is okay to create I care plans and narrative care plans where there are no columns and it reads more like a story about a person but by the person. More important would be discovering what a person in our care needs from us to meet his or her needs and goals.

In fact, in a workshop once when inviting my participants to write their own care plan, one nurse made exactly this point when she 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.

Kathie Snow similarly suggests that instead of viewing a disability as a problem we should look at the need. People who have impaired vision don't say, "I have a vision problem." Instead, they say, "I wear glasses." Snow asks us all,

> *Do you want to be known by your "problems" or by the multitude of positive characteristics which make you the unique individual you are (2012)?*

The Wisconsin Coalition of Person Directed Care agrees. They suggest that rather than care planning problems, we should identify a person's needs and challenges. Aside from true medical problems, it seems we should move toward identifying preferences. Identifying preferences covers so much, especially "the rest of the story" for each individual. Preferences are getting a lot of attention lately. Even CMS is giving resident preferences more focus than ever before. *Preferences* are mentioned numerous times even in Tag F325, Nutrition. The guidance for this tag was updated in 2008 and is focused on resident choices, goals and preferences. Preferences comes up strongly also in the CMS Tag 242 Self-determination and participation. New guidance came out for it in 2009. The new guidance on Tag 242 states that the facility is to be *actively seeking preferences* regarding waking, retiring, dining, and bathing. Preferences are now front and center also in CMS' QIS survey process as well as the MDS 3.0.

*Interventions →***what I need from you, support needed, assistance needed**

What is an intervention? It means something is wrong with you and you need to get it fixed. And this certainly is true of many of our care plans around the country that still identify "problems" and "interventions" as the appropriate response. Now some of our care plans have "approaches" instead, which is certainly softer but may be in need of some rethinking as well. Perhaps the language "support needed" would help us focus on what the person needs from us to meet their goals. Whatever we call it, let's make sure the terminology does not carry any connotation that anything is wrong with the person.

*ADLs →***personal cares**
"ADLs" refers to activities of daily living. It is common language but Wisconsin Coalition Person Directed Care suggests instead, "personal cares" in an effort to soften the medicalness of the language.   There are so many opportunities for softening the words we use. Here are some more from Wisconsin:

*Ambulation →***walking**
*Transport →***assist to**
*Two assist→***requires two helpers/people to assist**

Care

> "This is their house, it's not like I'm taking care of them like it's a chore or something. I feel like, if they were my grandparents what they would need? And so that's how I treat them."
>
> Theresa Hernandez, lead resident assistant in Brave New World, Pioneer Network, http://www.youtube.com/watch?v=wld1wHfwei4&NR=1)

Dr. Thomas, in the Forward to Dr. Al Power's book *Dementia beyond Drugs* (2010) makes the case that the words care and treatment have been "pushed and pulled so far from their original meaning it is worth revisiting them." He says, "The most common and useful definition of care I know goes like this: Care means helping a person or relationship to grow…." (ix-x, 2010). Dr. Thomas years ago got people thinking about care with his fourth Eden Principle: "The antidote to helplessness is the opportunity to give care." Persons who move into a nursing home normally no longer have the opportunity to give care, although this is what they have done their whole adult lives. Instead the *caregivers*, note that language, give all the care *to* the people living there. We *give them* care. We provide for their daily care. It is one- sided. It is task oriented. It is not usually synonymous with healthy development, progress or growth.

*Long term care→***nursing home living, long term living, supportive living, community living, continuing care**
Dr. Amy Elliott of the Pioneer Network made a comment on a research panel at the 2010 Eden International conference that in a study comparing assisted living and independent living, she never found the terminology "*nursing home living".* We call it independent *living* and assisted *living*, and then long term *care*. Karen Schoeneman with CMS reacted to this by pointing out that the first two identify the setting from the vantage point of the living going on there. Long term care, however identifies the setting from the vantage point of the care being given and received there.

Might the word *care* actually be contributing to our traditional institutional ways? Is the word care contributing to the "us versus them" mentality inherent in the institutional long term *care* setting? And the question is worth asking, do you want to *live* in a care center or nursing center? If we chose to no longer use the word care what word could we use instead? Is the word *support*? Support does seem to imply that the person still drives their life and we are on the sidelines offering our support for them to be able to do that. And yet perhaps supportive living is not clear enough to indicate nursing home care as supportive living can be found in other settings as well. Long term living? This certainly matches up better with independent living and assisted living but maybe doesn't sound quite right either. The Veteran's Administration officially changed the terminology from nursing homes to *community living centers.*   And Planetree refers to continuing care.

Fittingly, look at what two people told me once who live in a nursing home, "We're not living, we're existing." Unfortunately what they said fits the "lack-of-home" language currently being used while at the same time points to what we want, and more importantly what they want, a home for living.

*Facility, nursing facility→nursing home, nursing center, care center→***home, community***
Some find fault with the term, "nursing home." However, Eric Haider has said that that is what it is; people would not live there if they didn't need the nursing services provided there. The other side of the argument is that if we are working hard to create home and move away from the medical model, the medical part of the term, namely "nursing," should then be dropped leaving the word home:

> Throughout their work**,** Rosalie Kane and colleagues remind us that nursing homes should be dwelling places first and clinical workplaces second. Thankfully, with the changes that most culture changing homes are making, the focus is becoming more on "home" and less on "nursing" (Bowman, The Environmental Side of the Culture Change Movement, 14).

Some people believe that the term "the home" has traditionally also had a negative connotation i.e. when someone had to "be put in the home." Pioneer Network literature explains that "Culture change can turn a facility into a home, a schedule into a choice and patient into a person."

Care center is a term used quite frequently, probably with the intention of moving away from nursing home, another transitional term. Once again, however, it focuses on the care provided and not the life of the people who live there. Just as independent living and assisted living communities focus on the living part, so does community living center or living center. The word community, Dr. Al Power says, is "relationship rich" and promotes relationship-rich environments. The Perham Memorial Home in Perham, Minnesota is now simply Perham Living. Planetree uses *continuing care community*.

The Barkans and their work at Live Oak Community have always focused on community; creating a community as a repository of well-being which could expand and grow and

reach out to all involved participants. It became known as the Regenerative community and over time created a new role as community developers and community development practitioners (2002; The Life Oak Regenerative Community; Juicing the Process handout Pioneer Network conference).

"Facility is my new F word," said a brave soul at the 2008 Creating Home national symposium. One time an owner said, "This is not a facility but a home. Residents run it. We answer to them. We are their employees, not the owners." Around the country you will hear of nursing homes now being referred to as communities and homes along with households, small houses and Green Houses.

The Barkans once worked at what was called the Home for Jewish Parents. Look at the language the Chinese use to describe a nursing home – A Home for Respecting the Elderly - far from "facility" and a model for us perhaps of how to use language to create culture.

*Quality of life and quality of care →***individualized care***
When we are truly talking about giving care, perhaps individualized care is the answer. I've heard Barbara Frank and Jim Kinsey, leaders in the culture change movement, each articulate well that "individualized care" is something everyone agrees upon no matter their role or discipline. Yet, sometimes quality of care and quality of life seem to be at odds with each other. For instance, so often clinicians seem to be advocating for a certain treatment or care, when social workers advocate for a person's rights to not use the treatment or recommended course of care. When the team rallies around the person with the goal of serving the person, then individualized care is something everyone can agree upon. They can then together identify what individualized means to the person and their situation, and then develop a plan together.

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 Institute of Medicine findings and the writing of the Nursing Home Reform Act of OBRA '87, explains individualized care and also well-being:

> 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. 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).

*Medical model and social model →**a person first model***
Dr. Matthew Wayne explained on the Creating Home II national symposium webinar he gave with Dr. Karyn Leible that if we go strictly medical model or strictly social model, both are problematic as delineated here in this table below.

Concerns with Two Models of Care

Medical Model	Medical Model Concerns		Social Model	Social Model Concerns
-"Patient to be treated" -Residents are medically complex -Complex medical needs -Frail -Functionally impaired -Taking numerous medications	-Institutional routine dictates resident routine -Restrictive -Oppressive -Negative impact on quality of life		-"Someone to be valued" -Resident is a person, not a patient, and has a lifetime of experiences -Choice -Dignity -Self-Determination	-Ignoring or minimizing medical issues will lead to poor outcomes -Allowing choice will create chaos for institutional routines -Residents may make bad choices and this may lead to poor outcomes

Instead, as physicians involved both as leaders in the American Medical Directors Association and the culture change movement, they advocate for a person first model.

*Person-centered care → person-directed care →**self-directed living***

You will hear culture change leaders discuss these terms and as you can see they are a bit different from one another. Person-centered implies to center what we do around the people we serve. Person-directed is where the person actually directs their care; what they want and when; their way. Then along comes Dr. Margaret Calkins who shed even more light on this discussion at the first Creating Home national symposium sponsored by both CMS and Pioneer Network around culture change and the environment in 2008. Dr. Calkins pointed out that both person-centered and person-directed are still using language in the third person indicating others are in charge. She initially suggested instead self-directed care, but now recommends *self-directed relationship-based life.* So one way of thinking about this is that what staff gives is individualized care and what the person does is self-directed living. Self-directed uses the first person to indicate this is who is in charge of his or her life. For the Creating Home II national symposium on food and dining and culture change, again sponsored by CMS and Pioneer Network, the following language was used to describe the symposium: *This symposium is specifically focused on food and dining issues regarding culture change to support self-directed living*. Self-directed living – it's what we each do every day.

Honey, Hon, Dear – **accepted words of endearment**
Some people just naturally use words of endearment. When you get to know them, you understand it is simply a part of their normal vocabulary. Unfortunately, it may not appeal to some. If we banned all forms of endearment though we would have a problem too. When living in Baltimore I discovered that most Baltimoreans call people "hon." In the South it is "sugar." Now it is also true that there are bound to be people in Baltimore who hate being called hon and people in the south who hate being called sugar, so once again, it should be the person who decides.

Unacceptable and undignified terms/terms implying adults as children
During a survey once I observed four women residents being served and assisted to eat. The CNA assisting them referred to the ladies as "baby," "babies," and then turned to me and said, "I call them my babies. I know I'm not supposed to but I do." We have also heard "good girl" used when assisting someone to eat like we might say to our babies when learning to eat. Interestingly enough, at the same home where the CNA referred to residents as babies, I overheard another care giver call a woman who lived there, "Grandma." She then immediately turned to me and said, "It's care planned." Team members knew she preferred to be called Grandma, even identifying it in her personal care plan for all staff to know. And, sometimes, especially in rural areas, the person might very well be the staff member's Grandma!

During a survey back in 2001, residents told me "Sometimes they treat us like little kids, like babies. They boss you around. I tell them I'm not a child. I know they have our best interest in mind but sometimes it's a little too much." How is it that there are stereotypes out there that older people equal children? Have you ever seen something like this: Menu for all children ages under 12 and over 65. Dr. Thomas said on my *Conversations with Carmen* web talk show March of 2011 that ageism promotes this stereotype that we expect people to retreat into a second childhood becoming like a child again. Adults; people who are our elders, are not children and deserve to continue being treated as adults.

In a document entitled "Communicating with Older Adults" by Lutheran Health Systems, it was wisely stated, "Interaction with the older adult should be on an adult-to-adult level, never in a patronizing or adult-to-child manner" and "Effective communication with an older person can develop into a meaningful relationship that is of great benefit to both of you. The wealth of wisdom to be gained from the old is immeasurable!"

In this same publication by Lutheran Health Systems, it was identified, "Sometimes because residents are in a position of being cared for we take on a more parental role with them. And although it may be true that these older persons are in need of care from another, it does not give us permission to dismiss them as less of a person. Treating another with respect and dignity calls us to do it differently." In fact, CMS' requirement for Dignity at Tag F241 states,

> 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**.

Coffee time, bedtime, "It's time to…"→"Would you care to have some coffee?"
Most agree that when we put "time" on anything, it sounds childlike, i.e. bedtime, bath time, etc. In Germany, they refer to it as Kaffee und Kuchen (coffee and cake), not cake time. "It's time for your bath." "It's time for breakfast" "It's bedtime." All of these have the ring of kindergarten don't they? The adult and self-directed living way would be instead to ask, "Mrs. Smith, when would you like to (fill in the blank)?"

Socially isolated, isolator, antisocial →"She prefers some private time to herself," "He says he's always been a loner"
We've worried a lot about social isolation over the years; not "letting" people eat in their rooms; feeling people should get out of their rooms, come to "activities," etc. Dr. Al Power points out we even view someone as "antisocial" when they want to eat in their room (109). Yet, it is natural for many of us to desire some time alone occasionally to catch up with our desired reading or web surfing or game playing. We don't consider this anti-social, so why should it become labeled as such just because the setting has changed? And oddly enough, many "socials" like the typical ice cream social are not social at all. In many cases residents are taken to the social and not socialized with at all. In those cases, it might as well be titled "eating ice cream" on the activity calendar instead.

Refuse →decline, not interested, choosing to do something else
In a nursing home you might hear staff refer to residents who have refused activities or refused medication. Dr. Power (2010) often asks what the word implies and people reply, "difficult, disagreeable, combative, troublemaker" and cautions, "Note how the simple word *refused* has poisoned the attitude of all who will be approaching …" that person (p. 84). The use of the word refuse carries the connotation that there is something wrong with that person. Some culture changing homes take the position that a resident is never bad or wrong. Rather, they are always right and what they think goes.

Resident claims→ **"Joe states/says"**
Wisconsin Coalition of Person Directed Care suggests instead of using "resident claims," to use "resident states." "Resident claims "suggests that they are insisting something is correct or true even though it might be open to question.

*Diaper →***use the word that the person prefers**
Most agree that it is inappropriate and undignified to use the word diaper to describe what is actually a diaper for a person who is their elder or any adult in their care for that matter. So then what word is to be used? Brief has become a widely used replacement term and you will see it on some packaging. However, for many the word brief is a word which is only appropriate for male underwear; as are panties for female underwear. Thus it makes more sense to find the word that works best for each person.

*"Clothing protectors" →bibs →***bigger than a word or language issue only, a dignity issue,**
"Would you care for a linen napkin so you can keep your shirt clean?"
In a group interview with residents at a Colorado nursing home in May of 2001 residents said that the term bib made it sound as if you were "like a baby. You put a bib on a baby. We're not babies." Here are some other ponderings about bibs:

> No More Bibs! That's not what we call them is it? Instead we call them 'clothing protectors' or 'clothing covers.' I used to be the 'bib police' in my facility. I would correct anyone who called them bibs. Why? Because the word bib is not dignified, or at least that's what I thought. But what are they really? Bibs! Now I just shake my head at myself. Avoiding calling something by its name doesn't change what it is. In reality, they are adult sized baby bibs. That's what they really are. Do you wear one at home? Did any resident wear them before they moved into a nursing home? No. So why is it that as soon as a person becomes a nursing home resident he or she wears an adult sized baby bib? (Bowman, 2005-2006 Action Pact Porch Swing Series).

