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Sustainable Culture Change for Persons with Dementia in the Nursing Home: An Ethnographic Study of a Relationship Model Strengthened by Staff Training and Peer Support

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Final Report for

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This final report summarizes a multi-faceted research project that studied a two part culture change intervention in three long term care facilities using two distinct methodologies. The New York State Department of Health's format for a final report readily accommodates simpler projects. However, because of the complexity of this project, changes to the standard format are required. All of the information required by the New York State Department of Health in the final report is included in this report, but is presented in a format that differs only slightly from the standard format. An index to the final report presented below serves to orient readers to the overall report and to direct them to various portions of the report. Similarly, the complexity of the report requires that the final report exceed the 30 page limit by several pages.

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FINAL REPORT

I. Aims and Design

A. Aims

The project had four specific aims. They were (1) to implement a relationship-based model of culture change training and interventions, (2) to derive a model of new culture components based on variables that emerged in the course of observing and evaluating three nursing homes undergoing culture change using ethnographic methods, (3) to evaluate quality of care and quality of life outcomes of the culture change training and intervention program for residents and staff using both quantitative and qualitative methods, and (4) to produce a set of recommendations that will assist leaders seeking to initiate and sustain culture change in their long term care facilities.

B. Design

This project used both quantitative and qualitative longitudinal methods to develop a model of sustainable culture change in the nursing home (Aim #2) and to evaluate the impact of the culture change intervention (CCI) on three units in three nursing homes from the perspective of participants (Aim #3). Quantitative measures of resident functioning (cognitive, ADL, behavior, social, emotional) were gathered at baseline, 6 months and 1 year post-intervention implementation. Qualitative research began in Month 1 of the project and continued through Month 18, and included participant observation, ethnographic interviews and case studies. Interviews were conducted with participating facility staff, (cognitively capable) residents, their family members and Intervention consultants at multiple time points during the project. Participant observation of all participating staff was ongoing throughout the project, and case studies of selected staff, residents, and family members occurred at key points during the Intervention.

II. Background

A. The Literature

A brief review of the literature relevant to each aim of the project provides a context for the findings and recommendations of this report.

Aim # 1. Culture change through a relationship-based model using experiential training and peer support.

This Intervention was based in part on a previous grant funded by the New York State Dementia Program entitled "Cultivating Culture Change Catalysts" (1998 – 2000). This grant identified, trained, and supported an "indigenous change agent" in three nursing homes. Results of the study demonstrated that the Intervention was effective in reducing resident agitation and depression over the two-year period of study. However, "lessons learned" from that project suggested means of improving the Intervention that would result in an even greater enhancement of quality of life and quality of care for residents with dementia.

En suite, the project reported on here sought to enhance direct care staff training by using a curriculum of varied content and innovative teaching techniques, such as didactic instruction, exposure to new culture care at area facilities and "hands-on" experience with new culture care behavioral models. Experiential training – or "coaching" – has been demonstrated to be more

effective than didactic training for learning new skills (Burgio & Stevens 1999; Schnelle, Newman & Fogarty 1990). The Alzheimer's Association has developed a curriculum to facilitate this "coaching" process.

It was anticipated that a key element in sustaining the Intervention would be the introduction of internal and external peer support groups for front line staff. Over the past 30 years, in a wide range of organizational contexts, there has been an explosion of interest in structured peer support groups as a means of assisting people facing difficult situations, increasing competence, and in achieving higher morale. Support groups for families caring for relatives with Alzheimer's disease, new mothers' groups, work place discussion groups are examples and have been shown to enhance quality of life and quality of work (Oshry,1995).

Not surprisingly then, certified nursing assistants (CNAs) – the mainstay of care in nursing homes – are also likely to benefit from peer support and the importance of peer support for CNAs is widely recognized. For example, strong peer relationships among CNAs has been associated with higher quality care-giving performance (Foner 1994a; Anderson, Raird & Haslam 1991). Further, when CNAs receive peer support, they have been shown to have stronger ties to their job (Gipson 1999) and to perceive themselves as significantly helped in their work (McCracken & Gilster, 1992). Gipson's (1996) report on CNAs' thoughts about the meaning of having a peer gives a personal voice to these findings in the following quotes: "It's someone to talk to when you have a problem with a resident", "You help each other stay on the job through difficult and unpredictable times", "I don't have to feel that I am alone in this", "It's nonjudgmental acceptance. In response to these and similar findings, the New York State Certified Caregiver's Association (supported by the Pioneer Network) was created as a support group for CNAs. In the context of culture change, it has been shown that frequent peer support group attendance is an important element in sustaining a culture change initiative (Teresi, Holmes, Ramirez & Kong 1998).

Aim #2: Developing a New Model of the Components of a New Culture

Over the past decade, a significant amount of work has been focused on improving the quality of care and the quality of life of residents in long-term care settings. Meeting the "special care" needs of people with dementia has received special emphasis (Maslow & Ory 2001), yet despite our current knowledge, a new focus is clearly necessary to produce real and lasting change. Kitwood (1997) called for a re-conceptualization of our approach toward dementia both as a disease and as a care-giving experience, replacing our current bio-medical, task orientation with person-centered, relationship-based care. To achieve this aim, he argues, we must go "far beyond piecemeal improvements in care practice, better staff development, the more efficient running of organizations and the like" (Kitwood 1997: 133) and strive for a cultural transformation. For Kitwood, culture is a patterned, meaningful way of life that structures how each feature of care-giving is understood. His vision was a culture of care that emphasizes each person's uniqueness, personal experience, accomplishments and relationships. Others concur with Kitwood's vision even while expressing nuanced differences on the components and focus of a new care culture and the methods for creating it. For example, the Pioneers focus on the role and value of the nursing assistant staff in returning the locus of control to residents (Lustbader 2001; Unsino, 1999). The Eden Alternative focuses on creating an interactive living environment with plants, animals and children (Fagan, Williams & Burger 1997) and Joanne Rader focuses on the psychosocial environment to best meet the needs of the residents with dementia (Rader 1995).

Despite these differences, developing a personal, respectful, and caring relationship between resident and care-giving staff is the common goal. To reach this goal, the organizational culture must direct its effort to developing, supporting and sustaining that relationship. It requires the combined efforts of all the stakeholders in the community of care that makes up the nursing

home – residents, family members, nursing assistants, nurses, activity therapists, administrators, and so on. Past studies of culture change processes have tended to focus on one or two groups to the exclusion of others. This approach contributes to the body of knowledge about how culture change may affect a particular group, but it does not advance the field in terms of understanding the fundamental complexity of interrelationships between the participant groups. In fact, if person-centered culture change is ultimately construed to be about relationships between participant groups, then it can be argued that true culture change only occurs when there is a synergy among the participant groups. Knowledge about this synergy would be considerably advanced by a model of culture change specific to the nursing home organizational system that simultaneously represents all participant groups. Such a model would allow future studies to test specific hypotheses and linkages between different participant groups. Such a model would also provide a rich foundation for developing "best practice" recommendations for facilities interested in initiating and sustaining culture change interventions.

B. Project Rationale

The study of culture change in long term care settings is a young field of inquiry. The studies reviewed above contribute to the literature, but there remains a fundamental lack of consensus about culture change as a concept – what is it? How is it defined? Definitions of culture change abound and often conflict with one another. For example, some view culture change as an inherently organizational concept, while others regard it as a programmatic effort. Further, what is a culture change intervention? What shape does it take? How long does it take? What outcomes should be measured? What does success look like? How should culture change best be studied? Ethnographic inquiry – a qualitative approach adopted from cultural anthropology – lends is well-suited to the exploration of newly articulated, poorly understood, and little researched areas of inquiry such as culture change (Rubinstein, et. al. 1991). This final report presents research that was the first of its kind to examine a culture change intervention and its outcomes using ethnographic methods.

C. Description of the Facilities

Three facilities originally agreed to participate in the culture change intervention project. Due to the significant delays resulting from the events of September 11, 2001, one of the original participating facilities withdrew from the project. Finding an appropriate replacement further delayed the initiation of the project.

Prior to participating in the study, each facility had demonstrated a commitment to serving the special needs of residents with dementia through the development of specialized programs designed to foster change in the culture of dementia care at the facility. All three facilities were JCAHO accredited and based in an urban setting. None of the units involved in the study were labeled a dementia special care unit, though all had persons with dementia residing there. Throughout this report, the facilities will be labeled as Facility 1, 2 and 3.

Facility 1 was established in 1975. It is a 189-bed, free-standing, proprietary skilled nursing facility located in Brooklyn. Facility 1 offers a variety of specialized programs for long term care, short and long term rehabilitation and memory disorders. It was one of the first facilities in New York to implement an innovative dementia group program in conjunction with the Alzheimer's Association of New York City. As such, it has a large amount of historical experience with the initiation of culture change programs related to dementia.

Facility 2 was established in 1976 as a voluntary, nonsectarian health care facility, also located in Brooklyn. It is part of a larger organization that provides care across the long-term care

spectrum. Facility 2 has the capacity to care for 520 adults requiring skilled nursing care. Facility 2 has a history of developing programs to meet the diverse needs of the community, e.g. a restorative rehabilitation program, a residential dialysis unit, a medical sub-acute unit and a pain management ~ palliative care program. While Facility 2 did not have specific experience working with the Alzheimer's Association of New York City, it had implemented innovative dementia programs in conjunction with other sources.

Facility 3 was founded in 1975 as a 204 bed non-profit skilled nursing facility embedded within a hospital system. Facility 3 specializes in both short term rehabilitation and long term care. Like Facility 1, Facility 3 had previous experience implementing an innovative dementia group program in conjunction with the Alzheimer's Association of New York City.

III. Description of the Intervention

A. Characteristics of the Culture Change Intervention

The Culture Change Intervention mounted in this project was a complex set of environments, participants and activities aimed at developing, introducing and implementing a change in the culture of care at the participating facilities. Each aspect will be described below.

B. Description of the Intervention Units

The Intervention units were selected by the facility administrators in conjunction with the Intervention Consultant.

Facility #1 – The intervention unit had 40 beds, and was widely recognized and spoken of in the facility as the "best unit". Many unit staff members had worked together for almost a decade and were characterized as a "great team". The unit supervisor was a 19 year veteran who was affectionately and respectfully acknowledged at the facility for the strong guidance and support she gave to her staff. Two other units were considered for participation, but after considerable – and often contentious – debate, this unit was selected by administration, nursing management and the Intervention Consultant.

Facility #2 – The intervention unit had 40 beds, and was regarded as a "good but difficult unit" in the facility. Morale was low on the unit at the time of the intervention. Staff felt that they were the unfairly designated recipients of residents "nobody knew what to do with". In addition, factions among the front line nursing staff complicated unit team-work and often created a tense atmosphere. However, the unit had participated in previous projects aimed at "building community", and was guided by a highly respected unit supervisor with strong leadership skills and considerable personal charisma.

Facility #3 – The intervention unit had 50 beds, and was regarded in the facility as the "heaviest care unit". Many unit residents required heavy rehabilitative care that taxed front line staff resources, and high resident turnover depleted staff's emotional reserves. Morale was low. However, the unit supervisor was well-liked and respected on the unit and deeply concerned about her staff's low morale.

These units did not vary significantly from each other in terms of overall environmental quality indicators (as measured by the Therapeutic Environmental Screening Scale: Sloane & Matthew 1990), amount of staff turnover (e.g. over the course of 18 months only 4 front line staff from all three units turned over), or on any element measured in the overall organizational quality survey (OQS 2001).

C. Participants in the Intervention

A large number of people participated in this project. All together, 11 different categories of participants played a role in the project, and many of the participants had several roles during the life of the project. Participants included staff from the three nursing homes, residents and their families, consultants from the Alzheimer's Association New York City Chapter, additional local training and process consultants and research staff from the Abramson Center in North Wales. PA.

Description of the project's complex participant structure will be anchored around the intervention's participant roles. Each role will be described and the staff or others who filled those roles will be identified.

1. The Alzheimer's Association intervention consultant

Formally affiliated with the Alzheimer's Association, the intervention consultant had special training in and extensive experience with identifying, developing, and implementing dementia group programming in long term care facilities in the greater New York City area. In this project, his objective was to learn each facility's unique culture in order to develop and implement a dementia group program individually tailored to respond to each facility's needs and to capitalize on its strengths. In the initial months of the project, the intervention consultant introduced culture change concepts to participants at the three facilities, working with the project coordinators and administrators at each facility to assemble a group of staff that expressed interest in developing new programming consistent with the intervention's goals. Over the months of the project, the intervention consultant organized, escorted, coached and encouraged participating staff through the various activities of the intervention. In the closing months of the project, he served as a link between facilities in laying the foundation for a peer support network that would help sustain the program.

2. Training consultants

Several training consultants conducted the guided discussions at the facilities, and the 4 week training sessions at the Alzheimer's Association Manhattan chapter offices and the second wave of on-site trainings at each facility. With backgrounds in social work or the mental health professions, these consultants had experience-based knowledge about culture change in long term care settings, particularly with reference to dementia care. They were skilled in facilitating interpersonal and small group interactions and had expertise in teaching group work and leadership skills to others.

3. Process consultants

The process consultant helped group co-leaders develop and enhance their skills in working with residents through direct observation of them at work co-leading their groups, hands-on coaching during the program activity and in discussion with them about it afterward. (See Section D5 for a description of the "hands-on" trainings.)

4. Program coordinator

At each facility, the intervention activities were overseen, coordinated and implemented by a "program coordinator". The program coordinator was a department head, appointed by the facility administrator to fulfill this role. The program coordinator was a pivotal member of the Intervention team, providing supervision and support for project participants on the intervention units. She worked closely with the program consultant in scheduling and implementing the

various intervention activities. Similarly, she worked closely with nursing supervision on the intervention units to coordinate staff schedules with core team meetings and various training schedules. She assumed a central role in guiding and conducting the weekly core team meetings – assisting, supporting, encouraging and problem solving for core team members as they developed their dementia group programs. She served as liaison between participants on the intervention units and the facility's administration. She was also responsible for project related record keeping and for facilitating the research staff's execution of its various quantitative data collection tasks.

The program coordinator's role was configured differently in each of the three facilities, with different numbers and different disciplines represented. And, at each facility, there was a change in leadership in this role during the life of the project.

- § At Facility 1, the initial program coordinator was the Director of Social Work. She left the facility in the early months of the project and was replaced by the new Director of Recreation Therapy who remained as coordinator for the remainder of the project.
- § At Facility 2, there were two initial program coordinators the Director of Social Work and the Director of Recreation Therapy. At the end of the first year of the project, the Director of Social Work left the facility. The Director of Recreation Therapy continued on as the sole coordinator for the remainder of the project.
- At Facility 3, there were three program coordinators at the outset of the project the Director of Social Work, the Director of Speech and Hearing Therapy and the Director of Recreation Therapy. At the end of the project's first year, the Director of Speech and Hearing Therapy left the facility. A few months later, the Director of Social Work took a new position within the organization but resigned her post as coordinator. The Director Recreation continued as the sole coordinator for the remainder of the project.

5. Core team members

By the middle of the first year of the project, a cadre of participants had emerged from the group of people who expressed interest in the early months of the project. These individuals participated in intervention activities regularly and attentively, and were referred to as the "core team members". The responsibilities of the core team members were to develop and implement an organizational structure that would permit them to design, develop and then implement a dementia group program. (See Section D.4 for a detailed description of core team meeting activities.) The facilities varied in the disciplines represented by core team members:

- § At Facility 1, the core team members were the recreation therapist assigned to the designated intervention unit, two CNAs, a 2nd recreation therapist assigned to another unit in the facility, the program coordinator and the intervention consultant.
- § At Facility 2, the core team members were the recreation therapist, 5 CNAs, the unit supervisor, the nursing supervisor, the social worker, the 4th floor dietician, the program coordinator and the intervention consultant.
- § At Facility 3, the core team members were the recreation therapist, 6 CNAs, the unit charge nurse, the social worker, the dietician, the program coordinator and the intervention consultant.
- 6. Dementia group co-leaders

Dementia group co-leaders were the two core team members who conducted — or "co-led"— the residents in the new dementia group programming activities. Co-leaders worked in pairs, with one person leading the group collectively in conversation, and the other person speaking individually with residents, drawing them into the group activity. (See Section D.6 below for a detailed description of the dementia group program concept, purpose and activities.) Although the dementia group program co-leadership role was open to staff at any level in any discipline, in actuality, at each facility, the co-leaders were the recreation therapist assigned to the unit and a nurse aide. Identifying the aide who would "go into the dayroom" — i.e. share group leadership with the recreation therapist — was a central task of the core team at the end of the project's first year.

7. Co-leader back-ups

When a co-leader is absent from the dementia group program in the dayroom, there must be a replacement or "back-up" co-leader who can "step in and run the program". Consequently, "back-ups" were core team members and were identified simultaneously with the co-leaders. They participated fully in the intervention activities. They were typically CNAs, but a dietician, a charge nurse, and another unit's recreation therapist also served as back-ups.

8. Ancillary and peripheral staff

A number of staff members played ancillary or peripheral roles in the intervention activities overall. They were the facility owners, the nursing home administrator, the director of nursing, director of housekeeping and other department heads. They participated infrequently or not at all in intervention activities. However, because they had the authority to agree to the staffing changes and resource re-allocations that the intervention activities required and to resolve problems when they arose, they were essential to mounting the intervention.

9. Residents

Participation in the dementia group program was limited to approximately 25 residents on each intervention unit. Residents were selected for participation by the intervention units' core team members. Staff's selection criteria were grounded in their extensive knowledge about their residents and were, to a certain extent, highly individualized. However, some general guidelines were invoked by all. Residents recommended for participation were felt by staff to be:

- § Physiologically capable able to speak, able to make eye contact, ambulatory in some form
- § Cognitively "reachable" on some level ~ would benefit by more intense level of social interaction
- § Perception that resident "could do more with extra attention" than is customarily doing
- § Contribute to the overall balance of cognitive functioning capabilities
- § Tolerant of others' challenging behaviors
- § Have behaviors that inhibit care staff functioning
- § Physically aggressive or extremely anti-social residents were inappropriate candidates

10. Family members

Overall, the majority of residents' family members were peripheral participants in the project. The majority of family members were contacted twice about the intervention. At the outset of the project, each facility's social work staff notified all residents' family members by letter that a culture change intervention would take place on their relative's unit. Later, the family members of residents selected for participation in the intervention research component were contacted in

order to gain their informed consent on behalf of their relative who could not consent for himself or herself. Twenty family members participated in the intervention as research interview respondents.

D. Intervention Activities

This section enumerates the multiple and complex activities that comprised the Intervention. All of the activities were designed to communicate and reinforce culture change values by

- § combining institutions, discipline and staff levels to disrupt the traditional nursing home hierarchy
- § creating a setting in which trust relationships could be developed and flourish
- § clarifying and enhancing participants' sense of need for better relationships between staff and residents and between staff
- § demonstrating that participants were dependent on each other to begin the process of change

The nature of each activity is first described and then its purpose as a culture change mechanism is addressed. Participants' evaluations of these activities are discussed in Section IV.E of this report.

1. Information-disseminating meetings (e.g. "kick off meetings", project presentation meetings)

Two types of discussion activities presented information about the project to the people who were expected to be involved in it – "kick off meetings" and project presentation meetings. These activities shared the objective of informing staff about the new project, presenting to them information about it, and explaining their roles in it. However, participants in the two activities differed.

