Georgia State University
ScholarWorks @ Georgia State University

Gerontology Theses | Gerontology Institute

11-20-2008

Client and Caregiver Perceptions of Adult Day Services: A Program Evaluation

Dianne Maureen O'Donnell

Follow this and additional works at: http://scholarworks.gsu.edu/gerontology_theses

Recommended Citation
O'Donnell, Dianne Maureen, "Client and Caregiver Perceptions of Adult Day Services: A Program Evaluation" (2008). *Gerontology Theses.* Paper 12.

This Thesis is brought to you for free and open access by the Gerontology Institute at ScholarWorks @ Georgia State University. It has been accepted for inclusion in Gerontology Theses by an authorized administrator of ScholarWorks @ Georgia State University. For more information, please contact scholarworks@gsu.edu.

CLIENT AND CAREGIVER PERCEPTIONS OF ADULT DAY SERVICES:

A PROGRAM EVALUATION

by

DIANNE M. O'DONNELL

Under the Direction of Ann M. Pearman

ABSTRACT

The MJCCA Weinstein Center for Adult Days Services provides social activities and medical services to older adults, including individuals with memory loss. Center administrators requested a program evaluation to explore attraction and retention of clients, beneficial effects of Center activities, and the current case management program. Regular members of the Center's Traditional Group (n=14) and family caregivers of Memory Loss program attendees (n=10) participated in open-ended interviews in focus groups.

Content analysis revealed that clients consider Center activities, staff, and social environment superior to the few other day care alternatives. The activities benefit clients primarily physically and emotionally. Potential areas of improvement include enhanced communication with caregivers and more engaging, mentally-stimulating activities personally significant to participants.

Findings reveal that person-centered care is appropriate in the adult day service setting and may guide the Center in program modifications. The evaluation partially satisfies new rules in Georgia for licensure and quality assurance.

INDEX WORDS: Adult day care, Program evaluation, Care recipients, Caregivers, Satisfaction, Quality, Environment, Personhood, Person-centered care

CLIENT AND CAREGIVER PERCEPTIONS OF ADULT DAY SERVICES: A PROGRAM EVALUATION

by

DIANNE M. O'DONNELL

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of

Master of Arts

in the College of Arts and Sciences

Georgia State University

2008

Copyright by

Dianne Maureen O'Donnell

2008

CLIENT AND CAREGIVER PERCEPTIONS OF ADULT DAY SERVICES:

A PROGRAM EVALUATION

by

DIANNE M. O'DONNELL

Committee Chair: Ann M. Pearman

Committee: Elisabeth O. Burgess
Candace L. Kemp

Electronic Version Approved:

Office of Graduate Studies
College of Arts and Sciences
Georgia State University
December 2008

DEDICATION

This work is dedicated to the extraordinary men and women who attend the MJCCA Weinstein Center for Adult Day Services Traditional Program. Their willingness and courage to express their ideas and opinions made this evaluation possible. I am grateful for their wisdom.

I also dedicate this work to the family members of the Memory Loss Program clients. Each caregiver I met generously encouraged me in my master's studies and new career. While completion of a master's thesis does require dedication and hard work, it pales in comparison to the devotion and commitment these caregivers demonstrated time and time again when describing their daily struggles with their loved ones' suffering. I wish these families well.

ACKNOWLEDGEMENTS

I would like to thank Dr. Ann Pearman not only for her guidance and supervision as my thesis adviser but also for her dedication to excellence in research and program evaluation methods. I thank Dr. Candace Kemp for her direction and support, as her experience with conducting open-ended group interviews was extremely beneficial. It seemed fitting when Dr. Elisabeth Burgess joined my thesis committee, because when I began my studies at the Gerontology Institute, Dr. Burgess recommended I choose the "Research Track" given my prior career experiences and interests in numerous facets of aging. That decision has served me well. I regret that Dr. Frank Whittington was not here to see me finish the program he worked so hard to build. He was a source of inspiration for me in career and in life. I wish him the best in his new position at George Mason University.

Georgia Gunter, Director of the Weinstein Center and alumnae of The Gerontology Institute's Certificate Program, made the program evaluation possible. As a result of this research project I was able to explore adult day services, a fascinating and increasingly important community care alternative for older adults, as an objective advisor and evaluator to her organization. I thank Danelle Hubbard, fellow graduate student and member of the Advisory Board of the Weinstein Center, for recommending me for the evaluation.

I have enjoyed working with the members of Dr. Pearman's lab team: Nia Reed, Tiffany Young, and Ashley Myers. During the planning and development of my proposal for this project, they offered excellent ideas which improved the evaluation design. Furthermore, Tiffany Young was invaluable as my co-researcher in the focus groups. She did everything she could to make the focus group participants comfortable, from escorting them in their wheelchairs, answering questions on the Informed Consent, to assisting those who needed help. She took notes in the

focus groups and interjected with insightful follow-up questions when a participant touched on a critical subject for the evaluation.