Dr. Ronch, who comes from the east coast, always brings up that bibs are used in his part of the country … when eating lobster. Once when raising the issues that surround bibs in Montana, an administrator said he has told his staff members that if there are bibs there better *be* lobster for dinner!

There is an excellent 20 minute training video *Dining with Friends* developed and 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** *(emphasis added)*, 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."

Many homes have talked with their residents about how they protected their clothes prior to living in a nursing home and have together moved to using linen napkins, which is what is more commonly found at restaurants and in our homes.

*Patient → resident →**person, neighbor, community member, individual***
We've come a long way away from using the term *patient*. It was a big deal, and rightfully so, in the Nursing Home Reform Act within the OBRA of '87 when *resident* was purposefully chosen to portray a nursing home as a home where one resides and not as a medical patient. Now to a physician or nurse, any person being treated is a patient. In fact, an administrator who inadvertently referred to her residents as patients said, "I was just talking to the hospital so I have 'patients' on my mind."

The term resident is used by CMS in their regulations. Karen Schoeneman of CMS explains that the Office of General Counsel for CMS continues to use the term resident since federal statutes and laws giving CMS authority to enforce quality standards of nursing homes all use the term. However, many advanced and culture change homes have chosen other more normal words recognizing that although we are residents of our homes, we do not refer to each other as such. Some people who live in nursing homes have chosen to refer to themselves as neighbors or community members, which seems actually quite fitting when you live in a neighborhood and in a community.   And then it flows naturally to refer to the new neighbor instead of the new admit. Another lovely and common sense word is to refer to individuals.

*Elderly →**senior, older adults**→ people*
Isn't it ironic that the term elderly itself has become ageist? It brings with it the negative connotation of frail, sick, and old. Senior is debatable in the sense that it seems some like it and some don't. I have a friend who says she loved being a senior in high school and college, so she likes the term. Others say, "Give me the magazine and the discount but don't call me a senior." Our society perpetuates this ageism and declinist view of aging, that it is bad to get older as evidenced by "over the hill" and "I'm having a senior moment." Many older adults have passionate disagreements about what they think they and their age-peers should be called. So consensus may be a ways off for now. Dr. Ronch, Ms. Madjaroff and I agreed in thinking about language that we might use *person* and *people,* feeling that these words fit every time and don't offend anyone since that is what we all are.

*Admitted, placed, put →"**We helped Mom move to a nursing home," "a new neighbor moved in yesterday"***
When you moved into the house or apartment or condo you now live in, were you admitted? When are we admitted anywhere? To a movie; to the stock show; to the theater. Joan Devine, author of Word of the Week, defines admit as "allowing a person permission to enter a restricted area." Most admittance is temporary.

Then notice the word admitted sounds very close to … committed. People get committed to psych wards; what used to be called insane asylums. Unfortunately, that then reminds us of

having heard residents refer to themselves as inmates. Look how the language sort of fits, "We placed Mom in a nursing home," "We had to put Dad in an assisted living." People who work in the disability community with younger people avoid nursing home "placement" at all costs. They even say it like this, "she was at risk for nursing home placement."

*Tour →***visit**
People typically take a tour of a nursing home when considering it as a residence for themselves or someone they love. You might take a tour of my home, but it is usually during a visit we've planned or if my home is for sale. Joan Devine, author of the Word of the Week, defines a tour as "a brief journey through an area, often for the purpose of inspection" whereas a visit is "a short stay, often for purposes of discussion with acquaintances or friends." I've heard over the years that at the households of Meadowlark Hills in Manhattan, Kansas that you must ask the people who live there if you may come for a visit. If you do visit, they also insist that you stay a while and get to know them; not just pass through and look at them.

*Expired →***died or passed away**
In real life we are able to say "she died," so why not in a nursing home? We all know it happens there more frequently than many other communities.

*Admission coordinator →***move- in coordinator**
Many admission coordinators have renamed themselves move- in coordinators, since that is really what they coordinate. If you employ a moving company when you relocate your primary residence, the staff person who assists you is called the move-in coordinator or relocation coordinator. When you help a friend move to a new home, you don't say that you helped him or her get admitted.

*Discharge, discharged →***moving, moved, relocated**
When you relocate your residence or move out of a residence, do you refer to yourself as having been discharged? No. You get discharged from a hospital because you were previously admitted. It is also why there are discharge planners at a hospital. Joan Devine in the book Word of the Week says that to discharge means "to end a professional or clinical situation, as at the end of a military career or hospital stay, to send away whereas move out is to discontinue one's residence in a home or dwelling." Then she asks, "Are we sounding like the Army…or like a person's home?"

*Room 100, Room 302 →***address, person's name**
Do you refer to your room at home with a room number? Most homes have an address, but rooms are defined by what takes place within them, e.g. master bedroom, Sallie's bedroom, family room, kitchen, etc. Most state regulations require that rooms in healthcare communities have numbers for fire code purposes. That is why many nursing homes have given room number addresses to each resident. Instead of people's names, sometimes just room numbers are listed. Nancy Fox says, "This kind of language objectifies the person and then allows us to do whatever we want to her. She becomes a number instead of a name."

Old Way	Better Way
Residents who need assistance	Neighbors who need assistance
Room 101 B	Mr. Smith
Room 112 A	Mrs. Lockheed
Room 121 B	Mrs. Jones
Room 122 B	Mr. Lindeen

*Wing, unit →***neighborhood unless living in a household or a house**
In the 80's and 90's some homes began the process of deinstitutionalizing their environment by changing the names of halls and corridors to streets and avenues. This was a good attempt, but if you want people to think halls and corridors are something else, it takes more than just renaming them. For instance some homes have intentionally designed life to take place in what many call a town center and/or addresses with genuine street or avenue names that speak to the outside community. People don't live on a hall or corridor in their own home unless perhaps it's a mansion or a castle. Most of us live on a street or avenue.

The culture change movement has brought with it new nursing *home* configurations such as households, neighborhoods, Green Houses and small houses. However, most of today's homes were designed and built in the 1960's traditional "wing" layout. In many homes, residents have given them a name instead based upon their preferences, life experiences, or geographic location e.g. Garden Way, Marina View or Aspen Neighborhood. Dr. Margaret Calkins, a long term care consultant, notes,

> Language is also important at the larger scale of the [what is usually now called the] "unit." Many facilities are moving away from the term "unit" to calling these groupings of residents' clusters or pods. However, one could question how residential these terms are. As one administrator put it, "Whales and peas live in pods, and grapes come in clusters. People live in households." Language affects our thinking at a fundamental level and should be considered carefully. This may be why some facilities are giving their units names, such as "Hill House" or "Beacon Place." As architect Witold Rybczynski writes, "Words are important. Language is not just a medium, like a water pipe, it is a reflection of how we think (Calkins, 2003).

*Resident Council →***Neighborhood Council, Home Owner's Association**
The term resident council is nowhere to be found in the federal nursing home regulations. Instead, the federal regulations give residents the right to form groups. You will probably find it however in state requirements. But that doesn't stop us from calling it whatever we

wish. There is nothing wrong with the term resident council, of course, but in some homes the single large council for the entire community has morphed into several neighborhood councils. Neighborhood councils have had great success in that more residents take part when it concerns their immediate neighborhood and speak up when it is a smaller group. Staff who works with those who live on the neighborhood are also more likely to take part as the deliberations of the neighborhood council more directly concerns them. Alternatively, some homes have chosen to keep the main resident council with representatives from neighborhood councils. In Florida, many groups of residents have decided to call their Resident Council the Home Owner's Association. Tags 243 and 244 require the home to include resident input into operational decisions and policies governing the home. And like a real Home Owners Association, some councils have real authority to make important operating decisions; not just suggest a menu for one meal in the upcoming month. For example, at Parkview Care Center in Denver, when budget cuts have to be made, they are reviewed by both the resident council and administration; by the people who live there as well as the people paid to work there.

*Lobby, common area →***living room, parlor, den**
Do you have a lobby in your home? If you live in a high rise, most likely you do. But it is not a part of your apartment and certainly not if you live in a single family home. Lobbies are most often found in medical buildings or hotels. Therefore, many are renaming these living areas in long term care communities with words reflective of home such as living room, parlor, or den and more importantly making them comfortable enough to actually feel like a living room, parlor or den.

*Day room, activities room →***community room, family room, living room**
Do you have an activities room in your home? Other words being used are community room, multipurpose room, maybe family room. Environmental expert Dr. Margaret Calkins agrees, "It is also important to consider what rooms are called. At the simplest level, having a living room or family room is more familiar than having a day room or an activity room "which sounds more institutional or like a senior center" (2003).

*Ward clerk →***services coordinator**
Ward clerks perform receptionist and clerical duties. The term ward, of course, is a throwback to a time when large groups of residents were housed in a single room or ward. Most people with this role are now called a secretary or coordinator.

*Nursing assistants→resident assistants→***companions, eldercare specialists, household/neighbor/elder assistants**
There is nothing wrong with the title of nursing assistant. Certainly it is embedded within the credential of CNA – Certified Nursing Assistant. However, many nursing assistants around the country have changed their title to resident assistant, while proudly wearing the credential of CNA, explaining that it is really the residents they assist. And resident assistant might already be a transitional term as newer titles nursing assistants have given themselves are companions, eldercare specialists, elder assistants (Otterbein Homes) amongst others. Jim Wills a dementia care specialist in Louisville, Colorado suggests CNA really stands for "Certified Nursing Angel."

*Paid feeding assistants →***dining assistants, server**
Most agree, Paid Feeding Assistants is strange terminology. Even though CMS created this title, CMS does have a statement in its interpretive guidance at Tag F373 that other titles such as *dining assistant* may certainly be used. And why the word "paid" in the title? We don't call nurses "paid nurses," or any other staff members "paid" anything. Many teams use the term "dining assistant" which flows both with the quest to change undignified language to dignified and would actually be "more compliant" with CMS's *own* change to guidance at Tag F241 Dignity where CMS itself identifies the term "feeder" as an example of undignified, labeling language.

*Front line workers →***direct care givers, care givers, hands-on staff, team members**
A front line is a boundary, a military line or where a direct response team operates. It seems like the message is "You go in first. And if you come out, I'll join you." What are front line workers really? What do we mean really? Direct care worker became a transitional term. Softer, more natural language would be care givers, hands-on staff or team members. In the Otterbein newsletters you will see descriptions like "housekeeping department partners." Oddly enough, this term front line workers is still often seen even at culture change events and in culture change documents.

*Staff →***team members, care partners, colleague, associate**
The term staff implies belonging to or working under the direction of management, which of course staff members do. However, alternative terms in changing nursing homes have come to more strongly emphasize the responsive role to those receiving care instead of the reporting relationship to management. LaVrene Norton and Steve Shields say something similar:

> The people who live here are loved and served by a responsive, highly valued, decentralized, self-led service team that has responsibility and authority (Essential Elements of the Household Model No. 5).

I've heard only Carol Ende of the Eden Alternative point out how awkward the term *staff* really is, also referring to the misnomer of "my staff." Not surprising then, it is the Eden Alternative that has come up with a new word to describe what staff members really are: *care partners*. Here is their definition:

> The Elder is an active participant, or partner in her own care. Care partnership implies a balance of care – opportunities to give as well as receive are abundant and experienced by everyone involved in the care relationship. Once this exchange is identified, all involved benefit from the awareness that care is not a one-dimensional experience (Eden Alternative, 2012).

And care partner is also the term used by Planetree hospitals and continuing care communities according to *Putting Patients First: Designing and Practicing Patient-Centered Care* (2003). A care partner is the person who a patient or resident designates upon admission or moving in to become actively involved in their care even after a hospital stay

or short term nursing home stay (p. xxx-xxxi). The care partner is identified in the record, given a nametag so as to be easily identified, and training. They are encouraged to assist with care, enhance communication with the health care team and to challenge anything that doesn't seem right (p. 58), now that's living up to the word partner.

Here is agreement by Bryden (2005):

> Adopting a sole identity as our care-giver highlights our illness and strips both of us of other identities; we have become care-giver and sufferer, in a relationship of co-dependence….In this care-partnership the person with dementia is at the center of the relationship, not alone as an object to be looked at, as merely a care recipient. Instead we become an active partner in a circle of care (pp. 149-150).

In most workplaces workers refer to each other as colleagues, a dignified term. Life Care Centers of America workers refer to each other as associates.

*Charge nurse →***nurse, team leader, use care partner's name**
Who's in charge and how do they act in charge? If you want to change culture, here is a place to make change. If we want to put the person living there back "in charge" of their life, we can avoid using the word charge with any staff team member and instead use team-oriented words such as household nurse, neighborhood nurse or team leader. If you go to a Pioneer Network conference speakers are referred to as guides. In the Action Pact household training, titles like *mentor* and *guide* and *lead* are used. The term that is used fits the culture.

*Inservice →***provide education, training, exposure**
Often either the word itself or the way we use it implies that someone is in the wrong. You will frequently find it on plans of correction: "The staff will be inserviced." By saying it this way it is implied that "they" don't know what they are doing so "we" will inservice them to correct their bad behavior. And so often in the typical institution an inservice is given "to" the staff. I think a better term is exposure. Instead of "inservicing staff," what I have seen work very successfully is exposing staff to what is, so that they can see what can be. When you take team members to homes that have changed; to conferences to learn from those who have changed their culture; you will see a very different reaction than if you simply try to tell people about change ideas. Unfortunately, our human nature, especially in this business, tends to react to new ideas with: "You can't do that, the regs or the corporation or the state, etc. won't let you." When you simply expose team members to what IS in other homes, the next natural human reaction becomes, "wow if they can do that so can we" or "we can even do it better" … bringing out the competition rather than the naysaying. Bring out the best in your team by exposing them to what can be.

Professor Ronch also points out that exposure alone does not ensure adoption or behavior change. For some, indeed seeing is believing. For others there may be disbelief that what they saw could ever come to be where they work. He calls it attribution error. One may think "that home was able to make changes because of XYZ and though I would like it to happen we could never do that." Much more is needed after exposure. And as far as

language goes, he says that in the world of adult education he typically sees "training" applied to skill development and "education" to conceptual/critical thinking. The culture change movement's learning circle technique also brings the sharing and honoring of each person's opinion followed by that all important opportunity to discuss as a group how to move forward or make changes in response to the training/education/information staff members were exposed to.

*Work the floor →***assist residents, say what they do e.g. pass medications**
Sometimes nurses bemoan they had to "work the floor last night." But what did they really do? They cared for residents in some way; usually they passed medications. That is what most nurses do. Now separate yourself from long term care and what does "work the floor" sound like? I see a person mopping a floor in my mind. It was in California many years ago that a man in the middle of the large audience loudly said to me, "That's not what I thought of" … while winking!

*Elope, escape →***left the building**
One time, a resident overheard staff members talking at the nurses' station about another resident who eloped. The resident listening said, "I didn't even know she was dating." Our use of elope is not the normally accepted definition. And even worse than elope is, "She escaped." I once read in a medical record of a resident during a survey, "Resident attempted to escape the building many times today." In the real world people say someone left or perhaps someone got lost.