In the months prior to the actual start-date of the project, a "kick off meeting" was held at each facility. Participants were the facility's administrator and owners, department heads from all disciplines, nursing supervision, the program consultant, process consultant, program coordinator and the research group. At this meeting, the nursing home administrator introduced the project to the assembled group, explained the history, purpose and goals of the project, and identified which units were being considered as candidates for the intervention. The program consultant explained the concept of the dementia group program and outlined the process of its implementation. The research group explained their role in the project and reviewed the research related activities they would engage in. The meeting was then opened up for questions, answers and discussion. Similarly, in the early months of the project, the project was presented to the direct care and other staff on the intervention unit at each facility. Participants included the nursing home administrator, program consultant, program coordinator, the intervention unit's nursing supervision, CNAs, housekeeping and maintenance staff, recreation leader, social worker and the research group. At this meeting, the nursing home administrator introduced the project to the staff, explaining that their unit had been chosen as the intervention unit. The administrator explained the history, purpose and goals of the project. The program consultant explained the concept of the dementia group program and outlined the process of its implementation. The research group explained their role in the project and reviewed the research related activities they would engage in. The meeting was then opened up for questions, answers and discussion.

2. Information-gathering activities (e.g., administrative meetings and guided group discussions)

Two types of discussion activities sought to gather information from project participants – administrative meetings and focus groups. These activities had different topics and different participants. At each facility, administrative meetings were conducted by senior staff responsible for the intervention, namely, the project consultant, nursing home administrator, nursing administration, nursing supervision and project coordinators. These participants met in the early months of the project to share information about the units which had been chosen to participate (Facility 2 and 3) or were being considered for the intervention (Facility 1). The unit's "culture" or "personality" was discussed, its strengths and weakness reviewed, potential problems related to the intervention were anticipated and goals identified.

At each facility, guided discussions were conducted with direct care staff and nursing supervision in the early months of the project. Referred to as "focus groups", these were semistructured but open-ended discussions conducted by an outside process consultant. At each facility, 8 to 10 staff from the intervention unit – including CNAs, recreation leaders, nursing supervision, social work and the project coordinator – met in a conference room to participate in the group discussion. The focus groups typically lasted about 2 hours and a meal or refreshments were served during the discussion. The groups addressed different topics at different points in the project. For example, at the outset of the project, the purpose of the group was to learn and explore with direct care staff their perceptions of and reaction to the quality of care on their units, the quality of current recreation programming, the quality of their work lives, their relationships with co-workers and aspects of their daily life on the unit they would like to change. As part of the discussion, the process consultant recast participants' comments in language that reflected culture change values, such as "teamwork", "teambuilding", "trust relationships" and so on. The guided discussions were repeated at subsequent points during the project with new staff participants as part of the on-site training component of the project. (See Section D7 below for discussion of the on-site training component.)

3. Site visits

A site visit was a field trip made by the core team and the program consultant to visit another local nursing home where an established, successful dementia group program was in operation. Depending on the coverage available on their units, the core team went as a whole group or as two smaller groups on two separate days, traveling to the site by car or public transportation. At the site, they observed and participated in the host facility's morning dementia group program. After the observation period, the core team met with the host facility's program leaders to ask questions and discuss what they had seen. Then, the core team members adjourned to have lunch together and to talk further about their perceptions and reactions to what they had seen. The purpose of the site visits was to introduce participants to "the feeling" of the culture change experience and to expose them to a successful dementia group program (DGP). Watching other DGP leaders "run" their programs and then talking with them about it helped illustrated for project participants what a successful program "looked and felt like". Talking with each other about their observations, comparing reactions, contrasting perceptions, and exploring feelings with their co-team members made the experience real and illustrated what a successful dementia group program looked like. Core teams functioned as a team for the first time when they went on a site visit. The shared experience followed by shared discussion was intended to serve as relationship building activity. Site visits also represented an important short-term goal that the core team could achieve and celebrate. Each facility's core team members made three site visits to the dementia group programs of other New York area nursing homes. Since both Facilities 2 and 3 already had established DGPs on other units in their facilities, core team members from these two facilities made their third site visit to the program in their own facility.

4. Core Team Meetings

In the weeks following the guided discussion groups and while the site visits were underway, staff on the intervention unit at each facility began to hold meetings. The program consultant, the program coordinator, unit nursing supervision, recreation leader and social worker were present at every meeting and participation was open to any unit staff that was interested. During the early months of the project, attendance at the meeting was variable – different unit staff from different disciplines (i.e. CNAs, Housekeeping, Maintenance, Dietary) came to some meetings but not to others. As the project progressed, a group of individuals emerged as interested, regular participants and were referred to as "core team members". The "core team meeting" took place in a private area on the unit, at a fixed time, on a weekly basis. Minutes were taken and attendance was noted. Core team members were expected to attend consistently, to be punctual and prepared for meetings.

The core team meeting was envisioned to be an important mechanism of the change process as well as a practical activity. Its purpose was three-fold. In its formative stage, the aim of the core team meeting was to "get everybody on the same page" about the practical aspects of starting a dementia group program, for example, deciding what new programming would be introduced, discussing who among the unit staff would participate in the new programming, managing staff scheduling and coverage for work assignments and so on. As the project progressed, the core team meeting was also intended to serve as a problem solving mechanism by which members identified problems, aired their views and discussed solutions. Finally, the meeting was expected to represent an important opportunity to provide "peer support", that is, for members to talk about their experiences with the intervention, develop their sense of trust in each other as co-workers, and to reinforce their sense of a need for change.

5. The "Trainings"

A number and variety of didactic, experiential and in-situ activities were an important part of the Intervention. These activities were collectively referred to as "trainings" by participants.

The Four Day Workshop. A central training component of the Intervention was "Understanding Dementia: A four-day Workshop". Sponsored by the Alzheimer's Association, the Workshop was composed of 4 day-long sessions held on 4 consecutive weeks at the New York City Chapter of the Alzheimer's Association in downtown Manhattan. Participants left their facility to spend the day at the training session's location. Beginning at 9 am and ending about 3 pm, the training sessions were organized around structured and unstructured activities, punctuated by opportunities to talk, eat and relax at breaks and meals. Work assignment coverage for participating direct care staff was provided at each facility, and participants' transportation and meals were paid for by their facilities.

Participants in the training sessions were the interdisciplinary core team members from each facility and the program consultant. Although the training was open to the facilities' administrators and nursing management, their participation was limited.

The sessions were conducted and facilitated by two process consultants or facilitators, referred to as "trainers". In conjunction with the program consultant, they designed the structure, content and activities of the sessions based on the intervention's objectives. Using both didactic and interactive methods, they communicated the information-based parts of the training, conducted exercises and activities aimed at helping participants define, develop and practice relationship-based, interpersonal skills consistent with the intervention's objectives.

The training addressed a variety of content areas salient to the intervention. The sessions provided factual information about Alzheimer's disease and other dementias, offered practical guidance about how to work with nursing home residents who have dementia, exposed participants to the culture change aspect of dementia group programming and assisted participants in learning, practicing and gaining confidence with new interpersonal skills. For example, activities included exercises designed to help participants explore the concept of "what is therapeutic" for residents with dementia, "hands-on" demonstrations of dementia group program activities (e.g. baking cookies, making an abstract art mural, song and music activities), one-on-one and small group exercises to introduce participants to small group dynamics, learn, develop and evaluate co-leadership skills, and trust-building activities to help participants feel comfortable with each other. Copies of the 4 training sessions' agendas are included in Appendix B of this report.

TimeSlips Trainings. The core team members at each of the facilities received training in the TimeSlips process. The 10 week on-site training was conducted by facilitators from the National Center for Creative Aging: Elders Share the Arts located in Brooklyn, New York. Developed by Anne Basting in 1998, TimeSlips is an hour-long, group storytelling activity for individuals with mid stage dementia. In the nursing home setting, two facilitators work with a group of residents to create a story that is based on an interesting photograph. One facilitator asks open-ended questions about the people and the activity shown in the photograph and residents respond to the questions and the photograph, giving their thoughts, reactions and impressions. As they do so, the second facilitator, referred to as "the scribe", writes their statements down on a large pad of paper mounted on an easel. As responses accumulate, they are woven into a story by the facilitator. Every few minutes, the scribe reads the story back to the group, attributing each statement to the person who said it. When the story is completed and given a title, it is read back in its entirety to the group. Later, the scribe types up the story and places it in a binder to form a "book" of residents' stories. The activity encourages residents' creative response, from the poetic to the nonsensical, and offers the opportunity for person-centered interactions between staff and residents and between residents. More information about TimeSlips can be found on the web at www.timeslips.org.

The "Coachings". The core team members at each of the facilities received a 6 session, on-site experiential training. These trainings, referred to informally as the "coachings", were conducted by facilitators from the NCAA TimeSlips program. This demonstration and discussion training had two formats. In one training format, a facilitator observed the co-leaders running a program in the dayroom. In a naturalistic manner, the facilitator interacted with the co-leaders – offering suggestions, directions, coaching – while the activity was in progress. In the other training format, the co-leaders observed the facilitators running a program in the dayroom. In both formats, immediately after the group activity, the facilitators and the co-leaders met to conduct a debriefing. The facilitators offered constructive critiques of co-leaders' handling of the activity and answered co-leaders' questions about what they had observed. Co-leaders discussed what they learned from the activity, their concerns and issues about leading the group, and their perspectives on the activity.

"Hands-on" trainings. Core team members at Facility 1 requested and received an additional set of trainings in aroma therapy, hand massage and yoga.

The Second Wave of Trainings. In each of the facilities, there was staff on the intervention units who were interested in the intervention but were unable to participate in the Workshop, TimeSlips or Coachings, particularly staff on night and weekend shifts. In order to expose these interested staff members to the intervention, a "second wave" of trainings was conducted late in the last year of the project. These trainings were less formal than the initial trainings and were composed of a guided discussion and three subsequent 4 hours sessions that provided factual information about Alzheimer's disease and other dementias, offered practical guidance about working with residents who have dementia, discussed the culture change aspect of dementia group programming and conducted interpersonal and small group dynamic exercises.

6. The Dementia Group Program

Dementia Group Program refers to a recreational activity for nursing home residents with cognitive impairment. It is designed to be meaningfully entertaining and stimulating for them. More importantly, however, it is intended to foster a quality of interpersonal interaction between participants that has a therapeutic outcome for *all* involved – residents and staff.

Core team members were expected to develop, introduce and conduct a daily dementia group program in their facilities. Regarded as a culture change initiative, the dementia group program represented an additional intervention within the broader framework of the culture change project. In this section, the overall design of a dementia group program is discussed and its purpose as a culture change initiative is outlined.

While each facility's program developed within its own individual environment and reflected the needs and interests of its participants, the programs shared common features. Each program was located in the facility's dayroom and was "run" between the hours of 10 am and 3 pm on weekdays. The program room's furnishings and décor varied according to the facility's resources, the activities agenda, and the personal tastes and talents of the core team members. Approximately 25 residents participated in each facility's program, seated facing each other in a large circle or around a table. The unit's assigned recreation therapist and a nursing aide jointly conducted the activity—referred to as "running a program" or "leading a group". The recreation therapist and aide were referred to as "co-leaders" of the group. While an activity was in progress, the program room was "off-limits" for care-giving tasks. Staff members not participating in the program were discouraged from interrupting the program to remove a resident or to provide routine care. Program content varied according to the established activities agenda at each facility, although the TimeSlips training was adopted by each facility as a result of the training. Content was selected and developed to be meaningful, stimulating and entertaining for residents. The process of co-leading the group activity was dynamic and interactive. Working together and using a variety of interactive strategies, co-leaders actively engaged residents in conversation. No one was excluded, and the overall tone of the group interaction was energetic, exciting and "fun". The content of the activity served as a springboard into deeper, shared talk about personal feelings, experiences, beliefs and values. As residents and co-leaders shared their feelings and personal experiences, a "feeling" of emotional connection between residents and between residents and staff often emerged in the course of the program activity.

The "feeling" of emotional connection was regarded as the therapeutic component of the dementia group program. As a culture change intervention, its purpose was to increase the frequency and quality of these moments of emotional attunement between participants. Through daily, high quality interaction between residents and staff *and* between staff members,

relationships of mutual trust were anticipated to develop that would enhance the quality of life for both residents and staff.

7. The Hostings

The "Hosting" combined a site visit with a "hands-on training" and came at the end of the two year period covered by the dementia grant. Program participants from one facility invited their counterparts in the other two facilities – hence the name "Hosting" – to join them for a morning of observation and discussion about the dementia group related programming they had developed as part of the project. Participants in the Hosting were the recreation leaders and CNAs that had participated in the program throughout the length of the project, attended the various trainings, participated in the core team meetings, and who had been running dementia group programs in their dayrooms over the past year. Nursing supervisors, department heads and coordinators from the three facilities also attended. The NCAA process consultants and the program consultant were present.

The "Hostings" were structured like the "coachings" (see (5) above). At each facility, the coleaders on the intervention unit demonstrated their morning program while participants observed. At the conclusion of the morning program, the whole group adjourned to a private conference area, and the process consultants lead the group in a discussion about what they had observed. When lunch was served at 12 noon, the group continued their discussion informally, breaking into small groups as they ate their lunch, talking and exchanging experiences and reactions. Each Hosting was scheduled for 9.30 a.m. through 1.30 p.m. and was regarded as part of participating staff's work day. Visiting staff was compensated for their time and their work assignments were covered at their home facilities.

The Hosting had several objectives. First, its purpose was to deepen the quality of programming by exposing participants to each others' activities and co-leadership styles. It was anticipated that team members would learn new techniques and get new ideas for programming by observing their counterparts from the other facilities conduct their programs. Then, in a group discussion that followed, participants shared their observations, constructively critiquing what they had seen, comparing and contrasting with their own experience. Second, the Hosting was intended to introduce the idea of *peer support* and *peer network* to participants. The post-observation discussion period was anticipated to serve as an opportunity for the team members – now referred to as *peers* – to interact with each other, to problem solve and to brainstorm. Because nursing home staff rarely interact with their counterparts in other facilities, the effect of this interaction was intended to be supportive and to serve as *an opportunity to give and receive peer support*. Finally, taken together, the three "Hostings" were intended to establish the foundation for a continuing exchange of ideas between the three facilities' program participants – *a peer support network*. The peer support network was anticipated to be an important factor in sustaining the programs at each facility.

E. Timelines – Frequency and Duration of the Intervention

While each facility was exposed to the same activities agenda, there was no "boilerplate" for implementing the Intervention. The culture change activities were intended to be elastic or interchangeable and to occur sequentially or simultaneously, depending on the facility's needs. As anticipated, each facility developed and implemented the Intervention at a different pace, determined by its own unique personalities and circumstances. This is a hallmark of culture change.

The unique history of the Intervention at each facility is summarized and presented in the Intervention Timelines, located in Appendix C to this report. The Timelines are a month-by-

month descriptive summary of the Intervention's development at each facility, illustrating how and when each facility experienced the common features of the Intervention. The Timelines graphically demonstrate the individualized and fluid nature of the Intervention's development and implementation.

F. Launching the Intervention – Issues and Concerns

The events following September 11, 2001 caused a number of delays to the funding and commencement of this project. One of the original participating facilities withdrew from the research, necessitating the location of a replacement. Project "kick-off" meetings were delayed and then were rescheduled several times.

IV. Evaluating the Intervention

A. Description of the Evaluative Design

This research project utilized both quantitative and qualitative longitudinal methods to develop a descriptive model of sustainable culture change in the nursing home (Aim #2) and to evaluate the impact of the proposed culture change intervention (Aim #3) on the designated units. These two methodologies are profoundly different in their methodological and analytical approaches, yet productively complementary in their findings. Thus, for the sake of clarity, we present them separately in this section of the final report. In the concluding section of the report (V), we will synthesize the results obtained by two approaches in recommendations for best practice (Aim #4).

B. Quantitative Evaluation Methods

1. Design

The study utilized a repeated measure design focusing on resident quality of life outcomes. The study recruited samples of convenience. The N represents roughly half of the population residing on the intervention unit and consists of persons with varying degrees of intensity of exposure to the main intervention activity- the dementia group program.

2. Research Participants

Nursing home residents were the focus of quantitative evaluation efforts.

Recruitment procedures. Each facility was responsible for recruiting resident subjects to participate in the quantitative portion of the evaluation. Unit social workers contacted all resident responsible parties on the units to obtain written consent to participate in the evaluation. Recruitment efforts continued until returned written consents were obtained from up to half of the responsible parties on each unit. Facility 1 (n=40 bed unit) recruited 21 individuals (one later withdrew consent prior to any data collection). Facility 2 (n=40 bed unit) recruited 20 individuals, and Facility 3 (n=50 bed unit) recruited 25 individuals. A researcher then obtained consent from resident him or herself when possible to do so. Even if a resident was unable to provide verbal or written consent because of advanced levels of impairment, researchers were vigilant to any possible nonverbal indications that the residents may not want to participate in the project (e.g., any indication of distress at being observed by a researcher). Researchers did not encounter any indication that residents objected verbally or nonverbally to any aspect of the research evaluation procedures over the course of the project.

Rates of completion over time. Table 1 in Appendix D details the completion rates of nursing home resident participants over the three assessment periods-baseline, 6 months, and 12 months. A total of 65 residents were represented in the baseline assessment period prior to the initiation of culture change activities. Between Time 1 (baseline) and Time 2 (6 months) a total of 8 persons were dropped from the study, due to death (n=5) or transfer off the unit (n=2), resulting in a total of 57 remaining subjects. Between Time 2 and Time 3 (12 months), an additional 5 persons were dropped from the study due to death (n=3) and transfer (n=2), resulting in a final N of 52 subjects completing all three assessment batteries. These 52 individuals are represented in all analyses reported in the Results (V.) section of this report. Table 2 in Appendix D provides the descriptive characteristics of these subjects at baseline, prior to the implementation of any culture change interventions. Subjects had a mean age of 81.59 years and were 75.4% female. The majority of the sample was Caucasian (60%), with persons of Hispanic (12.3%), Black (18.5%), and Asian (9.2%) origins represented. The majority was widowed (59.4%). Nearly 37% of the sample carried a diagnosis of dementia of some type, with an additional third of the sample reporting a history of at least one CVA. 36.9% of the sample reported of depressive disorder. Medicaid recipient comprised 72.3% of the sample. Table 3 provides an overview of facilities' care practices. Two persons were restrained out of the sample of 65. A variety of treatments were offered to the sample, including nutrition (mean = 1.71 interventions per subject), restorative care (mean = 5.87 days per subject), traditional therapies (mean = 1.75 days per subject), and psychoactive medications (mean = 4.78 days per subject).

Rates of completion by Intervention Intensity group status over time. As culture change activities commenced. CORE team staff members selected residents to participate in the culture change interventions to take place in the unit's large activity day rooms. Researchers were not involved in the resident selection process. Details relevant to the selection of residents for interventions can be found in section III F of this report. On each of the units, staff targeted 70% of the residents enrolled in the research evaluation for direct participation in the culture change activities conducted in the activity day rooms. In this report these individuals are labeled as "Targeted Program Participants (TPP)". Residents not targeted for direct involvement in the culture change interventions, but who resided on the same units and received care from the same staff members are labeled as "General Program Participants (GPP)" in this report. While not a perfect control group, comparisons between the General Program Recipient group and the Targeted recipient group do allow for an examination of any differential impacts related to differing levels of "dosage" or intensity of intervention exposure. Of the 52 subjects that completed all three waves of data collection, 35 were in the Targeted Program Participants (TPP) group and 17 were in the General Program Participants (GPP) group. When we examine the sample based on the intensity level of their exposure to the group dementia program, one of the main intervention components described in the section above, very few difference emerge (See Table 10 in the Appendix D). Persons in the TPP group (defined as persons selected specifically by staff to participate in the Dementia Group Program), are less likely to have a diagnosis of aphasia (Chisq= 4.32, p<.04) but are more likely to have greater cognitive impairment (t= 2.32, p<.02) when compared to those persons in the GPP.

3. Quantitative Data collection methods

Data regarding resident outcomes was at three points in time over the course of the study-at baseline, 6-month follow-up, and 12-month follow-up. Outcome measures were obtained from questionnaires, direct observation and medical chart extraction. Certified Nursing Assistants completed questionnaires related to negative behavior, cognition, and depression. Researchers also completed a series of observations of the resident affect and resident –staff interactions.

