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March 14–16, 1997
Rochester, New York

Pioneer Network

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Final Report

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To paraphrase The Hundredth Monkey:

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Pioneer Network
(formerly The Century Circle)

MEETING OF PIONEERS IN NURSING HOME CULTURE CHANGE

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Rochester, New York

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Meeting sponsor: LIFESPAN of Greater Rochester
1900 S. Clinton Avenue
Rochester, NY 14618

Co-sponsor: National Citizen's Coalition for
Nursing Home Reform
1424 16th Street, NW, Suite 202
Washington, DC 20036

Funded by: Daisy Marquis Jones Foundation
1000 Elmwood Avenue
Rochester, NY 14620

EXECUTIVE SUMMARY

Leaders of four pioneering approaches to culture change in nursing homes met March 14-16, 1997, in Rochester, New York. The other 28 invited participants drawn from across the natio as well as the local area, were from the fields of regulation and law, nursing home administrat (administrators, directors of nursing and social workers), as well as advocates.

Pioneers subscribe to the belief that process must be consonant with goals and values. Accordingly there was diversity in many respects in the group gathered at the meeting from 8 states and the District of Columbia, with no identification on name tags of specialty or educat Consciousness of relationship to the natural world was represented in the Thanksgiving Addr given by a member of the Seneca Nation offering thanks for the earth's blessings. Communit building went on in the rituals developed out of the joy and significance of coming together. Homey surroundings were maintained as much as possible by meeting in an old Rochester ho now the Century Club. No formal papers were presented and the use of stories to illustrate salient points was encouraged.

Putting principles into practice, ancient tradition and newly-evolving rituals were integral part of the meeting, from the opening with the Thanksgiving of the Haudenosaunee to the formatic of The Century Circle at its close. Each day had its rituals from the placing of a "laurel" wrea on one member's head to honor her role in the meeting, to Sabbath Eve candle-lighting and prayers, and ending with the dancing of the hokey-pokey as participants stood in the newly formed Century Circle Saturday evening.

The goals of the meeting as set out by the funder, The Daisy Marquis Jones Foundation were:

- identification by the Pioneers of what was common among the four different approaches;
- identification of indicators of culture change;
- guidance on the research, evaluation and assessment of culture change.

The conclusions of the meeting were as follows:

I. Elements Common to the Different Pioneer Streams

A. Pioneers share a common starting point: they begin with the experience of the person who lives in the nursing home.

- To address residents' **profound feelings of disconnection**, The Regenerative Community (Barry and Debora Barkan) builds community, new connections between people and opens the way to explore meaning in life.

- To respond to residents' **loss of control** over significant aspects of their daily lives, Resident-Directed Care (Charlene Boyd and Robert Ogden) seeks to restore that control to them.

- To remove residents' **fear of often uncomfortable and unfamiliar routines** and ways of doing things, Individualized Care (Joanne Rader) is explored, developed and instituted.

- To respond to residents' **feelings of loneliness, helplessness and boredom** in a sterile social and physical environment, The Eden Alternative (Bill and Judy Thomas) restores diversity socially and biologically, bringing richness, spontaneity and greater normalcy to daily life.

B. Pioneers hold in common certain methods, practices and ideas about process by:

- projecting and recording a vision, identifying values and developing principles and practices that express the vision and the values;

- recognizing that culture change is an on-going process, a continuing process of growth, **not** a program to be installed once and for all. Culture change is not a destination but a journey. It is always **"work-in-progress."**

- practicing self-examination, probing and asking questions, always searching for how it can be done better.

C. Pioneers value and respect residents and staff by:

- seeking to respond to spirit as well as mind and body needs;
- acting on the belief that as staff are treated so will residents be treated;
- putting person before task;
- beginning decision-making with the resident;
- accepting risk-taking as a normal part of adult life;
- seeking to enjoy residents and staff as unique individuals;
- acting on the belief that each person can and should make a difference.

D. Pioneers value and promote the potential of residents and staff by:

- building teams so the talents of all staff can be utilized for the benefit of residents and for their own satisfaction;
- seeking the growth and development of residents and staff;
- promoting creativity in staff, residents and families;
- identifying strengths in staff, residents and families, and building on them;
- shaping and using the potential of the environment in all its aspects—organizational, psycho-social and physical—to embody and express values and make the most of individual growth and development.

E. Two other aspects of commonality Pioneers recognize in their work are:

- Culture change is anchored in identified values, principles, and practice (see diagram pages 9 A and B)
- Certain issues and experiences are common to the process of culture change:

Leadership: there must be a change-maker at the top, as well as some staff members throughout the organization committed to change;
Organization: culture change may bring about a different organizational chart, shifting from the familiar hierarchical organization to one that places residents in the position of prominence, with resources, especially in terms of staffing, clustered about them;
Staff development: the numerous staff antagonisms that commonly occur in nursing homes must be addressed by continuous re-education and effective empowerment of staff;
Costs: with the exception of some initial training costs, pioneer approaches call not for bigger budgets but different allocation of money maintaining the same overall expenditure;
Regulations: meeting regulations assures only a "mediocre" standard of care; pioneers move pro-actively to explain philosophy and purposes of actions responding to resident needs (see THE STORY OF OPAL), and work, if necessary, to change regulations.

II. Indicators That Culture Change Is Taking Place

The word "indicator" provides a basis for assessing change. Indicators are necessary to provide benchmarks that enable you to compare where you are now with where you were (baseline data) and where you want to be. Indicators have meaning in the context of the environment and the individual person. Culture profoundly impacts quality of life, but the two are not synonymous: culture refers to context, quality of life to aspects of life meaningful to the individual.

Indicators give evidence about practice that assists a home in discovering whether practice expresses pioneering culture change, values and principles. Thus, indicators are found in the answers to specific questions about practice in the areas of resident care, resident life, the environment, policy and organization (see pages 19-21).

III. Research, Evaluation and Assessment of Culture Change

Jeanie Kayser-Jones, nurse anthropologist, and Patrick McNees, research psychologist, described their current nursing home research projects. Kayser-Jones uses ethnographic methods and case studies, as well as quantitative analysis when that is indicated, in her study of eating in the nursing home. McNees is currently engaged in quantitative studies of resident communication and interactions with others and expects to move on to further enrichment of his data by individual case studies.

It was concluded that a combination of quantitative and qualitative research is necessary to capture the process and outcomes of culture change. Individualization in quality of life research is necessary. As individual interviews occur, new questions develop and can be pursued. Case studies and photographs further enrich research.

IV. Driving Forces For Culture Change and Possible Obstacles

Forces that are driving culture change include:

- Nursing Home Reform Law of 1987;
- Vision and leadership from an emerging group of pioneers;
- Growing consumer awareness.

Possible obstacles to culture change are:

- Societal attitudes, including fear of change, ageism and lack of community involvement;
- Staff attitudes, including resistance to sharing control, old antagonisms and the energy required to bring about change;
- Bureaucracy, including hierarchical system of decision-making, the established focus on the medical, acute hospital model, and short term cost of training;
- Education, including current education of all personnel, people's need to see the full pathway to the goal, and lack of widespread consumer education;
- Environment, including big buildings, the stifling of creativity, and the low value industry places on workers.

V. Building A Movement

The important element in the final sessions was the complete and enthusiastic consensus among all present to build a movement empowered to promote, transmit and continually evolve the culture change put forward by current and future Pioneers. It was agreed that for the movement:

- The report of the Meeting of Pioneers will be widely disseminated;
- Ways will be sought to broaden support for the movement and attract new members;
- There will be networking to form new alliances,
- Public policy issues will be monitored;
- Membership for facilities will be developed.

Until the next meeting, to be held in 6 months or as soon thereafter as possible, the Century Circle will be a mutual support network to its members and prepare for the further organization that will take place at the second gathering.

INTRODUCTION

The origin of this meeting can be traced to the fall of 1995 when a panel of pioneers in nursing home culture change was invited to speak at the annual meeting of the National Citizens' Coalition of Nursing Home Reform in Washington, DC. The panel members were:

Barry Barkan, CEO, Live Oak Living Center, El Sobrante, CA
Charlene Boyd, Administrator, Providence Mount St. Vincent, Seattle, Washington
Joanne Rader, Benedictine Institute for Long Term Care, Mt. Angel Oregon
William Thomas, The Eden Alternative Foundation, Sherburne, New York

These leaders in change recognized that pioneering work is arduous and often lonely. They expressed the need to meet together to identify common elements in their work, to support one another, and to seek out other pioneer partners.

A combination of circumstances in Monroe County, New York, resulted in the meeting taking place in Rochester in March, 1997. Two organizations had critical roles in bringing this about. LIFESPAN, through its Monroe County Long Term Care Ombudsman Program and sponsorship of the Long Term Care Community Forum, has since 1992 generated awareness of change. The Daisy Marquis Jones Foundation, in its continuing quest to advance quality in nursing home life, provided the funds for this small invitational meeting of pioneers in change.

The objectives of the Daisy Marquis Jones Foundation included identification by pioneers of the common elements in their different streams of culture change, identification of indicators of culture change, and guidance on the research, evaluation and assessment of culture change.

It is important to recognize that every nursing home has an existing culture. The word "culture" holds within it many aspects and dimensions of life that include at least the following:

- Values and core ideas that drive and nourish the culture;
- Organization of time and space;
- Nature of social networks, social relationships and patterns of interactions;
- Language and rules that govern everyday life (including the rules that govern allocation of resources and the identification, definition and resolution of problems);
- Artifacts (objects) that are integral to everyday life;
- Relationship to the natural world;
- Ways in which the community celebrates and mourns (traditions and rituals).

Culture is an organic, on-going process that has the potential for change, growth and development. There are no culprits—"good guys and bad guys." Rather, there is the presence, or not, of vision, energy and perseverance, and a willingness to nurture and support one another in these change efforts.

This report seeks to capture the spirit as well as the substance of the first gathering of pioneers.

SIGNIFICANT ASPECTS OF THE MEETING

Special characteristics of the Meeting of Pioneers in Nursing Home Culture Change grew out of the conviction that process goes hand-in-hand with outcome, and that the two cannot be separated. While the meeting operated under the familiar constraint of time—in this case a total of 48 hours—the conduct of the meeting expressed the values, principles and practices of the pioneers. These features included the composition of the assembled group, the way people were identified, the physical arrangements, the absence of formal papers, the intentional use of stories and the development of recognitions and celebrations involving the gathered community, i.e. rituals.

Thus, the group of 5 pioneers and 28 invited participants brought together at The Century Club in Rochester, New York, mid-day Friday, March 14, 1997 was both inclusive and diverse in terms of age, discipline and geographic distribution. Children of several pioneers often joined in for meals, and one, at age six weeks, attended most sessions, finding many welcoming arms among the several generations present.

Others who were invited to attend included regulators, advocates, researchers, administrators, directors of nursing, social workers, and people in the legal field. They came from across the country---eight states and the District of Columbia. All were given clearly printed name tags, but no further identification, so there was no invitation to ranking or stereotyping.

The tone of diversity and connectedness to the natural world and to each other was sounded in the Thanksgiving offered in the opening of the meeting by Peter Jemison, an artist and member of the Seneca Nation whose people were the first inhabitants of the greater-Rochester area.

In introducing Jemison, Rose Marie Fagan said, "The culture change of pioneering approaches expresses the values and philosophy of the original people who inhabited these lands, the Iroquois. In the Haudenosaunee culture, everyone is equally important including children and women. Elders are revered. Women are held in high esteem and treated with respect and dignity, not because it is a right that has to be protected, regulated and monitored, but because it is a way of life where there is a oneness—an interconnectedness with each other and with their natural world."

The physical setting of the meeting, purposely chosen for its non-institutional characteristics, was that of an old Rochester home, and meetings took place either on the large enclosed porch or the double living room. In spontaneous cooperation with pioneer values that include connection with the natural world, the windows framed heavy falls of lake-effect snow from time to time. Living flowers centered each dining table.

People sat in one big circle, without tables. Exchange of philosophies and experiences was encouraged, a sense of creativity and excitement was often present, and there was a remarkable building on each other's ideas. Bill Thomas captured the feeling of many when he expressed amazement at being in a group that agreed with and supported ideas and practices he has to work so hard to communicate to people in other groups.

It became evident as dialogue progressed that many invited participants quickly recognized and identified the pioneering spirit of culture change within themselves. One expressed this feeling in her comment that she thought she had found her lost tribe.

In communications with the founding pioneers before the meeting, the shape of the meeting was outlined, including an agenda. Shortly before the start of the conference, in the last planning meeting, the pioneers eliminated the formal written agenda and in its place presented at the initial session, the blocks of subject matter and themes they felt should be covered in the allotted 48 hours. There was nothing "cut and dried" about the meeting. The decision in the planning stage to develop and incorporate rituals during the time together led to further creativity, spontaneity, and sense of community.

The first session was devoted to what is common among us. We recognized at the outset that different streams of culture change flow from a common value source. Unity was affirmed as well as creative and diverse expression. This set the stage for participation by participant-observers and founding pioneers alike, and led to building on one another's ideas rather than competition and one-upmanship.

All sessions were recorded by both audio and video tape, and ample notes were made by a note taker. Because much of the spirit as well as the content of the sessions is in the dialogue, the choice was made to quote it liberally in the body of the report.

Traditions and Rituals

Part of culture change is the conscious development of traditions and rituals which have significance to each community.

Putting Pioneer values into practice, ancient tradition and newly-evolving rituals were integral parts of the meeting, from its opening with the traditional Thanksgiving of the Iroquois to the formation of The Century Circle at its close.

The founding pioneers determined in their pre-meeting discussions that there should be recognition of the part Carter Williams had played for a number of years in introducing them and their work to each other. By extraordinary efforts on a snowy day, they produced by the close of the Friday afternoon session a "laurel" wreath, made of fragrant eucalyptus and sprigs of spring flowers. Bill Thomas placed the crown on her head as a symbol of leadership and as "ongoing convener of the Pioneer Movement," asking all to gather around and "place a hand on us."

The next ritual was the Jewish ceremony of the Sabbath Eve lighting of the candles, to which Barry Barkan invited all who wished to come. People gathered around a large table at the rear of the dining room, and as night fell, Barry recited and explained to us the ancient prayers, lit the candles and blessed the bread and wine, which all were invited to share. Many also shared their thoughts, both serious and comic, it being noted by one participant that she agreed with a friend that God must want to hear some good jokes along with all the bad news from our world.