*Toilet →***use the bathroom**
The word toilet seems overused in institutions to me. It is all over the MDS, the care plan and you will even see signs like "Nurse Toilet." Also, it is frequently used as a verb, as in "I have to toilet Jane." Outside of the long term care community, we say that we go to the bathroom or we need to use the restroom. We do not say, "Excuse me I have to go toilet myself."

*Beds →***bedrooms, refer to the people living there**
A nursing home gets licensed for so many beds. Although the term "beds" is then used in this context, it isn't required that we use this terminology. You will hear long term care professionals talk about how they work at a "100 bed facility." Some companies talk about "heads in the beds" referring to census; ultimately referring to profit margin. Ask a hotel or resort manager how large his or her property is and they will say it has X number of sleeping rooms. When we refer to our homes, we list then number of bedrooms, not beds.

*Census or occupancy →***100 people live here today, 110 could live here**
Census and occupancy rate bypass the fact that we are talking about *people* who live there. So, instead of tallying your census, you might simply discuss how many people live in the home or community where you work. A hotel manager will tell you how many guests are staying at the property.

*Industry →***field, profession**

What comes to mind when you hear the word industry? Most people associate with it manufacturing. I see a refinery in my mind. What could we use instead of nursing home industry? Personally, I cannot say industry anymore. I noted that even Beth Baker made a similar comment in her book Old Age in a New Age; her study of the culture change movement, when she wrote, "The nursing home 'industry,' as it unfortunately calls itself..." (p. 18). When I ask crowds of people what we could refer to instead, they always say long term care field or long term care profession or long term care services. Aren't they much better descriptions of the work many of us love?

*Allow, let →**encourage, welcome, support***
"Each resident is allowed to have in their room one bed, one night stand, one chair, one television, two plants, the use of one closet and three drawers in the dresser." This is a direct quote from a list of Resident Room Responsibility/Regulations from a Colorado nursing home. Joan Devine in the Word of the Week resource states, "We say 'allow' to our residents to make their own choices, but, consider ... is it really OURS to allow?"(2009; unpaginated). Allow also implies that we have given someone a limited approval or permission to do something that was not their own to decide to do. We don't allow other adults to do anything, we support, encourage, welcome them to live their lives as they have always lived them.

*Hydration station →**snack bar, juice bar, drinking fountain***
No one in any community would ask the location of the nearest hydration station, because they wouldn't be understood. If you are seeking liquid refreshment, you ask for a bar (snack, juice or other), snack shop, a fast food outlet, restaurant or simply where you can get a drink.

*Nurses' station →**staff work area, desk, team area***
The nurse's station is the barrier behind which nurses and other staff can perform administrative functions when not interacting with residents. It is precisely because of the barrier created by the nursing station that many changing homes have removed it. It has been replaced by small decentralized work areas or desks where staff members and residents have the opportunity to engage with each other. Charlene Boyd, administrator of Providence Mt. St Vincent in Washington, is very funny and will tell you she always thought the nurse's station should be called the nervous station. Pat Maben Norton describes it this way:

> Often the first thing people see when they visit the traditional medical model nursing home is the nurses' station. It is the control center amid a buzz of activity, and it stands as a physical barrier separating the nursing staff from residents and family members as if to say, 'We (staff) are in charge.'

And LaVrene Norton goes on to say:

> Recreating spaces to be shared by residents reduces the barrier between residents and staff created by the titanic nurses' station. Caregivers are more available to residents and family members. Together they can sit in the comfort of the living

room to discuss care plans instead of standing at a large desk in the lobby area. Responses from residents, families, and workers in nursing homes that have made these changes are primarily positive…. Now, with room to converse, play cards, host visitors, and interact with staff, once-listless residents are awakening to the possibilities of friendships and community…. Simply put, 'If it looks like a hospital, we'll feel like a patient. If it looks like a house, we'll feel at home' (2004).

Optimally, we think that the best way to get rid of the term is to get rid of the object because no matter what you call it, the physical presence of this barrier is inconsistent with the kind of experience for which we advocate. We include the use of bibs in this category.

*Dietary department →**dining services, culinary arts, restaurant, the Weller Bistro***
The term dietary relates to food, of course, but it is not the way we normally refer to food or eating either at home or in a restaurant. It is a professional term; not a consumer term. In an article entitled *Continuing down the highway for Culture Change – Words do make a difference*, author Susan McCorkell Worth, RD, LD says:

> Most communities' food production area, in my experience, is termed "Dietary." The dietary manager is the department director and the dietician is "The Food Police." The root word "Diet" has a negative connotation to the general public and is treated by many as a four-letter word. Dining or Culinary Services seem more appropriate as we move away from the medical model of providing nutrition within healthcare (2009; p.9).

Green House® communities have Culinary Arts, not dietary departments. Many homes have renamed and redesigned what was their dietary department into dining services, room service and brought culinary arts into long term care. Dining staff members are invited to come out of the kitchen and get to know the people they cook for.   Executive chefs are being hired into the relationship-rich environment culture changing homes are creating. A chef, or any professional for that matter, can work in a place like a restaurant where people come and go or in a nursing home where people live, where you can get to know them and serve them and be in a relationship with them every day. Spring Creek in Ft. Collins, Colorado is developing what they call a "restaurant within a nursing home" and at Fairacres in Greeley, Colorado, you can dine with anyone who lives there in the Weller Bistro.

*Semi-private room →**shared room, double room***
Some people who live in nursing homes, households, small houses or Green House nursing homes, have a private room, a whole room, a real room all to themselves. The new trend we see across the country is a transition to more private rooms, turning the traditional shared room into a nice sized private room. Remodels or additions or transitions into households all usually include a conversion to private rooms. However, the majority of persons living in nursing homes still share a room with a stranger. Oddly enough we call these rooms semi-private. Another term being used is "companioned room" or "companion suite." But unless the "companions" chose each other it may be experienced as a word

change only. In addition, these are the more enhanced shared rooms where each person has their own territory.

Dr. Margaret Calkins says this about *semi-private*:

> What is semi-private? It is an oxymoron. It is a little like being "slightly pregnant." Let's start with an examination of privacy. The American Heritage dictionary defines private as "secluded from the sight, presence, or intrusion of others; designed or intended for one's exclusive use" (American Heritage nd). Dictionary.com defines it as "without the presence of others; alone" (Dictionary.com, nd) (Calkins, 2008).

Perhaps it is really a half a room. Once while consulting at a nursing home in Colorado, I was speaking with a person who lived there. We were sitting at the window on her side of a shared room. She commented that she waited a long time to "get this side with the window" and then said, "I used to be in a compartment like that" pointing to the other side of the room without the window.

And as far as better language goes, most architects and designers now call these rooms shared. Even better, many are also moving in the direction to create more privacy by building or retrofitting partitions to create what is being called privacy enhanced shared rooms.

*Homelike →***true home, feel at home, home**
Although "homelike" was well intended as it came about with the Nursing Home Reform Act of OBRA '87 along with resident instead of patient, it "suggests artificiality" points out Dr. Power (2010; p. 122).

Homelessness	Home	
Meaningless Space	Lived Space	
Insecurity and Uncertainty	Safety and Predictability	
Powerlessness and Dependence	Power and Autonomy	
Non-Personhood	Identity	*Carboni 1990*

Also from the background paper for the Creating Home symposium co-sponsored by the Pioneer Network written under contract with CMS :

> 'Homelike' was another great forward step of OBRA '87, much like the advent of the term 'resident.' Now the culture change movement is taking another step forward in creating something much more than homelike which is 'home.' Miguette Kaup said it best when she said; 'Homelike' implies 'Pretend this is your home.' 'Home' means 'This is where you live" (2005; p. 9). Although the culture change movement is moving away from the term 'homelike,' CMS is to be commended. The attempt on CMS' part to require nursing homes to create a 'homelike' environment that 'de-emphasizes the institutional character of the setting' is exemplary and certainly in accord with both OBRA's and the culture change movement's intent to help a person live out their highest quality of life possible (Bowman, 2008; p. 55).

Another approach is to create an environment where people can feel "at home" which means at ease, relaxed, well known and often feeling comfortable enough to move about and to get something out of the refrigerator without having to ask for permission. LaVrene Norton of Action Pact calls that "refrigerator rights" having or being given back the right to open the refrigerator and ponder just like you and I get to do.

New Vocabularies

<u>The Eden Alternative Creates New Language</u>
The Eden Alternative has done much work on language since its inception in 1996. Eden freely shares a helpful resource entitled *Creating a New Language for the Eden Alternative Journey* on their website www.edenalt.com (updated April 2012) and because Dr. William and Jude Thomas along with their Eden team have made Eden a leader in championing new language, we want to recognize them here with some of the terms they have identified and defined.

Care giver and care receiver→ care partner

> *"Care Partner"* describes the individuals who live and work in the home, as well as anyone who is connected to it. We are no longer a community of caregivers and care receivers, divided up by departments, titles or whether we live or work here. We are all partnering to ensure that everyone has the chance to grow and relationships are reciprocal. The care partner concept redefines people's roles and responsibilities. It acknowledges that opportunities to give and receive are abundant and experienced by everyone involved in the care relationship. The term "care partner" evens the playing field, as it is often easy to get trapped in the traditional, one-dimensional, care giver to care receiver relationship. Care partners work together toward mutual objectives and benefits. Care partners help each other to be their best.

Interdisciplinary team →care partner team

> Care Partners that come together consistently to support life within specific physical space in the community. They share in daily responsibilities and are committed to helping one another to grow. The team includes Elders, employees, healthcare professionals and families.

Caring Community

> An environment characterized by close and meaningful relationships. It is best created when the employee care partners have the opportunity to know a small number of Elders intimately so they are better able to respond to individual needs, desires and create a life worth living for all.

Daily rhythm of life, daily rhythm of the home/community

The flow of daily life in the home and individuals' lives, based on the needs, choices and preferences of the Elders, not the needs of the organization or the employees. That can include arising, sleeping, eating, bathing, social/community calendar, and treatments.

Departments→support teams, neighborhoods, households, blended roles

A description of a group of care partners who work together regularly to support the growth of all members of the team. Over time they become empowered and accountable to direct their own daily actions. Instead of narrow job descriptions, cross-training is provided to begin to blend roles so the needs of the Elder care partners can be met.

Job description→ care partner role

Job descriptions as they are traditionally written are a series of tasks a person is responsible for. Care Partner Roles describe a new type of relationship between the people who live and work in the home. It explains how each person contributes to the experience of home beyond any tasks they have the skills to complete. Care partner roles are designed to inform leadership and to help employees to realize the organization's objectives and purpose.

Manager, department head, supervisor → leader, team leader, coach, mentor, guide

The people who are accountable to support the care partners while ensuring the day-to-day operations of the home remain strong and stable. In The Eden Alternative, leadership is defined as the ability to influence others to bring about positive change.

Support care partners with expertise Care partners who assist others in their field of expertise, along with providing support for growth of the neighborhoods and the individuals who live and work in them.

Growth Partners

Growth Partners support, educate, and guide care partners to a successful life experience in their community. Growth Partners provide honest and timely feedback through regular evaluations and on-the-job training.

Policies and procedures → well-being strategies

Policies are rules and guidelines formulated or adopted by an organization to reach its long-term goals. Procedures are the specific methods employed to express policies in action in day-to-day operations of the organization. The ultimate outcome for person-directed care environments is to have everyone experience well-being. Therefore, the way the organization designs its systems and processes should center on the Eden Alternative Domains of Well-Being.

Shift →**names of the people working at that time of day**

As long as employee care partners are identified by their "shift" there will always be a division. Switch to identifying the people working by name.

Therapy services, therapists →**habilitation, habilitators, care partners**

Dr. William Thomas defines habilitation as "the effort to bring forth existing but latent potential within a person or a group of people." Therapists are part of the care partner team. Their role includes identifying an individual's strengths and sharing them with the rest of the team.

Administrator →**community mentor, guide, head coach, care partner**

This person is a servant leader/mentor/coach that helps others grow to become their very best. They help others to bring change and overcome barriers to create a Human Habitat, where life is worth living. They understand and teach others that the resources, policies and regulations ensure that each care partners' needs are met.

Nurse →**clinical advocate, resident care coordinator, quality of care coordinator, clinical mentor, care coach, care partner**

Responsible for monitoring clinical outcomes for the Elders and helping to grow the skills of those most closely caring for the Elders daily.

Medical records personnel →**legacy keeper, care partner**

The medical record document is where people go first to become acquainted with Elders who make their home in the community. A Legacy Keeper's responsibility is to collect the Elder's personal story, their preferences, simple pleasures, *and* their medical needs in this document. The story of the Elder is something that should be carefully constructed to ensure that the whole person is reflected in what it contains.

Director/manager→**leader, guide, coach, facilitator, liaison, mentor, care partner**

> The change in language helps shift the perspective from one of top-down authority to one of support, service, assistance, and helping others to grow through empowerment.

Certified nursing assistant→**professional care coordinators, care partners, resident assistants, resident aides, care housing attendants, resident service aides, elder associates, quality of life coordinator**

> The role of the Certified Nursing Assistant, by its very title, has led these individuals to focus on and be directed by those who supervise them more than those they support (the Elders). In Eden Alternative Registered homes, the individual's focus is to become a partner in care with the Elders. In our healthcare system, being a C.N.A. is also seen as one that is low on the hierarchy. Changing the title, description and their reporting relationships helps grow the individuals called to this important role in the home.

Annual performance evaluations→ **care partner growth plans and reviews**

> To summarize and review the care partner's performance over a set period of time, to help them to grow in areas where they need assistance, or to express an interest in learning more skills and to become better well-known."

Green Houses Create New Language

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 Project."

According to Thomas in his book What are Old People For? How Elders will Save the World (2004) the Green Houses have their own "idiosyncratic vocabulary that cultivates patterns of behavior that reinforces its goals and ideals" and "Institutional language, roles, and culture are surrendered in favor of the logic of intentional community:"

> The words and ideas that surround the Green Houses have special importance. Culture is no accident and it never misses an opportunity to reinforce its shared beliefs with the power of habit. Because new ways of thinking demand a new lexicon, Green House language has been designed to match its culture. This

vocabulary, some of which may sound strange at first hearing, helps protect the Green House from a thoughtless return to declinism.

Dr. Thomas has truly thought through how to do this work differently, so much so he says "the Green House offers the roots of a language that is liberated from declinism and from the legacy of enforced dependency. It is not an attempt to *change* the culture of long-term care because it *rejects* the very idea of long-term care" (emphasis added, 2004, p. 227). Thus Dr. Thomas advocates for building a whole new model instead of altering the old. Because of this, we felt it was worth the space to share the language they have chosen, defined and redefined to match the culture of the Green Houses:

Intentional community (*noun):* A group of unrelated people who come together in order to share the deliberate pursuit of some noble aim. Intentional communities avoid excessive hierarchy and have a history of accepting into their midst those who have been cast out of society.