4. Variables measured

The study examined a variety of outcome measures designed to test different constructs. The first set of variables "Clinical Outcome Indicators" examines a set of measures derived from the Minimum Data Set (MDS) designed to examine changes in basic clinical care issues over time. These outcome measures are viewed both from the perspective of clinical care outcomes as well as their potential as intervening variables that may influence other outcomes related to the intervention. These measures include the number of psychoactive medications, number of falls, number of therapy days provided, and a general rating of medical instability. The second set of variables "Cognitive and Functional Status" is also derived from the MDS and tracked over time. The two measures include MDS Cognition and ADL scales. Like the first set these variables were examined both from the perspective of their utility as an outcome measure and a potential intervening variable. The third set of outcome variables "Negative Behaviors and Affects" examines a set of measures focused on tracking changes in negative emotional states, including Anger, Anxiety, Sadness/Depression, Verbal and Physical agitation and Aggression, and other problem behaviors. The fourth set of outcome variables examines "Positive Behavior and Affect", a set of measures designed to capture positive emotional responses such as Pleasure and Interest, as well as positive behavior such as engagement in activities. The fifth set of outcome variables shifted the focus to the level of the quality of interaction observed between care-giving staff and residents. The final set of outcome variables examines the type of activity that was observed in the main activity room on the intervention units. These measures are designed to capture changes in the way in which activities were conducted over the course of the project.

5. Sources of Data

Copies of measures can be found in Appendix E. Each in measure will be described in turn.

The Minimum Data Set (MDS) Quarterly assessment form was extracted from the subject's medical chart during each of the three data collection periods. Specifically, the MDS provided descriptive information about the demographics and diagnoses of subjects as well as information about Clinical Outcome Indicators and resident Cognitive and Functional Status. The Cohen-Mansfield Agitation Inventory (CMAI) is a 29 item scale designed to assess four aspects of agitated behavior- Aggression, Physical Nonaggression, Verbal Agitation, and Hiding and Hoarding. Its psychometric properties have been well established in the literature (Cohen-Mansfield, Marx, & Rosenthal, 1989). The Cornell Scale for Depression in Dementia (Alexopoulos, Abrams, Young, & Shamoian, 1988) is a 19 item scale specifically designed to measure depressive symptomatology in persons with dementia using information gained from nursing staff. The scale has high interrater reliability (k=.67), internal consistency (alpha=.84), and sensitivity. The Apparent Affect Rating Scale (AARS) (Lawton, Van Haitsma, Klapper, 1996; Lawton, Van Haitsma, Perkinson, Ruckdeschel, 1999) was constructed in order to assess the full range of affect, both positive and negative dimensions, in those persons with dementia. The observer records the duration and intensity of positive and negative emotional states, targeting facial expression, body language, and nonword vocalizations. Psychometric properties have been well demonstrated, including inter-observer reliability, convergent and discriminant validity when compared with rating scales. The Activity Participation Scale is a 7 item scale of frequency ratings of types of activities (e.g., physical activity, group activity, religious activity, etc.) that are possible to perform in dementia care units (Lawton, Van Haitsma et al., 1998). The Quality of Interaction Schedule (QUIS) (Dean, Proudfoot, Lindesay, 1993; Skea, Lindesay, 1996) is an observational measure that records the quantity and quality of social interactions between residents with dementia and care staff. This information is used to code interactions as positive social, positive care, neutral, negative protective, and negative

restrictive. Inter-observer reliabilities are demonstrated as fair to excellent, it has documented construct validity, and sensitivity is demonstrated in distinguishing changes in quality of interactions in different settings. *Observation protocols* contained the AARS and QUIS measures mentioned above, and, in addition, information about the location of the resident, what type of activity s/he was involved in, and ratings of level of engagement. All observation protocols were conducted by trained researchers and were completed between the hours of 10 and Noon and 1 and 3 pm during weekdays. These times were selected to maximize the opportunities to observe interactions in the context of scheduled activities. Each subject was observed a total of 6 times during each data collection period on non-consecutive days over a two-week period. Observational outcome measures are represented by the mean of these 6 observation opportunities at each data collection period.

6. Frequency of data collection

The measures listed above were collected at baseline, 6 months, and 12 months in each of the three participating facilities.

7. Staff involved in data collection

Nursing assistants and activity therapists completed questionnaires. Researchers completed observation protocols and gathered medical chart extraction data with the assistance of MDS Coordinators.

8. Statistical methods used to analyze quantitative results

The focus of the quantitative measures is on behavioral and affective quality of life outcomes for residents that are hypothesized to be affected by the culture change interventions. A series of repeated measures ANOVAs were used to evaluate impact on outcomes. Bonferroni corrections were used to adjust for the biases inherent in conducting multiple ANOVAs within the same construct category. When appropriate, measures of intervening variables were entered as covariates in analyses.

C. Quantitative Results: Hypotheses and Interpretation

Please see the Data Tables in Appendix D. The results are discussed here in relationship to hypotheses and research questions.

Hypothesis #1: Compared to their own baseline status, nursing home residents who are the recipients of culture change interventions will experience no differences in Clinical Outcome Indicators or Cognitive or Functional impairments over time. Results of data analyses relating to this hypothesis can be found in Appendix D, Tables 4 and 5. Nursing home residents who reside on units undergoing culture change activities demonstrated no statistically significant change over time in a variety of clinical outcome indicators included the use of psychoactive medication, falls, days of therapy, general medical instability. These outcome indicators were not specifically the conceptual focus of the program (e.g., this was not a falls reduction program) and therefore were not expected to change as a result of the intervention. Similarly, reducing Cognitive and Functional impairments was not the focus of the program. In fact, given the nature of the population (most of the sample had a diagnosis of a neurological disorder) we would expect that these impairments would worsen over time. Results indicated that the sample became increasingly functionally impaired over time (f=4.90, p<.01) but did not demonstrate significant levels of increasing cognitive impairment over time. Therefore, ADL impairment will be examined as a covariate in all analyses related to Hypotheses #2 through #4.

Hypothesis #2: Compared to their own baseline status, nursing home residents who are the recipients of culture change interventions will experience decreased incidences of negative affect (depression, anxiety, anger) and behavior (physical agitation, aggression, verbal agitation). Results of data analyses relating to this hypothesis can be found in Appendix D, Table 6. Nursing home residents who reside on units undergoing culture change activities demonstrated statistically significant decreases in levels of depression as measured using two methods- observed sadness (f=11.55, p<.0001) and staff ratings of depression using the Cornell Depression in Dementia scale (f=20.81, p<.0001). The level of statistical significance of these results remains even after utilizing a Bonferroni correction for multiple comparisons. These significant results remained after controlling for ADL decline over time. No differences were noted in other affective variables such as Observed Anger or Observed Anxiety. In addition, no differences were noted for any negative behavior measure.

<u>Interpretation</u>. This result indicates that residents living on nursing home units undergoing the culture change interventions experienced a significant decrease in depressive symptoms over the course of the project. This finding is further strengthened by the fact that it was obtained via two independent sources- research observation and staff report.

Hypothesis #3: Compared to their own baseline status, nursing home residents who are the recipients of culture change interventions will experience increased incidence of positive affect (pleasure, interest) and behavior (activity participation). Results of data analyses relating to this hypothesis can be found in Appendix D, Table 7. Contrary to the hypothesis, nursing home residents who reside on units undergoing culture change activities demonstrated statistically significant decreases in Observed Pleasure (f= 40.17, p<.0001) over time. Consistent with the hypothesis, residents were observed being more actively engaged in activities that they participated in (f=6.31, p<.004) over time. There was a trend toward residents also increasing the overall frequency of activity participation over time as rated by staff (f=3.71, p<.03) (e.g., attending activities more frequently), but this result did not survive the Bonferroni correction procedures. These significant results remained after controlling for ADL decline over time. Interpretation. The finding that Observed Pleasure in nursing home residents with dementia decreases over time has been replicated many times in the literature. In the current study, it is interesting to note that the course of decline in Observed Pleasure did not continue in a linear fashion. Rather, the rate of decline slowed, and even reversed slightly, at the final data collection point. While these results were not statistically significant, they do suggest a potentially significant clinical impact on resident's well-being. More clearly, the finding that residents well observed being more actively engaged in activities indicates that the intervention program seemed to have a direct positive impact on resident's behavioral well-being.

Hypothesis #4: Compared to their own baseline status, staff and nursing home residents who are the recipients of culture change training's and interventions will demonstrate increasing incidents of positive interactions over time. Results of data analyses relating to this hypothesis can be found in Appendix D, Table 8.

Contrary to the hypothesis, staff members who work on units undergoing culture change activities did not demonstrate statistically significant increases in more positively valenced quality of interactions with residents. In fact, results indicate that observations of staff positively interacting with residents dropped significantly after the initiation of culture change activities (f=58.71, p<.0001). No differences in negative interactions were found, but it should be noted that the occurrence of <u>any</u> negatively toned interaction was very rare over the course of the project. These significant results remained after controlling for ADL decline over time. <u>Interpretation</u>. Positive staff – resident interactions in the dayroom observed by researchers dropped in frequency once the Intervention began and remained much lower than baseline levels over the course of the project. This drop was accompanied by an increase in more neutrally toned interactions. Negatively toned interactions were all but absent over the course of the project. This change in pattern of interactions points to a significant change in the milieu

on the unit. Staff members were being asked to engage in new activities with residents and utilize new skill sets in enacting these activities. Given all these transitions, it is not surprising that the quality of the interaction patterns between residents and staff was affected within the 12 month window of data collection. It is an open question as to whether this pattern of interaction would have stabilized and shifted yet again as staff members became more familiar with the new activities and interpersonal skill sets over time.

Hypothesis #5: Compared to their own baseline status, staff participating in the culture change intervention program will offer more one on one activity opportunities and more structured group activities.

Results of data analyses relating to this hypothesis can be found in Appendix D, Table 9. Staff members who were responsible for delivering the dementia group program (activity therapists and CNAs) demonstrated statistically significant increases in the delivery of one on one activities with residents between T2 and T3 (f=9.86, p<.0001), a temporary increase in the frequency of unstructured large group activities at T2 (f=13.98 p<.0001), and a fluctuating pattern of the frequency of large structured activities with an initial decrease in the frequency of large structured groups between T1 and T2, followed by an increase again at T3 (f=6.85, p<.003). *Interpretation*. This pattern of activities demonstrates that the Intervention had a significant impact on the manner in which psychosocial activities were delivered. Changes in large structured group activities reflected the effect of reorganizing staff and the introduction of new activities. These changes had the effect of temporarily shifting large group activities to a more unstructured approach. By T3, however, staff had settled into a more stable pattern characterized by more One on One activities and a resumption of large structured group activities.

Note that Hypotheses #6 through #10 relate to the question of whether differing levels of exposure to the intervention program has any demonstrable effect on resident quality of life outcomes or staff related outcomes. An examination of resident characteristics by program exposure (see Table 10 in Appendix D) revealed two significant differences between the groups, namely, that Targeted Program Participants are less likely than General Program Participants to have a diagnosis of Aphasia (t= 4.32, p<.04) but were more cognitively impaired (f=2.32 p<.02). While these results do not meet the Bonferroni correction requirement, they do suggest that staff may be using these two variables when considering whom to select for participation in the dementia group program. No other variable emerged when examining baseline care practices delivered to these two groups (See Table 11 in Appendix D). For this group of analyses, the test of the hypotheses is reflected in the interaction term (Participation type x Time) found on the tables. Between effects reported on the data tables reflect ways in which the two groups differ in general and may be indicative of selection effects utilized by staff when choosing who to include in the dementia grant program delivered in the day room.

Hypothesis #6: Compared to residents who resided on the same unit but were not selected to participate in the dementia group program (General Program Participants), residents who were selected by staff to participate in this program (Targeted Program Participant) will experience no differences in Clinical Outcome Indicators or Cognitive or Functional impairments over time. Results of data analyses relating to this hypothesis can be found in Appendix D, Tables 12 & 13. When comparing General Program Participants (GPP) to Targeted Program Participants (TPP) results indicated no significant differences between the groups on any Clinical Outcome Indicator variable or the Cognitive impairment variable. Table 13 does reveal a significant interaction term for ADL status (f= 4.36, p<.02). The pattern of differences between the groups reflects a fluctuating pattern of ADL impairment in the groups with the TPP group demonstrating a significant increase in impairment between Time 1 and Time 2, while the GPP group demonstrates significant increase in impairment between Time 2 and Time 3. Therefore, ADL impairment will be examined as a covariate in analyses related to Hypotheses #7-#8.

Hypothesis #7: Compared to residents who resided on the same unit but were not targeted by staff to participate in the dementia group program (General Program Participants), residents who were selected by staff to participate in this program (Targeted Program Participant) will experience decreased incidences of negative affect (depression, anxiety, anger) and behavior (physical agitation, aggression, verbal agitation).

Results of data analyses relating to this hypothesis can be found in Appendix D, Table 14. When comparing General Program Participants (GPP) to Targeted Program Participants (TPP) results indicated a complex fluctuation in two Negative Affect variables as indicated by significant interaction (Program x Time) terms. Compared to the GPP group, Observed Anxiety increased in the TPP group at Time 2, but decreased back to baseline levels by Time 3 (f=3.32, p<.05). Observed Sadness decreased in frequency for both groups at Time 2. The TPP group maintained these gains, but ground was lost for the GPP group who experienced an increase in Observed Sadness by Time 3, though not back to baseline levels (f=3.53, p<.04). As we indicated in testing Hypothesis #2, both groups experienced a significant reduction in depression as measured by the Cornell Depression in Dementia scale (f= 20.81, p<.0001). No negative behavior variables were found to be different between the two groups. These results remained after controlling for differences in ADL impairment over time. *Interpretation:* Residents specifically targeted by staff to participate in the dayroom program demonstrated an increase in observed anxiety levels between T1 and T2 of the Intervention when compared to other persons residing on the same unit. However, that increase disappeared by T3. Examination of the means in each facility indicated that the differences in observed anxiety were being driven by one facility in particular. This facility was experiencing a high level of staff conflict about the Intervention activities during the T2 data collection period. The increase in observed resident anxiety corresponded to an increase in staff conflict and was resolved when staff conflict was resolved. It also corresponds to the overall change in valence of interaction patterns between residents and staff which will be discussed under Hypothesis #9 to follow. This finding suggests that staff well-being and interaction patterns have a significant and observable impact on the well-being of residents to whom they provide care.

Hypothesis #8: Compared to residents who resided on the same unit but were not selected to participate in the dementia group program (General Program Participants), residents who were selected by staff to participate in this program (Targeted Program Participant) will experience increased incidence of positive affect (pleasure, interest) and behavior (activity participation). Results of data analyses relating to this hypothesis can be found in Appendix D, Table16). When comparing General Program Participants (GPP) to Targeted Program Participants (TPP) results indicated no significant differences between the groups over time on any positive behavior or affect variable. Interestingly however, a statistically significant difference emerged when examining the between effect for program exposure groups related to Observed Pleasure (f=8.95, p<.004) and Observed Participation (f=9.55, p<.003). Examination of the means revealed that the TPP group had started with higher levels of Observed Pleasure and Active Engagement when compared to the GPP group at baseline and retained that favorable status throughout the course of the intervention. Interpretation: Persons targeted for inclusion in the dayroom activity program experienced higher levels of Observed Pleasure and Participation levels prior to the beginning and throughout the formal intervention activities. This strongly suggests that these variables may figure prominently in staff decisions about who to include in the targeted intervention group. From an interpersonal perspective, it makes intuitive sense that staff would be drawn to include those individuals who are emotionally and behaviorally responsive to the social environment around them. It does raise the question, however, about the exclusion of residents who are not as emotionally and behaviorally responsive, but are deserving of attention nevertheless.

Hypothesis #9: Compared to residents who resided on the same unit but were not selected to participate in the dementia group program (General Program Participants), residents who were selected by staff to participate in this program (Targeted Program Participant) will demonstrate increasing incidents of positive interactions over time. Results of data analyses relating to this hypothesis can be found in Appendix D, Table16. When comparing General Program Participants (GPP) to Targeted Program Participants (TPP) results indicated no significant differences between the groups over time on any measure of quality of interaction between residents and staff. Differences did emerge, however, when considering the between effect of program exposure related to Positive Interactions (f=39.03, p<.0001), suggesting the two groups were fundamentally different in some way throughout the project. Examination of the means revealed that, even before the initiation of intervention activities, persons in the targeted group experienced a higher frequency of positive interactions with staff, compared to others residing on the same unit. The targeted group continued to maintain this relative advantage in number of positive interactions over the course of the project. Interpretation: Like the finding immediately preceding this one, this finding suggests that staff members may have selected a group of residents with whom they already were experiencing a high level of positive interactions. Again, this finding raises questions about the exclusion of residents with whom staff does not experience the same frequency of positive interactions.

Hypothesis #10: Compared to residents who were not selected to participate in the dementia group program, residents who are selected by staff to participate in this program will offer more one on one activity opportunities and more structured group activities. Results of data analyses relating to this hypothesis can be found in Appendix D, Table17. When comparing General Program Participants (GPP) to Targeted Program Participants (TPP) results indicated only one significant difference between the groups over time in regard to type of activities delivered by staff. The GPP experienced a significant decrease in the number of Care-related activities (f=5.09, p<.01) after the initiation of Intervention activities even when controlling for variables related to ADL and Cognitive levels. Differences also emerged when examining the type of activities experienced by both groups. A significant between effect of program exposure emerged when looking at difference in Large Structured Group activities (f=24.60, p<.0001) suggesting that staff selected those residents for the dayroom intervention activities who had already been experiencing a higher number of large structured group activities previously. Interpretation: Staff members were observed to deliver significantly fewer care-related activities to residents who were not directly participating in the dayroom programming. While these findings suggest a decrease in care-giving to residents as a result of the Intervention, they are potentially confounded by the fact that observation times were specifically selected to maximize opportunities to observe Intervention related activities. The decrease noted in care-related activities may simply have resulted from staff shifting care activities to another time in order to avoid conflicts with the dayroom program schedule.

D. Qualitative Evaluation Methods

1. Design

Qualitative methods were used to provide a descriptive base for evaluation of the Culture Change Intervention's impact on participants. The project adopted *ethnography* as its central methodological perspective. Traditionally associated with cultural anthropology, it is a well-established, widely used qualitative approach in investigating the experience of people in their cultures and learning the meaning their experience holds for them, i.e. "the insider's point of view" (Geertz 1973). The precedent for ethnographic research in nursing home contexts is well-founded (Bower & Van Haitsma 2005; Hendersen & Vesperi 1995; Savishinsky 1991; Hockey 1990; Shield 1988; Gubrium 1975) and in special care settings to a lesser extent (Moore 1999; Mclean & Perkinson 1995). There is increasing interest in using anthropological methods for

evaluation research (Copeland-Carson 2002). As was anticipated, an ethnographic approach was well suited to the project aims for two reasons. First, qualitative methods were particularly effective in gaining basic descriptive information about and new insights into the highly complex but poorly understood Intervention (Aim # 3). Second, an ethnographic approach permitted the development of a model (Aim # 2) and recommendations (Aim # 4) that are derived directly from the experience and meaning the Intervention held for participants in it.

As a preface to presenting the qualitative methods and findings, it is important to emphasize that ethnographic practice is based on a data gathering philosophy, technology, and analysis that differs dramatically from the standard behavioral research methods used in the quantitative portion of this project. Investigation proceeds through open-ended observation, participation and talk with participants in their cultural settings over an extended period of time. Participants' words and actions constitute the data which is represented as a text. The text is subjected to systematic, rigorous analysis that ideally produces a descriptive account in which all experiential perspectives are represented.