On the second and final evening of the meeting, some means were sought for symbolizing the support and strength this coming together had generated. All stood in a circle where several things developed, both planned and spontaneous. First, out of a need to give concrete expression to the pervading sense of connectedness, and having no other materials at hand, the extension cord of our video-taping equipment was found to reach nicely around the circle. Then Carter Williams, as on-going convener, presented to Elma Holder and Rose Marie Fagan written acknowledgements of their work, both early and late, which preceded and made this meeting possible.

Next, observing that dancing needed to be part of the ceremony, Barry Barkan led the group in the hokey-pokey. Still holding on to the extension cord, the group by consensus named our new movement for culture change "The Century Circle." Many people expressed hope, a new energy to take home with them, and anticipated enormous widening of the circle in years to come. Finally – on the impulse of the moment the extension cord was cut into pieces so that each person would have a concrete memento to take home.

Beginnings of rituals were underway, with the circle, ever-widening, as the basic symbol.

A. Elements Common To The Different Pioneer Streams

A prominent theme of the meeting was the affirmation of diversity in the pioneer approaches, reflecting the diversity and richness of life. Using the metaphor of the wellspring, the different pioneer streams are flowing from a common source of great abundance. The common elements in these various streams were identified and affirmed. Early in the meeting, agreement was reached on what was common to all, as follows:

- Pioneers share a common starting point: They begin with the experience of the person who lives in the nursing home. For all of them, this beginning point led them to identify a number of factors causing this experience to be destructive to health and well-being, and in their place, developing philosophy and practice that support life-giving daily experience.

  - Residents, as well as staff, family members, advocates and regulators, feel profoundly disconnected from life, with no shared vision that provides meaning to their lives. The Regenerative Community builds community, new connections between people and opens the way to explore meaning in life. (Barry and Debora Barkan)

  - Residents feel they have no control over their daily lives. The development of Resident-Directed Care aims to restore control to the resident. (Charlene Boyd and Robert Ogden)

  - Residents often feel uncomfortable and sometimes frightened by set routines and ways of doing things that are foreign to them. The development of Individualized Care helps them return to familiar and comfortable routines. (Joanne Rader)

  - Residents often feel lonely, helpless and bored in a sterile social and physical environment—an unhealthy human habitat. The healthy human habitat of The Eden Alternative philosophy restores social and biological diversity and brings richness, spontaneity and greater normalcy to daily life. (Bill and Judy Thomas)

- Pioneers, in response to this set of resident centered needs, have developed certain methods, practices and ideas about effective culture change which they all hold in common. These include:

  - projecting and recording a vision of changed culture, identifying values and developing principles and practices that express the vision and the values;

- recognizing that culture change is an on-going process, a continuing process of growth, **not** a program to be installed once and for all. Culture change is not a destination but a journey. It is always **"work-in-progress";**
- practicing self-examination, probing and asking questions, always searching for how it can be done better.

- Pioneers value and respect residents and staff by:
  - beginning decision-making with the resident;
  - seeking to respond to spirit as well as mind and body needs;
  - seeking to enjoy residents and staff as unique individuals;
  - acting on the belief that as staff are treated so will residents be treated;
  - putting person before task;
  - accepting risk-taking as a normal part of adult life;
  - acting on the belief that each person can and should make a difference.

- Pioneers value and promote the potential of residents and staff by:
  - identifying strengths in staff, residents and families, and building on them;
  - seeking the growth and development of residents and staff;
  - promoting spontaneity and creativity in staff, resident and family;
  - building teams so the talents and creativity of all staff can be utilized for the benefit of residents and for their own satisfaction;
  - shaping and using the potential of the environment in all its aspects—organizational, psycho-social and physical—to embody and express values and make the most of individual growth and development.

To Illustrate the Common Elements:

The Story of Opal *

Stories were often told during the meeting to capture the points the speaker of the moment was making. These narratives held within themselves aspects of body-mind-spirit that may be lost in conventional analyses with their orderly listing of points and rational summaries. **The Story of Opal** was offered by Joanne Rader to illustrate many of the common elements to be found in the various streams of pioneer work. Joanne presented it as a story of healing of the spirit and the ways the staff tried to help with that healing.

Opal came into the nursing home when she was 86 years old. She had a diagnosis of Alzheimer's Disease. But she was unusual in a couple of ways. One, well this isn't unusual--- she didn't think she lived in the nursing home - - she ran it. She had been an office manager and she was convinced that she was running the unit. She called the social worker over one day and said, "Did I hire you?" The social worker thought for a minute and said, "Yes." Opal responded, "Best decision I ever made." The social worker was delighted and reported Opal's comment to all she met.

She didn't like to be touched, which is unlike most people with dementia. If you touched her she would slap your hand away. She would also be aggressive toward others. She would take a glass of water and throw it on you or anybody that came up - - the staff or other residents- - for no reason. She could also wheel up behind someone who was sleeping in their wheelchair and whack them on the back of their head for no provocation, which is also unusual, very unusual for a person with dementia. Opal was one of our frequent fallers. She was falling a lot. We had lowered her bed and placed an alerting device on her so we knew when she was attempting to get up, but she never was restrained. She would sometimes crawl out of her low bed and curl up under her roommate's bed for some unknown reason. We would bring her back and put her in her bed.

She had been in our facility for quite a while and she was getting more frail. We had a nurses' station where Opal would park herself at the edge to see what was going on, and direct the activity of the unit. We decided to move her behind the desk so that when she stood up she would have something solid to hold onto. The desk created a distance between her and everybody else and for the reasons I told you, this was a good thing.

* *The Story of Opal comes from; the Benedictine Nursing Center, Mt. Angel, Oregon, where Joanne Rader has practiced for many years. It is also recounted in the following:*
Lustbader, W. (1996). Tales from individualized care, Journal of Gerontological Nursing, 22(3) :43-46.

Rader, J., Semradek, J., McKenzie, D. & Lavelle, M. (1995). Lessons from a restraint reduction project. In L. Gamroth, J. Semradek & E.M. Tornquist (Eds), Enhancing Autonomy in Long-Term Care. New York: Springer.

With Opal sitting at the desk, the call light and telephone were right there. So what did she do? I'm sure she took a number of doctor's orders answering the phone. She pulled the call system apart. And some of the staff were saying, "We can't have this, she is destroying and disrupting the desk. We've got to move her".

But most of the staff knew what their job was. They recognized this works for her. This place here is for Opal. We need to modify the environment. All they did was they pulled the cord for the telephone and pulled the cord for the call system, put it over the desk, which was inconvenient for the staff, but Opal couldn't see it, she couldn't reach it and it worked perfectly. She was there in an adapted environment and the staff could see what was going on. It kept her from bopping other people and kept her from falling because she had something solid to lean on.

As mentioned, she didn't like to sleep in her bed. One time she was sliding out of her wheelchair as she often did when fatigued. She wouldn't really fall, it was an ooze. She would ooze out and get into the little space under the desk where she fell asleep instantly. The staff covered her up. The next shift's nurse came on and Opal was sleeping under the nurses' station. The day nurse apologized, but the next nurse said it was all right. If she was not sleeping in her bed, let her sleep under there. So what did they do? They brought out a foam mat, a sheet, a pillow and her afghan and created a bed for her under the nurses' station. The staff didn't know why she liked to sleep there, but she did. They made a sign that said, "Please do not be alarmed; this area has been set up for the safety and well-being of this resident," because family and other people were distressed to see her sleeping in this little place.

Soon staff saw that Opal was in a dying process. She was too weak to get into that space herself. So the staff had to hold her to put her in the place. They were touching this woman who didn't like to be touched. As they were doing this one day, she raised her hand, and they had seen Opal raise her hand many times, but not in a kind way. But the staff person made eye contact and saw that instead of being distressed, she had what I call "friendly eyes" and Opal reached up and touched the staff member's cheek. For the last two weeks of her life, Opal allowed the staff to hold her, rock her, and cuddle her. Just hours before she died, she said to the nurse, with a beautiful smile on her face, "I can hear the angels coming". The nurse said, "Yes, the angels will be here for you soon, but until the angels come we're here with you".

The story has a postscript. Opal was estranged from her family. Her son never came to visit her. After she died, the son came in, and one of the nurses took the time to talk with him. What she found out was why Opal liked to sleep where she chose. Her son was estranged from her because he had been severely abused by her as a child. And from what we know and Opal's behavior about not wanting to be touched, or to sleep in her bed, it may be that she was also physically and sexually abused. The staff, by following Opal's lead without understanding her behavior, let her heal the hurts of a lifetime before she died.

The Story of Opal speaks to many of those elements held in common by all the Pioneers. Basic to the work of the staff in the final months of Opal's life, was an acceptance of what was satisfying and comfortable for her. They accepted her needs to maintain some sense of her identity in assuming the stance of an office manager, seeing this as a strength rather than something with which to do battle. Though they did not understand why she insisted on sleeping

under a bed or under the desk, they sensed that for her this was critical for rest and comfort. It is clear that their starting point was the experience of this particular individual and they responded to her in a way that helped her build on her remaining strengths. Thus, the decision-making remained with Opal even though she was coping with dementia.

It is clear, too, that this staff believed that risk-taking was a normal part of adult life. Further, they functioned well as a team, even across changes of shift. An atmosphere of fostering the creativity and talents of all pervaded this nursing home as seen in the creative staff responses to Opal. Thus, growth and development of those who live and work in the nursing home is amply illustrated in Opal's story. The healing of her troubled spirit is shown in Opal's acceptance of the staff's warm caring in the last days of her life, and her gesture of loving response. Capacity for growth is indeed life-long, even in the presence of dementia, if others can help along the way.

(see Appendix B for more stories)

B. Culture Change Is Anchored in Identified Values, Principles and Practice

Values, principles and practices of long-term care culture change were identified and affirmed at the conference. The center-fold page which follows is an initial effort to present in one diagram the cohesiveness that is necessary in culture change, first between values and principles, and then the expression of these values and principles in practice.

The values are familiar to us all, and are found in many mission and vision statements. Here they are accompanied by the principles that need to be observed and the practice that needs to be developed if values are to be more than comfortable words inscribed on paper.

Practice has to be examined in the twin spotlights of values and principles. Does practice express values and respect principles or does it negate them? How and why? No detail of daily life is too small to be examined under these spotlights. Can a person maintain identity and self-worth if she is not known as a unique individual with a special set of life experiences? Can she hold on to her sense of who she is if she has no favorite pieces of furniture, pictures, mementos and other chosen things around her to help her remain connected to her life? Can a person maintain a sense of dignity and self-respect if he cannot decide aspects of his daily schedule significant to him? Can a person know that she matters to others when there is no time, space or assistance in getting to know those with whom she lives? Can a person enjoy spontaneity, humor and the connections of normal daily life in an impersonal environment controlled by the rules of others and lacking contact with children, pets and the natural world? Can a person thrive when relationships with staff are driven by the latter's need "to get the job done?"

A cautionary note: It is not expected that any one nursing home or other setting, can institute all of these practices in an immediate sense. These are goals to be articulated and worked toward. It may take many years to achieve some, such as renovation of the physical plant. Others can be put in place once the re-education of staff, residents and families has reached a certain point. Culture change makers must keep this formulation of values, principles and practice before them so that they can keep their "eyes on the prize," and steer a steady course through the challenges and vicissitudes that are bound to come on their journeys toward culture change.

VALUES, PRINCIPLES AND PRACTICES

VALUES

For all who live and work in long-term care:

Identity

Self-respect

Dignity

Self-determination

Growth and development

Satisfaction

Pleasure

Creativity

Opportunity

Right to take risks

In their relationships:

Honesty

Compassion

Kindness

Patience

Consideration

Humor

Mutuality

Community

Respect

Trust

Hope

In their environment:

Homeyness

Normalcy

Diversity, biologically
socially

Dependability

Spontaneity

Comfort

Flexibility

Support

PRINCIPLES

Know each person.

Promote choice.

Respect individuality and risk-taking.

Treat staff as you wish staff to treat residents.

Support relationships with people of all ages, animals and the natural world.

Support function and mobility.

Build on strengths.

Build on potential for healing and growth.

Build strong teams.

Shape environment (social physical and organizational) to express values.

Devote time and space to building community.

Insure representation for all community members in policy decisions.

Expect leaders to model values.

Keep decision-making close to the resident.

Respect the need of all to give as well as receive.

Encourage creativity.

Look for meaning in all behavior.

Work with residents; do not fight and argue with them.

Express joy in each other.

Commend and congratulate real accomplishment in any aspect of life.

Respect ethnic, cultural and religious identities and beliefs.

Imbue whole organization with philosophy, principles, practice and need for congruence.

PRACTICES (Expression of values and principles)

GENERAL

Accept necessity for wide and deep culture change.
Identify and record your values and principles.
Learn how to examine and change practices so that they express your values and principles.
Continue to examine practices in the light of your values and principles.
Develop capacity to be flexible in routines and schedules significant to the resident.
Train designated staff member(s) as Community Developer/ Culture Builder/Culture Transmitter.
Recognize that culture change is a process and a journey, not a final, fixed program or destination.

ORGANIZATIONAL AND PSYCHO SOCIAL

Initiate and continue staff education in culture change.
Design and organize in-service training to make it person (resident) centered.
Re-organize and empower staff, focusing on responsibility, accountability and strong support to frontline staff (resident assistants).
Encourage creative ideas from staff, residents and families as together you build new culture.
Institute primary nursing (permanent assignment of staff).
Establish resident direction in goal setting (no goals set unilaterally by staff).
Enable resident choice in aspects of daily life significant to the resident, such as, but not limited to: times of getting up and going to bed, breakfast, snacks, naps, times out-of-doors, favorite pastimes, times and methods of bathing, content of meals and the ways meals are served.
Base toilet-use schedules on individual's bowel and bladder patterns.
Teach and model good communication, especially listening skills.
Welcome and provide for resident animals and birds for companionship, meaning, surprise, comfort and delight.
Maintain an abundance of living plants inside and out to enable daily contact with the natural world.
Integrate presence of children in daily life.
Accept, without judgment, resident's family as part of community and team.
Gather frequently and regularly as a community to discuss things of mutual interest and concern, to celebrate, to remember, and to mourn.