Green House (*noun):* An intentional community for elders built to a residential scale and devoted to the pursuit of the most positive elderhood possible. The value of clinical services is recognized and is then made part of a habilitative social framework that gives primacy to human development in late life.

Habilitation (*noun):* The effort to bring forth existing but latent potential within a person or group of people. It is distinguished from *rehabilitation* – a term that presumes a defect to be rectified or a brokenness that must be repaired, whereas *habilitation* presumes wholeness.

Well-being (*noun):* This is a much larger idea than either quality of life or customer satisfaction. It is based on a holistic understanding of human needs and capacities. Well-being is elusive, highly subjective, and the most valuable of all human possessions.

Elder (*noun):* A person who, by virtue of age or life experience, has transcended or has the potential to transcend the limitations and shortcomings of adulthood; a mature person who gives precedence to BEING-doing in daily life.

Elderhood (*noun):* The state of being and living as an elder. It is founded on the developmental potential that is latent in late life, and is as distinct from adulthood as adulthood is from childhood.

Care (*noun):* The common use of this term in the language of the institution has perverted the word's true meaning. In the Green House, the universe of care is defined as those thoughts, words and deeds that contribute to the growth of the people participating in its community. Care can include but is in no way limited to medical treatments.

Rhythm of daily life (*noun):* The pattern of behavior that best enhances the well-being of the people in the Green House. Because this pattern can be known only by paying attention to the needs and preferences of the people directly affected, the

household does not operate on a predefined schedule. Elders eat meals, bathe, sleep, rest, and socialize at times they choose. Elders can, if they like, participate in homemaking, including meal planning and preparation, gardening, caring for household pets, cleaning, and doing laundry. This rhythm is created by and evolved through household decisions made jointly by people living and working in the Green House.

Dr. Thomas didn't stop there; he also realized there needed to be not only new terminology but a whole new concept for those doing the sacred work of befriending and caring:

The conviction that we need a new framework around which to organize the experience of those who protect, sustain, and nurture our elders came to me early in my exploration of longevity. Much more challenging was the selection of a name for the people who would pursue these goals. I ransacked dictionaries in search of an English word or phrase that would convey the proper meaning. All of the words that might have serviced the purpose were tangled up with meanings that reinforced the tyranny of dependence and independence. I finally chose the word *shahbaz* precisely because it is unfamiliar. It is a Persian word that means, literally, "royal falcon." More than a few people have argued that the word is too strange, too foreign, and too unfamiliar. While there is a price to be paid for such unfamiliarity, the word does free us from the sediment that has accumulated around English words such as *worker, assistant* and *helper* (2004, p. 254).

In the modern industrial economy, the kinship group, in its stripped-down nuclear form, can no longer serve as the sole source of support for elders. Increasing numbers of families now rely on a non-familial system of therapists, services, and organizations. The people who work within this system are often generous and big-hearted, but the organizations themselves do not know love, cannot know love, and, indeed, reject the idea that love could form the basis for a reconsideration of our longevity. The rigorous application of professionalism and therapy expels love from the experience of elderhood.

The demand for what we now know as 'paid caregivers for the elder' exceeds the supply of the people willing to do this work, and the imbalance is growing. This shortage is a direct consequence of the long-term care industry's perverse habit of confining good people within narrow task-driven jobs. In exchange for a meager paycheck, they are expected to give themselves completely to their work and the people they serve. A shabaz, in contrast, is a big person in a big job. Not only does a shahbaz protect, sustain, and nurture elders as individuals, a shahbaz also cooperates with elders to create a new society-wide understanding of elderhood. They are allies of the new elderhood and will stand shoulder to shoulder with the nurses, doctors, and therapists whose skills also contribute to the well-being of elders (2004; 254-255). A shabaz is the midwife of a new elderhood. (2004; p. 231).

And the rich language of the Green House® goes on. For instance, people are employed in the culinary arts, not dietary departments. And instead of being taken to a large institutional dining room to eat three meals a day, those living in a Green House are invited

instead to join in convivium. Dr. Bill Thomas explains convivium in his book *What are Old People For?* :

> The Romans had a special term for the particular pleasure that accompanies the sharing of good food with people we know well.   They call this experience convivium. The word has enjoyed a revival recently. The "slow food" (an alternative to fast food) movement has seized on the word as a way of describing dining experiences that are rich in meaning. 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. The shabazim foster a convivium that enriches the lives of elder and shabaz alike (2004, p. 265).

Wellness, Well-being
Beautiful terms such as wellness and well-being have come about within the culture change movement. The Free Online Dictionary defines wellness as the *condition of good physical and mental health, especially when maintained by proper diet, exercise and habits* and defines well-being as *a contented state of being happy and healthy and prosperous.*
Can one have wellness and well-being in a nursing home, as an older person? Action Pact has developed a particular approach to the concept of wellness and says

> Unfortunately, in our society, the focus of the health care system is on illness and for many wellness is no more than a lack of sickness. This doesn't sufficiently address our needs as human beings - least of all those (like the elderly) who would be classified indefinitely as "unwell." All people have the ability to continually improve upon their quality of life - *regardless of health related issues.* The frail, chronically ill and elderly all retain the capacity to grow and better their existence, as well as the basic human need to continue their pursuit of living life to the fullest (Blacklock, 2010).

The regenerative community model developed by Barry and Debby Barkan also gives credence to this notion of focusing on wellness and what works. Dr. Carol Hutner Winograd (Barkan, undated) studied the regenerative community for a Robert Wood Johnson Foundation Clinical Fellowship and noted:

> The most striking aspect of the regenerative community model is that it relates to all the residents as true people. One of the first things I noticed in the mid-1970's in the original Live Oak Project was the vastly different focus of the regenerative community model and the medical model. The medical model focuses on what people can't do. The regenerative community model works hard to identify the kernel of function and to concentrate on it so that it can grow and expand. If a person is 97 percent dysfunctional, the focus shifts to the three percent that's well. This is the essence of the Live Oak Culture. At the daily Live Oak community meeting, we focused and acknowledged each person's contribution without judgment. We worked hard to accept each person as she shared herself. Every

contribution was seen as an opportunity to build a bridge to the person and to involve her in the life of the community.

I remember one woman who every time the city of Berkley was mentioned, would announce to the group, 'I used to live in Berkeley.' Apparently, that was all she could say. Instead of seeing this as a disruption, you went out of your way to mention Berkeley in the community meeting. When she would respond to her cue, you would point out to everyone in the group that this is Mrs. Gold and she used to live in Berkeley. You would seek to involve her in the community discussion.

The point is that the woman's reference to living in Berkeley was the one way that she could connect the group and to something meaningful beyond herself. By constantly making reference to this connection, the community developer was able to keep this connection alive. It enabled her true self to be manifest and to thrive. Over time the woman was able to speak a little bit about who she lived with in Berkeley and to describe where she lived. She also looked forward to the daily community meetings and became an eager participant. It was by no means a major recovery of cognition. But it was an expansion of function (Barkan, undated).

Expansion of function seems to fit both wellness and well-being and what CMS means by highest practicable level of well-being.

Highest Practicable Level of Well-being

In many requirements and at Tag F279 in particular, CMS brings the language of well-being into the discussion with a twist: *Each resident must receive and the facility must provide the necessary care and services to attain or maintain the highest practicable physical, mental, and psychosocial well-being*.

In the CMS satellite broadcast series "From Institutional to Individualized Care" Barbara Frank a developer of the Nursing Home Reform Act of OBRA '87 explained, "The authors of OBRA specifically chose practicable instead of practical. Practicable refers to what someone is innately capable of, regardless of external circumstances; practical refers to the limits of those external circumstances." The word and concept of highest practicable was chosen over

> Practicable: Innate capability – based solely on the individual's abilities, limitations, and potential – independent of external limitations.
>
> Practical: Capability based on resources available to support a person's abilities and potential, and address their limitations

twenty years ago. The culture change practices of honoring the person, offering individualized care to make self-directed living possible, and community life all assist a person to meet their highest practicable level of well-being in each of the areas physical, mental and psychosocial. "Highest practicable" is more than a term. It is a beautiful concept that remains to be fulfilled in the lives of most people living in nursing homes across our country.

Change –Growth - Transformation

Dr. Power (2010) teaches that "the term culture change is often misunderstood" and that "unfortunately the words culture and change can be problematic." Culture change is sometimes misunderstood to mean changing a person's personal or ethnic culture, this is certainly not the case nor even possible. Change is also often misunderstood as Dr. Power points out. People ask "is change being done by me or to me?" and he says "that a better word than change for what we wish to accomplish is growth…. You can change without growing, but you cannot grow without changing. When we refuse to change, we cease to grow" (p. 19). Advocates of culture change would also just remind all of us that the term culture change is very important in that it refers to the institutional culture that must be changed. If true home is our goal, institutional culture has no place there. Look at how Dr. Power shows that the term institution is not only a term, "…the word institution means much more than a building" and that even "care in one's own home can be just as institutional as in a nursing home" (p. 17). Some communities have latched on to the term transformation as well which brings with it positive connotations of beautiful changes such as when a caterpillar becomes a butterfly. The original Colorado Culture Change Coalition's logo is the transformation of the caterpillar to the butterfly.

Metaphors and Experience: Words into Action

Judah Ronch and Galina Madjaroff

Some metaphors:

- Time is money
- "Juliet is the sun" (Shakespeare, *Romeo and Juliet*)
- That was a bright idea

In Aristotle's words, metaphor is "giving the thing a name that belongs to something else" (Geary, 2011; p.8), and in so doing helps us understand it better. Metaphors are everywhere in language, say the eminent linguists George Lakoff and Mark Johnson. Metaphors improve comprehension of the less familiar experiences in life. "The essence of metaphor is understanding and experiencing one kind of thing in terms of another" (Lakoff and Johnson, 1980; p.5). We employ metaphors to provide partial understanding of a less familiar experience by using words that describe another, more familiar experience. For example, how much easier it is to say "My love is a red, red rose" (Robert Burns) when finding just the right words to describe how you love someone can be so difficult, or when we describe angry people as "hot blooded" or something we like as "cool."

A crucial question is whether changing the metaphors we use changes the culture? What is at the root of a practice where a person is given a name that belongs to an object (i.e. feeder) or an adult is spoken to as if he/she has the comprehension of a child (i.e. talking in institution-speak or baby talk)? We suggest that for a myriad of reasons, it has become acceptable to refer to older persons who are dependent, suffering from many physical and cognitive challenges, with ageist terminology, perhaps in order to protect our own emotions from what we see and fear about our own old age. Alex Comfort calls this "gerontophobia" in his book *A Good Age* (1981).

Language structures our experience and tells us what is important enough in the culture to have a name (Postman, 1993; p.123). Names take on a value. When new things are invented, we have to coin new words or phrases so we can talk about them, and these names take on social value. For example, all known languages have a word for mother and father, but not all have a word that is used to designate the parents of your child's spouse. In the latter case, that relationship is not important enough in all cultures to require a word describing the relationship. On the other hand, mother and father are important concepts everywhere.

Traditional nursing home cultures use language that is rife with ageist metaphors, as can be seen in the many examples Carmen and we provide. In fact, the whole chapter, The Status of Language in Long Term Care, provides many unfortunate examples. They function as powerful examples of how meaning is made and how these metaphors represent the

shared social realties among speakers in these environments. But the most power that metaphors have, say Lakoff and Johnson who wrote *Metaphors We Live By* (1980), may be their role in not just what we say but *in what we may do* (emphasis added). A metaphor, they write, "may be a guide for future action…which will fit the metaphor. This will in turn reinforce the power of the metaphor to make experience coherent. In this sense metaphors can be self-fulfilling prophecies" (p.156). If we accept the metaphor in our daily language of work, we provide, perhaps without knowing it, evidence for the ageist inferences that they carry to be seen as true, that is, *reality* (Lakoff and Johnson, 1980). This is how powerful the assumptions of metaphors are - that one thing can be described in terms of a specific other thing. (The preceding sentence contains a metaphor. Can you spot it? We say that metaphors have powerful assumptions, so we are describing them in terms used for people, who actually have assumptions and power.) If we see someone as a feeder, our future actions will be guided by this metaphor. For example, when Mary is listed on a task sheet as one of the feeders, it is as if she were an intake machine, not a person enjoying a meal. Think about the table of three elders we described earlier being fed without being looked at. Metaphors <u>are</u> primes, writes Greary (2011), and, he continues, names (ageist terms) are metaphors that prime us to respond in certain ways.

So let's go back to what we said about priming and stereotype threat to see how they work in the metaphors of ageist language; how priming conveys lowered expectations that may harm a person's self-concept. When elders hear ageist terms (i.e. feeder or sweetie) or the use of institution-speak, as in "we let our residents," "she is so cute", etc., the "prime" is that elders are expected to demonstrate certain behaviors expected of all members of the category in the upcoming interaction. The metaphor is: *old=child,* because old people are in their second childhood; or are here because they are totally helpless in anything that matters, so the metaphor is: *old=helpless like a* baby. The stereotype threat is triggered when such language is used. If asked a question such as "Are we ready for our bath?," the older person may multi-task to process what the appropriate response to the specific question would be while at the same time dealing with the anxiety and other discomfort that arises when infantilized and his/her self-esteem is damaged. This makes it harder for the person to answer as rapidly as he/she might be capable of doing, and so acts in a way that confirms the stereotyped view that he/she is mentally limited like a demented old person or infant. Put another way, how does it feel to be the female student who is told before a science test, "Try to do the best you can. Girls don't usually do well on these tests."

Language and what matters at work

Anthropologist Nancy Foner wrote about her experience working in a nursing home in her book *The Caregiving Dilemma* (1994). She drew attention to the prevalence of bureaucracy and striving for professionalism that characterizes so much of modern health care culture. Foner observed that by adopting the principles of scientific management (Taylor, 1911) developed for industrial production as the paragon of management excellence in health care and aging services, we became immersed in a culture based on distorting the tradition of the scientific method. So we lost sight of the person and their experience in the drive for efficiency and standardization.

The emphasis of the scientific method on professional rigor, observable and measurable outcomes and objectivity was an important breakthrough in our thinking about natural phenomena in the world around us that led to many scientific achievements. But the essential philosophy of nursing home culture, an emphasis on objective findings and scientific management geared to maximizing the efficiency of workers time and motion, devalues the importance of the personal and emotional work involved in care. When you work on an assembly line making cars or computers for example, your feelings about the product are not important. What is important is how productive you are and the quality of the product.

Caring for elders involves personal and emotional reactions to work that determine the quality of the relationship and the experience. In a cultural tradition of scientific management where efficient production is the focus, the language elements that carry personal/emotional meanings (vocabulary, intonation, physical positioning, gesture and eye contact, for example) are seen as reflecting dimensions of inefficiency that reduce productivity. In nursing homes, language that carries personal and emotional meaning has been replaced by language that speaks of efficiency, productivity and output. These last three dimensions are the primary measures of a nursing home's business efficiency, says Timothy Diamond in his book *Making Grey Gold* because they provide documentation that substantiates reimbursement (Diamond, 1992). Carmen quotes Dr. Al Power on this subject in her discussion (above) of medicalized diets.