Finally, to my mother and father Shirley and Clyde O'Donnell, to my sister Suzanne D'Abate, and to friend Tom McNamara, who wondered whether my study of Gerontology would generate a constant analysis of their actions as age-related issues or senior moments -- know that you are the best inspiration I could possibly have to go forward with a new and rewarding career. Thank you for your life-long love and support.

TABLE OF CONTENTS

ACKNOWLEDGEMENTS v

LIST OF TABLES ix

LIST OF FIGURES x

LIST OF ABBREVIATIONS xi

CHAPTER

I. INTRODUCTION AND EXECUTIVE SUMMARY 1

Scope and Approach 3

Findings and Recommendations 4

Future Directions 8

II. CONCEPTUAL FRAMEWORK 9

Literature Review 9

Research Questions 18

III. RESEARCH METHODS 20

Research Setting 20

Design 25

Procedures 25

Data Analysis 32

Guiding Principles for Program Evaluation 35

IV. RESULTS 37

Sample Characteristics 37

Attracting and Retaining Clients 41

Perceptions of Activities as Beneficial 55

Case Management Program 67

V. DISCUSSION 71

Contribution to ADS Evaluation Research 71

Current Limitation-Based Approach to Programming 73

Recommendations 74

Community Challenges for Adult Day Care 84

Limitations 85

Conclusion 87

REFERENCES 88

APPENDICES 91

Appendix A PROGRAMS AND SERVICES OF THE WEINSTEIN CENTER 92

Appendix B WEINSTEIN CENTER CAREGIVER/PARTICIPANT SATISFACTION SURVEY -- 2007 95

Appendix C PERMISSION TO PERFORM RESEARCH ON-SITE 98

Appendix D MATERIALS FOR PARTICIPANT RECRUITMENT 100

Appendix E SAMPLE INFORMED CONSENT FORMS 104

Appendix F INTERVIEW GUIDES 109

LIST OF TABLES

Table 3.1: Select Client Characteristics, 2007 22

Table 3.2: Retention Rates of Clients, 2007 23

Table 3.3: Characteristics of Focus Group Meetings 29

Table 4.1: Select Traditional Group Sample Characteristics by Sample Group 38

Table 4.2: Select Characteristics of Memory Loss Group Caregivers 40

LIST OF FIGURES

Figure 3.1: Example of Content Analysis Coding Structure for Positive Effects Reported by Participants 34

LIST OF ABBREVIATIONS

AAA	Area Agency on Aging
ADS	Adult Day Services
AEA	American Evaluation Association
ARC	Atlanta Regional Commission
CARF	Commission on Accreditation for Rehabilitation Facilities
Center	MJCCA Weinstein Center for Adult Day Services
MJCCA	Marcus Jewish Community Center of Atlanta
NADSA	National Association of Adult Day Services
TQM	Total Quality Management

CHAPTER I

INTRODUCTION AND EXECUTIVE SUMMARY

Adult day centers are community-based programs that offer a range of services to socially isolated, chronically ill, disabled, frail, and/or at-risk adults and seniors. The MJCCA Weinstein Center for Adult Day Services (the "Weinstein Center" or the "Center") in Atlanta, Georgia offers a combination of social and medical services. The Center has two distinct activity and social programs for clients, the Alzheimer's Program, for individuals with moderate to severe memory loss, and the Traditional Program, for persons who are cognitively competent but may have some physical limitations. The Dunwoody location of the Weinstein Center, the site of the present evaluation, was founded in 1982, serves an average of 46 clients per day, and employs 13 full-time equivalent staff members.

For the past three years, the Weinstein Center has conducted an annual survey completed by clients and family members. The survey asked the respondents to rate the operational features of the Center including activities, nursing services, personal care services, meals, and transportation, as well as staff, case management, location, and hours as "excellent," "very good," "fair," or "unsatisfactory". Because the survey respondents overwhelmingly answered "very good" or "excellent," the survey provided little concrete information about how the programs and services affect the clients and their families. The Advisory Board for the Center requested a program evaluation to assess how well its services are responding to client and community needs and to identify areas for improvement.

To provide background for the evaluation, the research began with an examination of the adult day service (ADS) industry from a national perspective followed by a consideration of recent initiatives in the State of Georgia to regulate ADS centers through licensing requirements.