PHYSICAL ENVIRONMENT

Encourage residents to use own furniture in their rooms and arrange it to their taste, best functioning, and convenience.
Choose warm colors and some "experienced" (used) furniture in different styles for common rooms which are both homey and, in their variety, stimulating to the senses.
Hang pictures that residents say have meaning to them.
Develop small units of 10 to 15 residents.
Cluster dining and sitting areas around kitchen on each unit.
Design and decorate user friendly, homey bathing rooms.
Provide good accommodations for pets and plants.
Develop welcoming, accessible outdoor space, including safe areas and opportunities for active gardening.
Incorporate child day-care facilities in overall design.

C. Issues and Experiences Common to the Process of Culture Change

Pioneers and participants reported many similar experiences in dealing with the issues that arise as the work of culture change moves forward. They include:

- **Leadership:** the role of the change-maker, as well as staff roles in bringing about change;
- **Organization**
- **Staff development:** all aspects including, re-education, dealing with established antagonisms, empowerment;
- **Costs**
- **Regulations**

The discussion about issues and experiences common in the process of culture change had to do with the challenges pioneers experience in the change process. A common element among pioneers is the belief that pioneering is **work in progress**. Pioneers feel they have a long way to go. Excerpts from the conference dialogue expand these points.

Leadership

It was emphasized repeatedly by participants that strong leadership was essential to change, but by no means the only ingredient. There must be convinced, committed change-makers at all levels of the organization. Barry Barkan, in a pre-meeting gathering of the Pioneers, spoke of the special gift nurse aides bring to teaching and transmitting the changed culture: "It is a thousand times more powerful when its transmitted by a number of people who have made it their own."

B. Thomas: I've never had success without a change maker. But if all you have is the change maker he/she will be a very lonely, very dissatisfied person. The change maker is essential but not sufficient.

Kayser Jones: It is important to include everyone in the process of change.

Frank: ...build ownership

Boyd: I've found one of the easiest methods to help with culture change is peers. When (staff) is part of the environmental change, then they could actually help the next group.

B. Barkan: The change maker in top management is important. But teaching people to be change makers from whatever level of ground they stand on is important, too. Everybody who wants to can buy in and say...these are the values I stand for... We want everybody at every level to learn how to advance the culture.

Organization

The organizational chart in a traditional nursing home is typically a triangle with administration at the top position and frontline staff at the broad base of the pyramid. The resident may not even appear on the organizational chart. In one pioneer home, the hierarchical organizational chart was dismantled and replaced with an inverted triangle with the resident at the broad top of the chart and top management at the bottom position. To do this successfully departments were flattened to create teams.

Boyd: But our biggest change happened when we actually changed, flattened our organization, and took what we call neighborhood coordinators and put [them as] mini-administrators in top leadership roles, people that had vision,...in the neighborhoods (living units)... [We] changed the hierarchy structure that I mentioned, got rid of directors, ...took as many task-oriented jobs as we could, like rehab aides, unit coordinators, bath aides, medication nurses, anybody that was just doing a task oriented job and eliminated their jobs and said if you want to work with us you are going to have a holistic approach. I'm giving you a huge picture of a five year phenomenon that went on in a building.

Hierarchical structures are not the only problem the Pioneers have confronted. The systems governing service delivery—such as food, laundry, supplies, cleaning—as well as all matters having to do with staffing, including shifts and scheduling, are all interdependently functioning elements and change in one will impact the others. Charlene Boyd gave an example of this.

Boyd: [Before our culture change work began] we felt we had done such a good job as far as organizing our hierarchy, our efficiencies, but it wasn't very resident focused, so we had to start rethinking. I have to say that this rethinking was only a few of us at the time and we began to say, what do we want this to look like...We needed to change environmentally and programmatically in what we did. Programmatically we needed to put as many resources as we could where the people (residents) were, and take as many existing kinds of resources in the building and put as many [as possible] with the residents themselves. So...we began our journey.

A number of us from administration went up to a floor, in a neighborhood, and decided the first thing we were going to do was change sleep and wake schedules and instead we were going to follow residents' individual sleep patterns. We all took different roles and different responsibilities at the time and I went up with the resident assistants, which is what we call our nurse assistants. The first thing we did is walk into this lady's room, turn the light on, and say, "Mrs. Jones, you now have a choice: you can sleep in or not." And we learned that ...all of our systems wouldn't allow that to happen, trays came up at a certain time, ...a shift came on at a certain time. We [had] designed these beautiful systems to do that, so we had a major, monumental change to make. So then we did lots of stops and starts to make the change happen.

Staff

Helping staff change was recognized as a very difficult process. Elements that make it difficult are the already established antagonisms and ways of doing things. The three major points in the discussion were:

- This version of the golden rule: "how management does unto the staff, the staff will do unto the resident."
- It is necessary in culture change to have a change maker in a leadership position. For long lasting results, it is equally important to teach everyone at all levels to be change makers and learn how to advance the culture.
- Essential elements in culture change include empowerment, creativity and continuous assignment of staff (primary nursing).

Boyd: ..we set up so many structures to make staff feel unempowered and left out of the decision making process, but yet we want them to have this holistic kind of approach with residents...we want them to take care of the whole person but we're not taking care of them as the whole person...we need to work on both pieces ...how we give them the freedom and latitude to make those choices so that they have the freedom and latitude to do the job we're asking them to do (give residents more freedom, choice, autonomy)
...[you] have to be creative about how resources are used...a lot of time creatively redirecting resources.

Green: ...our objective should be developing staff to be who they are, not to be the people to get the job done. ...use all the resources that an employee has. And to do that you must develop them, but that means that they may leave you. And that's a risk that we have to take as caring people, as people who really want to do what is right for everybody.

Staff: empowerment

Participants discussed several aspects of empowering staff, including the changing of titles to acknowledge the work each does, especially frontline staff. Deeper changes were also reported in terms of scheduling, work assignments and increased responsibility and accountability. In other words, **talk** of empowering staff was translated into deeds of empowerment.

Kayser Jones: (to Boyd) .... You call your staff "resident assistants" instead of "nursing assistants". It is so obvious yet for decades we've been calling them nursing assistants.

Boyd: When we changed the name, we made a big deal, we gave them certificates, changed their name tags...but a group of people thought they needed initials by their names too...we have initials RN, LPN...they earned those initials too. Now we offer the option of their name and resident assistant, or their name and initials, its up to them.

Misiorski: ...We started a Certified Nursing Assistant (CNA) empowerment program whereby they now have primary care assignments; they are no longer rotated. That was a huge change for us, a real huge change and met with some resistance, as all change sometimes is. But the overall

outcome has just been amazingly positive. And people who were negative about it in the beginning have become huge advocates of that program.

We also implemented the CNAs doing their own patient assignments as well as their own work schedules, which has just been amazingly fantastic. It has reduced call outs, they replace themselves; it just solved all kinds of problems for us and that is all benefiting the residents, which is why we are all there.

...We also had a [social worker] named Catherine Unsino come down and speak to our committee...and she talked a lot about how she came to realize that if the staff don't love themselves then they cannot in turn love the residents and until the staff really show love to the residents we're not getting where we need to be in the facility...That concept and that thought has caused us to say how can we help our staff, how can we help them with their life situation. That's a big chunk. I don't have the answer to it yet, but it is something that we are working really hard on and we're very excited about.

J. Thomas: We have tried to get several facilities who use... a time clock for their employees to punch out every day to eliminate that time card and try to let the staff that is working for you be trusted enough to come in and leave at the time they are needed. We feel that if a person is required to punch in and punch out on a daily basis, that is also how they in turn will treat their residents. OK, you've got to get up at such and such at time, you've got to get bathed, got to get down to the breakfast room, activities start at this and this time. Your whole life has to work around this, and you've got ten other residents you have to get to. Therefore that is how they tend to react to and treat their residents on a very rigid time schedule...By giving them the feeling that they are trusted and can do things on their own time that will in turn be passed on to the residents.

Another example...is asking the staff to make up their own work schedule, which a lot of people will say can't be done, and it certainly can be done. I've seen it done. It also gives the staff the feeling that they are trusted enough to make those steps and rather than hiring someone to come in and have a full time job doing nothing but writing up their schedule gives these people who are entrusted with the lives of Mom and Dad and Grandma, the ability to also hook their schedule in, fit it in the best way they can.

Staff: antagonisms

Participants spoke of the strong antagonisms within the long term care world, the most sobering being the antagonisms between residents and staff. Bill Thomas observed that the antagonisms had such strength and complexity that they seemed actually to be holding up the system. David Green's experience leads him to advise against dealing directly with these antagonisms but rather to seek "common ground". Joanne Rader described a Canadian nursing home that proscribes staff fighting the residents. She told a story that illustrates the important role creative staff can play.

Rader: ...I went to a facility [in Toronto] and one of their mottoes was, "We don't fight with residents." I was blown away by that because...it is very hard [not to]. Again, we don't physically fight with them, but [this story illustrates what they meant by their motto]: There was an aide that was coming up and talking to the Director of Nursing and she was practically in tears

because she had this gentleman that really needed a bath and he was refusing. And she tells [the Director], "I know we can't fight with residents but I just don't know what to do." And [the Director] said just go back and think what you can do. This gentleman was very modest, he had some dementia, but not too much, and so she was thinking and thinking how could she do this without fighting with him. So she said, "don't worry, I'm blind." And he said, "Oh, OK," and he was fine...They were so pleased with her creativity that they made up these buttons that said "DWIB" (don't worry, I'm blind)...There's a flip to that because somebody who is not thinking holistically enough could say, "What?! She deceived him. That was a violation of his rights", etc...You have to take a really broad picture.

B. Thomas: When I look at the nursing home world I see this incredible tangle of antagonistic relationships. I see antagonism between surveyors, owners and operators. I see antagonisms between management and staff, fighting between residents and staff, antagonism with families, antagonism with the ombudsmen.

I see this incredible jumble of antagonism. You'd think such an antagonist bundle would collapse, but what I see happening is that these antagonisms are supporting each other.

Brokaw: ...some like antagonisms...they are the security blanket for not taking responsibility...and the outside culture in this country reinforces that [attitude]—"I'm not a good union member if I like management." There are some who will not respond to taking on responsibility.

Boyd: ...[but] they're no longer there after a while.

Green: To try to deal with and try to figure out the antagonism, you spend a huge amount of effort and get very little for it. The approach I take is: **<u>We don't do problems</u>**. We focus on establishing a vision and then not worrying about the reality of what it takes to get from here to the vision. ...look for common ground...basically for nursing homes common ground is OBRA [Omnibus Budget Reconciliation Act] philosophy. It is totally resident (directed) from everybody's standpoint.

Schoeneman: Antagonism between groups fades away once you start having these communal type of gatherings in a supportive atmosphere where people hang around together without badges and do projects together.

Misorski: ...it creates antagonism when you tell somebody what they're going to do and how they're going to do it....the battle lines have been drawn. [Now it is different at our facilities.] Now we express genuine enthusiasm about our vision...we say to the staff these are the parameters within which we must work. You tell us how we're going to get there and working together in that regard, the antagonism is then eliminated. The staff comes up with phenomenal ideas about how we can implement changes that accomplish those visions that don't cost us that much money.

Costs

Discussion of costs centered on the the internal budget of the facility itself. A basic point made by several people is that it is not primarily a matter of adding money to the budget, but rather of re-allocating what is available. Creativity was again identified as a necessary element in allocating money, with the suggestion that the principle to be followed is to put money where it has the most direct impact on residents.

B. Thomas: Whether the pie gets bigger or smaller isn't the question; the question is how you slice the pie differently.

Boyd: I totally agree with what Bill said. It's how you slice the pie and the more you allocate to the residents obviously the better it is.

McNees: If you take your budget and assign all your budget to the residents, all of it, whatever your budget is internally, just internal distribution, how you cut the pie internally...the question is, "How many of those dollars impact the resident directly?"...you find a shift occurring, where the dollars are getting redistributed closer and closer to the residents themselves.

Boyd: So we have to be creative in how we use our resources, the more creative we are the better. And we spend an awful lot of time on creativity in my building to try to redirect resources...Look at the time card issue...I had two staff people doing time cards, by neighborhood staff taking on that task I could reallocate those resources...We did the best when we gave them [neighborhood coordinators] the money...our budgets are already decentralized...we don't manage by hours or patients, they just have a dollar amount [based on number of beds], it's up to them how they allocate it.

As to added costs connected to culture change there were two different experiences reported, one in regard to the shift to restraint-free care and the other noting very specific additional costs in terms of training. Finally, there was a reminder that we should also measure the benefits of culture change, and not dwell solely on costs.

Misiorski: [Restraint-free care] is not costing anything at all [in our nursing homes].

Green: The initial training costs of staff can be rather significant in terms of preparing them. We've done 30 hours of Continuous Quality Improvement (CQI) training for all of our staff. Now we are going through a whole management development program because we've not done anything systematic.

Kayser-Jones: ...if we are going to talk about costs we should also measure benefits. What are the benefits and benefits for whom, staff, administration and/or the residents?

Regulations

Four themes pervaded this discussion:

- The need for more **constructive approaches** on the part of regulators;
- The importance of **communication** between providers and regulators at the systems level;
- Significance of a **successful survey**;
- The importance of providers taking a **pro-active stance**.

Need for Constructive Approaches

Andrzejewski: I'm told that in the current culture, the only time you encounter a regulator is at survey and then you hear a bunch of negatives and get a statement of deficiencies. Create systems that create opportunities to talk in places and times aside from survey time, prior to survey, after survey. Build the understanding and the trust. Provide good news before we provide bad news. Change "statement of deficiencies" to say "statement of challenges". Regulators need to get in the frame of mind of prevention and early intervention. Suggestion: look at a group of surveys in a facility, look for a trend in survey performance and why it is where it is. The survey tool has improved. What follows after the survey is not an improvement. It is not total quality management. It is not continuous quality improvement. It is big brother slapping people around.