This tradition of documenting using measureable, precise quantified methods for readily measured biological areas of life (i.e. bowel and bladder output, pain intensity, medication records, treatment records, meal intake records) has made the language of work in the nursing home emphasize the information communicated through the vocabulary of science and technology, and confers its high status on those who master the scientific language, such as the doctors and nurses.

So while the degree of pain a person reports is documented on a pain scale and made part of the "official record," how the person feels about what the pain is doing to his/her quality of life is not. The person may go to physical therapy or a group activity and attendance or participation is documented, but whether the person enjoyed it, is not.

The late culture critic, communication theorist and scholar Neal Postman (1993) observed that "social institutions sometimes do their work....principally by directing how much weight and therefore, how much value one must give to information" (p.73). We see this in nursing home culture by analyzing the kinds of words we write down for the record (in the resident chart) and how much work goes into teaching employees how to use the most efficient language for documentation purposes (Diamond, 1992). Albert Einstein said that "Not everything that can be counted counts and not everything that counts can be counted", a cultural tradition Postman termed "scientism." Unfortunately, that delusion is perpetuated by how much more weight is given to documenting tasks and processes (quality of care) than is devoted to the value and impact of people's experience (quality of life) in the words we use to communicate everyday information (Postman, 1993) in medical model nursing homes.

Dr. Rosalie Kane has proposed quality-of-life domains that should be included in any assessment of how good a nursing home's care is. Adding these domains would begin the process of establishing a comprehensive assessment of quality of life/quality of care as a holistic portfolio of outcome measures that are appropriately both objective and subjective. These domains are: security, comfort, meaningful activity, relationships, enjoyment, dignity, autonomy, privacy, individuality, spiritual well-being and functional competence. Kane says that these domains are "given credence only after health and safety outcomes are considered" (Kane, 2001; p.293), a reality that reflects the biases we have discussed in the preceding pages.

These domains have established their "scientific" value since they are amenable to valid and reliable measurement and so merit more extensive development. Some may serve as the foundation of how subjective experiences in nursing homes can be documented. Research studies (Noelker and Harel, 2001; Lawton, 1991; Rabins, et. al, 2000), among others) have for years employed quality of life measures in their outcome research. These need to be further developed so that they can become part of the standard measurement of the nature of the experience of living in a nursing home.

Normal everyday experiences can add to a person's quality of life, but don't need to be recast as "scientific" to have extraordinary value. Putting the label "therapy" on normal activity has become a tradition in nursing homes and other health care settings in order to establish the "professionalism" of those who do it. This is a case of "scientism" (Postman, 1993), a social trend toward elevating status of an action by medicalizing it. People do things that are "therapeutic" all the time without therapists around because we feel better when we do them. When you go for a walk, for example, is that physical therapy or just exercise? Doing something you enjoy should not take on a stigma of having something wrong with you and that's why you do it. How about going to the store as "retail therapy"?

Language as Behavior: How Words Shape Our Reality

The medical model bias that makes what you have more important than who you are and how you feel is reflected in the way we document for dollars or reimbursement (Diamond, 1992). This supports the tendency to identify people by their conditions instead of their names. The diagnosis becomes the most important fact in a person's story. Jerome Bruner, the psychologist and professor at Harvard and Oxford wrote a wise and wonderful book about how identity is made, called *Making Stories: Law, literature, life* (2002). In it he relates the negative results of medical training that led doctors to "stick to the facts" (p.105); objective results only (blood tests, temperature, heart rate) when treating their patients' conditions. The result was that many patients had bad outcomes and experienced suffering and even death "because," he wrote, "they (the doctors) didn't listen to what the patients told them, to the patients' stories" (p.105) and patients gave up hope. The patients' conditions were not completely communicated by the facts. What was missing was *how they felt* about their conditions and how that was affecting their recovery.

An illness is more than its facts. An illness becomes part of a story (Nuland, 2009) because people don't experience illnesses passively. The famous neurologist Dr. Oliver Sacks wrote that "an illness is never a mere loss or excess - there is always a reaction on the part of the affected organism or individual to preserve, to replace, to compensate for and to preserve its identity, no matter how strange the means" (Sacks, 1984; p.4). In other words, good medical care requires the practitioner to know how the illness impacts the person's story to fully understand the clinical presentation.

In her book *How doctors think* (2006), Dr. Kathryn Montgomery, Professor of Medical Humanities and Bioethics and of Medicine at the Northwestern University Feinberg School of Medicine describes medicine as the clinical practice of synthesizing scientific skills and knowledge with subjective skills like intuition (or the art of medicine). Clinical practice, she says, is an interpretive exercise that relies on both in order to obtain the full picture, and though the subjective part appears to be less scientific it is equally important. The narrative, subjective information interprets what the illness or condition mean to the person, and it is the person who is the physician's ultimate concern.

We want to be clear that we are not pointing an accusing finger at physicians. Rather, we are shedding light on the origins and cultural legacy of the medical model in nursing homes that has come to champion the objective, scientific information and its language while subordinating or ignoring the subjective language of the patient's experience (see the discussion of the language of documentation, above). In the medical model nursing home, the scientific aspect of a person's illness or condition has become the largest part of conversations with and about him/her and occupies most of the medical chart. Subjective emotional states, for which there are no formal diagnoses, scientific scales or other measures, such as loneliness, community, joy, fear, engagement, boredom, self-esteem, contentment and depersonalization, are not part of "the record" or the conversation.

In his analysis of identity, Bruner (2002) says that people's lives are actively woven into a multi-threaded story, called a life narrative; the basis of a person's identity. It is this story that each person encodes and remembers about the events of his/her life. It is, he says, the

core activity in the act of "self-making" that establishes each of us as a unique individual (p.66). An individual's narrative contains threads, or sub-stories, that hold the personal narrative (who we are), the social narrative (how we are viewed by society), and when we have a disease or health problem, the illness narrative. These narratives become dominant or most important in particular circumstances but are not relevant in others. They can, however, be elevated in importance by cultural practices in certain settings (Morris, 2000). When a person's age, condition or diagnosis replaces her name as the way she is known, language communicates that the personal narrative is less important than the social narrative- their aging (Grimm, 2003). The illness narrative, the conditions or diseases a person has, can likewise be put into the dominant position in the overall story. Then what a person has, or how long he has lived, becomes more important in relating to them than the total story of their lives. When this is seen as normal talk for a particular environment, the words are not a mere slip of the tongue but more likely portray a deeper cultural reality of how people are seen. Words make worlds, and even change identities.

Illness can overtake a personal narrative of an elder. When the writer Anatole Broyard was dying of cancer he wrote about how he decided to have control at that difficult time in his life by not letting the cancer be all that his life was about. He said that there is therapeutic value in claiming back one's identity as a way of making the illness "less toxic" (Broyard, 1992), that is less poisonous, in creating meaning out of the experience in one's life by integrating it into his overall life narrative. The act of someone substituting your diagnosis for your name, while something that medical practitioners might do, seems on closer examination to be counter-productive. That is, reducing your identity to the sum total of your diagnoses and the objective data of test results while not considering how you are reacting to the condition may do more harm than good. As Bruner described (above), when physicians did not attend to the patient's experience of the illness, unanticipated patients' suffering and death occurred.

The practice of referring and relating to an elder, or anyone else for that matter, by his diagnosis or condition (such as "Ruth is a schizophrenic/a diabetic/a feeder") illustrates how in common language we substitute one aspect of that person for how we see them as a whole. The illness thread of the life narrative (a part) becomes the whole and replaces the ongoing life narrative. The "person" goes from first to last. When someone is called a "feeder," naming/labeling him or her that way indicates that all that the person is can be reduced to how they take in food. Who the person really is becomes invisible by using that language. The illness or condition he/she has is made prominent.

A similar thing happens when the person's age (the social narrative) becomes the primary focus of social interactions with him, as when elders are called Pops or Granny instead of their correct name (personal narrative). Person-first language always preserves who the person is at the center of what they mean to us, and therefore how we will engage them in a relationship where we present ourselves as a source of assistance. Person first language confirms to people that we are joining in their life stories.

Using institution-speak signals that the speaker does not see the listener as a "whole" adult and reflects the speaker's idea that the illness or social narrative, and its associated stereotypes, have become the primary factor in how he/she views the person.

There are markers of institution-speak:

- using infantilizing speech,
- "dumbing down" sentences by eliminating some of the words that in normal speech would be part of a complete sentence. This is also called telegraphic speech, which is similar to how people text.
- speaking in sing-song cadence and pitch (Williams, et. al., 2010; Brown and Draper, 2003).

Researchers have investigated the everyday use of what we are referring to as institution-speak and have found that components of speech such as intonation, voice pitch and vocabulary can have a profound effect on elders' self-esteem and relationships with staff. This is an important finding that points to how language has psychological effects on listeners. For example, Brown and Draper (2002) found that "over-accommodation" by health workers, that is addressing older people in a simplified vocabulary with high pitch and slower speech, was generally found by older people in their sample to be "unwelcome, condescending, offensive, disempowering and demoralizing" (p.19). They propose that the implications of such speech on the well-being of older people "may include fostered dependence, lowered self-esteem, avoidance of speech situations and the gradual acceptance of impolite speech" (p.20). Brown and Draper asked the same question we have asked in this paper: What makes people talk this way? What motivates them? They conclude that what they call over-accommodative speech is largely non-malicious; that the negative consequences are unintended, and that the speakers are unaware of the harmful potential of such speech. We would add that these findings support the observation that we made earlier that stereotype threat and priming appear to have negative consequences for their recipients.

Kenwright (1998) looked at the same question of motivation, and concluded that condescending language toward older persons living in institutions is the result of conflict that comes from playing two clashing roles, namely trying "to reconcile the caring approach that nurses are expected to have, while actually operating in a controlling manner and adopting the role of parent" (p.28). These results agree with those of Kemper and Harden (1999) who also found that such language was associated with less effective communication and failure to demonstrate an attitude of caring. These results are examples of how speech illustrates cultural values in an institution.

One of the most frequently cited staff behaviors that demonstrate institution-speak is the use of the tag or pseudo-question such as "It's time for your bath now, OK?" (Parents often use this pattern with children where the child is to think that he has been consulted in the matter and is supposed to agree, thus producing a pseudo-mutual decision. If the child refuses, will that be accepted?) The intonation of this phrasing in addressing the person indicates that there is really not a question that is to be answered, and that the answer is a foregone conclusion. The correct response is to agree. In spoken English, we signal that we are asking a question by using a rising intonation. In the pseudo-question, the first element

has the intonation of a statement, rising then falling. The second part is, in our view, a pseudo-question that is meant to give the impression that the elder has an equal part in decision making. What if the elder says "No"? Who decides then? This infantilizing pattern is a mixed message that at some level of awareness is likely to trigger stereotype threat in the elder.

Places, spaces and the language of relationships

Judah Ronch and Galina Madjaroff

We have discussed how language can alter expectations. But is it possible that words can actually change our beliefs about our abilities and improve our performance on certain tasks and thus help us counteract physiological limits? In a series of studies, Professor Ellen Langer of Harvard University and colleagues (Langer, et.al., 2010) found that in a sample of college students, visual acuity and athleticism were limited by mind sets that were created by reading priming material. These findings lent support to earlier studies by Langer (1989, 2009) with older men who were primed by living in a physical environment that replicated the interior design cues of twenty years earlier. The men "looked younger and exhibited increased hand strength, joint flexibility and visual performance" (Langer, et. al., 2010; p.5).

These results have important implications not only for what is communicated through speech or verbal language, but what the "language" of the physical environments where elders live communicate to those who live and work there. As Langer's study found (2010), physical space can serve a priming function, just like words do. Louise Revelli and Maree Stenglin, authors of *Feeling space: Interpersonal communication and spatial semiotics* in *The APA Handbook of interpersonal communication,* (2010) explain the ways that the built environment communicates messages about how people will feel about themselves and others in interpersonal relationships. Buildings, like words, "make us *feel*; they may seem inviting or intimidating; they may make us feel comfortable or uncomfortable; as if we belong or are intruding." (Revelli and Stenglin, 2010; p.77). For example, people usually feel differently in vast open spaces, in a cathedral, museum, or palace, and have a different group of feelings in their former primary school, childhood home or living room. Each is designed to evoke a different emotion, and therefore have different emotional meanings as far as intimacy and distance are concerned. The physical environment "speaks" to us through the visual metaphor they present.

We discussed above that language has multiple ways of communicating power and degree of involvement among its users, specifically by how it conveys the relative equality, detachment and social control between speakers. Buildings do this as well, and by their design create opportunities for interactions that may equalize or skew power among conversants. Building design can influence language by how its spaces and access to various locations determine who may speak to whom, when and where, simply by what it takes to gain access to spaces, and by whether spaces are designed to be public or private (for example, if an office door has the word "private" on it we understand that the message is we are not to enter). Spaces in building or public places evoke behavior that has been learned by members of the culture, and violations of the rules of decorum are very evident, as when someone has a private conversation on their cell phone in an elevator in a loud voice or questions a nursing home resident whether they are incontinent in a nursing home lobby. We get too much information and may feel uncomfortable with the sudden familiarity with a complete stranger's life.

In traditional nursing homes, the design of the nurses' station, break room, dining room, lobby, conference room, and residents' rooms all have influence on communication and language because their designs signal who will speak there, what kinds of language to be used in them should be, when it is appropriate to talk in them, and by whom. Therefore, one significant way to change language in nursing homes is to redesign spaces so that elders have more opportunities to converse in private in more places with people of their choosing – friends, family and staff, or to be alone if they wish.

Think about the kinds of interactions and language that take place in large spaces vs. in small, intimate ones. Large spaces don't typically promote intimate conversations where people take turns talking in a relatively equal relationship. Large, indoor spaces are usually places where one person or group actively "communicates" and others, the "audience," listens and responds at certain predictable, well-known, socially sanctioned points. As examples, audience responses during pauses or at exceptional displays of talent with a standing ovation at the end of a musical performance or "Amen" in a sermon. The audience is expected to remain essentially non-verbal and silent, except for these culturally congruent times or when at large team sports events, where cheering and other responses are allowed.

Contrast these with the experience of communication in a small, intimate space, where communication is more or less reciprocal, people take turns and silence is a signal for the other party to speak. Silence, alternatively, may also be seen as a communicating displeasure, disengagement, or rudeness, unless two people agree that one is allowed a monologue. The personal narrative of vitality and intimacy is written by action and reaction in rapid succession. Long corridors, dining in groups of 40, no private space except for one's half of a shared room, all reinforce the metaphor created by the large building design, best characterized by the observation that "In a palace there is no place for intimacy" (Stilgoe, 1994). Intimate conversation, informal speech, require private places as a signal that they welcome and are normative in the culture.