2. Qualitative Data Collection Methods

Frequency of Data Collection. The events following September 11, 2001 caused a number of delays to the funding and commencement of this project. One of the original participating facilities withdrew from the research, necessitating the location of a replacement. Project "kick-off" meetings were delayed and then were rescheduled several times. The discourse around these delays and their effect on the Intervention represented important data for the study. Consequently, fieldwork germane to the project began in August 2003, 11 months prior to the project's official start date in July 2004. When all three facilities were on board, fieldwork was conducted simultaneously in all three beginning in Month 1 and concluding in Month 18.

Data Collection Methods. Four continuous and simultaneous ethnographic methods were used to learn and explore participants' experience of the Intervention and the meaning it held for them. These were participant observation, ethnographic interviewing, case study, and event sampling and collectively comprised the project's fieldwork. An extensive technical literature discusses these and other qualitative methods (e.g. Rubinstein 2001, 1992; Agar 1996; Yin 1993; Strauss & Corbin 1990; Pelto & Pelto 1988; Werner & Schoefle 1987; Spradley, 1980; Eckert 1983). Participant observation (PO) was a naturalistic, on-site research method in which the ethnographer was present in the specific settings and situations of interest, participating in and observing the meetings and activities that occurred at each stage of the Intervention. Ethnographic interviewing (EI) consisted of in-depth, semi-structured but open-ended conversations with Intervention participants. Interview topics included participants' knowledge, beliefs and values about dementia, their experiences with and evaluation of types of dementia care, institutional rules and practices that were perceived to formally and informally affect dementia care, the experience of and reaction to the intervention training, and so on. A central set of questions guided the interview, but participants' naturalistic responses were used as springboards to additional lines of inquiry. This open-ended discussion permitted the discovery and exploration of multiple histories, experiences, perspectives and purposes that make up the collective setting—information that is not usually accessible through standardized formats. A total of 105 Intervention participants completed an EI over the course of the project. See Appendix F for the ethnographic interview schedules. The case study (CS) method was introduced into the context of ongoing PO and EI as a means of gaining more specialized or focused information about some aspect of the Intervention from individuals who emerged as "key informants" (Pelto & Pelto 1988). These respondents possessed deep or distinctive knowledge about specific activities, events and meanings related to the Intervention. Their knowledge was critical to learning how participants selected between alternative, possibly conflicting, norms of behavior in an Intervention activity (Van Velsen 1967). A total of 14 indepth case studies were conducted over the course of the project. <u>Event sampling</u> is the activity-based counterpart to *case study*. This method was used to investigate participants' experience of the Intervention activities as they were introduced, implemented and unfolded on the Intervention units. Events sampled included new programming activities in the dayroom (e.g. TimeSlips), core team meetings, Manhattan Workshops and Hostings. The purpose of event sampling was to learn what parts of the event were relevant to participants, and what meaning the parts of an event may have held. The ethnographer investigated each activity through direct observation as it took place on the units, talked with participants about their subjective experience of and reaction to each aspect of the activity as it unfolded. Following the activity, the ethnographer engaged participants in a "debriefing" conversation about the activity, paying particular attention to aspects of the activity that participants indicated could be altered to enhance the outcome. A total of 19 event sampling episodes were conducted over the course of the project.

Data Sources. The "data sources" were the Intervention participants. A total of 105 participants completed in-depth ethnographic interviews during the course of the project. All participant groups were represented, including 6 Intervention consultants. Seven administrative personnel, 3 nurse management staff, 5 nursing supervision staff, 9 department heads, 27 front line caregivers, 28 residents and 20 family members. For a narrative discussion of the Intervention's participant segments, please see Section III.B of this report. It should be noted that residents interviewed were identified by staff as cognitively capable of the interview. At the outset of each interview, information about the study was reviewed with the resident, and his or her verbal consent to the interview was reaffirmed. Many of these participants engaged in multiple EIs over the course of the project.

3. Qualitative Data – Texts

Using the ethnographic methods identified above, the ethnographer observed, participated and talked with participants about the Intervention. Through their words and behaviors, the ethnographer gained access to participants' experience, thoughts, feelings, and attitudes about dementia care-giving, about the Culture Change Intervention, about the quality of their work life, and so on. These were the "data" for the study – the "raw material" of the study – that is, participants' subjective experience, thoughts, feelings, beliefs, values and attitudes about the Intervention and the meaning it held for them as conveyed through their words and actions. The ethnographer recorded and represented what participants said and revealed about their experience in the form of a written text. The text took several forms – field notes, interview transcripts and memos. Field notes were detailed, descriptive notes that recorded the content, sequence and tone of the events as they unfolded. Taken by hand in the field, the notes were expanded in post-fieldwork sessions, and entered on computer disk. The fieldwork produced approximately 1500 pages of single-spaced, type written field notes. Field notes represented both the documentary evidence for and chronicle of the Intervention as it unfolded over the life of the project. Transcripts refers to the type-written, verbatim transcriptions of the tape-recorded ethnographic interviews. Stored electronically, they represented important and rich textual resources about participants' experience of the intervention training and the process of culture change on the units at various points in time. The 105 Els produced approximately 1200 pages of transcript. Memos were spontaneous, informal, written notations made by the ethnographer at various times, e.g. while writing up field notes or transcribing tapes and at other times away from the field. Distinct from field notes, memos recorded insights, thoughts, ideas, interpretations, analytic insights, connections between emerging concepts, and questions. They were important texts that linked data collection to data analysis. Approximately 325 pages of single-spaced, type written memos formed the basis for qualitative analysis of the data.

4. Qualitative Data Analysis Methods

Like qualitative data collection, qualitative analysis is a multi-faceted activity, continuous and simultaneous activity. Data analytic methods included: *data inventory, coding, theme analysis, semantic expansion and reconstruction.* <u>Data inventory</u> was a first review, a gross-level categorization and general assessment of the type and content of the data represented in the field notes and the interview transcripts. Through this inventory, data were sorted into categories and initial definitions were formulated, developed and refined.

<u>Coding</u> was the second level of sorting. It was a repetitive search process for identifying additional categories and the meaningful interrelationships between categories. <u>Theme analysis</u> proceeded from data inventory and coding. A *theme* is a central, cultural principle that organizes behavior and conveys meaning for participants.

<u>Semantic expansion</u> and <u>reconstruction</u> were linguistic analytic techniques that were used to identify and explicate implicit or coded meanings in participants' statements. Frequency of mention was taken to indirectly indicate salience and participants' overt statements about what they considered to be important beliefs, values or practice was taken to indicate significance.

Several methods were used in conjunction to ensure validity in the qualitative data. <u>Triangulation</u> (use of several data collection methods and sources) reduced the likelihood of developing analytic categories based on chance or biased assumptions and reduced the risk of over-reliance on a single method or source. <u>Pattern saturation</u> (an obvious pattern of repetition in the data) indicated the salience of the material for participants. <u>Member checking</u> (gaining participants' feedback on an analytic finding) enhanced data representativeness. <u>Disconfirmation search</u> (active, systematic seeking of data that disproves assumptions and conclusions) clarified and refined analytic concepts.

E. Qualitative Findings

By the end of the project, each facility had developed and implemented a dementia group program on the Intervention unit it regarded as successful. The programs "ran" five days a week, typically between 10 am and 2 pm. Each program had two staff co-leaders and a back-up co-leader. Facilities differed in their staffing approach, using either the "regular" system or some variation of the "rotation" system. An additional nurse aide provided coverage of work assignments for participating staff during program hours. Overall, most participants felt their programs were "successful" and some explained that their program had "become a way of life on the unit".

The range of experience with the Intervention was staggeringly complex and participants' evaluation of their experience reflects this complexity. The facilities overlapped in many aspects of their Intervention experience but each facility experienced some aspects uniquely. Similarly, participant segment experiences were both overlapping and unique. Further, individual participants played pivotal roles that uniquely shaped their facility's Intervention experience. In all, 19 categories for evaluation emerged from the qualitative study of participants Intervention experience, and these categories can be discussed from a variety of different perspectives.

The qualitative findings reported here reflect the most salient and commonly experienced aspects of the three facilities' Intervention experience relevant to the evaluation. The extent and complexity of the Intervention requires that the qualitative evaluation of the Intervention presented here achieve breadth at the expense of depth. Page limitations on this report impose additional restrictions on the depth of the discussion. Consequently, we present findings here that capture the most important and commonly experienced aspects of the three facility's collective experience of the culture change Intervention. Differences in *participant segment* responses will be addressed where highly salient. Differences *between* facilities will be addressed in later publications, as will the different participant segment experiences, and the roles of individuals in shaping the overall success of the Intervention.

Qualitative findings are presented in four categories of experience. In response to the New York State Department of Health's mandate to report findings bearing directly on the evaluation of the Intervention, the qualitative findings are organized under the following headings:

- § Participants' evaluation of the Intervention specific activities
- § Participants' perception of the Intervention's effect on residents
- § Participants' perceptions of the Intervention's effect on staff
- § Evaluation of the Intervention overall
- 1. Participants' evaluation of the Intervention specific activities

Overall, participants reacted positively to the various Intervention activities, but several were considered to be particularly important. (For a detailed description of the purpose and nature of the Intervention activities, please see Section III.D of this report.)

The experiential trainings included TimeSlips, the "coachings" and the "hands-on" trainings were widely agreed to be valuable modalities for learning and practicing new skills. Staff regarded TimeSlips as a positive engaging experience for residents, that made "their faces light up" and "even the most withdrawn residents could react". It was felt to be "a very good program because it's not just making noise, it's making sense". Staff observed that TimeSlips was a "good program for families to see" because "it shows what the residents can do." Staff directly attributed positive changes in residents' behavior to their participation in TimeSlips, commenting that "it really turned some residents around". TimeSlips also held the interest of staff participants because, of all the activities, it gave them the greatest opportunity to learn more about their residents' biographies and capabilities. Described as an "unpredictable" activity, staff noted "the residents can take you anywhere, down any avenue with TimeSlips!" These benefits of the TimeSlips activities were felt to outweigh the disadvantages. However, participants complained about the 8 session training program which they felt was overly long and they struggled with the "scribing" requirements of the activity. The structure of the "coaching" training was widely regarded as a valuable and interesting way to learn and practice new skills and techniques that helped involve residents more in activities, particularly those with difficult behaviors. Intervention coordinators and consultants saw the post- "coaching" debriefings as an important opportunity for staff "peer support" and "peer networking". However, front line staff rarely commented on this aspect of the trainings as meaningful for them, but rather focused on learning and improving their interactional skills. Some participants received "hands-on" trainings that included aroma therapy, yoga or massage trainings. These literal, tactile trainings were popular and positively described as "new", "real", "easy to grasp" and immediately applicable to residents.

The site-visits and Hostings were felt to be in situ venues for learning how other facilities approach programming. Participants said they "learned more by seeing what others are doing" than by "sitting in a classroom". By the end of the project, many participants also regarded site visits as an opportunity to "bond with staff" from other facilities.

Although less popular than the experiential and off-site activities, Core Team Meetings and the Four Day Workshop in Manhattan were recognized as important mechanisms for program development. Although, initially, many participants were unwilling to commit their time to weekly Core Team Meetings, by the end of the project, the team meetings were valued as an important forum for problem solving, relationship building and program quality maintenance. The majority of participants felt that the information about dementia and dementia care-giving presented in the Four Day Workshop in Manhattan gave them new information that would help them provide better care for persons with dementia. They recommended that the workshop be offered again and to other staff. Participants also enjoyed the opportunity to meet and talk with staff from other facilities.

2. Participants' perception of the Intervention's effect on residents

Front line staff & nursing supervision demonstrated a high level of awareness of and knowledge about their residents' personalities, interaction styles, and preferences. They were attentive to resident's non-verbal behaviors, interpreted those behaviors as meaningful and strongly expressed the belief that residents at all levels of cognitive ability were aware of the dayroom programming and attended to it. Staff was exquisitely sensitive to incremental changes in their residents' participation styles. They identified as important and meaningful behavior changes that might appear insignificant to outsiders or fail to be captured by quantitative instruments.

Participants felt that the Intervention was primarily aimed at benefiting the residents, and overall, felt that residents had benefited from the Intervention activities. They perceived an increase in the number of residents who participated in the programming and an improvement in the level of residents' engagement in the programming. Even in the earliest phases of the Intervention, staff perceived an increase in the number of residents who were actively participating in the dayroom activities. They attributed the increase to residents' positive reaction to the improving program quality. Further, front line staff felt that the experiential trainings (i.e. TimeSlips, "coaching" and "hands-on" trainings) had helped them "reach" residents more satisfactorily and consistently. Even participants who initially felt the Intervention to be inappropriate for residents with dementia because of their cognitive limitations acknowledged an improvement in the level of residents' engagement in and enjoyment of programming in the dayroom. They attributed this improvement to the Intervention.

However, participants' focus remained centered largely on improved activities and skills rather than on deepened relationships. Their observations of and perceptions about the enhanced extent and level of residents' engagement in dayroom activities were largely performance centered, e.g. enhanced function, better memory, increased verbal participation, reduction in difficult behaviors, fewer requests for care-giving attention, and so-on. For their residents' sake, staff was pleased by these perceived improvements but also acknowledged that they benefited as well in the reduction of some of their care-giving workload. Overall, however, with a few notable exceptions, staff did not talk about their own deepened relationships with residents or a deepening of relationship between residents.

In sharp contrast to staff perceptions, the majority of residents (interviewed) and their family members (interviewed) did not notice any changes in recreational activities or staff behavior during the Intervention.

During the Intervention, residents described the staff and the environment on their unit as "pretty much the same as always". Residents typically spoke enthusiastically and affectionately about the recreation leaders on their units, but did not perceive any changes in dayroom programming or staffing. Although family members had been informed about the research project at its outset, they were unaware that the Intervention was underway. While a few family members mentioned

some changes in their relative's behavior, they did not attribute the changes to the Intervention. Similarly, family members did not perceive any changes in recreational activities, in staff behavior or attitudes, or in the environment.

3. Participants' perception of the Intervention's effect on staff

The Intervention's impact on staff relationships was among the most salient theme in participants' experience.

At the outset of the Intervention, participants felt that their relationships with their co-workers were good, frequently describing their units as having "good teamwork", "open communication" and "respect for each other". However, at the end of the project, staff participants acknowledged improvements in their relationships in several areas.

Coverage of work assignments dominated participants' discourse and represented a crucible for co-worker relationships. Against the backdrop of unit staff's initial protestations about teamwork, communication and respect, the discourse about "coverage" clearly revealed intra-unit factions and frictions as well as a culturally entrenched mistrust of management. Staff members were skeptical that they would actually be relieved of their work assignments when they participated in Intervention activities or anticipated that they would be required to pick up the work of other Intervention participants in addition to their own. Discussion about this topic was often highly charged, erupted into open friction at times, and extended well into the second year of the project. Front line nursing staff called for an additional staff person to provide coverage for Intervention participants. Administration urged staff to experiment with different coverage systems using existing staff. Nursing supervision, program coordinators and consultants developed and debated different coverage strategies. As a result, two strategies were adopted to meet Intervention participants' coverage needs - the "rotation system" and the "regular system". In the rotation system, each aide took a turn in the dayroom, co-leading with the recreation leader while her work assignments were distributed equitably among other staff. When all aides who wanted to take a turn had done so, the rotation began again. In the regular system, one aide (and a back-up) was permanently assigned to co-lead with the recreation leader, and her work was distributed equitably among other staff. Despite the tension and open friction about coverage strategies, Intervention participants persisted in their implementation of one or the other. The "pay-off" was big, however. As they developed, tensions were discussed with increasing openness at core team meetings. Over time, core team members' argument about and resolution of these tensions served as important mechanisms for deepening levels of teamwork, communication and respect between co-workers.

Staff participants successfully involved co-workers on the unit who were initially reluctant to participate in the Intervention. Front line staff had the option to decline to participate in the Intervention activities. Initially, many did so on the grounds that it would interfere with their work, make additional work for them, was outside their job description, or was incompatible with their care-giving philosophy. Program coordinators and participating front line staff respectfully but persistently worked to involve non-participating co-workers in Intervention activities – inviting them to core team meetings, site visits and trainings. Non-participants were coaxed, lured and gently pressured – sometimes subtly, sometimes not – by co-workers, program coordinators and nursing supervisors to "at least try" leading a a dayroom activity, "just to get a flavor of what it's like". The rotation system was developed in order to permit every aide on the unit to work with the recreation leader in co-leading programs in the dayroom. As a result, each of the non-participating staff did work with the recreation leaders several times during the life of the project. Many became comfortable with co-leading an activity, came to like doing so, and finally came to look forward to their rotation in the dayroom. Participants regarded the ability of all unit staff to "run a program" as an advantage for the unit because it creates a larger pool of "back up" co-

leaders who can "step in to keep the program running" if the recreation or other committed dayroom staff are absent.

Recreation staff felt strongly that the Intervention had fore-grounded and ratified for nursing staff the importance of recreational activities as therapeutic for residents rather than as "just time fillers". They attributed this perceived change in perspective directly to CNAs participation as coleaders in dayroom programming, bolstered by their joint participation in the Interventions experiential trainings. As a result, recreation staff felt that front line nursing staff had "a better understanding" of their work and consequently "more respect" for recreation staff. Front line nursing staff perceptions agreed with this assessment, and expressed satisfaction with and enjoyment in working with recreation leaders in the dayroom programs. These claims were substantiated in core team meetings, where both nursing staff and recreation staff consistently requested "more time and more training" in co-leading dayroom activities.

Staff perceptions about the effect of their Intervention work on them personally was highly individualized.

As mentioned in section I. above, front line staff typically regarded the Intervention as a series of trainings aimed at improving the quality of care they provided for residents with dementia. The large majority never moved far past their task and activity orientation to dayroom programming. They did not grasp the person-centered, relationship-based component of the Intervention. Consequently, they did not consider their residents in the light of these concepts, nor themselves. However, by the end of the project, the behavior of a small minority of front line staff suggest a nascent awareness of the value of their program work for them and the value of their program work for others. For example, for the larger part of the project, front line staff did not speak about their own personal reaction to their Intervention work and the effect it was having on them. However, in the last month of the project, some front line staff began to speak personally about their increased confidence in working in a new capacity with residents - "I used to be scared, but now I'm just nervous" - and their discovery of heretofore unsuspected capabilities in working - "It brought out a side of me that I never knew I had in me." Further, some staff began to complain more loudly and with more authority about dayroom conditions they had previously accepted as inevitable, e.g. the many environmental distractions, caregiving interruptions, and so on. Several took the initiative of speaking to their co-workers about ways to limit these distractions, citing the importance of the dayroom programming as their reason - "I just approached my co-workers and said I don't want any distractions while I'm running my program. I explained it, and they understood. And they know, now." Taken together, these developments suggest staff's growing awareness of the value of their work, their value as workers, and their confidence in asking for the support they want in order to do their work.

Despite a sense of improved relationships among co-workers, front line staff did not resonate with Intervention concepts of "peer status", "peer support" and "peer network". Even in later phases of the project where these concepts were consistently presented to them as important "next steps" of the Intervention, they evoked little sustained interest. A mild flurry of interest in the peer concept was spontaneously expressed in the last Hosting of the Intervention. Participants agreed that they enjoyed demonstrating their programs, exchanging ideas for activities and approaches with their counterparts from the other facilities, and articulated a sense of having "bonded" with them. There was some tentative discussion about continuing the cross-site Hostings and about developing joint recreational activities between facilities. However, this interest appears to have been largely situational, since there has been little subsequent inter-facility activity ("peer networking") since the conclusion of the project.