Barkan: There is a paradigm conflict. The legislation is brilliant. It is bringing us into thinking about quality, into looking at ourselves, raising questions, being involved in an ongoing learning process. That's one paradigm. The other paradigm is the inspector walks in the door; they are there to catch you doing what's wrong. There is not consistency between the quality of the evaluators...[There is a] need to identify that 10% to 15% of the homes need to be moved along because they are not willing to do the job. But most of the people out there are willing to try to learn how to do the job. There has to be consistency, paradigmatic consistency, between people who are doing the implementation of the regulations, and the intent and spirit of the [law] and the regulations, and the process of what we are trying to get going on in the facility.

Communication

Rader: Our trainings[in restraint-free care in Oregon] were all integrated... the providers, the regulators and the advocates were all in the same room, hearing the same information, getting the same vision at the same time. ...that became the model for education related to changing practice.

...[We were collaborative]. We established a coordinating committee. We met monthly initially. Now we meet quarterly. If a problem arises from any arena that needs a system level solution, it is brought to the committee. The skills that we had yesterday are not as good as the skills we'll have tomorrow. The standard that we have today will not be the same as the one we'll have tomorrow because we're evolving in the process. Those involved felt it was necessary to have a

way to change practice that avoided the adversarial stance of the systems and the different groups.

Dazey: The State of Oregon's Vision 2000 statement says the state is willing to work with the organization to step back and let them do their thing and then after a period of time look at it with them and say whether its wrong. By the year 2000, Oregon envisions a service and a regulatory system driven by a recognition of and a responsiveness to the needs of the individual served...This requires going beyond our existing structures and practices. Oregon foresees delivery of services in ways that support the values declared herein...in four main areas: individual, service satisfaction, collaborative and environment...We have a community group with the state, community members, residents, families and staff coming up with what really measures quality...an example of how they are working with us to enable us to start some of this change.

Holder: ...We need to deal with the whole way that regulations are presented to staff. ...management often interprets government regulations in an extremely negative context to the staff that's working. Its like this horrible thing that's come down upon us that the government is making us do. When staff sees regulations as standards to be upheld that are publicly acknowledged and publicly developed that is part of the cultural change. Bring it back to the standards...talk more about the broad concepts, not the nitty gritty of all the regulations, but the law itself.

Webster: ...look at what is **really** required...not what someone just thought was required.

Holder: ...people talk about the regulations in terms of, "the federal government is coming down on us and forcing us to do this." Time after time we find out that it's a state specific regulation that is driving somebody crazy...most states' regulations have to be revisited...most were written in the early 1970's.

Schoeneman: We should have a paperwork initiative where we get out these papers. Some of them come from old nursing practices that say this is how you get to cleanliness by a bath three times a week. Have all the people who are responsible for all of it get together all at once and say which of these are really necessary.

Frank: It is more about how regulations are used. If we are talking about culture change in relation to regulation, it might also be about how we communicate about that, if that communication promotes more conflict or more connection. It is not just a shared vision, but a shared accountability.

Andrzejewski: I think all of us here are coming with the assumption that everybody in this business wants to do good. The process regardless of politics ought to recognize that.

Gardner: [In regard to the Opal story] What would the regulator say about somebody sleeping on the floor?

Rader: I knew what they were going to say. They were going to say, "Bravo".

Green: Because of OBRA [Omnibus Reconciliation Budget Act].

Rader: And because we had been working with them. I was so excited when I heard about this intervention that I called up the person who is the head of the survey team and said you are going to love this story. But this story could not have happened if we hadn't gone through "it's OK to put an egg crate on the floor." Something as simple as that will stifle the kind of creativity that allowed Opal to go to a peaceful death. But because of the work we had done in Oregon we knew we had their kind of support. Now if you had twenty people sleeping under the nurses' station that would be another issue, but [in Opal's case] it's individualized care.

Significance of a successful survey:

Andrzejewski: ...In my judgement regulations are the lowest common denominator, not something that you shoot for. If someone goes through what we call a deficiency free survey—all that shows me is that they are mediocre. That's it. It says nothing more than that.

Gardner: That is what is confusing to funders. I've had people come to me and say we want to convert some of our medical model rooms to nice, elaborate lounges. I say, well, let me see your review [survey report] and there is nothing on there. It is clean. And I say, how do I know you have a good culture? And they say we have it. There is nothing here that says we aren't fully functional as a cultural institution, we've got good quality care. So I have no leverage as a funder to say improve your culture of care and I'll fund this remodeling project. There is nothing there for me to hang my hat on,...you know, there is no hammer for me.

Green: I don't think you can expect that from a regulator ever.

Gardner: Ever? So if they have a clean slate they say, "I've got a clean slate, I'm a quality institution."

Green: All it measures is at that point in time that the regulator was there, that they found from the perspective of the regulator only, not the perspective of the regulations because they weren't looking at all 1500 regulations and every aspect. From the perspective of the regulator at that point in time, they were complying and that's all.

Frank: It is about our values, our principles and our practices and making them part of all the systems we relate to.

C. Williams: In almost every nursing home the mission or vision statements say all the good and comfortable words about compassion and kindness, but practice doesn't express these values.

Proactive Stance by Providers

Green: Regulations can be changed with the stroke of the pen. If they don't make sense, if they don't have value, if they don't have real need within the organization then it is our obligation to

work for their change. Never, never, never say that the government is requiring you do this because if that's the case you had better work at getting it changed.

Reardon: Regulations are an interpretation of the law so we should always first go to the source and see if the regulation carries through the spirit of the law. It's a great and powerful law...we find over and over, the interpretations of the regulations are not consistent with the law.

Rader: The perception of regulations by providers, regulators and advocates can be a huge deterrent to change. Each group makes care decisions based on perceptions of the regulations when the interpretation may not be accurate. If someone's interpretation seems contrary to good care, it needs to be challenged. Everybody needs to challenge that perception, to say, is this accurate? Is this what it really means? because false perceptions can be so limiting.

Green: I try not to do anything because it is a regulation. Do we need it to do a better job? to know where we are? what's happening? and oh, by the way, it complies with the regulation....[also we've] got to have more documentation but less paperwork.. ...we have to be able to justify what we're doing and the outcomes. In the world we're in now, it is not enough to have good intentions. You've got to be able to prove it and so that means computerization and management information systems.

II. INDICATORS THAT CULTURE CHANGE IS TAKING PLACE

The discussions about the indicators that culture change is taking place were perhaps the most difficult. The topic was revisited throughout the conference. Participants wrestled with the subject in general discussion and small groups. The consensus of the group was that the subject requires more analysis than could be given in this short time. Participants recognized the need for more study and research, both qualitative and quantitative, to identify indicators that culture change is taking place.

Indicators are closely linked to values and principles. Practice expresses values and principles and indicates what the nursing home culture is.

The word "indicator" provides a basis for assessing change. Indicators are necessary to provide benchmarks that enable you to compare where you are now with where you were (baseline data), and where you want to be. A home needs to collect evidence to establish a baseline, and again after efforts to make culture change have been in effect for a period of time. Every facility will have a different baseline. Indicators need to be applied more than once. Researchers advise qualitative and quantitative research methods.

The products of traditional nursing home culture supply the negative indicators that often characterize nursing home life such as boredom, waiting, loneliness, things being done for you that you are capable of doing, low interaction among residents and staff, low engagement, isolation and no connection to the future. These things are bad any place, but become accentuated in the nursing home.

A caution is that culture cannot always be reduced to a single set of indicators, and indicators should not be used as formulas when studying culture. Indicators are meaningful only in context--in the context of the environment and the individual person. Although culture has an obvious and powerful impact on residents' quality of life, it is important to clarify that the two are not synonymous. Culture refers to context, quality of life to aspects of life meaningful to the individual. Quality of life is not culture.

SOME INDICATORS OF THE NATURE OF CULTURE AND WHETHER CULTURE CHANGE IS TAKING PLACE

Resident Care

- Is the home restraint-free?
- Are daily activities individualized?
- Are daily schedules individualized? Do residents awake of their own accord and decide their own bed-times, rest-times and outdoors-times? Are residents assisted in using the toilet according to their own bowel and bladder patterns?
- What is the setting, atmosphere and general tone of mealtimes? Are meals served family style? Can residents choose what they want to eat and how much? Are many residents receiving pureed food or fed by stomach tubes? How are food supplements used? What is staff/resident interaction at mealtime?

Resident life

- What is the resident doing throughout the day?
- Ask the resident: "What is important to you? What makes a good day for you? Do you get to have your good day? How often? How much choice do you have? Do you know the other people here—staff and residents?"
- When you know average resident outcomes in any dimension, what can you learn from the resident outcomes that don't fit the pattern?
- Do residents have positive and significant relationships? Is there mutuality in relationships and reciprocated affection?
- Do residents have a relationship to the future?
- Are family members present and involved in meaningful ways?
- Do staff/residents share humor and humorous experiences?
- What is the degree of contact and interaction of people? What is the content of engagement with people? Who initiates the interaction?

Organizational environment

- How are opportunities provided for residents to engage in activities they want to engage in?
- What are the community building practices?
- What is the extent of the biological and social diversity? Are there children, plants and animals on a continuous basis?
- Do practices pass the test of being continuous, close to the resident and promoting growth?
- What traditions and rituals are present?

Policy and administration

- How is money allocated? How much money is allocated to impact residents directly?
- What is written about what the home wants to do and where it wants to go? Are practices anchored in a well thought-out philosophy?
- Are practices performed with intention? Are functions accomplished in terms of the values of the culture?
- Ask different staff: what is the most important thing you do for/with the resident? What is your attitude toward regulations? How do your beliefs about regulations affect resident care? What do you do moment to moment to return all decision making to this resident?
- Who is the change maker(s)?
- Are time cards used? What is the rate of staff overtime?
- Is there continuous/permanent assignment of staff to residents?
- Who decides what and how things are done?
- What are the rates of staff absenteeism, use of agency staff and staff turnover?

III. RESEARCH, EVALUATION AND ASSESSMENT OF CULTURE CHANGE

The conference arranged for two people experienced in nursing home research to give guidance about research in culture-change. They were **Jeanie Kayser-Jones**, nurse anthropologist, and **Patrick McNees**, research psychologist. They described their current research projects: Kayser-Jones in a four year study funded by the National Institute on Aging, is investigating "the social, cultural, clinical and environmental factors that influence eating behavior" in two nursing homes in California. McNees is studying the process and outcomes of culture-change at Providence Mount St. Vincent, Seattle.

Kayser-Jones described how she proceeds with her ethnographic work, initially learning everything she can about each nursing home, talking to everyone she can in all parts of the organization. Key informants are identified and observations begin to be focused in her current study —"to really see what is going on at meal time". Observations are made "at all hours and every day of the week because a Sunday is very different from a Monday." Guides are developed for interviews with staff at all levels as well as with residents and families.

"Event analysis" follows. "We found immediately...that the evenings were much shorter staffed, so I began to watch; I wanted to see what happens in the evening...One of the administrators had said to me a lot of food goes back to the kitchen in the evening. We begin to make hypotheses and say, is it because there are fewer staff and they're not being fed or are people not hungry?" She learned a great deal from one orderly who described the frantic way he tried to feed fifteen people already in their beds, running from one room to the other between bites. Her observations led to detailed study of the use and misuse of Ensure and pureed food, including the frustrations of both residents and staff as meal time takes place in rushed, graceless settings.

Kayser-Jones does both quantitative and qualitative studies, and in the latter she uses many case studies, as well as photography. "Although I try to quantify what I do when I can and when I think it is important to make a point, I never look at what I am doing as statistics, because I want people to know that these are people, they're not numbers, they're not case numbers, they're my mother, they're your mother, your grandmother."

Responses by Kayser-Jones to specific questions

B. Barkan: I wanted to know if you are formulating your questions before you start your research, or do the questions come from the process?

Kayser-Jones: It's both. I always start out with a very clearly stated purpose, specific aims, but other questions emerge. I think that's the value of qualitative research--instead of going in with a lot of instruments that often don't suit the people anyhow, like quality of life instruments. I would never use a quality of life instrument in a nursing home because I ask the resident, "Can you tell me...what is important to you?" [and then] I hear it from their perspective. And then I ask the nurse and the physicians and the nurse aides, and it's fascinating to see the difference.

I'll never forget this woman who had peripheral vascular disease. She had both of her legs completely amputated and she was blind and she had had a mastectomy for cancer. When I asked her about quality of life, she said, "I know it must seem strange. I can't walk and I can't see and I've had one breast removed, but just to have this conversation with you is life itself." As we lose some of our abilities I think some of us value others more. And that's very different from those of us who can walk and talk and see and hear without any disability. So,...Barry, constantly I take, I learn from the environment, and I learn what's important ...from the residents and from the staff.

Green: Am I right in...[understanding] you don't use a single quality of life instrument? Just because there is no single instrument that will measure it, what each resident feels is important to them?

Kayser-Jones: I think, for example, [that in] quality of life...functional status is very important. That is one thing to look at. But here is a woman who couldn't walk. There are many people who can't do anything for themselves and yet they feel they have a high quality of life. But if you use those instruments one of the items would be ability to walk, feed yourself—those would be the items that are on there. My mother was quite impaired at the end of her life, but it would make a good day for her in the fall just to get out and see the falling leaves. Now we might not think of that because most of the doctors and nurses who I interview say, "if I'm mentally impaired I don't want to live. I would commit suicide." That's a very different perspective so we really have to learn from the people themselves.

Green: Quality of life is what we are really talking about. Ultimately, what we're trying to achieve with our culture change is quality of life. Quality of life is the end point; culture is the means. How do we know if we can't measure the quality of life, if there aren't any tools? How do we know what progress we are making?

Kayser-Jones: I think it...[is]really important to ask the residents what's important to them. [For some it may be pets, for others it is food, or a private room, or for others not being alone is important. We cannot make generalizations from the literature about what any one individual finds important.]...Loneliness, as Bill has said in his book, is one of the hardest things.

Frank: I think one of the things you are posing to us as a challenge...is that people are always looking for indicators and turn them into something else and then they become formulas and...they lose all the context that made them valid in the situation where you found them.

Patrick McNees, research psychologist, then spoke of his work at Providence Mount St. Vincent. At the outset he offered some qualifiers. "The first is a scientific qualifier. We don't have all the answers. The ones we think we understand are not based on controlled, random trials. This is applied research, it's in the real world. The caveat is we think we understand some of the data. The second caveat is we don't think we have all the answers in terms of these quality of life issues. This is a process, it's an ongoing process, we think we do have a handle on some things."