The Language of Time
On the 2006 CMS satellite broadcast about CMS's new Psychosocial Severity Outcome Guide, Ronch points out that how we respect residents' time is actually a form of language. We may see a lot of helplessness that looks normal, but applying "the reasonable person concept" makes us ask these questions:

> If I were sitting there would that be what I want? Content to wait to eat, wait to use the bathroom, wait for something to do? Would I as a reasonable person be upset when my needs are thwarted like that?

Just being quiet, cooperative and compliant with care doesn't necessarily mean a positive adjustment. Learned dependency can lead to depression and is entirely preventable and reversible.

This raises a great point about the language of time. As Wendy Lustbader so beautifully writes, having to wait for everything communicates volumes about social status and power.

She quotes a woman in her eighties who was confined by illness as saying that "Ageing was a desert of time" with little to do (1991; p.2). If all one has to do is wait for help, writes Lustbader, the "inferior status of the person who is being helped" is emphasized (p. 7).

The linguist Edward S. Hall wrote a book called The Silent Language (1959), which begins:

> Time talks. It speaks more plainly than words. Because it is manipulated less consciously, it is subject to less distortion than spoken language. It can shout the truth where words lie (Hall, 1959; p.1).

Hall says that time is handled like a material; "we earn it, spend it, save it, waste it" (Hall, 1959; p.7). So time is another metaphor we use in our language (time=material), and as Lustbader tells us, it is a metaphor with powerful connotations. In our culture, it communicates low status simply by how long a person is kept waiting. We may know how this feels in our culture when we are kept waiting in a doctor's office, in the hospital emergency room, or when we are in line to get a new driver's license. Conversely, those with high status are expedited, such as frequent travelers directed to faster security lanes at the airport. In our culture there are messages that we perceive through informal rules such as when it is acceptable to be "fashionably late" to a party or that it is not good form to show up too early to someone's home.

Does the "silent language" of time in nursing homes "shout the truth" about what we really think of people?

What People are saying about Language

Carmen Bowman

"The words we choose communicate powerful messages that can potentially 'poison' other interactions," says Dr. Power (2010). As identified above, "the word *refused* implies difficult, disagreeable, combative, troublemaker" and Dr. Power cautions, "Note how the simple word refused has poisoned the attitude of all who will be approaching …" that person (p. 84).

From Creating a New Language for the Eden Alternative Journey,

> Words make worlds… The language we use to describe who we are and what we do in an Eldercare organization defines what the environment will be like. The history of long-term care is based on institutional language that diminishes the role of some and elevates the role of others. The language itself contributes to the hierarchical decision-making that creates a routine-driven daily schedule that drains the spirit of those who live and work there.

> Dr. William Thomas would say that our language is dragon food. It feeds the ever present dragon that is waiting to re-establish the status quo of the institutional model of care and destroy all efforts to change the culture and improve the well-being of all (Creating a New Vocabulary for the Eden Alternative, updated 2012).

Karen Schoeneman wrote an article for *Provider* magazine January 2003 called *Rewriting the Book on 'Institution-Speak'* bringing attention to what the words we use do to people. In it she encourages us by saying, "I really believe the words we use must change if we wish to change nursing homes for the better. Words that make people who live in nursing homes passive recipients of care that is provided by and designed by others have to go."

Piggy-backing on what Karen has taught me all these years, I've learned that, "Just by conscientiously using dignified language, we begin to raise standards. By paying attention to the language and terms we use, we set the stage for treating people in a more dignified manner as well. Language takes place first, then change follows" (Bowman, Quality of Life, 2003).

Back in 1987 I had the privilege to work with Susan Kratzke of the then Lutheran Health Services which had a few things figured out. Way back then here is what I learned from their July 1987 Visions newsletter for LHHS Aging Services employees. "Language is a powerful tool. A word can carry with it many meanings and attitudes" and advocated for "language changes that remind us that our facilities are homes, our residents are adults, and that aging is a process, not an illness."

"Words are important. Language is not just a medium, like a water pipe, it is a reflection of how we think" (Rybczynski, 1986.) And how we think, how we care for and love people who live in nursing homes whether old or young, is not truly being reflected in our common institution-speak language and *we get* to change all that.

It has been widely said that whatever many may say about the future,
it is ours – not only that it may happen to us, but it is in part made by us.
Dr. Ethel Percy Andrus, Social Activist, 1884-1967

Learning from those who have Changed Language

Carmen Bowman

So how do you change language? At a workshop I gave once on culture change someone said to me, "New language is awkward and you have to push through the awkwardness in order to create a new norm." Great advice. What follows are ideas on how to create new beautiful language.

Lutheran Senior Services in Missouri thought about a different word each week. Leader Joan Devine sent out an email each week in 2008 with words to ponder. All were invited to react to the word and then they, as a community, decided on "out with the old" old words they tossed and "in with the new" new words they embraced. This team did such dedicated work it ended up in a dictionary they call Word of the Week, which can be purchased at www.lssliving.org. Whether you purchase this resource or not, the act of reviewing and contemplating "old" or "common" language compared to "new" or more "person honoring" language is worth considering. They also include a CD with a template for your community to go through the healthy struggle and thinking through the meaning of words as they did.

The Institute for Caregiver Education laminated business card size cards for staff team members to keep with them entitled Language and Labels that carried the following message:

> Language is the key to the soul. Because of this, it is important to choose our words carefully. To help transform our "facility" into a true community, try using the following:
> * Use "Home" or "Community" instead of facility.
> * Address and refer to people by name, not diagnosis or job function.
> * Avoid excessive medical terminology when talking to residents or co-workers without a clinical background.
> * Don't just bark orders. Try to explain the why's of what you are asking for.

Think "Equalize Everyone. "Culture change leader and social worker Christine Krugh and I developed a concept called *SOFTEN the Assessment Process*, a workbook and training DVD. Using SOFTEN as a mnemonic device we came up with these ideas for softening yet another very institutionalized process, the assessment process which includes residents being bombarded with many of the same questions by different professionals, intimate questions upon just meeting a person, and little if any choice in "getting assessed:"

> S – Support Simple Pleasures
> O – Offer Options
> F – Foster Friendships
> T – Tie-in to Tasks
> E – Equalize Everyone
> N – Normalize Now.

We've had great interest in this "SOFTEN" thinking, with packed workshops and interested in making change professionals. Pertinent to this discussion is the notion of "equalizing everyone." Here is what we said about it and language:

> Consider all language and titles and labels used to equalize. What are equalizing words? Consider changing your vocabulary to words that promote equalizing: new admit or new neighbor?, fractured hip or patient or resident or client or person or Janet Marie Smith (the person's name)? Which best honor the person? (undated, p.15).

So what do we want with the change of language? What does a change of culture look like? Terms Dr. Al Power uses are: a more humane, relationship-rich approach (2010, p. 2) where well-being and personhood are well tended to, an "experiential approach" instead of the traditional biomedical approach where "we reduce the person to a series of discrete cognitive tasks that can or cannot be performed (p. 13)." This is akin to what I call "reducing people to beds" when we say "this is a 120 bed facility" or refer to census instead of the people who live there.

Eden Alternative board member Sarah Rowan tells the story of her husband Joseph who lived with Alzheimer's disease. She tells of a picnic they once had where Joseph dug up a little sapling and presented it to her as a gift, to which she responded:

> "Oh Joseph what makes you the miracle you are?" He looked at me and said back to me, "What makes you the miracle you are?"

> I thought about how it felt hearing my own words repeated back, and I thought, "If every word I spoke were echoed back to me, would I feel celebrated, or just tolerated?"

> ...Words can be a tool of torture or an instrument of inspiration. The words we choose can determine if a situation will be escalated or de-escalated and if a person will be humanized or de-humanized.

Sarah exudes love and inspires me personally to think about what if my words were whispered back to me. In fact, love is not mentioned much in our work. Oddly enough the person I hear talk more than anyone about love is Steve Shields, former oil man, former CEO of Meadowlark Hills and now with Action Pact working with owners and developers sitting at a lot of board room tables and not afraid to bring up love. It's the truth that we're really in the business of loving people but we rarely admit it. LaVrene Norton and I mention it in our book *Vibrant Living* (Norton and Bowman, 2011):

> Love is not often talked about in the world of nursing home care. It is a business and is treated as such. However, it is a business of caring for people. Thus, love comes into the picture. Love between people happens naturally. It is easy to come to love a person you care for, just as it is easy to love a person who cares for you. So, let's not ignore love, let's embrace it (p. 31).

Remember the Generations of Hope Community we mentioned earlier? As they serve the three vulnerable populations of foster children, foster families and retired seniors, their intentional use of inclusive, non-stigmatizing language has resulted in the elimination of hurtful labels and instead created new scripts and stories that affirm the normality of all community members and community life. What a beautiful picture of how it can be done.

Here is an honest observation by an administrator of her colleague, director of nursing in a home working hard to change language. Notice that although the home is working to make language more dignified and normal, the clinical, medical terminology is what is reverted to in the clinical realm:

> (Her) … language was 100% clinical. The person's ambulation, transfer status, fall risk and more clinical language was used, rather than the language she would have used in her 'I Care Plan' and that she is attempting to get away from in managing her staff.
>
> It occurred to me that you can take the clinical out of the nurse but you can't take the nurse out of the clinical world. In communicating with medical entities outside of our building, I suspect she would feel unprofessional about referring to a person walking with help rather than ambulating with a gait belt. It must be very difficult to use one set of language in certain settings and another set in another setting. Yet, I am convinced that using clinical language is one of the ways we keep the environment clinical and it just doesn't sound like home (private email).

Leaders who have created new honoring language say it will be awkward at first. The new words do not roll off the tongue as easily; you feel awkward and it is easy to step back and use the words we have all used for decades, especially when around those who are using it "loudly" so to speak. It will take concentrated effort and time, but it's worth it. You and I have the privilege of creating a new normal.

Since we know that language has power, how else can we use it to our advantage to create more dignified places with more dignified language? Karen Schoeneman, of the CMS Division of Nursing Homes has always said, "Language drives practice." Just think how you will not only be affecting language in the home where you work, you will undoubtedly and indirectly be affecting actions and practice as well. If language drives practice, let's do some driving.

Hacking, through his research about abuse, agrees with this and writes that:

> People are affected by what we call them and, more importantly, by the available classifications within which they can describe their own actions and make their own constrained choices. People act and decide under descriptions, **and as new possibilities for description emerge, so do new kinds of action** (emphasis added) (1991, p. 253).

Eheart and Power (2009) tell us, "It often takes serious effort to change habits of speech" (p.9) so let's get on with it, let's together do the hard work of improving our language and create one that is respectful and honoring, even loving, at all times to those we serve and to one another. Let's use the power of language to create the culture we all want to live and work in.

Saying what we believe and believing what we say:

The hard work to change language

Judah Ronch and Galina Madjaroff

Languages reflect the history of the times in which they were formed. For example, there was no word for computer until technology made it a reality. For example, "homeland security" is a new coinage using existing words put together in a new and intentional way that reflect the times we are living in.

Our work is to change the values of the culture of nursing homes and the words that speak of these values, not merely to re-code speech while old values persist in the heart of the culture. We will not be able to "re-value" the nursing home (Ronch, 2003) by adding euphemisms to re-label medical model nursing homes and realistically expect that the cultures inside them will change. It will take time, a concerted effort and a sustainable plan to change each organization's culture and its language, so that in each nursing home people "say what they mean and mean what they say." Our first job is to clearly define what they <u>must</u> say, not what they may say. That will take a concerted effort to make the new language the high prestige way to speak in nursing homes that people will want to emulate. Prestige is one way a language remains resilient (Winnick, 2010). That matters because language change takes time.

That means that new language has to become a part of measuring if the organization's culture is totally aligned. Does the new language show up in individual, departmental and organizational performance metrics, and is it expressed in organizational vision, mission and values statements? Does the new language shape the organization's metaphors to create and reinforce ways of thinking about the people who live, work and visit there? A major process will involve introducing new metaphors to take the place of the old ones. We have offered some examples in this paper that provide immediate opportunity.

A critical transformation will involve re-aligning the "language of work" and "the language at work." The language of formal and intimate domains will need to be synthesized into a high prestige vocabulary used by everyone in the nursing home so that everyday talk honors elders, people served of all ages and those who work there and what they do. In addition to the medically/scientifically based, highly measurable objective information we already document, we will need a more precise language that speaks of the psychosocial quality of each person's experience. We believe that quality of life and quality of care are inseparable and that one language that has documentable concepts and terminology must convey them as a whole pointing again to individualized care just as Frank and Kinsey recommend above (see page 50).

A remarkable illustration of how conceptual images of aging rooted in popular culture effect older persons comes from the research of Becca Levy, who found that among a sample of 60-92 year olds, those who watched more television had more negative views of aging. In another study she found that elders exposed to negative images of old age performed worse on hearing tests and showed a greater cardiovascular response to stress.

These results look like priming and stereotype threat at work. She also found that deaf Americans had fewer negative stereotypes about aging than hearing Americans, and she theorizes that her results may reflect the greater intergenerational character of socialization experiences found in deaf culture (Levy, 2010). So words, the words you hear, and don't hear, apparently do matter.

We bring up this research to point out how vulnerable elders are living in nursing homes immersed in two of the experiences that characterize a culture that Levy found to be associated with negative self-image in aging – TV watching and age-segregated social groupings. Add to that, where priming and stereotype threat exist, this may be responsible for some of the excess disability we see in nursing home elders.

As we have pointed out throughout this paper, looking at our language provides an insight to our beliefs. In her examination of why people make errors called *Being Wrong,* Kathryn Schulz says that beliefs are "models of the world; they help us take action; and accordingly, they incur consequences." Our beliefs are wrapped up in our identities. Having a belief challenged is, says Schulz, "a challenge to our sense of self" (Schulz, 2010, p. 95). A successful journey for language change in nursing homes, like the rest of culture change, has to be sensitive to this idea – namely, that we are asking people to change more than what they say. We want them to change what they believe about people who live there.

We are up against some formidable obstacles because of how people think and because nursing homes as places to work have characteristics that make change especially challenging. We will talk more about how people's thinking is a challenge below. We would characterize too many nursing homes as communities where the following circumstances still exist to preserve the culture status quo (Schulz, 2010):

- Because we have little traffic from the outside world we all live in, we are exposed to disproportionate support for our own ideas of cultural normality, the "total institution" sociologist Erving Goffman wrote about in his classic *Asylums* (1959).
- The lack of coming and going of others shields us from the disagreement of outsiders, and if outsiders do disagree, we discount what they disagree about and put them onto the "problem team."
- The community mentality acts to punish disagreement from within.

This, says Schulz, creates an organizational counterpart to an individual phenomenon called <u>confirmation bias</u> (once we have formed an idea about what something might be for example an illness we look for evidence to support that idea) that bolsters the conviction that those in the culture are right and outsiders are wrong. Since communities rely on fostering shared beliefs in order to survive, those in them are overexposed to people who agree about most things and underexposed to ways of thinking that challenge prevailing ideas. In fact, we tend to hire people who share those beliefs and are likely to fire those who do not. Culture change and the needed language change we advocate, are up against these social dynamics. That means that our attempts to change language have to take into consideration that language change efforts in a nursing home are going to be seen as challenging peoples' beliefs and therefore their identities. (Dr. Al Power points this out in

Carmen's chapter when discussing reactions to the words "culture change".) We have to change minds, not just words.