Where administration's witness of the Intervention activities was concrete and consistent, front line staff, program coordinators and nursing supervision had the strongest sense of identification with the Intervention's goals and their own importance in it. Staff was keenly aware of,

monitored and discussed administration's involvement in the Intervention activities. For staff, acta non verba was the watchword – actions, not words. They interpreted administrators' visible and regular attendance at core team meetings, dayroom programs, trainings and site-visits as concrete evidence of administration's commitment to them and their Intervention related work. Similarly, when administration allocated funds to Intervention participants in support of their activities – e.g. new furniture in the dayroom, funds for new recreation supplies and props, releasing staff to participate in all day Interventions, paying for lunch at the conclusion of a training day – staff felt that both they and their work was valued. The effect was cumulative. And, when administration heeded their request for additional staff to cover their work assignments while they engaged in Intervention activities, the effect on front line staff was palpable. They regarded this as clear evidence of administration's commitment to the Intervention and to their role in it, and many described this as a positive "turning point" in their own commitment to the Intervention.

4. Evaluation of the Intervention overall

Throughout the life of the project, the nature and purpose of the Intervention as a person-centered, relationship-based culture change initiative was never clearly articulated for front line staff nor consistently communicated to them. Participants typically referred to the Intervention as "it" or "the grant", but with very few exceptions, "it" was not defined clearly, consistently and repeatedly. The term "culture change" was infrequently used, never defined when it was, and rarely presented as a coherent concept by management, supervision and consultants who were responsible for presenting the project to intervention unit staff. The rationale for the different Intervention activities, the sequence of activities, and the connection of the training agenda to identifiable care-giving behaviors was neither clearly nor consistently articulated to front line staff. Consequently, the majority of the front line staff did not have a substantive or a clear understanding of the Intervention's overarching rationale, purpose and benefits as a culture change initiative.

The majority of front line staff perceived the Intervention activities to be a training program. Their overall evaluation of it was positive. Staff consistently spoke about the Intervention in "training" terms – as new knowledge and new skills gained. They evaluated the Intervention activities positively. Participants felt that the quality of recreational programming in the dayroom had improved because of the Intervention. They felt the activities and trainings had helped them improve their understanding of the needs of residents with dementia and their skills in providing care to those residents. Nursing and recreation staff agreed that they had gained new knowledge about dementia care-giving and reinforced what they knew already. They felt they had learned and practiced new interpersonal skills that would help them interact more effectively or more enjoyably with dementia residents, and many commented positively that their teamwork had improved as a result of the Intervention activities.

However, staff's fundamental task and activity orientation was not significantly supplanted by person-centered, relationship-based culture change concepts. The majority of staff did not appear to connect these concepts to Intervention activities and trainings. Although many staff noted that through the course of the Intervention they learned things about their residents' biographies and capabilities that they had not known before, staff did not speak about these new insights as leading to deeper relationships between themselves and residents. Similarly, although some staff believed the Intervention had helped "team-building" on their unit, they did not appear to equate "teamwork" with increased depth of relationship between co-workers.

Yet, within this context, a small number of participants did grasp, internalize and express the person-centered, relationship-based values of the Intervention. A few individuals acutely felt the power of the culture change concepts as a means of re-structuring quality of work and quality of care for all involved. In both formal and informal leadership roles, these individuals eloquently and consistently articulated for front line staff the culture change values that underpinned the

Intervention's activities. Further, they consistently demonstrated those values in their behavior toward other participants and toward residents. As a result, a few staff experienced and internalized the culture change objectives to such an extent that, by the end of the project, they described themselves as "transformed" and their relationships with residents and co-workers as "completely different from what it was."

V. Synthesis, Discussion and Recommendations

This section reports on the project aims achieved. For each aim, it synthesizes and discusses quantitative and qualitative findings and concludes with recommendations.

A. Aim # 1 – Implementing the Intervention

Aim # 1 was to implement a relationship-based model of culture change training and interventions. Aim # 1 was achieved by the Intervention Consultant representing the NYC Alzheimer's Association, Manhattan chapter. The Intervention is described in detail in Section III of this report. Researcher-structured observations affirm that Intervention staff demonstrated a statistically significant increase in the number of one-on-one and structured group programs with residents on the unit.

B. Aim # 2 - The Model

Aim # 2 was to derive a model of new culture components based on variables that emerged in the course of observing and evaluating three nursing homes undergoing culture change using ethnographic methods.

Aim # 2 was achieved by the research team. The model is discussed in this section and a schematic representation of the model is presented in Appendix G.

Behavioral and social scientists who study culture change in long term care settings agree that describing culture change initiatives is a challenging proposition. Culture change initiatives (CCI) are characteristically a loosely held set of activities, utilizing different modalities, focusing on different aspects of the institutional systems, and varying in their definitions of successful outcome. The nursing home's multi-tiered socio-cultural structure imposes additional levels of complexity. The number and variety of individuals who participate in a nursing home CCI results in a number and variety of different culture change experiences. Further, those many, varied experiences will hold different meanings for participants. In other words, a hallmark of culture change are its many and varied *voices*. Taken as a gestalt, the harmony and dissonance among these voices makes up the organic nature of an organization's culture. If it is to be successful, any effort to change an organizational culture must include a method of assessing the viewpoints of all participant segments – the *voices* of the culture – and find a way to bring them into harmony.

Consistent with the ethnographic perspective of the research, the aim was to derive a model directly from the perspective of the participants themselves without imposing external expectations about what culture change outcomes "should" or "could" result. Consequently, the model is derived directly from the experience and meaning the Intervention held for participants in it. It identifies the voices that participated in the CCI and delineates the categories of the culture change experience. It demonstrates how voice and experiential category interact, and reveals the multiple layers of culture change experience and meaning that result.

Participant segments. The model identifies the participant segments – or voices – central to the Intervention. Participant segment refers to a grouping of individuals who are stakeholders in the organization, but who have distinct roles within it. In this Intervention were 7 segments: (1)

Administration (e.g. NHA, Owners), (2) Nursing management (e.g. DON, ADON, Nurse educator), (3) Nursing Supervision (e.g., unit supervisor, charge nurse), (4) Department heads (e.g. Recreation, Social Work, Dietary, Housekeeping, etc.), (5) Front line staff (e.g. CNAs, recreation therapists, housekeepers), (6) Residents and (7) Residents' family members. This component of the model is elastic. Other stakeholder groups can easily be added – or subtracted – as a segment in the model where their presence or absence is regarded as salient by Intervention participants.

For example, some culture change advocates argue for the inclusion of the board of directors as a participant group. This model can easily accommodate this addition. A board of directors segment does not appear in the present model because it was not a salient segment in this Intervention. Each segment in the model represents a sub-culture within the broader nursing home culture, with values, norms, attitudes, beliefs, behaviors and standards that shape and give meaning to the experience of providing care to frail elders. Each segment's reaction to culture change activities is grounded in its own experience and holds its own meaning. Thus, in developing this model, we observed that each segment was likely to perceive its own experience and interpretation of events as the "correct" interpretation and to perceive other segments' interpretation as "incorrect" when the two diverged. This situation was further complicated when segments shared the same words to describe an event but meant something different by them. The words "culture change" were a glaring example of this semantic dichotomy at work in this Intervention. There was considerable confusion about how to refer to the Intervention activities. The words "culture change" were rarely used by any segment other than Administration. Yet, analysis of Administrators' discourse revealed they employed the words "culture change" in a variety of contexts with a variety of referents. Other examples of this semantic dichotomy – "shared words, different meanings" – included "buy-in" and "ownership". See Appendix H for conference presentations providing additional analysis related to this phenomenon.

Experiential categories. A set of five experiential categories emerged from participants' observations, encounters, perceptions, understandings and discussions about the Intervention. The categories are derived from and reflect what was meaningful for participants in their culture change experience. The categories were expectations, practical experience, reactions, explanations, and recommendations. Expectations reflect what participants perceive the Intervention's purpose to be, and encompass perceptions of its advantages and disadvantages. Practical experiences reflects participants' objective statements or factual descriptive comments about the Intervention. Reactions refers to participants' personal, evaluative statements about their objective experience of some aspect of the Intervention, e.g. it went "well" or "badly"; it was "useful" or "useless". Explanations are participants' statements that reveal how they interpreted their objective and evaluative experience of the Intervention – how they made sense of what they experienced. Recommendations refers to participants' views about what could be changed or improved in the Intervention and what the next steps should be.

The relationship between participant segments and experiential categories is schematicized here in a grid, with participant segments running along the horizontal axis and experiential categories on the vertical axis. This schema is presented in Appendix G.

C. Aim # 3 - Evaluation of the Intervention

Aim # 3 was to evaluate quality of care and quality of life outcomes related to the Intervention for residents and staff using both quantitative and qualitative methods. This aim was achieved by the research team. Quantitative results and qualitative findings are presented in Section III of this report.

D. Aim # 4 - Recommendations

Aim # 4 was to produce a set of recommendations to assist leaders seeking to initiate and sustain culture change in their long term care facilities. Aim # 4 was achieved by the research team. In contrast to other studies of culture change activities where recommendations are externally imposed, the recommendations presented here are derived from the descriptive CCI model discussed in the preceding section and from a synthesis of the quantitative outcomes and qualitative findings. This means that they are grounded in a rich, authentic description of the lived experience of Intervention participants. Recommendations are presented and discussed below.

§ Recommendation # 1: Facilities can use the descriptive CCI model (Aim # 2 discussed above) to assist exploration of a wide range of CCIs. The grid schema can serve as a tool to facilitate discussions about staff reactions to CCIs as they unfold and can be applied and reapplied at different points as the change process unfolds.

This research demonstrated that facilities with greater agreement between participant segments' experience consistently reported better Intervention related outcomes. Where facilities were unable to create harmony (within the grant imposed time limits), reported outcomes were less successful. Clearly, CCIs have a greater chance of success when grounded in collaborative conversations between participants about their understanding of and reaction to the change process. Admittedly, initiating and conducting such conversations can be difficult, but the grid schema serves as a reminder that, despite their daunting complexity, CCIs must be inclusive, each *voice* must have equal value, and that opportunities for unspoken disagreements to derail the change process are numerous. This schema provides one possible framework that leaders can use to enter into collaborative, inclusive conversation with culture change participants.

The grid schema provides an easy-to-grasp, bird's-eye-view of the all participant segments' experience of a CCI and highlights areas of agreement and disagreement. It offers a systematic method that a facility can use to ensure that all relevant *voices* are included in the discussion and that their meaningful experience of the CCI is represented. In addition, the grid schema can serve as a valuable tool for facilitating discussions among segment groups. To this end, the model includes in each category a sample question designed to elicit participants' experience of that category.

Recommendation # 2: Front line staff preferred to learn new concepts in experiential learning settings and their learning was maximized in such settings. In future CCIs, these settings should be emphasized and formal or informal teachers skilled at creating an ideal adult learning environment should be selected. Further, opportunities for experiential learning should be extended into routine situations, e.g. clinical and core team meetings.

The Intervention consisted of numerous training and program activities. Overall, participants reacted positively to all of the various activities, but they considered experiential activities to be particularly valuable modalities for learning and practicing new skills. This reaction is well supported in the literature on adult learning. Social constructivism, a theory of learning developed by Vygotsky (1978), views learning as an inherently interactive process that is maximized when knowledge is presented in a real-life context. A skillful teacher of adult learners will work to actively create a social environment that fosters participants' reflection about their own lived experience (e.g. How does this information relate to what I experience as a caregiver?) and collaborative learning (e.g. What can I learn from the experiences of others?). This dynamic was clearly in operation in the Intervention's experience-based trainings,

specifically TimeSlips, "hands-on" trainings and site visits. Similarly, the "coachings" maximized learning via skillful transmission of new information that built on the real life experiences of front line staff. In addition, many program coordinators and CNAs facilitated informal learning among peers through discussion of "mini-case studies" that recounted and discussed their experiences with residents.

§ Recommendation # 3: The Intervention's dementia group program demonstrated clear benefits to residents and has replication value.

Staff participants felt that the program was primarily aimed at the residents. Overall, they felt that residents had indeed benefited from the program activities, and cited residents increased participation, functional capabilities and a reduction in difficult behaviors as evidence. Quantitative findings concur to some extent with staff perceptions. Over time, residents living on the Intervention units demonstrated significantly less depressive symptoms and researchers observed them to be more actively engaged in dayroom program activities, e.g. increased direct eye gaze, increased verbal or physical response to ongoing activities. These improvements were observed in all residents who were assessed on the Intervention units, whether or not they participated directly in dayroom program activities. This suggests that the dementia group program had a positive, overall systemic effect on resident well-being for the unit as a whole.

Recommendation # 4: An important objective of future CCIs should be to communicate clearly and regularly with residents' family members about the Intervention and involve them more directly in Intervention activities. Staff-family relationships and family-resident relationships could be enhanced by family witness to and participation in Intervention programming activities.

In sharp contrast to staff perceptions, the majority of residents and family members who were interviewed did not report any perceived changes in recreational activities or staff behavior during the course of the Intervention. In fact, residents and family members appeared to have only a minimal awareness that the Intervention was underway. Several factors may account for their lack of awareness. For example, the majority of residents was cognitively impaired and may not have been able to articulate or remember changes in specific activities or staff behavior. Family members typically did not visit during the main times of Intervention related programming which was between 10am and 2pm on weekdays. Further, the majority of family members and friends were not involved in any aspects of the Intervention activities and staff was not formally encouraged to include family members in any aspect of the Intervention activities.

§ Recommendation # 5: Measures of observed resident emotion can be used to help staff monitor their impact on resident well-being and to reinforce for them the importance of the quality of their relationships with residents.

When quantitative data comparing residents specifically targeted by staff to participate in the dayroom program was compared with data on residents who lived on the same unit but were not consistently included in the dayroom portion of the intervention, the targeted group demonstrated an increase in observed anxiety levels between T1 and T2 of the Intervention. However, that increase disappeared by T3. Examination of the means in each facility indicated that the differences in observed anxiety were being driven by one facility in particular. This facility was experiencing a high level of staff conflict about the Intervention activities during the T2 data collection period. The increase in observed resident anxiety corresponded to an increase in staff conflict and was resolved when staff conflict was resolved. This finding provides clear evidence that staff well-being has a significant impact on the well-being of residents to whom they provide care. It is consistent with the literature that demonstrates that

persons with dementia remain exquisitely sensitive to the emotional climate around them (Lawton, Van Haitsma, et al. 1996; Edelman et al 2005). Consequently, developing and reinforcing staff awareness of the effects their behavior on residents' well-being can assist staff in monitoring the success of their efforts to enhance care.

§ Recommendation # 6: The potential for a CCI to enhance staff co-worker relationships is great. However, program coordinators, consultants and administration should bear in mind that "one size does not fit all" in culture change. Staff proceeds in their own ways and at their own speed toward person-centered, relationship-based goals, and are more successful when they are permitted the latitude to do so.

The Intervention's impact on staff co-worker relationships was among the most salient aspects of participants' experience. For front line staff, closer co-worker relationships resulted from grappling with work assignment coverage issues. Recreation staff felt strongly that the Intervention activities had fore-grounded and ratified for nursing staff the importance of recreational activities as therapeutic rather than as "time fillers". Many staff members who were initially reluctant to participate in the Intervention were successfully and productively involved in it through the respectful perseverance of their co-workers. Different staffing systems met different unit needs. The rotation system that gave each staff member the opportunity to take a "hands-on" turn in co-leading a dayroom program was felt to be particularly advantageous for two reasons. First, it reduced the anxiety of "reluctant" participants about recreational work with residents. Second, it provided a larger, experienced pool of "back-ups" in the event of regular staff absences.

Recommendation # 7: Peer contact between facilities can be used successfully as an experiential training tool, but staff members did not appear to strongly desire a formal or sustained relationship with peers from other facilities. If a CCI wishes to include a peer network component, then new approaches for introducing, developing and implementing "peer network" as a valuable concept to front line staff should be considered.

While improved relationships between co-workers in the same facility were widely noted, the same did not hold true for co-worker relationships *between* facilities. Although front line staff appeared to enjoy demonstrating their programs to staff from other facilities and exchanging ideas with them, few articulated a strong desire to continue these relationships in any systematic way. The shape a successful peer network implementation would take is a subject for future research.

Recommendation # 8: Person-centered, relationship-based concepts are difficult for staff at all levels to grasp and internalize. Administrators' consistent presence and witness to front line staff culture change work significantly enhances staff's perception of these concepts as relevant for and applicable to themselves. Administrators should refresh their thinking about the positive impact their consistent presence has for staff and change their behavior accordingly.

A person-centered, relationship-based CCI seeks to benefit staff as much as residents. Ideally, the initiative results in staff members' enhanced sense of self-worth and clearer understanding of the value inherent in the care they provide to residents. The Intervention was not fully successful in achieving this goal. The majority of participants never moved past their task and activity orientation to the dayroom programming. They did not relate to each other or themselves in light of the person-centered, relationship based Intervention concepts. Not surprisingly, then, they did not relate in this way to residents either. However, by the end of the project, the behavior of a small minority of front line staff suggested a nascent awareness of the value of their work, their value as workers, and their confidence in asking for the support they

wanted in order to do their work. This was especially true in facilities were administration was a highly visible participant in Intervention activities. Where administrative staff were consistently present and strong in their follow-through when addressing participants' needs and wants, front line staff, program coordinators and nursing supervision had the strongest sense of identification with the Intervention's goals and their own importance in it.

§ Recommendation # 11: Successfully communicating person-centered, relationship based culture change concepts is difficult and the process for doing so is poorly understood. An overall re-conceptualization of the Intervention's current design may be required.

Intervention consultants articulated as a goal of the program the deepened relationships between residents and front line staff. This was viewed as a crucial outcome that would reflect true person-centered, relationship-based culture change in the nursing home. By this measure, success would be demonstrated by profound changes in the way staff perceived the value of their own work, the manner in which they related to each other as co-workers, and the manner in which they related to the residents they cared for.

Yet, throughout the project, the majority of front line staff did not appear to have a clear understanding of the Intervention's overarching rationale, purpose, or benefits as a personcentered, relationship-based initiative. Rather, they regarded it as a training program aimed at improving residents' quality of life.

We attribute this perception to the absence of a clearly articulated and consistently communicated statement about the person-centered, relationship-based components of the initiative. Lacking a clear and consistent statement about the rationale for the activities they were engaging in, front line staff was left to their own devices in identifying the purpose and meaning of the Intervention activities. Lacking assistance in "connecting the dots" between training activities and person-centered culture change concepts, staff's fundamental task and activity orientation was not significantly supplanted by person-centered, relationship-based culture change concepts. Theories of adult learning support this interpretation. The first principle of successful adult learning is that adult learners need to know "how the learning will be conducted, what learning will occur, and why learning is important" (Knowles et al. 1998: 133). Ambiguous and inconsistent communication of rationale violates this principle and impedes effective learning. Thus, the absence of a clearly communicated statement about the Intervention's person-centered component may have been a significant impediment to achieving the "deepened relationships" goal.

This is not to say that no participant experienced these changes. Clearly, a significant minority of participants did grasp the person-centered, relationship-based rationale and were profoundly affected by this aspect of the Intervention, describing themselves as "transformed" and able to relate in "a new way" to residents and co-workers. And, to reiterate, participants' overall evaluation of the program was clearly positive. They felt that the quality of the activity programming had improved and that they had gained new skills over the course of the project. However, the basic point remains that, for the majority of participants, the fundamental way in which they viewed their work and their relationships to residents and co-workers did not appear to change substantially as a result of the Intervention.

Therefore, an overall re-conceptualization of the Intervention's current design may be required to achieve the "deepened relationships" goal. It may be advisable to re-conceptualize culture change as a fluid, ongoing developmental process rather than as a static, temporally bounded "intervention". Achieving change to the culture of care is only beginning to be explored as a developmental process. For example, initial research suggests that facilities progress through stages of change at different rates depending on their readiness to change (Grant et. al. 2003). In the present project, such variations are readily identified in the three facilities' Intervention

timelines (See Intervention Timelines in the Appendix). In a related field of inquiry, the literature about the care-planning process in nursing homes suggests that an 18 month window may not be sufficient to produce significant changes in the care-giving system where the goal is a holistic, interdisciplinary care-planning team that requires fundamental changes in the way staff relate to each other (Qualls, S. & Czirr, 1988; Van Haitsma et. al. 2000).