McNees presented his work in three chapters entitled:

"A Day in the Life of a Nursing Home Resident or the Lack Thereof"
"How to Create an Impaired and Debilitated Person in A Nursing Home and and How to Reverse It"
"Beyond Medically Safe Passage to Death"

In the first chapter of his work, "A Day in the Life of a Nursing Home Resident or the Lack Thereof," McNees explained that Providence Mount St. Vincent (PMSV), before any changes began, "was a place that was recognized by experts for care, for a caring staff, a dedicated staff. It had every single feature that a good nursing home should have. The typical characterization of life at PMSV by the staff was we do a good job of feeding people, we do a good job of toileting people, we do a good job of putting people to bed. And you notice that characterization was one of we do a good job of doing things for people. That's where we started from."

When observers looked at the residents through their days they saw a great deal of isolation – "literal isolation, parallel isolation,...nothing to interact about, ...no stimuli to speak of. We saw extraordinary low levels of any human activity whatsoever." Thus they identified levels of engagement and interaction as important things to study, which they did through a system of time samples. Time sampling "basically involves taking a whole bunch of instantaneous snapshots at a particular moment in time and saying here's what is going on...The data I'm going to be telling you about today largely are quantitative. So in that sense it's kind of like I can sketch what I think an outline of reality may be, not total reality, but some reality. But I can't give you the rich texture that Jeanie can give you from qualitative studies."

They found "extraordinary low levels of interaction...Human interaction was consuming less than 7% of a resident's waking day. When other forms of engagement (response to any external stimuli such as radio, touching someone or looking at someone, eating, receiving care, etc.) were noted, over two-thirds of the day was spent doing absolutely nothing at all. If you take meals out of it,...the figure shot up into 80%, 82% of the day was spent doing nothing, And I mean literally nothing."

Frank Williams said it would be important "to know about outliers and why they were different" and McNees agreed that studying the people at the extremes "may give us a lead on what the issues really are."

McNees reported that they found "the average amount of time the resident was agitated was slightly lower than interaction. We established reliability on all the data. The most reliable was the engagement data, it ran in the 92% range. The interaction data had the .86 and the agitation in the .82 on each. So we went through and basically did 1400 time samples at PMSV to establish a bench rate." We also knew that our data would be looked at very critically, and one of the criticisms that could be leveled at us was you "were successful in creating this culture change...but the care is going to hell in a hand basket...We generated a baseline, base rates on essentially every risk indicator we could think of...We did site studies on food consumption, did some site studies on urinary incontinence and on pressure ulcers as well as a number of other risk indicators...We took the MDS,...every measure of change condition that we could get our hands on, we took incident reports and basically we plotted as close as we could the physical and cognitive profile of the person from the time they entered PMSV throughout the process and we were able to demonstrate that cognitive and physical decline we're all so familiar with."

The surprises came in Chapter 2 of the work: "How to Create an Impaired and Debilitated Person in a Nursing Home and How to Reverse It." "So Charlene Boyd and Bob Ogden...took a neighborhood - - the unit with the highest rate of acuity -- ...and recreated all the positions again and made essentially everyone a resident assistant. Took all the resources we had and made them indiscriminately resident assistants and said there're a couple of rules, and beyond that we don't have a lot of rules here.

- The first rule is that you do whatever you can on a moment to moment basis to return all decision making to the resident. That doesn't mean you can return it all but you try every instant to return it moment to moment to the resident.
- The second rule is equally simple. You provide an environment where there are opportunities for the resident to engage in activities each chooses to engage in."

"There were lots of trials and tribulation...but in the end there was a change. The change resulted in a median of an increase of roughly 50% in activity. There was an increase in interactions, social interactions essentially across the board." Outliers presented interesting pictures: "There was the case of the lady that was essentially comatose that within two weeks was eating. There was the case of a lady who wasn't talking - - people thought that she couldn't talk anymore - - started talking. There were lots of those individual cases where we weren't able to capture the essence of what was going on. But what we did capture was change. There was the reduction in agitation. There was an increase in social interaction, an increase that continued

over time...What we found in the experimental neighborhood was surprising. It surprised us. Our hypothesis was that we might be able to impede cognitive and physical decline. They actually improved on our cognitive measures and on our functional measures...We found there were zero changes in other neighborhoods...The risk indicators not only didn't get worse, without exception they got wildly better, even including such things as urinary tract infection, which is one of the oddest ones. Why would they get better?...The answer was that before we were toileting people on our schedule...This was all done, by the way, in an unrenovated environment."

The third chapter is called "Beyond Medically Safe Passage to Death," which is a two part study. "We went back in and established the fact that the effects were reproducible essentially, even though we cannot say point blank that we understand the cause and effect relationship but the effects are reproducible. Now we're going back in again and this time we are going to look not only at quantitative things...but now we want to look at some individual residents and see if we can get a handle on those outliers."

Conclusion: Based on these presentations and discussions, a combination of quantitative and qualitative research is necessary to capture the process and outcomes of culture change. Individualization in certain aspects of research, especially in regard to quality of life outcomes, is strongly indicated. Ethnographic methods, which enable research questions to develop as the research proceeds, are particularly useful. Case studies and photographs further enrich research.

DRIVING FORCES FOR CHANGE

Nursing Home Reform Law of 1987

A two-hour discussion generating a long list of constraints for culture change, as noted below, did not include regulations and the law. In reality, the Nursing Home Reform Law of 1987 mandates a culture change. The pioneering culture change expresses intent and practice, the values, principles and spirit of the Nursing Home Reform Law of 1987. The Nursing Home Reform Law of 1987 is viewed by the pioneers as a driving force and not a constraining force.

Leadership and Vision

Consistency in leadership and a vision that is communicated are key elements to culture change. When the leaders understand where they are going, all the constraints become challenges that have to be worked out.

Power of Consumer Awareness

Many providers, regulators, families, residents and advocates know in their hearts that life in a nursing home can be different. When these individuals become linked to an articulated vision and subsequently shown a pathway to culture change, a movement will begin. When people know things can be different, they do it.

POSSIBLE OBSTACLES TO CULTURE CHANGE

A round robin discussion resulted in an extensive list of reasons why individuals and facilities might not move toward the culture change. The reasons include but are not limited to the following:

Societal Attitudes

- Fear of change
- Lack of community involvement (community involvement results in better care)
- Change requires painful sense of urgency
- Feelings of powerlessness, oppression and overwhelming disempowerment
- Society's inability to regard every human being as intrinsically valuable. Society links human value to productivity (money).
- Ageism
- Many different kinds of fears, especially involvement with the ill. Fear of being close to someone who needs a nursing home. Old people are aliens- -"not me".
- Expectation that change needs to happen all at once. Unwillingness to recognize change takes time.

Financial

- Reimbursement practices- -dependent population
- Profit making nature in the system- - allocation of resources
- Lack of marketing plan

Staff

- Turnover in administration and management staff
- Support and socialization needs of staff - - staff who have never known love are expected to give it
- "Big voice in the sky" the voice (of the Director of Nursing..Social worker..Medical Director) in our heads saying "You must..."
- Our own individual fears and insecurities about change
- Antagonisms can be a habit
- Fear of giving up power
- Good days/bad days
- Change is exhausting, coasting is comfortable.

Bureaucracy

- Overwhelming focus on medical model
- Legal liability issues
- Hierarchy of leadership, rigid hierarchy regarding decision making
- Difficult to challenge the system
- Short term cost and training
- Lack of governmental leadership
- Political and bureaucratic process

Education

- Uninformed consumers
- Lack of consumer demand---consumers not in the forefront
- Not enough facilities modeling culture change
- People who misunderstand the intention and practices of the culture change movement
- People not seeing full pathway to the goal
- Lack of knowledge of how to get new beneficial ideas incorporated into systems to be broadly accepted (Research Utilization)
- Lack of research methodology and base
- Current training of all personnel

Environment

- Lack of permission to use imagination, creativity
- Creativity stifled
- Buildings---too big---big bad buildings---physical environment restrictive
- Lack of vision
- Not being grounded in values and principles
- Lack of ritual (traditions)
- Low value industry places on workers

WHERE DO WE GO FROM HERE?

Strategies to Generate a Movement

"I want the first step of this movement to be about stopping those things that are an insult to the human spirit."

Barry Barkan

The second and final night of the meeting, people began to look ahead to the future development of nursing home culture change. Heartened and exhilarated by the conversations of the previous day and a half, spirits and hopes were high. Many expressed the importance of building a movement to carry forward the work begun at this gathering.

Barry Barkan expressed the feeling of a number of people Saturday night when he said we should think about how to develop our work "entrepreneurially" in a way that would ground it in the world, and provide the resources and structure for its growth. Bill Thomas synthesized much of that idea when he suggested that since we are so different from the medical model, we should ultimately come up with an accreditation body based in Pioneer values and practice. This was greeted with delight and comments as to the strength and power of accreditation possibilities.

Out of many hours of intense exchange—questioning, agreeing, amending and building on each other's ideas—a very strong sense of connectedness was present in the Saturday night gathering.

Seeking some means of concrete expression of this feeling, people stood in the familiar pattern of this meeting, a circle, appropriating an extension cord to reach around the circle for every person to hold on to. Thus symbolically connected, all proceeded with the fun and serious commitment that go hand-in-hand in pioneer work. Lifetime achievement awards were presented to Elma Holder and Rose Marie Fagan, all in the circle danced the hokey-pokey, chose the name of "The Century Circle', and offered ideas on its significance: it notes the closing of one century in which the pioneer work has begun and the threshold of a new century in which the movement will grow and flourish. It links participants to the experience of the Rochester meeting and of the founding meeting at The Century Club.

Sunday morning, the final session, brought us to the reality of differing opinions about some aspects of organizing. The differences occurred over how closely the Century Circle wants to be identified with the consumer movement. A suggestion by Barbara Frank that NCCNHR's annual meeting was scheduled at a convenient time and place to cluster further Pioneer activities, brought a warning from Wendy Webster, with David Green concurring, that the attitudes many providers have toward advocates could drive some potential members away.

The important element in this session, however, was that there was complete consensus among all present that they wanted to empower a movement and build an organization that will promote, transmit and continually evolve the culture change put forward by the Pioneers.

Generally speaking, it was the Pioneers who had a sense of urgency to accelerate the process while it was many of the other participants who had a need to make sure that all who join in the future have an opportunity to experience the culture.
Both positions have their proper place. Barry Barkan suggested that we keep both going at the same time, allowing The Century Circle to grow organically. The Pioneers will keep their identity and connection and do what they need to do without reflecting on The Century Circle. In this sense, The Century Circle would be evolutionary and the Pioneers revolutionary. Bernie Shore commented that this was "pen and sword in accord".

IT WAS AGREED:

That for the movement:

- The report of the Meeting of Pioneers will be widely disseminated;
- Ways will be sought to broaden support for the movement and attract new members;
- There will be networking to form new alliances,
- Public policy issues will be monitored;
- Membership for facilities will be developed.

Until the next meeting, to be held in 6 months or as soon thereafter as possible, The Century Circle will be a mutual support network to its members and prepare for the further organization that will take place at the second gathering.

APPENDIX A

Pre-meeting Dialogue
Thursday afternoon and evening
March 13, 1997

Present: Barry Barkan, Charlene Boyd, Bill Thomas, Judy Thomas, Sarah Burger, Elma Holder, Joanne Rader, Rose Marie Fagan, Carter Williams

Ostensibly a meeting to finalize the agenda and draw up a statement of purpose for the meeting, this session became a valuable time for exploring in depth each other's ideas and approaches. Experiences were described, views expressed, questions asked. Feelings of mutuality of purpose developed and there was creative building on one another's ideas. The major themes follow.

Culture, Values and Principles

Boyd: Is it culture we want to pass on or is it principles and values? Do I want to advocate for a culture change in the nursing homes or culture change in long term care or do I want to advocate for changes in how people approach those people and from that comes all the other things?

B. Thomas: I go in that camp. Culture is a construct with principles and practices.

Barkan: I don't disagree with what you're saying in terms of the outcome but I think that culture embodies principles. It embodies values. It embodies the innoculation. It embodies recruitment. It embodies the rights of passage as people grow in their skill and knowledge of doing this. Culture just is. It's not like we're saying that there was no culture in the nursing home when we're coming in, saying now we're going to put a culture in place. There has been a culture, a hierarchical culture based on the physician being the pope in the church and everybody else following that.

The culture of diagnosis, ICD-9, the codes, and all these things have a tendency to separate us out from the experience of what it means to be a human being in a collective sense, connected to the past, moving toward a future together.

B. Thomas: I think right there is a pretty good definition of what we want in the context of institutional long term care. To put a fine point on it, a group of people who feel a sense of context, share a collective experience, can feel that they move from a past to a future that they all share. That's one of the bad things about a conventional nursing home. They're not moving toward a shared future. You come in, that door swings shut, you're there until you die, alone. There's a sharp dividing line between what we try to build and what exists, that sense of the collective, that feeling of shared memory, no actual shared memory, and a sense of movement inside relationship.

Barkan: Relationship to a future. And the building of values that is a growing system going on.

Transmission/Communication

B. Thomas: The transmission thing is important to me in two senses. I know everybody has had the same experience. Many times those visitors you get, they want the quick fix. This is really great. We could do this. They want to plug it in and they don't listen very well when you tell them it is going to take a couple of years or even longer. The second thing I want to say about transmission - - when you do the quick fix thing and you make a copy of it, the copy is degraded, it's not as good as the original. When you have a set of codes and values that are being transmitted, they don't get weaker. As long as the community is alive the values get stronger and richer. It's the opposite when you can knock off a dozen Edenized homes, quickly in a row, and by the time you get to the last one it would be barely recognizable. Just a shadow.

Fagan: Bird in the lobby.

B. Thomas: That's all it would be. But when you're building a culture, if you do it right, over time it gets richer, and more firmly rooted.

Barkan: The first nurses aides that we worked with, took a while to grasp it, but now they have become the transmitters and they transmitted it to the new people, and each time it gets transmitted--as great as we like to think we are, (you know I have an ego), as great as I like to think I'd like to be-- it's a thousand times more powerful when its transmitted by a number of people who have made it their own.