A thorough discussion of the many lessons learned from the rich psychological, neuroscience and management literature about changing minds is beyond the scope of this paper, and we recommend Howard Gardner's classic book *Changing Minds* as a place to start a deeper exploration of this subject. But we can mention a few important principles to consider when strategizing how to change language (Gardner, 2004; Ronch, 2003).

- Change in any organization, especially changing language, requires leaders who want to make change happen. One of the most compelling ways to get staff to be open to changing language is through using a "compelling narrative that tells a compelling story about a new vision for change" (Gardner, p. 101). In a gathering of elders or staff, ask an elder or staff team member to share a time that using new language instead of the old language made a resident feel better, do better, or experience greater joy. Ask how the staff member felt better about their work and themselves and how this change might feel to co-workers or other elders.
- A related action is to use narrative to appeal to peoples' values, life experience and aspirations for themselves. Staff can share stories about using the new language at work and discuss how this language more truly represented how they see themselves, is truer to their own personal values, and how their experiences support their preferences for their own behavior.
- Address peoples' feelings about how words matter to them, in their lives as a way of providing them ways to use language that is more in line with how they see themselves being at their best (Ronch, 2003). Engage their empathy to help realize how the words we have described here can cause people to be uncomfortable.
- Make use of staff education to challenge "groupthink" about what is said and why. Carmen discussed "inservices," earlier in this paper. We believe that these experiences are often places where groupthink is reinforced and not where new ideas are discussed. When leading discussions like brainstorming or planning new approaches, a leader in the new culture might, to demonstrate a point, advocate for the unpopular alternative or audacious goal that seems totally removed from how things are currently done. Make sure that education sessions encourage the expressions of a wide range of alternatives, and celebrate the positive impact and contribution of people who are not afraid to go against the crowd.
- Address people's feelings about being uncomfortable. Ask a group of elders of staff about a time that the language currently used made them feel uncomfortable, and how they would like to change that.
- Prepare a comprehensive plan for culture change – and language change - that starts with your organization's narrative, the story about how it was founded and why it exists, and how changing language will get the organization's story and language aligned. Changing language and culture take time and concerted effort (Ronch, 2003), so giving people a new vocabulary list is just one part of the job. A temporary campaign to change language will be seen as a "flavor of the month" initiative and

people who are not comfortable with change or not trusting of it can wait it out until it goes away.

- Address beliefs about aging and, where needed, replace misinformation with the latest findings about how people keep developing throughout life. When beliefs change, language change is much more easily monitored in each person's head when people "hear themselves" speak. New mental maps of concepts and ideas about people drive new language adoption.
- Utilize principles of adult education that involve small group experiences, taking on practical issues, cultivating empowerment for creating change in everyone who lives and works at the nursing home, and active learning. Everyone is on the solution team.
- Create a group of leaders from the middle of the organization (in the animal world, leaders are found in the center of the herd) to be the "young" examples of the new language.
- Have "teachers" who get it and can give feedback in real time and in a respectful way. Learning new beliefs and a new way of talking takes time (unless you are a teenager!).
- Create positive expectations by celebrating peoples' successes and making new speakers feel comfortable even when they experience difficulty.
- The best way for a person to learn a new language is to speak it. Leaders need to encourage people to use the new language so that their brains make the new connections that make the words come into mind automatically –just like the old ones do now.
- Leaders and teachers need to keep reminding people that learning the new language requires three kinds of knowledge: know *that* (facts/information), know *why* (motivations and beliefs) and know *how* (the new words/concepts/language are spoken). All education needs to promote all three kinds of knowing if the new language is to take hold and become the dominant way of speaking.
- Beware of the *herd effect* in language, when people enter the organization and adopt the prevailing language to lose their newcomer status. Remember, the leaders of animal herds are usually in the middle of the group, so get these informal leaders to model what you want to hear said. Start at orientation.
- When you hear language that dishonors people in nursing homes, be on the lookout for opportunities to *reframe* someone's experience so that their beliefs – and so their language - might be changed. Reframing means to change the way we interpret or give meaning to an event, so when a person in a nursing home is called "resistant," reframe it to "making a choice" (and all the many other examples Carmen provides in her chapters). Reframing produces another way of looking at a situation and that is the beginning of changing beliefs since the new view calls into question the former belief.
- The best strategy of all to establish the new language is for as many people as possible to use the key element in language acquisition– use it, use it and then use it some more.

We are proposing that our work is about changing what people MUST say, not what they may say. This will take <u>courage,</u> not as we use it in the conventional sense to mean bravery, but as its roots in the French word *coeur,* meaning heart or heartfelt. Courageous speech, says the poet and organizational consultant David Whyte, is talking from the heart even at work "with all its terrifying fears and hierarchies of power" (Whyte, p.120). Language gives voice to our inner worlds; it must also create a beautiful world for all of us to flourish in together.

References

Adair, M., Adair, J. B., &Nygard, K. (2008). The Sage Movement: Replacing Ageism with Sageism: A call for
    Culture change. Walden, TN: Waldenhouse Publishers
    Inc.

Albert, S., Logsdon, R. (Eds). Assessing quality of life in Alzheimers disease. New York; Savinger Publishing:
    p. 51-68

Atchley, R. (2003). Why most people cope well with retirement. In Ronch, J. and Goldfield, J. (Ed). Mental
    wellness in aging: Strengths-based approaches. Baltimore: Health Professions Press. 123-138.

Baier, S. (1996). The view from Bed Number Ten. Healthcare Forum Journal , 61-67.

Barkan, B. (2002). The Way of the Champion. Pioneer Network.

Barkan B and D. (2002) The Life Oak Regenerative Community; Juicing the Process handout Pioneer
    Network conference.

Barkan, B. (undated) *The Renewal of our Culture, Dementia in Community and the Liberation of the True Self.*

Blacklock, Glenn. Action Pact's Wellness Conversations with Carmen, 7/16/10).

Bowman, C. (2006). Changing the Culture of Care Planning: a person-directed approach. Milwaukee, WI:
    Action Pact Press .

Bowman, C. (1987). Living Life to the Fullest: A Match made in OBRA. Milwaukee, WI: Action Pact Press.

Bowman, C. (2003). Qualify of Life: The Differences between Deficient Practice, Common Practice and
    Culture CHange Practice. Milwaukee, WI: Action Pact Press.

Bowman, C. (2006). Regulatory Support for Culture Change: How OBRA '87. Milwaukee, WI: Action Pact
    Press.

Bowman, C. (2008). The Environmental Side of Culture Change Movement: Identifying Barriers and
    Potential Solutions to furthering Innovation in Nursing Homes. Creating Home in the Nursing
    Home: A National Symposium on Culture Change and the Environment Requirements, (p. 14).

Bowman, C., &Krugh, C. (undated). SOFTEN the Assessment Process. Milwaukee, WI: Action Pact Press.

Bump, L. (2005).Life Happens in the Kitchen."Porch Swing Series" Culture Change Workbooks. Milwaukee, WI.

Bargh, J., Chen, M., and Burows, L. (1996). Automaticity of social behavior: Direct effects of trait construct and stereotype activation on action. Journal of Personality and Social Psychology. 71 (2): 230-244.

Brown, A. and Draper, P. (2003). Accommodative speech and terms of endearment: Elements of a language mode often experienced by older adults. Journal of Advanced Nursing. 41(1): 15-21.

Broyard, A. (1992). Intoxicated by my illness and other writings on life and death, ed. by Alexandra Broyard. New York, NY. Clarkson Potter.

Bruner, J. (2002). Making stories: Law, literature, life. New York, NY. Farrar, Straus and Giroux.

Bryden, C. (2005). *Dancing with dementia: My story of living positively with dementia.* Philadelphia: Jessica Kingsley Publishers.

Calkins, M. (2008). Envisioning your Future in a Nursing Home. Creating National Symposium on Culture Change and the Environment Requirements for Pioneer Network.

Calkins, M. (2003). More than carpets and chintz-creating a place for living. Contemporary Long Term Care.

Caporael, L. (1981). The paralanguage of caregiving: Baby talk to the institutionalized aged. Journal of Personality and Social Psychology. 40 (5): 876-884.

Clapp, W., Rubens, M., Sabharwal, J. and Gazzeley, A. (2011). Deficits in switching between functional brain networks underlies the impact of multitasking on working memory in older adults. Proceedings of the National Academy of Sciences.108 (17); 7212-7217.

Comfort, A. (1976). *A good age*. New York: Crown Publishers.

Deegan, P. (1993). Recovering our Sense of Value After Being Labeled. Journal of Psychosocial Nursing , 31 (4), 7-11.

Diamond, T (1992). Making gray gold: narratives of nursing home care. Chicago. University of Chicago Press.

Devine, J. (2009). Word of the Week. MI: Lutheran Senior Services.

Eden Alternative, *Creating a New Language for the Eden Alternative Journey* updated April 2012
http://www.edenalt.org/images/stories/path_to_mastery/PTMMi1Gap15Dictionary.pdf

Eheart, B., & Bauman, M. (2009). Creating the Everyday Magic of a GHC: Language. GHDC White Paper Generations of Hope Development Corporation, 3 , 1.

Fox, N. (2007). The Journey of a Lifetime: Leadership Pathways to Culture Change in Long-Term Care.

Foner, N. (1994). The caregiving dilemma: Work in an American nursing home. Berkeley. University of California Press.

Geary, J. (2011) I is an other: The secret life of metaphors and how it shapes the way we see the world. New York, NY. HarperCollins.

Gladwell, M. (2005). Blink: The power of thinking without thinking. New Tork., NY. Back Bay Books.

Grimm, R. (2003). Narrative therapy with older adults. In Ronch J. and Goldfield, J. (Ed). Mental wellness in aging: Strengths-based approaches. Baltimore: Health Professions Press. 237-272.

Gardner, H. (2004). Changing minds. Boston; Harvard Business School Press.

Hacking, I. (1991). The making and molding of child abuse. Critical Inquire, 17, 253-288.

Hagestad, G. (1998). Towards a Society for All Ages: New Thinking, New Language, New Conversations. Keynote Address: The United Nations.

Hall, E. (1959).The silent language. New York. Anchor Books.

Hess, T., Auman, C., Colcombe, S. J. and Rahal, T.A. (2002). The impact of stereotype threat on age differences in memory performance. Journal of Gerontology: Psychological Sciences. 58B, No. 1: P3-P11.

Karnik, N. (2001). Between victim and victimizer: The narrow corporeal path of being a foster child. Child and Youth Services Review. 743-759. Wisconsin Coalition for Person Directed Care. The Gerontologist. 41 (3); 293-304.

Kaup, M. (2005). The Impact of the Built Environment: Is it the Place or the Policy that Makes a Difference? Culture Change Now, Volume 3, Milwaukee, WI: Action Pact Press; 9.

Kemper, S. and Harden, T. (1999). Experimentally disentangling what's beneficial about elderspeak and
      what's not. Psychological Aging. 14: 656-670.

Kenwright, T. (1998). Terms of endearment. Kai Tiaki: Nursing New Zealand. December/January. 28-29.

Lakoff, G. and Johnson, M. (1980). Metaphors we live by. Chicago. University of Chicago Press.

Langer, E. (1989). Mindfulness. Reading, MA: Addison-Wesley.

Langer, E. (2009). Counterclockwise: Mindful health and the power of possibility. New York, NY.: Ballantine
      Books.

Langer, E., Djikic, M., Pirson, M., Medenci, A., and Donohue, R. (2010). Believing is seeing: Using
      mindlessness (mindfully) to improve visual acuity. Psychological Science. 21 (5). 1-6.

L'Engle, Madeleine. (1974). The Summer of the Great Grandmother. New York: The Seabury Press. 28.

Levy, B. (2002). Negative stereotypes about aging may shorten life. Personality and Social
      Psychology.August, 2002. http/www.apa.org/releases/longevity.html.

Levy, B. (2010). Talking with Becca Levy: Age stereotypes and elder health. Retrieved from Caring.com,
      12/25/10.

Lustbader, W. (1991). Counting on kindness: The dilemmas of dependency. New York: The Free Press.

Meisner, B. (2011). A meta-analysis of positive and negative age stereotype priming effects on behavior
      among older adults. The Journals of Gerontology.

Montgomery, K. (2006). How doctors think. Oxford. Oxford University Press.

Morris, D. (2000). Illness and culture in the postmodern age. Berkely. University of California Press.

Noelker, L. and Harel, Z. (2001). Humanizing long-term care: Forging a link between quality of care and
      quality of life. In Noelker, L. and Harel, Z. (Ed). Linking quality of care and quality of life. New York.

Springer. 3-26.

Nuland, S. (2009). The soul of medicine. New York, NY: Kaplan Publishing.

Norton, L. (2004). The Stages of Culture Change presentation at the Colorado Culture Change Coalition April 23, 2012.

Norton, L. (2004). Home and Homelessness presentation at the Colorado Culture Change Coalition, April 23

Maben, P. (2005). Rethinking the Nurses Station. Culture Change Now, 3, 11.

Osburn, J. (1998). An overview of Social Role Valorization Theory. The International Social Role Valorization Journal. 3 (1): 7-12.

Pioneer Network, Old and New Wordsathttp://pioneernetwork.net/CultureChange/Language/

Postman, N. (1993). Technopoly: The surrender of culture to technology. New York, NY. Vintage Books.

Powers, A. (2010). Dementia Beyond Drugs: Changing the Culture of Care. Baltimore: Health Professions Press.

Rabins, P.V., Kasper, J., Kleinman, L., Black, B., Patrick. D. (2000). Concepts and methods in the development of the ADRQL: An instrument for assessing health-related quality of life for persons with Alzheimer's disease.

Ravelli, L. and Stenglin, M. (2010). Feeling space: Interpersonal communication and spatial semiotics. In Matsumoto, D. (Ed). APA Handbook of interpersonal communication. Washington, DC. American Psychological Association. 77-110.

Ronch, J. (2003). Changing institutional culture: Can we re-value the nursing home? In Ronch, J. and Goldfield, J. (Ed). Mental wellness in aging: Strengths-based approaches. Baltimore: Health Professions Press. 161-180.

Ronch, J. (2004). Changing institutional culture: Turning adversaries into partners. In Levine, C. and Murray, T. (Ed). The cultures of caregiving. Baltimore; Johns Hopkins University Press; 155-170.

Ronch, J. and Thomas, W. (2009). Words matter. Journal on Jewish Aging. 3 (1): 1-4.

Ronch, J., & Thomas, W. (2009). Featured Point-of-View: Words Matter. Journal on Jewish Aging, 3 (1).

Ronch, J. (2003). Leading culture change in long-term care: A map for the road ahead. In Weiner, A. and Ronch, J. (Ed.) Culture change in long-term care. New York; The Haworth Press.