The present Intervention was carried out over an 18 month period. This may not be an adequate period of time in which to achieve person-centered, relationship-based culture change. It may be that, given a longer time frame, more participants may have progressed much farther down the path of culture change development.

E. Presentations Related to Evaluation Findings

The following presentations have reported on this project's evaluation findings (See Appendix H):

- § Bower, A. & Van Haitsma, K. (2005) Categories of Experience and Voice: A Model for Describing Culture Change Initiatives in Long Term Care Settings. Poster presented at the 2005 annual meeting of the Gerontological Society of America: Orlando, FL.
- § Bower, A. & Van Haitsma, K. (2004) *Models for Leadership in Person Centered Care Programs for People with Dementia*. Poster presented at the National Alzheimer's Association Education Conference. Philadelphia, PA: July.

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- A. References Cited
- B. Alzheimer's Association 4 Day Workshop
- C. Intervention Timelines
- D. Tables of Quantitative Results
- E. Quantitative Instruments and Protocols
- F. Qualitative Interview Schedules
- G. The Descriptive Model
- H. Presentations of Evaluation Related Findings

Appendix A

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Appendix B

Agenda for the 4 day workshop offered by the Alzheimer's Association, NYC Chapter

Appendix C

Intervention Implementation Timelines for each participating facility

Intervention Time Line at Facility One

August 2003

- § 1st kick off meeting at Facility 1
- § Unit A is identified as intervention unit b/c (1) it is the dementia unit & (2) staff has most dementia training
- § One facility drops out of project
- § Facility 2 is approached and makes the commitment to join the project

September 2003

- § DON & DSS appoint a program coordinator Dir of Recreation
- § DON & DSS question the choice of intervention unit

October 2003

- § NHA participates in Facility 3 kick off meeting
- NHA participates in Facility 2 kick off meeting
- IC conducts informal meetings with Facility 1 participants i.e. "doing walk-throughs" speaking to the people who weren't at the kick off meeting

November & December 2003

- § IC, NHA & nursing management meet to decide which floor will be the intervention unit debate is intense ~ no decision reached
- § Nursing management decides on Unit B as the intervention unit
- § IC works with Unit B supervisors to identify time line for core team meetings, site visits and sample program days
- § First core team meeting set for 24th December meeting does not take place & is rescheduled for Jan 2004

January 2004

- § IC presents time line to NHA, ADON and Unit B nursing supervision
- § DON & ADON identify Unit B as the intervention unit
- § Unit B recreation therapist is designated as dementia group co-leader & introduced to the project at the core team meeting
- § 1st core team meeting convenes

February 2004

- § Program coordinator (Dir Recreation) resigns
- § Clinical staff supervision and management decline to coordinate the program "no one steps up to become the leader"
- § IC works to schedule site visits for Facility 1

March 2004

- § 1st Albany meeting convenes for all project participants
- § Scheduled site visits are cancelled or rescheduled and then cancelled
- New Director of Recreation comes on board NHA and nursing management designate her as Program Coordinator

April 2004

- § IC waiting for new program coordinator (Dir Recreation) to set up site visits
- § Program coordinator familiarizes herself w/ the grant proposal
- § Core team meetings are not taking place meetings scheduled are cancelled
- Research formally introduces quantitative piece to Intervention unit participants ~ explains staff responsibilities
- In research follow-up, unit CNAs & nursing supervision are unavailable for, unaware of or unfamiliar w/ the quantitative measures
- § Program coordinator unfamiliar with procedure for selecting residents for program participation ~ unit social worker begins gaining resident consents

May 2004

- § Intervention unit social worker procedures for gaining resident consents violates IRB guidelines ~ requires a start over re: gaining resident & family consents
- § Core team meetings begin
- § Research begins to conduct IVs w/ CNAs
- § 1st site visit ~ to area nursing home

June 2004

- § Program coordinator asks for trainings
- § Program coordinator ask for assistant director
- 2nd site visit ~ to Facility 3

July 2004

- § Facility 1 begins 10 week TimeSlips training
- § Core team meetings continue
- § Quantitative data collection continues

August 2004

§ Program coordinator requests additional trainings: aroma, yoga & drawing therapy

September 2004

- S Core team members "waiting" for the Manhattan Workshop trainings to begin
- § Dementia group program runs daily 10 am 11.45 am and resumes from 2 pm 4 pm
- § Core team meetings occur sporadically ~ program does not have a name
- § Process consultant conducts guided discussions (focus groups) to identify core team's training needs prior to Manhattan trainings
- New research assistant for the quantitative piece and the resident interviews introduced to core team

October 2004

§ Intervention unit incorporates TimeSlips activity into the program schedule

November 2004

§ 1st Manhattan training takes place

December 2004

§ 2nd, 3rd & 4th Manhattan trainings take place ~ and are completed

January 2005

§ Intervention unit drops core team meetings in favor of "meeting informally"

February 2005

- § 10 week "hands-on" trainings begin aroma therapy, hand massage, yoga therapy
- § Core team members spontaneously mention perceived improvement in some residents' participation levels

March 2005

- § Core team meeting meets to identify participants for 2nd wave of on-site trainings
- § Environmental survey conducted ~ OQS conducted w/ program coordinator

April 2005

- Process consultant conducts interviews with key staff to identify perceived needs for the 2nd wave of trainings
- § Process consultant conducts guided discussions with staff for the 2nd wave of trainings

May 2005

- Quantitative data collection completed
 Process consultant begins 2nd wave of trainings "on-site"
 "Coachings" begin on another floor ~ Intervention unit staff who did not participate in the Manhattan & TimeSlips training participate

June 2005

- Facility 1 attends the 1st Hosting ~ at Facility 2 Facility 1 misses the 2nd Hosting ~ at Facility 3 "Hands-on" training continue on another floor
- New Assistant Recreation Director (a participant in previous DOH dementia grant & former Facility 1 recreation therapist) comes on board

July 2005

§ Facility 1 hosts the 3rd Hosting

Intervention Time Line at Facility 2

October 2003

§ Kick-off meeting at Facility 2 ~ participants include NHA, OWNER, DON, ADON, ASSOC DONs, Department Heads (Dietary, Housekeeping, Alzheimer's Programs, Social Work, Therapeutic Recreation, AIT) – Facility 1 NHA, OWNER, -- NYC AA – Research

November 2003

- § Unit A identified as the intervention unit
- § NHA appoints two DIR SOCIAL SERVICES & DIR RECREATION to co-coordinate the project

December 2003 ~ January 2004

- § Co-coordinators develop draft of the project time line
- § Kick-off meeting on Intervention unit to introduce the project to unit staff
- § NHA identifies the project as "Phase 2" "Phase 1" was completed in 2003 in the context of the intervention unit's renovation
- Intervention unit staff meet to discuss organizational issues re: starting the dayroom program reassignment of work loads recreation leader reassignments
- Intervention unit NURSING SUPERVISION & INTERVENTION CONSULTANT debate how to identify REC AIDE "rotation" vs. "regular" system

February 2004

§ Intervention unit waiting for new REC LEADER to be hired

March 2004

- § New REC LEADER starts on Intervention unit
- Sore team makes 1st site visit to area nursing home
- S Core team makes 2nd site visit to area nursing home
- S Core team makes 3rd site visit to the dementia group program on Unit B at its own facility

April 2004

- § Intervention unit fundraiser conducted to raise funds for residents fundraiser not related to culture change project but is a special project initiated and developed by unit staff very popular and very successful
- § Core team makes 4th site visit to area nursing home
- § Quantitative research component is presented to unit staff
- § Core team members & coordinators discuss the possibility of using volunteers to help distribute the work load

May 2004

- § Unit core team meets for the first time
- § Core team members struggle to identify a week day as a "sample day" express concerns re: work assignments & coverage for the aide who becomes the REC AIDE learn that there will be no extra staff to cover assignments learn that workloads will be "split"
- § Not all staff have participated in a site visit do not know "what the program is all about"
- § Core team decides on a weekly rotation schema 1st week rotation begins

June 2004

- § CNAs' weekly rotation in/out of the dayroom is suspended
- Core team members continue to articulate their concerns about work loads & coverage feel they are not "up to speed" handling the work load & participating in the dayroom for 1 day a week feel they will "have a problem" if they move to 2 days a week call for "an extra pair of hands" some do not want to participate in the project at all some who do want to participate feel they cannot because of their heavy workload debate how to choose which aide will be the permanent REC AIDE
- § Student CNAs assist unit staff in completing their work assignments
- REC LEADER & REC AIDE persevere in "working with reluctant residents"

- § Staff spontaneously articulate perceptions of increased resident participation in dayroom programs
- § Volunteers are assigned to the dayroom & to assist CNAs with workload

July 2004

- § TimeSlips trainings begin
- § Intervention unit plans to go to 2 sample program days once all of the CNAs have completed a rotation in the dayroom

August 2004

- § PROCESS CONSULTANT conducts guided discussions (focus groups) with unit staff to identify what training they want
- § Staff acknowledges that current volunteers "are working out"
- § Quantitative data collection continues
- § A staff showdown re: coverage causes a crisis on the unit

September 2004

- § Resident and family qualitative interviews begin
- § Site visit to area nursing home for unit staff who had not previously participated
- § PROCESS CONSULTANT conducts a guided discussion w/ Intervention unit staff aimed at resolving the tension on the unit

October 2004

- § DIR SOCIAL SERVICES (Co-coordinator) leaves the facility.
- § TimeSlips trainings continue

November 2004

§ Intervention unit staff begins the Manhattan Workshop trainings

December 2004

- § Intervention unit staff complete the Manhattan trainings
- § Intervention unit SOCIAL WORKER leaves the facility
- § DIR ALZHEIMER'S PROGRAMS leaves the facility

January 2005

- § New DIR SOCIAL SERVICES is hired -- does not participate as co-coordinator of the project
- § New Intervention unit SOCIAL WORKER is hired & joins the project

February 2005

- § Flu epidemic on Intervention unit floor quarantined
- § Administrative staff completes the OQS instrument

March 2005 - April 2005

- § Dayroom program is now at 5 days
- § A "floater" helps with the workload "doing well"
- § Intervention unit perceives with pride a facility wide awareness of & curiosity about their program related activities
- Intervention unit staff want to keep working on team-building between REC LEADER & REC AIDE
- § TimeSlips trainings conclude
- § "Coachings" are scheduled to begin
- § NHA's attention turns to a new project collaboration w/ another facility & 1199 to train CNAs in decision making skills unrelated to the culture change project
- NEW PROGRAM CONSULT brought in as per NHA to do 2nd wave of culture change on-site trainings & serve as liaison between culture change project and decision making project
- § Final quantitative data collection begins

May 2005

- § Unit fundraiser conducted to raise funds for residents fundraiser not related to culture change project very successful
- § Core team settles on a weekly rotation pattern one aide per week rather than a permanent REC AIDE assignment
- § Participants perceive residents as increasingly "talking & speaking & doing things they've never done before"
- § Quantitative data collection continues
- § Family & resident qualitative interviews are concluded

June 2005

- § NEW PROGRAM CONSULT conducts abbreviated guided discussions to learn participants' training needs
- § Facility 2 serves as the first Hosting site
- § Facility 2 attends Facility 3 Hosting
- § Quantitative data collection concludes

July 2005

§ Facility 2 attends Facility 1 Hosting

Intervention Time Line at Facility 3

September 2003

- § Kick-off meeting at Facility 3 ~ participants include NHA, DON, ADON, Director of Nursing Education, Director of Speech Pathology, Director Social Services, Director of Building Services, Director of Dietary Services, intervention unit charge nurse & dietician, Facility 1 NHA, Intervention Consultant, Research Evaluator & Ethnographer
- § Unit A is announced as the intervention unit

November 2003

- § First core team meeting on the intervention unit is held ~ selects the time and place for weekly core team meetings, introduce the project to core team members, identify the guidelines for the program agenda
- § REC DIR working on hiring a full time REC LEADER for Intervention unit ~ a part-time REC LEADER is identified for the interim
- § INTERVENTION CONSULT and core team members present the project to Intervention unit staff
- PROGRAM CO-ORDINATORS ask NHA for additional nursing covering for 10 am 6 pm

December 2003

- § Intervention unit staff responds positively to project presence on their floor
- § REC DIR announces new REC LEADER hire
- § Core team meets regularly, considers 1) criteria for including residents in the program, 2) attributes for CNAs appropriate for REC AIDE position
- § Site visit schedules are developed, discussed & decisions are made about who will participate in the trainings and site visits
- § Intervention unit core team invites Unit B dementia group program team to be involved in their program development
- § Staffing and adequate coverage are important topics of discussion
- § PROGRAM CO-ORDINATORS orient core team to dementia grant activities

January 2004

- § Site visits are scheduled for February & March
- § Project goals are reiterated and discussed the nature and purpose of the core team meeting is reaffirmed
- § CNAs express concerns about adequate coverage when they participate in project activities
- S Core team members discuss different systems for exposing staff to dayroom programming and REC LEADER "rotation" vs "regular system" is proposed

February 2004

§ Core team makes 1st site visit to area nursing home

March 2004

- § DIR REC (CO-ORD) continues to seek full time REC LEADER for Intervention unit
- S Discussion continues about whether to adopt rotation or regular system who, how often, for how long
- § DIR NURSING ED continues to tell NHA & DON that Intervention unit core team members need more coverage is needed in order to accomplish project goals
- § REC DIR explains that recent lay-offs at Facility 3 make it difficult to hire a full time REC LEADER at present ~ continues to struggle to provide partial REC LEADER coverage for Intervention unit in the interim
- S Core team makes site visit to Unit B program at their facility ~ expresses a positive reaction
- § Core team does not feel their program is started yet trying to get the program started 1 day a week

April 2004

§ REC DIR receives approval to hire a new full-time REC LEADER for Intervention unit ~ program development delayed until the new REC LEADER is hired

- In the meantime, Unit B and Unit C REC LEADERS will conduct one activity a day on the Intervention unit
- S Decided that each unit aide will have a chance to work with the REC LEADER to "try out the role" after work completed & "on a voluntary basis"
- § CNAs began taking turns at rotation ~ CNAs continue to express concerns about covering during the off-site trainings ~ DIR NURSING ED continues to work with DON on staffing issues
- § Increased staff satisfaction is introduced formally as a project goal in the context of discussing the quantitative portion of the project
- Research formally presents the quantitative portion of the grant to the CO-ORDS, DON, DIR NURSING ED
- § Quantitative portion of the project begins
- § Intervention unit CHARGE NURSE, DIR NURSING ED & CNAs decide which residents will participate in the program
- § Core team endorses the rotation system as the desired approach
- § REC DIR hires a new full time REC LEADER

May 2004

- § Intervention unit CNAs continue to participate in programming activity ~ informally visit Unit B dementia group program
- § Unit staff waiting for the new REC LEADER to start
- § CNAs articulate perceptions that residents are "opening up" more as a result of programming
- § Core team continues to discuss rotation vs regular system
- § DIR NURSING ED & CO-ORDINATORS continues to advocate NHA for 10 am − 6 pm coverage
- § New REC LEADER is introduced to the core team
- § CNAs continue to fill out research questionnaires
- § Resident interviews conducted
- § NHA visits core team meeting

June 2004

- § State survey occurs grant activities placed on hold during the survey
- § New Intervention unit REC LEADER begins
- § CNAs continue to be rotate in dayroom programming
- S CNAs continue to fill out quantitative questionnaires
- § Facility 3 hosts a site visit from Facility 1
- § CNAs continue to report increased resident alertness, verbal interaction and decreased demands
- § Individual aides' initiatives re: their participation in the program are acknowledged
- § CO-ORDINATORS continue to ask for 10 − 6 assistance
- § Core team members are working on a name for their program ~ COORDINATORS affirm core team's "spirit".
- § Key CO-ORDINATOR resigns
- § DIR HOSPITALITY SERVICES joins the core team as a replacement –
- § Team decides on rotation system each aide will work with the REC LEADER one day a week rotation will last 7 weeks AIDE will be covered by a replacement aide rotation will be positioned as a "training day" and cost will be covered by 1199
- § First all day programming begins Wednesday is assigned as the regular program day
- § Staff report increased activity and attention from residents
- § Family interviews conducted

July 2005

- § Permanent coverage for the dayroom still under discussion ~ personality attributes & qualifications appropriate for the dayroom REC AIDE are the topic
- § CNAs report that residents are so involved in the program they do not ask to leave no interruptions or distractions
- § CNAs are looking forward to their dayroom audition with the new REC LEADER
- § Farewell party for the outgoing CO-ORDINATOR
- § Quantitative questionnaires completed
- § Invitations to see the program are extended to 1199 Benefit Fund

§ 1st full dayroom rotation for Intervention unit CNAs is completed -- all had a chance to participate – will begin the rotation again

August 2004

- § 2nd full rotation begins, with extra coverage approved
- § Intervention unit residents and CNAs hold a baby shower for REC LEADER

September 2004

- § Intervention unit aide appointed as "permanent" REC AIDE
- § 2nd PROGRAM CO-ORDINATOR resigns
- § Core team participates in guided discussion about next wave of training

October 2004

- § Core team announces Dementia Group Program name
- § Core team works on identifying and selecting back up CNAs for dayroom program
- § CNAs continue to rotate as dayroom co-leaders when permanent REC AIDE is absent

November 2004 - December 2004

- § Intervention unit participates in and completes 4 day Workshop in Manhattan
- § Intervention unit REC LEADER goes out on maternity leave ~ new part-time unit REC LEADER joins the team

January 2005 - February 2005 - March 2005

- § TimeSlips trainings are conducted
- § REC LEADERS and REC AIDES continue to work on group dynamics and leadership skills
- § Dayroom dementia group program is running daily ~ rotation continues ~ many unit staff are coleading programs as back-ups

April 2005 - May 2005

- § Observers from Alzheimer's Assn and PROCESS CONSULTANTS observe Intervention unit TimeSlips programming
- § 2nd Wave of trainings (4 day workshop) is conducted with Intervention unit staff not participating in Manhattan Workshops and staff from other units
- § Quantitative portion of research completed

June 2005 - July 2005

- § "Coachings" begin on Intervention unit
- § REC LEADER returns to work after maternity leave ~ substitute REC LEADERS stays on parttime because she "loves the work and the unit"
- § Core team attends Facility 1 Hosting
- § Facility 3 sponsors their Hosting

Appendix D Tables of Quantitative Results

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Table 1 Completion rates and Reasons for Noncompletion

				Time 1 Baseline				Time 2 6 mths				Time 3 12 mths
Facility ID	F1	F2	F3	Total	F1	F2	F3	Total	F1	F2	F3	Total
Completed Assessment	20	20	25	65	19	20	18	57	17	19	16	52
N of Program Participants	14	12	18	44	13	12	14	39	11	12	12	35
N of Nonparticipants	6	8	7	21	6	8	4	18	6	7	4	17
Drop outs					1	0	7	8	2	1	2	5
Died					0	0	5	5	1	0	2	3
Transferred					1	0	2	3	1	1	0	2

Table 2: Subject Descriptive Characteristics at Baseline derived from Minimum Data Set (N=65)