We had a discussion yesterday about the word replication. The word replication is mechanistic. I loved what you said about the copy - - that each generation's copy gets more fuzzy and less clear. Transmission is really a good word for how the culture gets passed on rather than replication. Transmitted and communicated.

Vision

Barkan: As we think about what we want to accomplish here we ought to stretch our vision as far as we possibly can. Then build the conference and agenda based upon stretching our vision.

J. Thomas: Another issue we all need to look at is trying to help people to be able to see the vision we're talking about. Some people just don't see that vision. And how do we help them?

C. Williams: People may not catch the vision until they have an experience that touches them in just the right place. It may take two or three years for that to happen.

J. Thomas: That's why I think one of our missions needs to be to help them see that, without having necessarily to be touched by it personally... We have to help people have the vision. We use vision, education, implementation as our three steps...I think all of us would say that the vision has to be in place and you have to educate people before you can even think about implementation.

Barkan: I think it is up to us to really empower the vision so that it can spread, and to define channels for it to spread into other places.

Movement

Barkan: I want this movement to be about the first step in moving towards stopping those things happening that are an insult to the human spirit.

Holder: ...The very process we're going through this weekend moves us forward. It's as you say - - it's a changing event and we've declared it to be so this weekend.

Barkan: That's right. We've declared it!

Defining Long Term Care in Today's World

Boyd: When you say long term care, for my benefit, what do you mean?

B. Thomas: I've been thinking about long term care too, because I think it's good that we don't pin ourselves down to nursing homes.

Boyd: That's very important to me.

B. Thomas: In thinking about all of health care I see two key factors that can intersect. One is density of services... and the other is duration - - short or long. [Bill then diagrammed and discussed these intersections.] Where most institutional long term care has always lived has been a fairly dense cluster of services over a long period of time.

Boyd: I'm thinking broader than the nursing home - - about community based settings, wherever they are, some directed by a service program. It could be an adult family home, it could be an adult day home, it could be a PACE project...My point is I just don't want to be stuck with the word "nursing home."

B. Thomas: I agree with you. My candidate is "Elder Garden" to get the idea that from elders, not just elders who need nursing, but the garden idea has to be much more holistic.

Special Contributions to Long Term Care

Barkan: ...We're in the ballpark now of bringing about change, of seeing a cultural revolution going on in health care that could be driven from long term care as opposed to driven from the medical model.

B. Thomas: It's the perfect entry point, I think, because despite all its ills, long term care is the most interdisciplinary, if you look at the continuum. It's the least technologically dependent and it has a very mixed history, but has at least some brave attempts to put the resident, the patient first. Long term care can attract rather than repel.

C. Williams: You cannot avoid the person in long term care. You can avoid the person in acute care.

B. Thomas: Yes, Right! Bingo!! Easy, the hip in room 6.

Barkan: There are things that happen in life that increase your risk and increase your danger. And the answer to them isn't in the pill, or the shot or surgery. The answer to them is very often in the cultural support system for you, and the values.

B. Thomas: How I would put that would be in terms of a social shelter, that human beings need shelters like this to keep the cold March wind out. They also need social shelters to keep out the cold wind of grief and loss and pain and suffering, disease and disability that blow on you.

Barkan: And to provide the rites of passages and the repository of knowledge and wisdom that give people the tools to deal with all this.

B. Thomas: I think a religiously oriented person would say, why are you reinventing the wheel, we've had this for thousands of years...we're communities of faith. I can remember when my Grandpa passed away, there was a very strong faith there that stepped in, cooked meals, did all these things to help the family through that time. Nobody gave a second thought to it.

Barkan: The thing you said about the church, reinventing the church. In a sense, this is something that I really feel is at the foundation of this work - - we are at a point of cultural transition in society. We've had a culture that's gone on and on in family ways for hundreds and hundreds and hundreds of years without a big shift. I came from European Jews. They moved from Russia and Lithuania to the lower East side of New York and then they moved among people like themselves with the same background to a neighborhood in Brooklyn and up and down the street there were like people living life in like ways with some changes due to Americanization in a sense. And then there were suburbs and then there was the experience of the 60's... As the institutions have degenerated the new thing is not yet formed. We stand between the old which is no longer functional except in small isolated communities where your grandfather was.

Energy and Resources

B. Thomas: I know you travel and speak. Isn't it so true that you go, you show, you talk, any time you give a talk someone comes up and says, oh yes, it was very nice, but the people who come up after you talk about this stuff are like, this is what I always believed! I can't believe it! Then you wind up getting resumes on your desk from people all over the place that want to come work with you. That's the energy that has to be tapped. It's there. It's all there, its just bound down with the status quo, and finding a way to loosen it up a little bit. I guess there are two ways to move things, by repulsion and by attraction and part of what's happened in long term care for a long time is that people have moved out from repulsion.

Barkan: Repulsion or revolution?

B. Thomas: I mean feeling repelled by the status quo, what is conventional long term care. If we could set up something that is an attractant, people can say well, yes, I can move from this situation to that situation. I think it's a more positive alternative. I don't know how to do that, but...

Barkan: I think we do know how to do it. I think that by the time we get this over it will be established and will be growing. I think we do know how to do it, each in our own way has done it. I really mean each of us. Elma, you went into the places where the heads were the hardest, the hearts were the most closed and brought a breath of fresh thinking. I think that there is a tremendous resource here and we will.

Boyd: I think people are hungry for resources. I probably take one or two calls a week from somewhere and two or three systems a month travel to see us. It's a time drain in the sense of doing that with your staff. It can be energizing at the same time to know that you've been a source of gratification and support for other people, pat you on the back when you do this, and give you new ideas, too... The more partnerships there are, the more places there are for people to see.

Barriers

J. Thomas: I think people are overwhelmed with it. They're excited about it and they want to be part of it but then they get overwhelmed with the regulatory barriers. So people need to see that this is not just talk, this is where we get into the research component. It really **can** be done. You need to be able to look at what we've done.

Boyd: And the barriers to me are inside the box of our industry. They're everybody whose had any kind of link to long term care. It's the outside people that don't have that kind of barrier and that's where we get some of that inspiration. Everybody who doesn't get part of the vision, or who is having difficulty with it, or hasn't stepped beyond it, typically is inside the box inside the industry.

B. Thomas: You know what happens to me when I talk about Eden...The people that go from the vision to, " I don't know how the birds get watered every day"...they're not going to make it. They have an enthusiasm and an interest but they are allowing themselves to be trapped. Going to the worst case scenario to disprove the case is a protective mechanism.

Research

Barkan: ...We need to begin a discussion about research because research is something that seeks to become, (and I'm reflecting my own bias here), it seeks to become the tail that wags the dog. So we need to look at research and what the research models are so that research is feedback into our growth and development, so research doesn't steal energy from our growth and development.

B. Thomas: I have the very same feeling that I think you do about research. Often I put it to people when it comes up – show me the double blind controlled study that says we should live in a democracy...I do want to make sure that research is kept in the proper confines and doesn't spill out.

J. Thomas: It is a dilemma because when we hear from people, regardless of what aspect of a culture change in a nursing home they're talking about, that's what everyone wants. What are the research results? What have you got to back this up?

And as Bill says, if anyone can come up with a measurement for quality of life for a nursing home resident, let us know, because how do you measure that? Is that not a different thing for every person here?

Public Policy and Work of Pioneers

Holder: I'm just hoping that in the context of things you said about the law, that the message that comes out of this meeting will illustrate to people how what the Pioneers do is within the spirit of our public policy. Put regulation aside, frame this thing in terms of the words that are in the law itself.

C. Williams: This is the real flowering of the Nursing Home Reform Act.

Barkan: This is the essence of underlying meaning of the law. You said something to me, Sarah, that was very important. You said that what went on with the Health Care Finance Administration (HCFA) about the implementation of OBRA was terrific, except that when it came to meetings that were around enforcement, at which time they pushed everyone out the door and then did it behind closed doors. That's what impacts all of us in the field trying to do the best that we can and it really steals a lot of the best energy from us because enforcement is not consistent necessarily. I know this is our continuing debate.

APPENDIX B

STORIES THAT ILLUSTRATE WHAT IS COMMON AMONG US

- **As the starting point, Pioneers have sought to understand what life is like for the person who is the resident. What is the daily experience of the person who lives in long term care, whether in a nursing home, assisted living, boarding home or at home?**

Rader: During my study of bathing I asked staff to bathe me the same way they bathe residents. Staff response was "Oh my, you're brave!" But they did it. They took off all my clothes, wrapped me in a sheet, sat me on dough-nut hole chair and rolled me down the hall. After the shower I was again wrapped in the sheet and trundled back to my room. I can tell you it's a very uncomfortable and drafty experience which gives you the feeling that you may be exposed in ways you don't want to be. Although they were caring and careful, there is nothing relaxing and pleasant about it.

As a follow-up to my story I am going to give you all an assignment. I want you all to go back to find a facility, a nursing facility of some sort—go back and arrange for someone in that facility to bathe you in the way that they bathe their residents. That's your assignment. How do you feel about that? Would you resist care?

Barkan: I think that part of looking at life from the residents' point of view is to create a forum for the residents' point of view to be expressed. So that we can begin to learn what the point of view is...I wanted to find out what wandering residents do when they wander so I would just follow them...There was this one woman who would dress up, put on her hat, you know looked really nice, walk down the street, and then since no one stopped her she took the next step, got on the bus...I ran back and got my car and quickly followed the bus, so there was this old beat up VW bus following the city bus, going all over the city right behind the bus...Finally we got to the end of the line and I met the woman there and she said "so nice of you to be here to pick me up." We got in my VW bus and drove back to the facility. Everybody was just fascinated by the fact that she just wanted to go through an activity of daily living which is going from here to somewhere else even though she didn't know where the somewhere else was.

- **Pioneers project and record a vision, identify values, and develop principles and practice that express both the vision and values.**
  The riches at the common source are manifold. The streams are many (see appendix D).

- **Pioneers recognize that culture change is an on-going process, a continuing process of growth, <u>not</u> a program to be installed once and for all. Culture change is not a destination but a journey. It will always be called "work-in-progress".**

B. Thomas: There's always a temptation among people who are attracted to it [The Eden Alternative] to install it. Back up the tractor trailer and unload the dogs and cats and birds and plants and snap it into place like it is an interchangeable part on a machine. I think that attitude is really reflective of a factory mentality. If there's a problem with our assembly line, well this

new machine will fix our assembly line and we'll be better. I think what is common to us is we say no, it is much more difficult than this. It's like growing a garden. You don't go out and sow the seeds in the spring time and just leave them. You tend to them all the time, year after year, and gradually you become a better gardener. You don't become a master gardener overnight.

- **Pioneers practice self-examination, probe and ask questions, searching for how it can be done better.**

Holder: We've known these pioneers for years and years and I would just give the situation [when Joanne and I] first met, ...many years ago. There was a program on teaching nursing homes. The teaching nursing home people were all up front talking about what they had learned with their teaching nursing homes...I was trying to hear something that I didn't hear the whole day. They never seemed to be talking about the resident; they were talking about the nurses in the teaching nursing homes and what happens to nurses. And finally I just couldn't bear it and ...I said I haven't heard you talk about the resident yet. And I got this cold, icy [reaction] and I mean everybody just froze...But later in the afternoon Joanne Rader and John Hogan the administrator came up to me and they started asking me, " what are you talking about?"...Everybody else had shunned me at the meeting, but Joanne and John took me to a table and...[wanted to know] what I was talking about. It was that [willingness for] self examination, [though I'm sure they were] feeling hurt ...So to me that is the kind of self-examination, not being defensive at all but seeking me out.

Andrzejewski: From the standpoint of the regulator: the epitome of the regulator these days is non self-examination. We are the last word. The only questions that we ask are questions of you. We don't ask questions of ourselves as to how we can do better.

Rader: ...In Oregon when teaching about changing the culture we always do that in the context of having providers and the advocates and regulators all in the same room, hearing the same information, at the same time, hearing the same vision. Unless everybody, regardless of your job, has experienced a profound shift in the way you think about your job, you haven't got it yet, and you can't make the shift unless you start asking questions.

- **Pioneers believe that as staff are treated so will residents be treated.**

J. Thomas: We have tried to get several facilities who use a time clock for their employees to punch out every day, to eliminate that time card and try to let the staff that is working for you be trusted enough to come in and leave at the time they are needed. We feel that if a person is required to punch in and punch out on a daily basis, that is also how they in turn will treat their residents. OK, you've got to get up at such and such at time, you've got to get bathed, got to get down to the breakfast room, activities start at this and this time. Your whole life has to work around this, and you've got ten other residents you have to get to. Therefore that is how they tend to react to and treat their residents on a very rigid time schedule...By giving them the feeling that they are trusted and can do things on their own time that will in turn be passed on to the residents.

Another example...is asking the staff to make up their own work schedule, which a lot of people will say can't be done, and it certainly can be done. I've seen it done. It also gives the staff the feeling that they are trusted enough to make those steps. Rather than hiring someone to come in and have a full time job doing nothing but writing up their schedule, it gives these people who are entrusted with the lives of Mom and Dad and Grandma, the ability to also hook their schedule in ... fit it in the best way they can.

Dannefer: Do you hear objections to that, or are there problems in terms of legal liability if there aren't enough people who happen to be there at a given time?

J. Thomas: We always hear objections to it. We always hear people say it can't be done in my facility...We always have someone to oversee it, particularly in the initial stages...What will happen is you will repeatedly get a schedule back that will have all week-ends totally empty, nobody is scheduled to work on week-ends and you continue to hand it back and hand it back, explaining over and over again. What happened was that really neat things developed where certain people would work out with another nurse aide, another nurse, another staff member, I'll work this week-end if you take my kids, and then next week-end you'll work. A lot of these relationships were working among staff to do this. Can anyone speak to the legal ramifications of this?

Reardon: I'm assuming, Judy, that you're not leaving the care undone. There is an implicit assumption in that question that if someone is allowed to make up their own schedule, that no one is watching, no one is making sure somebody shows up.