Rybczynski, Witold. (1986). Home: A Short History of an Idea, New York: Penguin Books, 20-21

Sacks, O. (1984).The man who mistook his wife for a hat. New York, NY: Summit Books.

Schoeneman, Karen. *May Day!* http://pioneernetwork.net/CultureChange/Language/

Schoeneman, K., (2003). Rewriting the book on "Institution Speak". Provider. Jan. 2003: 39-40.

Schwartz, B. (2004). The paradox of choice: Why less is more. New York, NY. HarperCollins.

Sharkey, S., Hudak, S., Horn, S., James, B. and Howes, J. (2010). Frontline caregiver daily practices: A comparison of traditional nursing homes and the Green House Project sites. Journal of the American Geriatrics Society.59 (1); 126-131.

Shulz, K. (2010). Being wrong. New York; Harper Collins Books.

Steele, C. (2010). Whistling Vivaldi and other clues to how stereotyping effects us. New York: W. W. Norton and Company.

Stilgoe, J. (1994). Introduction to G. Bachelard, The poetics of space. Boston: Beacon Press.

Schoeneman, K. (n.d.). May Day. Retrieved from http://pioneernetwork.net/Culturechange/language

Schoeneman, K. (2003). Rewriting the Book on Institution-Speak. Provider.

Schwarz, B. (1996). Nursing Home Design: Consequences of Employing the Medical Model. New York, NY: Garland Publishing.

Sheilds, S. (2004). Restoring "Rampant Normalcy: the Power of Small Moments. Pioneer Network.

Snow, K. (n.d.). To ensure Inclusion, Freedom and Respect for all, we must use People First Language. Retrieved from http://www.disabilityisnatural.com

Stevens, W.D., Hasher, L., Chiew, K.S. and Grady, C.L. (2008). A neural mechanism underlying memory failure in older adults. Journal of Neuroscience.Nov. 26; 28 (48). 12820-12824.

Taylor, F. W. (1911).The principles of scientific management. New York. Harper Brothers.

Taylor, J.B. (2006). My stroke of insight: A brain scientist's personal journey. New York, NY: Plume.

Thomas, W. (2009). Personal communication.

Thomas, W. 2003. *Evolution of Eden*. In A. S. Weiner and J.L. Ronch (Eds.) *Culture Change in Long Term Care*. Pp. 146-157. New York: Haworth Press.

Williams, K., Herman, R., Gajewski, B and Wilson, K. (2009). Elderspeak communication: Impact on dementia care. American Journal of Alzheimer's disease and other dementias. 24 (1): 11-20. Whyte, D. (1994). The heart aroused: Poetry and the preservation of the soul in corporate America. New York; Currency-Doubleday.

Winnick, D. (2010). Preserving and revitalizing endangered languages. Anthropology News. January. 21-22.

Wolfensberger, W. (1972). The principle of normalization in human services. Toronto: National Institute of Mental Retardation.

Wolfensberger, W. (1992). A brief introduction to Social Role Valorization as a high-order concept for structuring human services (2nd Rev. Ed.). Syracuse, NY. Training Institute for Human Service Planning: Syracuse University.

Yoon, C. (2009). Naming nature: The clash between instinct and science. New York, NY. W.W. Norton and Company.

Glossary of Terms

This Glossary of Terms is designed to show words or phrases that are part of the "old" language, and options found in cultures that are characterized by the new, person centered approach. The Glossary lists new terms that are not offered as <u>the standard</u>, but rather as examples of newer terminology that has been introduced in settings, or suggested terms to consider when looking to change language. Some of the terms we include are currently in use in some settings, perhaps yours, while in other settings; they have already been replaced by other words and/or phrases.

Languages are living things; terms come and go in response to how speakers like them, how easily they roll off the tongue, whether what they denote (actual meaning) and connote (more subtle, implied meanings) accurately reflect the values of the speakers in the culture, and the values of the organizational culture, and if they make sense to speakers. Some of the terms we suggest as alternatives can be considered "transitional terminology" (see page 11), words or phrases that are part of the journey of changing a culture but not the final word. They represent the results of awareness that language needs changing, but are not necessarily the final product. Other items are specific to a particular cultural model (e.g. Green House, Eden) and examples of what are called *linguistic markers.* These help identify with great accuracy the exact culture a speaker comes from, such as the term householders which clearly comes from the household model. The interesting thing about languages is that they grow and change naturally, sometimes despite attempts to standardize how they should be spoken. That is one of the most remarkable features of this aspect of human behavior- languages just keep developing new ways to say things.

We expect that readers will bring to mind the terms they use in their workplace that have replaced the old ones we have listed, and so encourage you to copy this list and add a blank column where you can build your own culture's glossary of terms to capture the richness of your unique language as well as to have a quick reference for newcomers to your setting. Just as human language has in recent history been so profoundly affected by the contact of people from different cultures through the use of social media, the Internet, and international travel; we anticipate that the language in our settings will change rapidly in coming years thanks to the same ways of connecting.

Older Language	**Newer Language**
"Against medical advice"	making choices, living my life, living life on my terms
"Bibs," "Clothing protectors"	bigger than a word or language issue only, a dignity issue, "Would you care for a linen napkin so you can keep your shirt clean?"
"Non-compliant"	a person making their own choices, i.e. "She chooses to not take a recommended medication and has articulated Understanding of the pros and cons."
Activities	community life, living life, engagement, a meaningful day, vibrant living, "what are you going to do today?"
Activity/recreation therapy director	community life coordinator/developer, life wellness coordinator, life enrichment coordinator, community development guide/advocate
ADLs	personal cares
Admission coordinator	move- in coordinator
Admitted, placed, put	move in, "We helped Mom move to a nursing home," a new neighbor moved in
Allow, let	encourage, welcome, offer
Alzheimer unit/dementia care/memory care	residents might select a name representative of their culture, geography or interests, such as the Aspen Neighborhood
Ambulation	walking
Assessment, assessment process	getting to know you, becoming well known, "Tell us about yourself"
Beds	refer to the people or the bedrooms
Behaviors, belligerent, difficult, problems, behavior symptoms	reactions, unmet needs, coping, behavior communication
Care plan	Life Plan, Living Plan, is it a plan? All About Me, My Care Plan, My Goals, My Day, Growth Plan
Census or occupancy	100 people live here today, 110 could live here
Charge nurse	nurse, team leader, use care partner's name
Coffee time, bedtime, "It's time to…"	"Would you care to have some coffee?"
Day/activities room	community room, family room, living room
Diaper	use the word that the person prefers
Dietary department	culinary arts, dining services

Difficult family member	a care partner who cares
Discharge, discharged	moving, moved, relocated
Elderly, senior, older adults	people
Elope/escape	left the building
Expired	died or passed away
Facility, nursing home/care center	home, community
Front line workers	direct care givers, care givers, hands-on staff/team members
High functioning or low functioning	no label, no description, none necessary
Hoarder	person's name, describe what the person does and find out why
Homelike	true home, feel at home, home
Honey, Hon, Dear	accepted words of endearment
Hydration station	snack bar, juice bar, drinking fountain
Industry	field, profession
Inservice	provide education, training, exposure, education
Interventions	what I need from you, support needed, assistance needed
Lobby, common area	living room, parlor, den
Long term care, nursing center, care center	nursing home living, long term living, supportive living, community living, continuing care community
Medical model and Social model	a person first model
Medicalized diets, liberalized diets	regular diet, regular food
Nurses' station	staff work area, desk, team area
Nursing assistants, resident assistants	companions, eldercare specialists, household/neighbor/elder assistants
Paid feeding assistants	Dining assistants, server
Patient, resident	person, neighbor, community member
Person-centered care, person-directed care	self-directed living
Pet therapy	enjoys his or her pet; fond of animals
Physician order	physician recommendation, prescription

Problems	needs, challenges, preferences
Quality of life and quality of care	individualized care
Refuse	decline, not interested, choosing to do something else
Resident claims	"Joe states/says"
Resident Council	Neighborhood Council, Home Owner's Association
Room 100, Room 302	address, person's name
Semi-private room	shared room, double room
Socially isolated, isolator, antisocial	"She prefers some private time to herself," "He says he's always been a loner"
Staff	team members, care partners, colleague, associate
The Alzheimer's patient/resident, person's name	the tube feed, the new admit
Toilet	use the bathroom
Tour	visit
Transport	assist to
Two assist	requires two helpers/assist from two people
Unacceptable, undignified terms, terms implying adults as children i.e. girls, babies, my babies	person, people, person's name
Wanderer, wandering	"that's Mary, she loves to walk, always has;" or "that's George, he is probably looking for his cows"
Ward clerk	services coordinator
Wing, unit	neighborhood unless living in a household or a house
Work the floor	assist residents, say what they do e.g. pass medications

About the Rothschild Foundation

The Hulda B. & Maurice L. Rothschild Foundation is a national philanthropy committed to bringing person-centered care to the healthcare experience of patients, residents and families. For two decades, the Rothschild Foundation has supported the work of many national organizations, in an effort to strengthen and broaden this movement. Through initiatives including support of a wide variety of advocacy media, research, competitions and convenings, the Foundation has sought to deepen available resources for those on the journey, and to break down traditional barriers between the fields of acute and chronic care.

A major strategy of the Foundation is the creation and support of a series of national task forces, which are working with the regulatory community to craft regulations and guidelines, which balance the need for safety and security with choice, dignity, and quality of life. Its commitment was recognized in 2009 by the Council on Foundations with the Critical Impact Award, given for innovative leadership and bold vision to solve societal issues and enhance the common good.

www.theRothschildFoundation.us

About the Authors

Judah L. Ronch, Ph.D.

Dr. Ronch is currently Professor of Practice and Dean of the Erickson School at The University of Maryland Baltimore County.

Prior to coming to the Erickson School, he was Vice President of Resident Life, Mental Health and Wellness for Erickson Retirement Communities, where he was responsible for developing person-centered, strengths based approaches to best serve the mental wellness needs of Erickson's over 20,000 residents on 18 campuses. Chief among his responsibilities was to develop resident services and staff education programs to optimize the mental wellness of all residents regardless of their cognitive or emotional challenges.

Prior to coming to Erickson in 2004, Dr. Ronch was the founder and Executive Director of LifeSpan DevelopMental Systems, which for over 30 years created numerous innovative programs of clinical service, research, staff development systems consultation and organizational development to meet the mental health needs of the aging in various parts of the United States. He was principal content consultant for programs developed by The Centers for Medicare and Medicaid Services and The NY State Department of Health in long term care.

He is the former Executive Director of the Brookdale Center on Aging of Hunter College, and has been on the faculties of Vassar College, The University of Miami, and Dutchess Community College.

Dr. Ronch's numerous publications include the critically acclaimed <u>Alzheimer's Disease: A practical guide for families and other helpers</u> and <u>The Counseling Sourcebook: A practical reference on contemporary issues,</u> winner of the 1995 Catholic Press Association of the United States Book Award. He is co-editor of, <u>Mental Wellness in Aging: Strength Based Approaches,</u> winner of a 2004 Mature Media Award, <u>Culture Change in Long-Term Care,</u> the first text published about culture change in aging services, and the forthcoming <u>Making the Case for Culture Change</u>. His numerous journal articles and professional presentations include contributions in psychotherapy and counseling with the aged, care of persons with Alzheimer's Disease and related disorders, caregiver issues, staff training and service delivery issues in geriatric care.

Contact information:

Judah L. Ronch, Ph.D
The Erickson School
University of Maryland Baltimore County
5523 Research Park Drive, Suite 230
Baltimore, MD 21228
ronch@umbc.edu
Phone 443-543-5647; Fax 410-543-5639

Galina Madjaroff, MA

Galina is currently the Undergraduate Program Director and Lecturer at the Erickson School at University of Maryland Baltimore County.

Galina is originally from Sofia, Bulgaria and immigrated to the United States in 1997. Prior to her employment with the Erickson School, Galina pursued her Bachelor's degree in Psychology, Biology and Creative Writing at UMBC.

Today, she is a graduate of the school's Management of Aging Services M.A. program, a lecturer and mentor to undergraduate students in the field as well as Erickson School's Undergraduate Program Director.

In addition to her passion for teaching, Galina is engaged in research to improve the lives of older adults. As part of UMBC's PhD program in Human Centered Computing she explores how technology is used in eldercare environments, and how it can have a positive impact on elders' quality of life.

Contact information:
Galina Madjaroff, MA
The Erickson School | University of Maryland Baltimore County
5523 Research Park Drive, Suite 230 | Baltimore, MD 21228
galina1@umbc.edu | P. 443-543-5648 | F. 410-543-5639

Carmen Bowman, MHS

Carmen Bowman is a consultant, trainer, author and owner of Edu-Catering: Catering Education for Compliance and Culture Change turning her former role of regulator into educator. She is a nationally-recognized expert in culture change, and is a frequently invited speaker at national long term care and culture change conferences including the Pioneer Network.

Carmen was a Colorado state surveyor for nine years, a policy analyst with CMS Central Office where she taught the national Basic Surveyor Course and was the first certified activity professional to be a surveyor also serving on the four year panel with CMS developing the new guidance to Tags 248 Activities and 249 Qualified Activity Director.

She presented the surveyor segments of the 2000 CMS satellite broadcast "Surveying the Activities Requirements in Nursing Homes" and the 2002 CMS satellite broadcast "Innovations in Quality of Life - the Pioneer Network."

As a contractor to CMS, Carmen facilitated and authored the background papers for the 2008 *Creating Home* and 2010 *Creating Home II* national symposiums and co-developed the Artifacts of Culture Change measurement tool. Working under contract with Pioneer Network she is developing a web based toolkit to go along with the Artifacts of Culture Change measurement tool with resources, regulations and results/outcomes to each of the 79 items and leading the Task Force to develop the New Dining Practice Standards.

For the American Association of Nurse Assessment Coordinators grant project on the MDS and culture change she co-authored a manual called *The Softer Side of the MDS*.

Carmen has a Master's degree in Healthcare Systems from Denver University and a Bachelor's in Social Work and German from Concordia College in Moorhead, Minnesota.

Carmen is a Certified Eden Associate and Eden Mentor, Certified Validation Worker and Group Practitioner. In 2002, she co-founded the Colorado Culture Change Coalition. With Action Pact she hosts a monthly web culture change talk show called *Conversations with Carmen* and has authored seven culture change workbooks:
- *Quality of Life: the Differences between Deficient Practice, Common Practice and Culture Change Practice;*
- *Living Life to the Fullest: A Match Made in OBRA '87*and *Meaningful Activity Assessment* combined as a kit*;*
- *Changing the Culture of Care Planning: A Person- Directed Approach;*
- *Regulatory Support for Culture Change;*
- *Lighting the Way: Building Culture Change Coalitions;*
- *SOFTEN the Assessment Process* and training DVD*;*
- *Vibrant Living: Inspirations to Energize Daily Life; and*
- *Eliminating Alarms and Reducing Falls by Engaging the Whole Person*

Contact Information:
Carmen Bowman
8209 WCR 2, Brighton, CO 80603
carmen@edu-catering.com
Phone: 303-981-7228