Variables (range)	Interpretation of High Score	N(%)	X(sd)
Age (50-99years)	Older		81.59
			(9.85)
Gender	Female	49 (75.4)	
Race			
Asian/Pacific Islander		6 (9.2)	
Black, not of Hispanic origin		12(18.5)	
Hispanic		8 (12.3)	
White, not of Hispanic origin		39(60.0)	
Marital Status			
Never married		10 (15.6)	
Married		9 (14.1)	
Widowed		38(59.4)	
Separated		7 (10.8)	
Missing		1(1.5)	
Cognition (0-7)	More cognitive impairment		4.37
			(1.27)
ADL (0-40)	More functional impairment		21.85
			(10.96)
Diagnoses			
Diagnostic Categories:			
Neurological			
Alzheimer's Disease		10 (15.4)	
Other Dementia		13 (21.5)	
CVA		18 (27.7)	
Parkinson's		6 (9.2)	
Aphasia		2 (3.1)	
Psychiatric			
Anxiety disorder		4 (6.2)	
Depressive disorder		24 (36.9)	
Manic- depression		2 (3.1)	

Table 3 Baseline care practices for subjects in study

Variables	High Score	Total (all subjects) N=65
Payor Status		N(%)
Medicaid recipients		47 (72.3)
Medicare recipients		19 (29.2)
Private Insurance		6 (9.2)
MDS Restraints	More people restrained	2 (31%)
(N of persons restrained %)		
Treatments offered:		X (sd)
Nutrition (0-8)	More nutrition interventions	1.71 (.86)
Restorative care (0-21)	More days of restorative care given	5.87 (5.88)
Therapies (0-14 days)	More days of therapies given	1.75 (3.46)
Mood, Behavior, Cognitive Interventions (0-2 days)	More days of interventions given	.60 (.74)
MDS Psychoactive meds	High frequency of	4.78 (5.44)
(0-21 days)	psychoactive drug use	
Hospitalizations in past 90 days (0-6)	More frequent hospitalizations	.35 (.89)

Table 4 Means (standard deviations) of Clinical Outcome Indicators for Research Subjects over Time (n=52)

		Time 1	Time 2	Time 3	Main effect for time	
Measure (Range)	High Score	X(sd)	X(sd)	X(sd)	Wilks' Lambda	
					f(p)	
MDS Psychoactive	Higher number	4.85	5.83	5.73	2.09	
meds	of days of drug	(5.29)	(4.90)	(5.18)	(p=.13)	
(0-28)	use					
MDS Falls	Fell down more	.37	.40	.35	.49	
(0-2)	often	(.53)	(.50)	(.48)	(p=.63)	
MDS Therapy days	More days of	.88	.33	.17	3.58	
(0-10)	therapy sessions	(2.56)	(1.17)	(.88)	(p<.04)	
MDS Instability	Greater	.15	.13	.13	.06	
(0-1)	instability of	(.36)	(.34)	(.34)	(p=.94)	
	conditions					

Table 5 Means (Standard deviations) of Cognitive and Functional Status over Time (n=52)

		Time 1	Time 2	Time 3	Main effect
					for time f(p)
Measure	High				
(Range)	Score				
Global	Impaired	3.02	3.88	3.63	5.62
Deterioration		(1.87)	(1.94)	(1.91)	(p<.006)
Scale (1-7)					_
MDS Cognition	Impaired	4.48	3.63	3.83	2.86
(0-7)		(1.23)	(2.26)	(2.24)	(p=.07)
MDS ADL	Impaired	21.44	22.31	24.56	4.90
(0-40)		(11.34)	(12.07)	(12.58)	(p<.01)

Table 6 Means (Standard deviations) of Negative Behaviors and Affects over Time

Measure (Range)	High Score	Time 1	Time 2	Time 3	Main effect for Time
					f(p)
Observed Anger	Anger observed	1.10	1.04	1.04	.57
(4-20)	frequently	(.40)	(.17)	(.15)	(p = .57)
Observed Anxiety	Anxiety observed	1.09	1.15	1.09	.02
(4-20)	frequently	(.48)	(.35)	(.24)	(p=.98)
Observed Sadness	Sadness observed	1.65	1.07	1.11	11.55
(4-20)	frequently	(.78)	(.21)	(.31)	(p < .0001)
MDS Mood	Poor mood	1.31	1.17	1.25	.50
(0-32)		(1.99)	(1.80)	(2.07)	(p=.61)
Cornell Depression	Severe depression	30.87	23.62	11.33	20.81
in Dementia (0-38)		(24.24)	(15.48)	(12.12)	(p<.0001)
MDS Problem	Occurred frequently	.40	.44	.17	1.44
Behavior (0-15)		(.96)	(1.06)	(.51)	(p=.25)
CMAI Aggression	Several times an	7.08	6.90	6.83	.07
(6-42)	hour	(2.59)	(2.60)	(2.25)	(p=.94)
CMAI Physical	Several times an	8.56	8.52	7.98	.31
Nonaggression	hour	(3.44)	(4.05)	(3.44)	(p=.73)
(6-42)					
CMAI Verbal	Several times an	7.87	7.98	7.19	.44
Agitation (4-28)	hour	(4.69)	(5.30)	(4.42)	(p=.65)
CMAI Hiding	Several times an	2.81	2.73	4.08	2.96
(2-14)	hour	(2.21)	(1.83)	(3.20)	(p=.06)
CMAI Total Score	Several times an	38.15	38.42	38.27	.03
(29-203)	hour	(10.75)	(13.40)	(9.65)	(p=.97)

Table 7 Means and Standard Deviations for Positive behaviors and affects over time

		Time 1	Time 2	Time 3	Main effect for
					Time
Measure	High Score	N = 48	N = 48	N = 48	Wilks Lambda f
(Range)	g				(p)
Observed	More	3.04	1.65	1.74	40.17
Pleasure	Pleasure	(.97)	(.75)	(.88)	(p < .0001)
(4-20)	observed				
Observed	More	4.27	4.10	4.30	.80
Interest	Interest	(.93)	(1.01)	(1.07)	(.46)
(4-20)	observed				
Activity	More	18.65	18.00	19.81	3.71
Participation	activity	(4.96)	(4.55)	(4.37)	(p < .03)
Scale (6-30)	participation				
Observed	More active	6.10	5.56	6.44	6.31
Participation	participation	(1.39)	(1.61)	(1.46)	(p < .004)
(4-8)	observed				

Table 8 Means and Standard Deviations for Quality of Interactions between Staff and Resident over time

		Time 1	Time 2	Time 3	Main effect: time
Measure (Range)	High	N = 48			f(p)
	Score				
POSITIVE SOC	More	.80	.46	.48	23.06
(0-4)	Interaction observed	(.27)	(.36)	(.34)	(p < .0001)
POSITIVE	More	.83	.10	.11	54.10
CAR	Interaction	(.40)	(.16)	(.15)	(p < .0001)
(0-4)	observed				
NEUTRAL	More	.09	.17	.03	13.94
(0-4)	Interaction	(.34)	(.20)	(.08)	(p < .0001)
	observed				
NEGATIVE	More	.07	.02	.01	.53
PROTECTIVE	Interaction	(.33)	(.06)	(.05)	(.59)
(0-4)	observed				
NEGATIVE	More	.05	.02	0	.96
RESTRICTIVE	Interaction	(.33)	(.08)		(.39)
(0-4)	observed				
POSITIVE SUM	More	1.63	.56	.59	58.71
(0-8)	Interaction	(.59)	(.38)	(.34)	(p < .0001)
	observed				_
NEGATIVE SUM	More	.12	.03	.01	1.22
(0-8)	Interaction observed	(.65)	(.10)	(.05)	(.30)

Table 9 Means and Standard Deviations Type of Activity over time

		Time 1	Time 2	Time 3	Main effect for time
Measure	High				f(p)
(Range)	Score				
Care-related	Activity	.60	.69	.35	2.85
	observed	(1.14)	(.95)	(.53)	(.07)
Family visit	Activity	0	0	.06	.37
	Observed			(.43)	(.55)
One on One	Activity	.10	.19	.65	9.86
	observed	(.42)	(.39)	(.84)	(p < .0001)
Small	Activity	.21	.15	.02	2.21
unstructured	observed	(.58)	(.46)	(.14)	(.12)
Small	Activity	0	0	0	
structured	observed				
Large	Activity	.33	.77	.21	6.85
unstructured	observed	(.72)	(.95)	(.41)	(p < .003)
Large	Activity	2.72	1.42	1.63	13.98
structured	observed	(1.32)	(1.37)	(1.42)	(p < .0001)

Table 10: Resident Characteristics at Baseline for Targeted Program Participants (TPP) versus General Program Participants (GPP)

Variables	High Score	TPP N= 40	GPP N= 25	Total Subjects N=65	
		N (% within	N(% within	N(% within	ChiSq(p)
		group)	group)	group	
Gender (% female)	Female	33 (75)	16 (76.2)	49(75.4)	.01 (p=.58)
Race					4.99 (p=.17)
Asian/Pacific Islander		2 (4.5)	4 (19.0)	6(9.2)	
Black, not of		9 (20.5)	3 (14.3)	12(18.5)	
Hispanic origin		, ,	, ,	, ,	
Hispanic		7 (15.9)	1 (4.8)	8(12.3)	
White, not of Hispanic origin		26 (59.1)	13 (61.9)	39(60.0)	
Marital Status					7.34(p=.12)
Never married		9(20.9)	1 (4.8)	10(15.6)	\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \
Married		6 (14)	3 (14.3)	9(14.1)	
Widowed		24 (55.8)	14 (66.7)	38(59.4)	
Separated/Divorced		4 (14.3)	3 (9.3)	7(10.8)	
Diagnostic Categories:		(2.110)		. (2333)	
Neurological		5 (1.5.0)	2 (1 4 2)	10/15 1	0.2 (0.7)
Alzheimer's Disease		7 (15.9)	3 (14.3)	10(15.4)	.03 (p = .87)
Other Dementia		9 (20.5)	5 (22.9)	13 (21.5)	10 (n- 76)
CVA			5 (23.8)		.10 (p=.76)
		10 (22.7)	8 (38.1)	18 (27.7)	1.68 (p=.20)
Parkinson's		5 (11.4)	1 (4.8)	6 (9.2)	.74 (p=.39)
Aphasia		0	2 (9.5)	2 (3.1)	4.32 (p<.04)
Psychiatric					
Anxiety disorder		4 (9.1)	0	4 (6.2)	.2.03(.15)
Depressive disorder		15 (34.1)	9 (42.9)	24 (36.9)	.47 (p=.49)
Manic- depression		2 (4.5)	0	2 (3.1)	.99 (.32)
		X(sd)	X(sd)	X(sd)	T test (p)
Age (50-99 years)	Older	81.76(10.60)	81.24(8.28)	81.59 (9.85)	2.36(p=.13)
Cognitive function	More	4.61 (1.13)	3.86 (1.42)	4.37 (1.27)	2.32 (p<.02)
(0-7)	cognitive impairment	, ,			
ADL function (0-40)	More functional impairment	21.48 (9.88)	22.62 (13.18)	21.85 (10.96)	39 (.70)

Table 11 Baseline care practices for Targeted Program Participants (TPP) versus General Program Participants (GPP)

Variables	High Score	TPP (n= 40)	GPP	Total (all	Test of
			(n=25)	subjects)	differences
				N=65	
Payor Status					Chisq (p)
Medicaid (N, %)		28 (70%)	19 (76%)	47 (72.3%)	.28 (p = .78)
Medicare (N,%)		11 (28%)	8 (32%)	19 (29.2%)	.15 (p = .70)
Private Insurance		6 (15%)	0	6 (9.2%)	4.13 (p = .07)
(n,%)					
MDS Restraints	More people	1	1	2	.12 (p = .73)
(N of people	restrained				
restrained)					
Treatments		X (sd)	X (sd)	X(sd)	T-test (p)
offered:					
Nutrition	More nutrition	1.68	1.72	1.71	.20 (p= .84)
(0-8)	interventions	(.94)	(.74)	(.86)	
Restorative	More days of	5.95	5.60	5.87	23 (p = .82)
care (0-21)	restorative care	(5.62)	(6.39)	(5.88)	
	given				
Therapies (0-	More days of	1.63	2.16	1.75	.59 (p = .56)
14)	therapies given	(3.23)	(3.98)	(3.46)	
Mood, Beh, Cog	More days of	.55	.68	.60	.70 (p = .49)
Interventions	interventions	(.71)	(.75)	(.74)	
(0-2)	given				
MDS	More days of	4.45	5.04	4.78	.43 (p = .67)
Psychoactive	psychoactive	(5.61)	(5.16)	(5.44)	
meds (0-21)	drug use				
Hospitalizations	More frequent	.50	.16	.35	-1.78 (p = .08)
in past 90 days	hospitalizations	(1.11)	(.37)	(.89)	
(0-6)					

Table 12 Means (Standard deviations) of Clinical outcome indicators for Targeted Program Participants (TPP) versus General Program Participants (GPP)

		Time 1		Time 2		Time 3		Main effect for Time f(p)	Interacti on effect Participa tion type X Time f(p)	Between effect for Program Exposure
Measure (Range)	High Score	TPP	GPP	TPP	GPP	TPP	GPP			
MDS Psychoactive	High	4.20	6.18	5.66	6.18	5.71	5.76	.97	1.57	.37
meds	number of	(5.42)	(4.88)	(4.67)	(5.47)	(4.72)	(6.18)	(p = .39)	(p = .22)	(p = .54)
(0-28)	days of drug							_	_	_
	use									
MDS Falls	Fell down	.43	.24	.46	.29	.37	.29	.35	.20	1.55
(0-2)	more often	(.56)	(.44)	(.51)	(.47)	(.49)	(.47)	(p = .71)	(p = .82)	(p = .22)
MDS Therapy days	Attended	1.03	.59	.49	0	.26	0	2.57	.42	1.11
(0-10)	more	(2.65)	(2.43)	(1.40)	0.0	(1.07)	0	(p=.09)	(p=.66)	(p=.29)
	therapy								_	_
	sessions									
MDS Instability	Greater	.20	.05	.17	.05	.14	.12	.02	.46	2.04
(0-1)	instability of	(.44)	(.24)	(.38)	(.24)	(.36)	(.32)	(p = .97)	(p = .63)	(p=.16)
, ,	conditions	. ,	. ,	, ,	, ,	, ,	, ,	,	/	,

Table 13 Means (Standard deviations) of Cognitive and Functional Status for Targeted Program Participants (TPP) versus General Program

		Time 1	8	Time 2		Time 3	_	Main effect	Interaction	B/W
								for time	effect	effect for
									Participation	Program
									type X time	Exposure
Measure	High	TPP	GPP	TPP	GPP	TPP	GPP	f(p)	f(p)	f(p)
(Range)	Score									
Global	Impaired	2.94	3.19	3.86	3.94	3.43	4.06	4.72	.47	.46
Deterioration		(1.83)	(2.01)	(1.78)	(2.29)	(1.77)	(2.17)	(p < .01)	(p = .63)	(p = .50)
Scale (1-7)										
MDS	Impaired	4.71	4.00	3.49	3.94	3.80	3.88	1.44	1.53	.02
Cognition		(1.02)	(1.5)	(2.23)	(2.36)	(1.98)	(2.76)	(p = .25)	(p = .23)	(p = .89)
(0-7)										
MDS ADL	Impaired	21.46	21.41	23.11	20.65	24.06	25.59	5.93	4.36	.009
(0-40)		(10.09)	(13.90)	(11.21)	(13.90)	(11.56)	(14.78)	(p < .005)	(p < .02)	(p = .92)

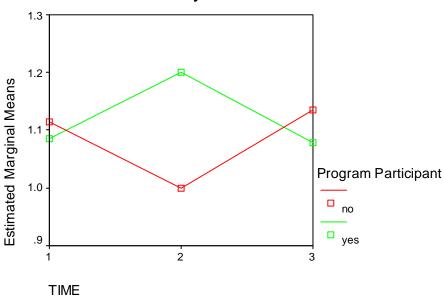
Participants (GPP)

Table 14 Means (Standard deviations) of Negative Behaviors and Affects by Program Exposure type over Time

	andaru deviations	Time 1	2011011011	Time 2	9 9 9 1 1 9 8 1 1 1	Time 3	type over a	Main	Interaction:	B/W effect:
		1 11116 1		I IIIC 2		Time J		effect:	participation	Program
								Time	type x time	exposure
Measure (Range)	High Score	TPP	GPP	TPP	GPP	TPP	GPP	F(p)	F(p)	f(p)
Wieasure (Kange)	High Score	N = 35	N = 17	111	GH	111	GH	r(p)	r (p)	I(p)
Observed Anger	Angor	1.10	1.12	1.05	1.00	1.04	1.04	.58	.34	.07
O	Anger									
(4-20)	observed	(.40)	(.42)	(.20)	(.00)	(.15)	(.14)	(.57)	(.72)	(.79)
01 1	frequently	1.00	1.11	1.20	1.00	1.00	1 10	0.2	2.22	1.5
Observed	Anxiety	1.09	1.11	1.20	1.00	1.08	1.13	.02	3.32	.15
Anxiety (4-20)	observed	(.51)	(.42)	(.40)	(.00)	(.24)	(.24)	(.98)	(.05)	(.70)
	frequently									
Observed	Sadness	1.62	1.73	1.10	1.00	1.06	1.25	11.55	3.53	.55
Sadness (4-20)	observed	(.77)	(.83)	(.24)	(.00)	(.27)	(.40)	(.0001)	(.04)	(.46)
	frequently									
MDS Mood (0-	Poor mood	1.17	1.59	1.06	1.41	1.03	1.71	.50	.30	.82
32)		(1.98)	(2.03)	(1.75)	(1.94)	(2.08)	(2.02)	(.61)	(.77)	(.37)
Cornell	Severe	31.69	29.18	24.20	22.41	12.66	8.59	20.81	.12	.58
Depression in	depression	(25.67)	(21.65)	(16.42)	(13.75)	(14.02)	(6.22)	(.0001)	(.89)	(.45)
Dementia (0-38)										
MDS Problem	Occurred	.43	.35	.46	.41	.11	.29	1.44	.48	.008
Behavior (0-15)	frequently	(.92)	(1.06)	(1.07)	(1.06)	(.40)	(.69)	(.25)	(.62)	(.93)
CMAI	Several times	7.34	6.53	7.08	6.53	6.63	7.24	.07	1.50	.21
Aggression (6-42)	an hour	(2.98)	(1.46)	(3.04)	(1.28)	(1.31)	(3.49)	(.94)	(.23)	(.65)
CMAI Physical	Several times	8.77	8.12	9.03	7.47	7.86	8.24	.31	1.77	.44
Nonaggression	an hour	(3.65)	(3.02)	(4.59)	(2.37)	(2.97)	(4.34)	(.73)	(.18)	(.51)
(6-42)						, ,				
CMAI Verbal	Several times	8.31	6.94	8.66	6.58	7.37	6.82	.44	.83	1.14
Agitation (4-28)	an hour	(5.05)	(3.82)	(5.79)	(3.92)	(4.91)	(3.30)	(.65)	(.44)	(.29)
CMAI Hiding	Several times	2.83	2.76	2.51	3.18	4.40	3.41	2.96	2.71	.06
(2-14)	an hour	(2.49)	(1.56)	(1.48)	(2.38)	(3.18)	(3.22)	(.06)	(.08)	(.81)
CMAI Total	Several times	39.34	35.71	39.94	35.29	38.06	38.71	.16	1.56	.78
Score (29-203)	an hour	(11.76)	(8.04)	(15.27)	(7.84)	(9.33)	(10.55)	(.88)	(.22)	(.38)

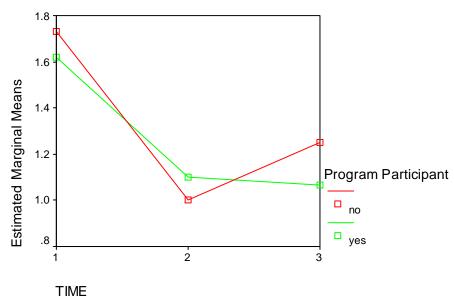
Estimated Marginal Means of

Observed Anxiety



Estimated Marginal Means of

Observed Sadness



Estimated Marginal Means of

Cornell Depression in Dementia

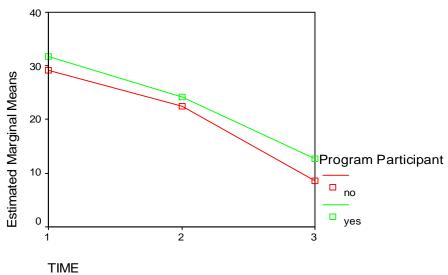


Table 15 Means and Standard Deviations for Positive behaviors and affects by Targeted Program Participants (TPP) versus General Program Participants (GPP) over time