J. Thomas: There is still someone that will oversee it and will make sure that people are always cared for. The beauty of it is once you get everybody in tune with that, the issue just isn't there. Somebody can just glance at the schedule and make sure all the hours are covered and it just doesn't take all that much time.

Green: We speak of front line staff, rather than "assistants", because I think we have to redefine how we describe the relationship...they are the most important staff members. You have to design an environment that allows them to be efficient in their work, and with that goes increased satisfaction because you cut out the grunge work they had to do by providing the resources. We designed the entire facility from their perspective; the heights, the location of everything is where they said it should be. So that the nurse now becomes the helper to the front line staff...as the other staff are.

C. Williams: I feel as though I'm hearing Charlene Boyd speak because at Providence Mount St. Vincent they also brought support to front line staff as you have.

Barkan: I think that there is a word that is very, very important in all this and it is called love. It's really about loving staff. The traditional rounds are you go around to find out what staff is doing wrong or what's not happening the way it is supposed to happen. I think one of the main purposes of rounds is to go around to bond with the staff, bond with the residents, find out what is going on in their lives, speak to that, be involved with them. If what is going on in their lives is that they have been evicted and they need $475 to take a new apartment, then it's our job to

figure out how they can get $475 to get that new apartment because we are trying to build a family, and in families we are all concerned with one another.

Pioneers:

- **seek to respond to spirit as well as body and mind needs;**
- **promote creativity in staff, resident and family;**
- **build teams;**
- **put person before task;**
- **seek growth and development of residents and staff;**
- **begin decision-making with the resident;**
- **accept risk-taking as a normal part of adult life;**
- **seek to enjoy residents and staff as unique individuals.**

For story illustration see The Story of Opal, page 7.

- **Pioneers identify strengths in staff, residents and families, and build on them.**

Barkan: Even if there is only 2% capacity left, you build on that.

J. Thomas: There was a woman with Huntington's Chorea. She didn't have much ability to communicate in any way. She was in the final stages. We would take a cat into her every day and, you know, many of the staff there just couldn't understand why we were bothering with this woman and spending the amount of time we were spending there. But every day we would go in and we would take her hand and rub it on the cat and we would put the cat on her bed and every day we would say, "Can you feel the cat, Cindy?" She was a relatively young woman. Then one day we went in and we were taking her hand and stroking the cat and we always said to her, "Can you open your hand, Cindy?" One day she just opened her hand wide and she stroked the cat. All the time that people said we were wasting on this woman, there was something in her that was very aware of the live, living, warm creature that was there and it was very worth the time that we spent.

Andrzewski: I'd like to add something from the regulator's perspective. We know also, intuitively, and I would guess the psychologists would tell us too, that somebody is more likely to accept criticism if it is first constructive and if it follows some sort of positive set of statements before the negatives. In the regulatory environment I don't think that we do that. We call what we do, or what we produce, a statement of deficiencies.

- **Pioneers shape and use the environment in all its aspects: organizational, psycho-social and physical—to embody and express values.**

B. Thomas: I'll say something about the environment. If you think about a farmer planting seeds in the springtime, think of a farmer with a bag of corn and he goes out in the middle of a parking lot and throws seeds around on the parking lot. You'd drive by and think he's a fool. Everyone knows the seeds won't grow on black top, but you take frail, ill, elderly people and you remove them from the soil of their daily life, the world they've known, and you plunk them

down in a concrete box with a professional staff of caregivers...not people who are part of your heart. Then what you say is we don't expect you to flourish, we don't expect you to grow, we don't expect you to be part of life, we expect you to be quiet until the angels come. So we get a self-fulfilling prophesy. We create environments that destroy the human spirit and then the human spirit is destroyed. No surprise there. But what we need to do is change it around so that we build an environment that nurtures the human spirit, not only of those who live there, but those who work there. And we'll see amazing things come from that. We'll share many of those stories of amazing things coming from that. Once you change the environment, you change many of the underlying assumptions. You change outcome.

- **Pioneers act on the belief that each person can and should make a difference.**

J. Thomas: I'd like to add, too, that each of us also believes that everyone here, and many others outside of here, can and also should, make a difference.

APPENDIX C

DIFFERENT STREAMS FROM THE COMMON SOURCE

Regenerative Community
Debora and Barry Barkan
Live Oak Living Center
El Sobrante, California

Resident-Directed Care
Charlene Boyd and Robert Ogden
Providence Mount St. Vincent
Seattle, Washington

Restraint-free Care
Individualized Care
Joanne Rader
Benedictine Institute for Long Term Care
Mt. Angel, Oregon

The Eden Alternative
Judy and William Thomas, MD
The Eden Alternative Foundation
Sherburne, NY

DIFFERENT STREAMS

I. The Regenerative Community by Barry Barkan

The Live Oak Regenerative Community is a living culture. It is grounded in ancient wisdom, the way of the tree of life that calls forth the renewal of a potent, meaningful and connected role for elders in society. It is through the regeneration of the community of elders that the people will recover our living bridge to past and future and the sacred values that nurture and sustain life.

Since 1977, primary efforts at cultivating the Live Oak Regenerative Community culture have centered in long term care, the social environment permeated with a sense of dread brought on by isolation, disconnection and loss of meaningful role. People in long term care were known for their illnesses and related to in terms of the problems that were based in the staff view of the pathology of the residents. They commonly had fewer rights than the worst criminals on death row. As a sacrifice to the frustration of staff, or, worse yet, for the convenience of staff, they were routinely drugged and/or tied down where they sat or slept.

Wherever we went, our efforts at community development conveyed a bold vision. The people in nursing homes were the elders of our society. Beginning on the ground on which we stood together, we were determined to contribute to a revolution that would change the nature of aging in America.

Like other great movements that have come before, our efforts at community development among elders began with consciousness raising: *To be a "patient" was not a meaningful role. We challenged head-on the long held stereotypes that we peaked in our mid-years, or worse yet in our youth, and in old age we were left with a shadow of our former selves.*

We advocated our knowledge that growth and development is a life long process. Each life stage has its own work and its own contribution. A healthy community of elders in the long term care environment not only fundamentally changes the nature of the institution, but it brings healing and renewal to all who encounter the community either directly or indirectly. By restoring the individual and collective role of elder in society, we are enabling life to progress organically through its different stages with continuity, meaning and connection to the healthy flow of the generations.

Our expectation has been that each person—no matter how physically, mentally or emotionally, she or he might be ravaged by disease—has within a place that is healthy, that is capable of growth and development. While the medical model relates primarily to what is not well, the regenerative community relates to the part within each of us, individually and collectively, which is connected to the well-stream of health. If 98 percent of a person or a group was in decline and two percent was vital, we cultivated the two percent so that we could bring it to four percent and then eight percent. Small miracles became the every day workings of the community.

In some small, but significant way, the living model of the Live Oak Regenerative Community, contributed to the major social paradigm shift that has resulted in federal standards for long term

care that are driving a once scandalous sector of service delivery to become one of the most progressive in terms of approach, vision and outcome.

The work of building the regenerative community begins with the *Live Oak community developer,* a person who takes on the responsibility to cultivate the regenerative community. The community developer is a teacher, leader, organizer and most importantly, a member of the community who takes responsibility for teaching the values of the regenerative community and builds bridges between people, their experience and one another. The community developer helps the community to establish its collective memory, to articulate what is important and to actively engage the future. The community developer's role is to help each person, even those impaired by the ravages of cognitive and physical loss, to be seen as an important member of the community with a significant contribution to make.

The work of Live Oak Community development is simple, yet subtle. It requires bringing people together at the same time and in the same place according to a predictable and regular schedule. The community developer culls from the community stories, experiences, songs and shared values that are embodied in regular ritual that forms the structure of community life. The community developer works hard to put a positive spin on communal experience and unusual behaviors and to keep the community moving towards its goals of hope, unity and empowerment.

Although Live Oak Community development begins with residents, it does not stop there. Staff, family members, volunteers, ombudsmen and state inspectors are all part of the community. From the start, the Live Oak model has promoted the idea that if we want staff to respect the individual needs of each resident and to love each resident, then the culture of the long term care environment has to promote love and respect for staff. The regenerative community actively promotes the idea that the whole multigenerational community of the long term care environment is a sacred place in which love is the great healer. Over time the regenerative community softens the hard edges of the institution and transforms it into a living system in which each person's needs and contributions makes the community what it is and what it is becoming.

In recent years, Live Oak Institute, the organization that has mid-wifed the regenerative community culture has focussed on creating tangible program systems that convey the regenerative community model. The first of these was Live Oak Community development training that has been conducted for professionals in different settings around the country over the years.

More recently, institute staff has created program products that can seed aspects of the regenerative community in a variety of settings throughout the long term care continuum. For example, *The Pleasure of Your Company* tm , comprehensive individualized activity program, enables the long term care environment to be organized so that programmatic bridges can be built to the large numbers of people who can't or won't participate in group activities. *Friendship Circle* tm , a community development program for people with cognitive loss, is currently in the advanced stages of development. These program products were developed and tested at the Live Oak Living Center, a skilled nursing and residential care environment in El

Sobrante, California, which has in large part been a laboratory for the development of Live Oak Programs.

The next step in the cultivation and transmission of the living culture of the Live Oak Regenerative Community culture is now looking beyond the borders of long term care environments to the wider society. A major project under development is the inter-generational Live Oak Elders Guild which provides for a real rite of passage into the role of elder, a path of mastery for those who accept the role and a community of learning, growth and social renewal for the guild members. Our vision is far reaching. The transformation of the role of elder in all segments of society, not just for our generation, but for the next millennium and beyond, remains the mission of the Live Oak Regenerative Community.

Regenerative Principles

1. Every organization is a living organism.

2. In every such organism there is an imperative towards health, wholeness and well being and meaning.

3. This imperative towards health is present in people who are well, suffering chronic and with degenerative illness, acute illness, or dying.

4. The driving mission of the regenerative community is to empower this imperative towards health within a purposeful cultural context that promotes renewal.

4. The regenerative community is a living system that exists to promote healing and renewal of all its members and each member shares in the responsibility to serve this purpose.

5. Every member in the renenerative community is a whole person who has spiritual, emotional, social- relational and physical needs and potential.

6. The primary goal of the regenerative community is to integrate vision and action in all practice, programs and management.

7. Community is the natural anecdote to isolation. It provides a structure and context for living a meaning- rich life.

8. The culture of the regenerative community is driven by shared values which support and promote high level well being.

9. The regenerative community values and welcomes the uniquness, diversity and cultural legacy of all of its members.

10. The regenerative community supports the building of meaningful relationships which promote a sense of belonging, security, and commitment.

Code of Practice in the Regenerative Community

1. We accept membership in a community consisting of residents, staff, family, volunteers, physicians, ombudsmen, union representatives and all others committed to the well being of all members.

2. We relate to residents as whole people who, like ourselves, have physical, psychological, spiritual and relationship strengths, needs and desires.

3. We honor residents as our Elders and seek to help them to live in the present, draw from the past and prepare for the future.

4. We follow the golden rule and honor and treat everyone in our community with respect, kindness and courtesy as we listen to them and respond to their needs.

5. We empower residents by providing them with choices so that they can make a meaningful life with dignity and autonomy.

6. We see ourselves as healers and advocates as we work together to help residents to function at their highest possible level of well being.

7. We communicate by listening carefully and using all means possible to understand one another.

8. We are members of a team and take responsibility to model and nourish a positive attitude, cooperative team spirit, and good morale.

9. Each of us is committed to learning, growing and becoming the best we can be in the practice of our work and to help our colleagues to do their best.

10. We are committed to making a good-will effort to work through difficulties and problems with other community members and to perservere until resolution is achieved.

DIFFERENT STREAMS

II. Resident-directed care by Charlene Boyd

Over the past five years Providence Mount St. Vincent (PMSV) has been in a process of "a vision for resident-directed care". We realized that to restore control and choice to seniors' lives, we had to move away from a strictly scheduled medical model. That it was time for a social model of care, where residents have maximum freedom of choice.

In a social model or resident-directed model, the care team is there to support resident decisions and share responsibility. If a resident wants to sleep late each day, the staff accommodates her. If a resident with memory problems enjoys making tea, a staff member makes sure the burner gets turned off. Care teams always serve the same group, so understanding and relationships deepen.

Profound changes in thinking and behavior have assisted PMSV in making this transition. These changes are reflected in our physical environment and programs. For PMSV this meant downsizing the nursing floor from 215 to 173 beds.

We then remodeled each nursing floor to have a sense of "lifestyle". Instead of hospital like "floors" there now are new fully carpeted neighborhoods. Each neighborhood has 20-24 residents and a permanently assigned staff. Staff members do have titles and responsibilities, but their jobs are no longer limited by previous definition. A housekeeper can lead an activity, a nurse can do dishes, and every member of the care team providing the services a resident needs right at the moment.

As this holistic approach is strengthened and refined by experience, traditional institutional hierarchy is phasing out.

In the heart of each neighborhood is a family style kitchen. Kitchens are open and easy, with plenty of light from large windows. Every kitchen is outfitted with tablecloths, napkins, refrigerator, stove, oven microwave, toaster, etc. Meals are served through a steam table system so sleep schedules can be honored and food remains hot. Cabinets and refrigerators are stocked with food and drinks based on neighborhood preferences.

Also on each neighborhood is their own laundry. Care team members will help out with personal laundry; those residents who enjoy folding warm clothes have this opportunity. The remodel has added a sense of warmth, space and color to a place once constructed by medical guidelines. The layout invites freedom of movement, choice and variety and reassures with accessibility.

We are making all these changes because our residents are telling us how they want to live "their" lives. To support their choices we needed to change. We are trying to move away from institutional thinking to the natural, lively expression of individual preference.

Resident-Directed Care is care directed by the resident, who chooses the daily routines and services he or she wishes to receive. Staff place supreme value on listening and knowing resident backgrounds and personal preferences, while educating residents about concerns related to their well-being.

Understanding needs, learning and collaboration are the ingredients which create the plan of care; a plan which is fluid and evolves with changing needs and wishes, and continued sharing and listening.

DIFFERENT STREAMS

III. Restraint Free Care and Individualized Care by Joanne Rader

When I began working in the field of long term care 20 years ago, there was little information to guide us in practice. The majority of clients had dementia or what we then called senility, yet the only tools we had at our disposal to address their behavioral symptoms were physical restraints, psychoactive medications and reality orientation. None of these was very effective and the restraints and medications were dangerous and damaging. For the most part, these individuals were treated as if they didn't have the right to say "no". The staff also lacked the skills and knowledge to identify when their own behavior or the environment acted as the trigger causing the behavioral symptom and creating excess disability.

My work has been directed at teaching staff how to be creative and compassionate when addressing behavioral symptoms related to dementia and to see that persons with dementia still retain the right to direct their own care. A key issue is teaching caregivers to view the world through the eyes and the heart of the person they are caring for. They also need to learn that to work well with persons with dementia requires that they learn to speak the language of dementia. In addition, caregivers need to look not only at the physical environment, but the organizational and psychosocial environment for causes of excess disability.

Staff need to be empowered to view all aspects of the environment as open to alteration and individualization to meet the specific needs of the resident. This requires breaking out of the medical model of thinking and acting. When we follow the residents' lead, often solutions emerge.

Two specific areas of care I have studied serve to illustrate how care can improve when individualization occurs. These are eliminating physical restraints and personalizing bathing. Physical restraints are often imposed upon a person without any thought to what the underlying cause of the behavior, such as sliding out of a wheelchair might be. Often this is related to an inappropriate wheelchair, not designed to meet the person's needs. When the person is properly seated, he/she is more comfortable, able to be up for longer periods, and has fewer behavioral symptoms, such as calling out or crying that is distressing to others. In addition there is no need for a physical restraint. Related to bathing, when a person with dementia resists a bath or shower, his/her behaviors are telling us "I can't tolerate the way you are trying to bathe me. Please create a way to meet my hygiene needs that I can tolerate." There are hundreds of ways to adapt and adjust how people are washed, yet often staff feel confined to the tub bath or shower method.

The story of Opal (pages 7-8) clearly illustrates how a staff can be empowered to be creative and follow the resident's lead, resulting in positive outcomes for all. This work is sacred work in the most universal sense of the word, and those who have done the work for any length of time know its sacred value. Caregivers have a special responsibility to respect the autonomy of residents who depend on them to recognize and meet so many of their needs.

DIFFERENT STREAMS

IV. The Eden Alternative by William H. Thomas, M.D.

I am a doctor. More specifically, I am a nursing home doctor. I provide medical care for people who live in long term care institutions and my work fascinates me. It holds all of the challenge and variety one usually associates with the more glamorous medical specialties. My work as a geriatrician, however, has also led me to reflect upon the enormous impact the design and operation of nursing homes has upon residents. Nowadays, I spend about half of my time in clinical practice and the other half thinking, teaching and writing about a new way of designing and operating long-term care facilities. We call this approach the Eden Alternative.

I began my work on long term care in 1991 and began my career as a rather reluctant recruit. I took the job as medical director and sole physician at a local nursing home initially because it was close to my home and I could ride my bicycle to work. Almost the only good thing I can say for myself at that time is that my ignorance left me free of the cobwebs that can entangle those most familiar with conventional routines and policies. As I settled into my new practice I became troubled by the yawning gap between the diagnoses and treatments I provided for my patients' bodies and the afflictions that so troubled their spirits. I soon saw that I had no pill that could remove the sting of loneliness, no injection that could lift a person from the depths of helplessness and no lotion that could soothe the ache of boredom.

I began to see that genuine caring and medical treatment were very different things. All my years of medical education and training had left me with a deeply flawed understanding of what it means to take care of another human being. I believed that Care = treatment + empathy. In other words if I was skilled with the methods of diagnosis and treatment and I spiced those skills with a gentle bedside manner I was doing my job. In truth real caring is something both more simple and more difficult. Caring = helping another person to grow. Lonely, helpless and bored people can not grow. We have an obligation to provide them with companionship, opportunities to give care, variety and spontaneity just as we provide them with food, water and shelter.

THE BIRTH OF THE EDEN ALTERNATIVE

People who own, operate, manage and design long term care facilities are in a unique position in society. They are world makers. People who come to live in a long-term care facility enter the universe you have created for them. They will leave only on the rarest occasions. For those interested in the business of world-making, our eldest tale of creation, the Eden story, is the best place to begin. Whatever your religious views this ancient story is worthy of some reflection. Consider the ironies. The all-powerful creator made the sun, the moon and the stars, he fashioned the dry land and the seas and even brought forth the human being in his own image. All of this without a hitch. He wasn't even tired yet. The first problem encountered in the story of Eden is the suffering of a lonely man. The first divine repair job was aimed at soothing the pain of human loneliness.

The Eden Alternative is a management and design philosophy that can challenge and overturn the conventional approach to long-term care. Whereas the typical day in a typical nursing home

revolves around diagnostic and therapeutic activities, we aim for environments where the plants, animals, and children are the axis around which daily life turns. Medical treatment must be deposed from its position as master of caring and replaced to its more proper place as servant of genuine human caring.

For two years we conducted in depth studies comparing a conventional skilled nursing facility with an "Edenized" home. We brought in over 120 birds of a half dozen varieties, thousands of green growing plants, dogs and cats came as well, and children from an on-site child care facility became fixtures in daily life. We resolved to place the maximum possible decision making authority with the resident or as close to the resident as possible. This led to the demolition and rebuilding of the nursing department and our first concrete steps on the road to continuous staff empowerment. The Eden Alternative is designed to transform a facility inside and out and to be felt by residents, staff and visitors 24 hours a day, seven days a week. We found the reward for our efforts in a 25 percent drop in mortality and a similar 26 percent drop in nurse assistant turnover. Infections were cut in half and medication costs were cut by $75,000 a year. In follow up research conducted at three other facilities that embraced the Eden Alternative philosophy we were able to document decreases in resident agitation, irritability, and depression. Preliminary results from other investigations currently underway have suggested a link with decreased resident to resident aggression.

SOME EDEN ALTERNATIVE PRINCIPLES

What are the keys to creating an Eden Alternative? Our research and experience have shown that some fundamental principles apply.

1. **Size**. Big is bad. Sorry, I know it would be much more convenient if this wasn't true, but it is. Existing nursing homes may be stuck with the building they have, but they can reorganize their people in ways that create a set of smaller homes inside one building. Think of the way large universities organize themselves into smaller schools each with its own substance and style. Success can be measured by walking from neighborhood to neighborhood (the terms "floor", "unit", "wing" etc. reinforce the very idea you are trying to eradicate.) If you can feel a real difference in the feeling and flavor of the social fabric created by residents and staff, you are on the right track. When there is honestly little difference between neighborhoods other than the decorations on the walls, you need to keep trying.

2. **Management philosophy.** Remember the golden rule of facility management. "As management does unto staff so shall staff do unto residents." As I travel and lecture I find facility operators all over the country who tell me that dignity, self-determination and respectfulness are the key words that describe how they want staff to treat the residents. Can you truly say that these are the hallmarks of management in your facility? Is there a gap between what your managers are saying and what they are doing? If there is, it is your residents who will be paying the price.
3. **Think like a naturalist.** When an ecologist sets out to study the health of a natural habitat one of his first tasks is to count the number of species living there. All other things being equal, the greater the number of species a habitat supports, the healthier the environment. In

other words, increased diversity increases the capacity to sustain life. What if I came to your facility and conducted a species count? What would I find? In the conventional nursing facility Homo Sapiens is king and he is a lonely sovereign. As a world maker you must think of building a diverse, vibrant, healthy human habitat. Plants, animals and children should be present in abundance. Make every attempt to fill your facility with the sparkle and spontaneity that come with living things and the first thing you find is that you will become better givers of care. More importantly, you will have provided the soil in which companionship, meaning and the joy of daily life can grow. Help your residents enjoy a life worth living by surrounding them with lives being lived.

4. **Be a better neighbor**. Conventional long-term care facilities are often poor neighbors. The lack of contact between community and facility is most often due to a lack of a middle ground where the people can meet and interact. Visitors will often comment that visits are difficult because there is so little to talk about. One administrator of an Edenizing home told me the story of her regular Saturday visit to the facility to make rounds. Such visits had been her habit for years. Not long after starting the Eden Alternative process she began to notice that her usual parking spot was often taken. As the months went by she found the lot was often full of the cars of resident families and friends. Families were visiting more often because her home was also home to thousands of green growing plants, over two hundred birds, as well as dogs, cats and a nursery school. She had created a middle ground that staff, residents and visitors could all share.

The long-term care market is changing quickly and unpredictably. Winners will be those who recognize the central role design will be playing in the years ahead. Physical surroundings must move decisively away from the nursing station oriented medical model. We know that. Beyond that given, I believe that approaches like the Eden Alternative will increase the demand for surroundings that can also be home to a huge array of plants, animals and children. We have kindergartens, we need eldergartens. Finally, remember that you must also take out a clean sheet of paper when you reconsider the way you structure, manage and deploy the people who provide the hands on care. Conventional top-down management systems stymie change and hobble your progress into the new age of long-term care.

I wrote a book called *Life Worth Living: How Someone You Love Can Still Enjoy Life In A Nursing Home.* It was published by VanderWyk and Burnham in the fall of 1996. The idea behind the book is to give the reader a detailed introduction to the principles and practices of the Eden Alternative. There are now well over a hundred facilities all across the country that are building their own human habitats. By the year's end we will have trained more than 150 Eden Alternative Associates who are encouraged to teach, think and write about the Eden Alternative approach. Our goal? Simple. We want to change the way America thinks about nursing homes. Forever.

The Ten Principles of
The Eden Alternative

Guidelines for an Edenizing Home

he following are The Eden Alternative's 10 Principles with interpretive breakdowns developed by our Certified den Associate Miriam Stermer of Charlotte, N.C. We feel that this is an excellent guideline for long term care omes to self-evaluate themselves AND to assist family members or others in determining if a facility is an denizing home.

. **Understand that loneliness, helplessness and boredom account for the bulk of suffering in a typical long term care facility.**
- What companionship is provided to combat loneliness?
- What opportunities are residents provided with to give care rather than just receive care?
- What measures are being taken to create spontaneity in the daily lives of the residents?

. **Commits itself to surrendering the institutional point of view and adopts the Human Habitat mode which makes pets, plants and children the axis around which daily life in the facility turns.**
- Are plants, animals and children promoting growth among residents?
- How many and what kinds of animals are living in the facility?
- How are residents encouraged to participate in the daily care of the animals?
- Are there any artificial arrangements in the facility?
- Are there living plants in the facility and are residents encouraged to have plants in their rooms?
- Are there gardening opportunities made available to residents?
- Are residents engaged in **meaningful** activity with children or do they mainly observe?

. **Provides easy access to companionship by promoting close and continuing contact between the elements of the Human Habitat and the residents.**
- How many residents share a dog or cat?
- Are residents encouraged to have birds and plants in their room?
- Are residents encouraged to help care for their birds and plants?
- Are there any aviaries and are the aviary birds the only birds in the facility?
- Are opportunities provided for residents to develop one-on-one relationships with children?
- How often do children visit and to what extent do residents engage in **meaningful** activity with the children OR do they mainly observe?

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. **Provides <u>daily opportunities to give as well as receive care</u> by promoting resident participation in the daily round of activities that are necessary to maintain the Human Habitat.**
- Are residents encouraged to participate in the daily care of the plants and animals to the maximum extent possible?
- Are the residents encouraged to participate in the birdmobile rounds?
- Are residents given opportunities to interact with children on a daily basis!
- Are the residents given an opportunity to help children to grow? (ie: reading)

. **Imbues daily life with <u>variety and spontaneity</u> by creating an environment in which unexpected and unpredictable interactions and happenings can take place.**
- Are all of the elements (plants, animals, and children) present in the facility?
- Is there a variety of different children?
- Is there variety in animal breeds, sizes and colors, etc.?
- Are there different kinds of plants in resident's rooms and throughout the facility?

. **<u>De-emphasizes the programmed activities</u> approach to life and devotes these resources to the maintenance and growth of the Human Habitat.**
- How are the activities staff being utilized to support the Edenizing process?
- Are the activities staff placing less emphasis on scheduled activities and encouraging residents to participate in the Human Habitat?
- Are the activities staff placing less emphasis on scheduled activities and encouraging residents to participate in the Human Habitat?
- Are the activities staff integrating the Edenizing process into the daily lives of the residents?

. **<u>De-emphasizes the role of prescription drugs</u> in the residents' daily life and commits these resources to the maintenance and growth of the Human Habitat.**
- Does the facility have a program to insure residents are receiving only needed medications?
- What is the facility's policy regarding the use of chemical restraints?
- What interventions are being used to address residents' behavioral issues?

. **<u>De-emphasizes top-down bureaucratic authority</u> in the facility and seeks instead to place the maximum possible decision-making authority in the hands of those closest to the residents.**
- Are employees able to state the purpose and intention of The Eden Alternative?
- Are Planning Teams consisting of residents, family members, staff, and community members) in place in the nursing home?
- Are Teams & Team Leaders provided with the training and resources to insure success in their role?
- Are Teams meeting on a regularly scheduled basis?
- Are Team members required to attend Team meetings?
- Are Teams interdisciplinary in nature to the maximum extent possible?
- Are Teams empowered to make decisions within their defined parameters?
- Are Teams working with residents to encourage them to participate to the maximum extent possible?

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9. **Understands that Edenizing is a <u>never-ending process, NOT a program</u> and that the Human Habitat, once created, should be helped to grow and develop like any other living thing.**
    - Have the Board of Directors and/or owners gone on record publicly in support of The Eden Alternative?
    - Is there evidence of community involvement?
    - Is the facility committed to the ongoing development of the Human Habitat?
    - What resources have been committed to the Edenizing process?

10. **Is blessed with <u>leadership that places the need to improve resident quality of life over and above the inevitable objections to change</u>. Leadership is the lifeblood of the Edenizing process and for it there is no substitute.**
    - What support is provided by the Board of Directors, owners and/or Medical Director?
    - Does the Administrator understand the difference between a "fur and feathers program" and The Eden Alternative philosophy?
    - Is the Administrator leading the Edenizing process?
    - What steps have been taken to include residents, families, community and employees in the Edenizing process?
    - Have ALL employees received the education needed to make the Edenizing process successful?
    - Does the Administrator support the Planning Teams?

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APPENDIX D
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APPENDIX E

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