		Time 1		Time 2		Time 3		Interaction	B/W for
								participation	Program
								type x time	Exposure
								(f)	
Measure	High Score	TPP	GPP	TPP	GPP	TPP	GPP		
(Range)		(N=35)	(N = 13)	(N=35)	(N = 13)	(N=35)	(N = 13)		
Observed	More	3.22	2.54	1.78	1.31	1.90	1.31	.22	8.95
Pleasure	Pleasure	(.93)	(.93)	(.76)	(.65)	(.87)	(.77)	(.81)	(p < .004)
(4-20)	observed								
Observed	More	4.45	3.79	4.29	3.58	4.46	3.85	.03	7.94
Interest	Interest	(.77)	(1.19)	(.72)	(1.44)	(.93)	(1.30)	(.97)	(.15)
(4-20)	observed								
Activity	More	18.94	18.06	18.60	16.76	20.77	17.82	1.50	2.85
Participation	activity	(4.91)	(5.17)	(4.03)	(5.38)	(3.77)	(4.93)	(.23)	(.09)
Scale (6-30)	participation								
Observed	More active	6.31	5.54	6.00	4.38	6.51	6.23	2.02	9.55
Participation	participation	(1.39)	(1.27)	(1.43)	(1.50)	(1.40)	(1.64)	(.14)	(p < .003)
(4-8)	observed								

Observed Level of Participation

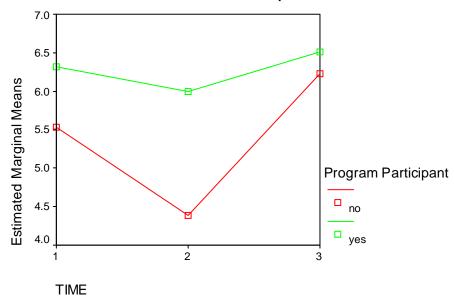
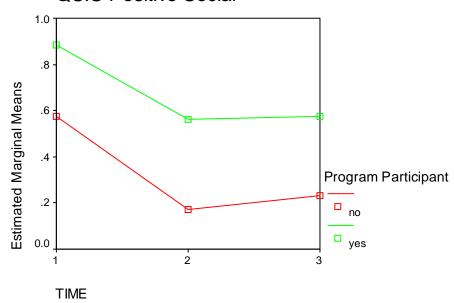


Table 16 Means and Standard Deviations for Quality of Interactions between Staff and Resident by Targeted Program Participants (TPP) versus General Program Participants (GPP) over time

		Time 1		Time 2		Time 3		Interaction effect participation type x time	B/W effect for Program exposure
Measure (Range)	High Score	TPP	GPP	TPP	GPP	TPP	GPP	f(p)	f(p)
POSITIVE SOC (0-4)	More Interaction observed	.89 (.19)	.58 (.33)	.56 (.32)	.17 (.30)	.57 (.33)	.23 (.24)	.24 (.79)	30.21 (p<.0001)
POSITIVE CAR (0-4)	More Interaction observed	.92 (.41)	.58 (.24)	.11 (.18)	.06 (.12)	.11 (.15)	.12 (.17)	3.28 (p < .05)	8.16 (p < .006)
NEUTRAL (0-4)	More Interaction observed	.04 (.11)	.25 (.62)	.17 (.21)	.17 (.19)	.04 (.09)	.02 (.07)	2.28 (.11)	2.51 (.21)
NEGATIVE PROTECTIVE (0-4)	More Interaction observed	.09 (.39)	.02 (.06)	.01 (.06)	.02 (.07)	.01 (.06)	0	.40 (.67)	.58 (.49)
NEGATIVE RESTRICTIVE (0-4)	More Interaction observed	.07 (.38)	0	.01 (.08)	.02 (.07)	0	0	.25 (.78)	.36 (.55)
POSITIVE SUM (0-8)	More Interaction observed	1.81 (.51)	1.15 (.55)	.68 (.34)	.24 (.32)	.69 (.32)	.35 (.28)	1.08 (.35)	39.03 (p<.0001)
NEGATIVE SUM (0-8)	More Interaction observed	.16 (.76)	.02 (.07)	.03 (.10)	.04 (.10)	.01 (.06)	0	.39 (.68)	.44 (.51)

QUIS Positive Social



Estimated Marginal Means of

QUIS Positive Care

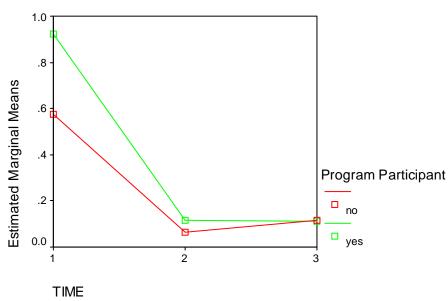
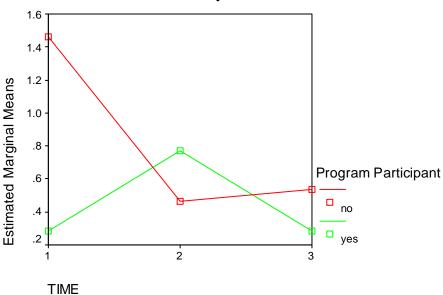


Table 17 Means and Standard Deviations Type of Activity by Targeted Program Participants (TPP) versus General Program Participants (GPP) over time

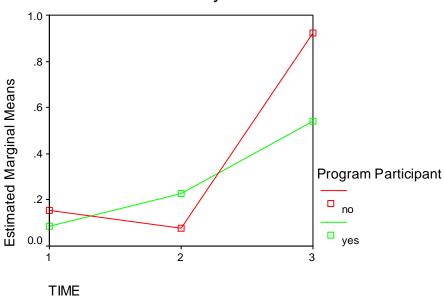
		Time 1		Time 2		Time 3		Interaction effect participation type x time	Between effect for Program exposure
Measure (Range)	High Score	TPP	GPP	TPP	GPP	TPP	GPP	f(p)	f(p)
Care-related	More Activity observed	.29 (.67)	1.46 (1.66)	.77 (1.03)	.46 (.66)	.29 (.52)	.54 (.52)	5.09 (p<.01)	5.86 (p<.02)
Family visit	More Activity Observed	0	0	0	0	.09 (.51)	0	.36 (.09)	.37 (.55)
One on One	More Activity observed	.09 (.37)	.15 (.55)	.23 (.43)	.08 (.24)	.54 (.82)	.92 (.86)	2.69 (.08)	.80 (.38)
Small unstructured	More Activity observed	.29 (.67)	0	.14 (.43)	.15 (.55)	.03 (.17)	0	.88 (.42)	1.79 (.19)
Small structured	More Activity observed	0	0	0	0	0	0		
Large unstructured	More Activity observed	.40 (.77)	.15 (.55)	.74 (.89)	.84 (1.14)	.22 (.42)	.15 (.38)	.76 (.48)	.21 (.65)
Large structured	More Activity observed	2.94 (1.11)	2.15 (1.68)	1.77 (1.28)	.46 (1.13)	2.03 (1.40)	.54 (.78)	.67 (.52)	24.60 (p < .0001)

Care-related Activity

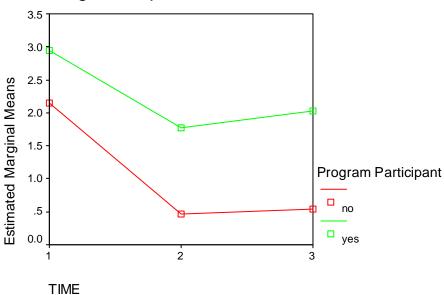


Estimated Marginal Means of

One on One Activity



Large Group- Structured



Appendix E

Quantitative Instruments and Protocols

THE COHEN-MANSFIELD AGITATION INVENTORY - Long Form

Please read each of the 29 agitated behaviors, and circle how often (from 1-7) each was manifested by the resident during the last 2 weeks.

		Never 1	Less than once a week 2	Once or twice a week 3	Several times a week 4	Once or twice a day 5	Several times a day 6	Several times an hour 7
1.	Pace, aimless wandering	1	2	3	4	5	6	7
2.	Inappropriate dress or disrobing	1	2	3	4	5	6	7
3.	Spitting (include at meals)	1	2	3	4	5	6	7
4.	Cursing or verbal aggression	1	2	3	4	5	6	7
5.	Constant unwarranted request for attention or help	1	2	3	4	5	6	7
6.	Repetitive sentences or questions	1	2	3	4	5	6	7
7.	Hitting (including self)	1	2	3	4	5	6	7
8.	Kicking	1	2	3	4	5	6	7
9.	Grabbing onto people	1	2	3	4	5	6	7
10.	Pushing	1	2	3	4	5	6	7
11.	Throwing things	1	2	3	4	5	6	7
12.	Strange noises (weird laughter or crying)	1	2	3	4	5	6	7
13.	Screaming	1	2	3	4	5	6	7
14.	Biting	1	2	3	4	5	6	7

15.	Scratching	1	2	3	4	5	6	7
		Never 1	Less than once a week 2	Once or twice a week 3	Several times a week 4	Once or twice a day 5	Several times a day 6	Several times an hour 7
16.	Trying to get to a different place (e.g., out of the room, building)	1	2	3	4	5	6	7
17.	Intentional falling	1	2	3	4	5	6	7
18.	Complaining	1	2	3	4	5	6	7
19.	Negativism	1	2	3	4	5	6	7
20.	Eating/drinking Inappropriate substances	1	2	3	4	5	6	7
21.	Hurt self or other (cigarette, hot water, etc.)	1	2	3	4	5	6	7
22.	Handling things inappropriately	1	2	3	4	5	6	7
23.	Hiding things	1	2	3	4	5	6	7
24.	Hoarding things	1	2	3	4	5	6	7
25.	Tearing things or destroying property	1	2	3	4	5	6	7
26.	Performing repetitious mannerisms	1	2	3	4	5	6	7
27.	Making verbal sexual advances	1	2	3	4	5	6	7
28.	Making physical sexual advances	1	2	3	4	5	6	7

29. General restlessness 1 2 3 4 5 6 7

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CORNELL SCALE FOR DEPRESSION IN DEMENTIA

Ratings should be based on symptoms and signs occurring during the week prior to interview. No score should be given if symptoms result from physical disability or illness.

Scorin	Scoring System: 0=absent 1=mild or intermittent 9=unable to evaluate		2=seve			
A.	Mood 1.	Related Signs Anxiety anxious expression, ruminations, worrying	0	1	2	9
	2.	Sadness sad expression, sad voice, tearfulness	0	1	2	9
	3.	Lack of Reactivity to Pleasant Events	0	1	2	9
	4.	Irritability easily annoyed, short tempered	0	1	2	9
В.	Behav 5.	ioral Disturbance Agitation restlessness, handwringing, hairpulling	0	1	2	9
	6.	Retardation slow movements, slow speech, slow reactions	0	1	2	9
	7.	Multiple Physical Complaints (score 0 if GI symptoms only)	0	1	2	9
	8.	Loss of Interest less involved in usual activities (score only if change occurred acutely i.e. less than	0 one mo	1 onth)	2	9
C.	Physic 9.	al Signs Appetite Loss eating less than usual	0	1	2	9
	10.	Weight Loss (score 2 if greater than 5 lbs in one month)	0	1	2	9
	11.	Lack of Energy fatigues easily, unable to sustain activities	0	1	2	9

(score only if change occurred acutely i.e. less than one month)

D.	Cycli	c Functions						
	12.	Diurnal Variation of Mood symptoms worse in the morning	0	1	2	9		
	13.	Difficulty Falling Asleep later than usual for this individual	0	1	2	9		
	14.	Multiple Awakenings During Sleep	0	1	2	9		
	15.	Early Morning Awakening earlier than usual for this individual	0	1	2	9		

E. Ideational Disturbance

(For items 16-19, probe to see how much the informant knows. If the informant does not know or is usure, code items as 9.)

16.	Suicide Feels life is not worth living, has suicidal wishes, or make suicide attempt	0	1	2	9
17.	Self-Depreciation self-blame, poor self-esteem, feelings of failure	0	1	2	9
18.	Pessimism anticipation of the worst	0	1	2	9
19.	Mood Congruent Delusions Delusions of poverty, illness, or loss	0	1	2	9

Apparent Affect Rating Scale

Please rate the extent or duration of each affect over a ten-minute period. Some possible signs of each emotion are listed. If you see no sign of a particular feeling, rate "Never."

are listed.11 you see <u>no sign</u> of a partic	<u></u>	7	1	2	3	4	5
PLEASURE		Not in view	Never	Less than 16 sec.	16-59 sec.	1-5 min.	more than 5 min.
Signs: Laughing; singing; smiling; kissing; stroking or gently touching other; reaching out warmly to other; responding to music (only counts as pleasure if in combination with another sign).							
ANGER Signs: Physical aggression; yelling; cursing; berating; shaking fist; drawing eyebrows together; clenching teeth; pursing lips; narrowing eyes; making distancing gesture.							
ANXIETY/FEAR Signs: Shrieking; repetitive calling out; restlessness; wincing/grimacing; repeated or agitated movement; line between eyebrows; lines across forehead; hand wringing; tremor; leg jiggling; rapid breathing; eyes wide; tight facial muscles.	(6 g)						
SADNESS Signs: Crying; frowning; eyes drooping; moaning; sighing; head in hand; eyes/head turned down and face expressionless (only counts as sadness if paired with another sign).							
GENERAL ALERTNESS Signs: Participating in a task; maintaining eye contact; eyes following object or person; looking around room; responding by moving or saying something; turning body or moving toward person or object.							

Activity Participation Scale

Check the frequency with which the resident performed each type of activity. USE THE PAST WEEK as the basis for your estimate. Try to fit any Activity not named below into one of the categories A through G.

		Never	Once a week	2-5 times per week	Almost every day	A couple times a day
1.	Unplanned, nonsolitary social Activities (games, etc.)	О	О	O	О	О
2.	Planned social activities (games, music, parties, group crafts, etc.)	О	О	О	O	O
3.	Planned physical activities (walking indoors, exercise, remedial exercise, dancing)	О	О	О	О	O
4.	Planned outdoor activities walking trips, gardening, sports, etc.)	О	O	O	O	O
5.	Television or radio (attentive)	О	О	O	О	О
6.	Other solitary activities (reading, games, hobby)	О	0	O	О	О
7.	Religious activities (attends services, reads, talks with religious figure, prays)	О	O	0	О	0

Activity Observation Protocol

Please check all that apply.

1.	Location (if more than one, number	4.	Interpersonal Distance:
	sequence visited):		
	Living room		4+ feet
	Dining room		30-48 inches
	Therapeutic kitchen		18-30 inches
	Porch		<18 inches
	Nurses support station		
	Hall		
	Den	5.	Person(s) Interacting With:
	Resident's room		Nursing Staff
	Another's room		Activity Staff
	Bathroom		Support Staff
	Tub/shower room		Other Staff
	Other		Other Resident
			Family
2.	At a table: Y N		Other Visitor
3.	Interaction Situation (if more than one, number	6.	Level of Participation
	sequence of events):		Active
	Care-related		Passive
	Family visit		
	One-on-one unstructured		
	Small unstructured group (2-5 persons)		
	Small structured group		
	Large unstructured group (6+ persons)		
	Large structured group		

Quality of Interaction Schedule (QUIS)

Please indicate which of the following interactions were observed over a 5 minute observation period. Some examples of each interaction are listed. If you see no sign of a particular interaction, rate "Not Present." Use "Can't tell" only when you are really uncertain.

		Not present	Present	Can't Tell
1.	Positive Social	0	1	9

Interaction principally involving good, constructive, beneficial conversation and companionship:

- Greetings directed to individuals
- General chat and conversation, on its own or during other social and physical care activities
- Offering choices (eg food, drink, nail colour)
- Serving food while saying what it is, asking if the subject likes it, who made it, etc.
- Offering more food/asking if finished, only if carer waits for a response
- Verbal explanation, encouragement, and comfort during other care tasks (lifting, moving, walking, bathing, etc.) that is more than necessary to carry out the task.

2. Positive Care 0 1	9
----------------------	---

Interactions during the appropriate delivery of care:

- Toiletting, bathing, medication, feeding, etc. These may involve brief verbal explanations and encouragement, but only that necessary to carry out the task. No general conversation
- Keeping safe or removal from danger with explanation and reassurance
- 3. Neutral 0 1 9

Brief, indifferent interactions not meeting the definitions of the other categories:

- Putting plates down without verbal or nonverbal contact
- Undirected 'good morning/hello/goodbye'
- 4. Negative Protective 0 1 9

Providing care, keeping safe or removing from danger, but in a restrictive manner, without explanation or reassurance:

- 'Don't eat that, its been on the floor'
- 'Don't hit X'
- Being told to wait for medication/treatment
- Being fed too quickly
- 5. Negative Restrictive 0 1 9

Interactions that oppose or resist residents' freedom of action without good reason, or which resident as a person:

• Being moved without warning or explanation

- Told to do something (eg button dress) without discussion, explanation, or help offered
- Being told can't have something (eg cup of tea) without good reason/explanation
- Being told not allowed to swear/show anger
- Being sworn at or physically or verbally assaulted

QUALITY OF INTERACTIONS SCHEDULE (QUIS)

APPENDIX

QUIS Guidelines and examples for coding interactions

Positive social interaction principally involving good, constructive, beneficial conversation and companionship:

- Greetings directed to individuals
- General chat and conversation, on its own or during other social and physical care activities
- Offering choices (e.g., food, drink, nail colour)
- Serving food while saying what it is, asking if subject likes it, who made it, etc.
- Offering more food, asking if finished, only if carer waits for a response
- Verbal explanation, encouragement and comfort during other care tasks (lifting, moving, walking, bathing, etc.) that is more than necessary to carry out the task

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Positive care

Interactions during the appropriate delivery of physical care:

- Toileting, bathing, medication, feeding, etc. These may involve brief verbal explanations and encouragement, but only that necessary to carry out the task. No general conversation.
- Keeping safe or removal from danger with explanation and reassurance

Neutral

Brief, indifferent interactions not meeting the definitions of the other categories:

- Putting plates down without verbal or non-verbal contact
- Undirected "good morning/hello/goodbye"

Negative protective

Providing care, keeping safe or removing from danger, but in a restrictive manner, without explanation or assurance:

- "Don't eat that, it's been on the floor."
- "Don't hit X"
- Being told to wait for medication/treatment
- Being fed too quickly

Negative restrictive

Interactions that oppose or resist residents' freedom of action without good reason, or which ignore resident as a person:

- Being moved without warning or explanation
- Told to do something (e.g., button dress) without discussion, explanation or help offered
- Being told can't have something (e.g., cup of tea) without good reason/explanation
- Being told not allowed to swear/show anger
- Being sworn at or physically assaulted

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Appendix F Qualitative Interview Schedules

Appendix G

Descriptive Model of Participants' Experience of Culture Change Interventions

	Participant	Participant	Participant	Participant
EXPERIENTIAL	Segment	Segment	Segment	Segment
CATEGORIES	# 1	# 2	# 3	# 4
Expectations				
What will happen?				
Practical				
experience				
What is				
happening?				
Reaction				
Is it positive or				
negative?				
Explanation				
Why is it				
happening this				
way?				
Recommendation				
What should				
happen next?				

Appendix H

Presentations of Intervention Evaluation Related Findings