There are approximately 3,400 ADS organizations in the U.S., and 78% are either non-profit or government-based (NADSA, 2008). There is no federal regulation of ADS, and oversight at the state level is extremely varied in scope and purpose. In 2003, the state of Georgia adopted a licensure law for ADS centers, and corresponding regulations remain under consideration in proposed form. Among other requirements, the rules require ADS organizations subject to the licensure law to perform a program evaluation for quality assurance purposes at least annually.

Evaluation studies examining the effectiveness of ADS typically review objective clinical outcomes and/or subjective patient attitudes, which often produce equivocal results. For example, one study found that while most of the care recipients indicated that ADS services had relieved their loneliness and reduced feelings of depression and anxiety, objective clinical outcomes of depression, anxiety or, functional status were not significantly impacted by ADS services (Baumgarten, Lebel, Laprise, LeClerc, & Quinn, 2002). This same study also found that caregivers reported lowered burden with more frequent ADS use, but the objective measurement of caregiver burden was not significantly improved.

Satisfaction is also a common subjective measure of the effectiveness of ADS, and quality improvement initiatives in the health care and long term care industries stress the importance of incorporating consumer satisfaction into quality assessment processes. Several evaluations examining client satisfaction found that staff caring, facility environment, alignment of expectations to experience, and quality of communications contributed to satisfaction (Townsend & Kosloski, 2002; Warren, Kerr, Smith, Godkin, & Schalm, 2003, Buelow & Conrad, 1992). Many of the previous evaluations, however, used written satisfaction surveys, closed-end questionnaires, or caregiver perspectives only, which limited the amount of specific detail that could be learned about the actual day-to-day activities of the ADS programs. Stern &

Caro (2004) addressed this limitation in the evaluation field by conducting focus groups with care recipients and caregivers, using open-ended interviews, and conceptualizing quality in the areas of reliability, consistency, and responsiveness to consumers.

Scope and Approach

Background information about the Weinstein Center's programs, services, and client base as well as its expressed goals for an evaluation assisted with the design of the evaluation. The evaluation was intended to further the Weinstein Center's understanding of client needs for programs and activities by documenting the daily realities of the participants and their family caregivers. Additional goals for the evaluation were to enrich the information reported to stakeholders and to identify areas for programming improvements. The research questions agreed upon by Weinstein Center management and the primary investigator were:

1. Which programs and services most attract and retain clients?
2. To what extent do the clients or caregivers perceive the activities offered by the Weinstein Center to be beneficial?
3. To what extent is the Case Management Program meeting client and caregiver needs?

To assess the existing programs and services, the evaluation's naturalistic inquiry required data collection on-site at the Weinstein Center. To make the evaluation feasible in time and scope, only the Dunwoody location was used for this study. Following approval from the Georgia State University's Institutional Review Board, two groups of participants were recruited for participation – members of the Traditional Program and primary caregivers of members in the Memory Loss Program. I made announcements to the Traditional Program group gatherings and met with each interested member privately to discuss the research further and obtain his or

her decision to participate in the evaluation. I recruited caregivers by telephone, explaining the purpose of the evaluation and scheduled a meeting with individuals interested in participating. In total, 23 Traditional Program members agreed to participate and 10 caregivers agreed to participate. To gather information from as many participants as possible, I designed the data collection in the form of focus groups, each of which contained two, three, or four members, depending on schedule of attendance and availability. Two of the Traditional Group members who had indicated a willingness to participate were not included in the study, because they were not present at the Center during any of the scheduled focus group meetings.

After obtaining written informed consent from each participant in the focus group, I managed each meeting, most of them with the assistance of a co-researcher, using an Interview Guide that included open-ended interview questions designed to answer the research questions. Each focus group meeting was recorded using a digital recorder, and the interviews were transcribed verbatim and verified for accuracy. All caregiver focus groups were included in the analysis, and four of the six Traditional Program groups were used. Two focus groups were excluded through purposeful sampling. The transcriptions and other field notes were analyzed qualitatively using content analysis (Weber, 1990). I designed and implemented an open coding scheme to analyze the data inductively. Grouping the coded data revealed patterns and themes, the interpretation of which was used to answer the research questions and to suggest other observations about the participants' experiences with the Weinstein Center.

Findings and Recommendations

Traditional Group members reported that they chose the Weinstein Center because of specific needs that ADS as a care model can satisfy, such as to have something to do, to be around other people, or for medical attention or supervision. Their selection of the Weinstein

Center in particular was typically instigated by family or professionals, who concluded the Weinstein Center provided a well-run operation and environment. The caregivers for the Memory Loss members expressed similar reasons as the Traditional Group members for selecting the Weinstein Center for their loved ones' needs, particularly the medical, supervisory and personal care services. Unanimously expressing feelings of being overwhelmed and underprepared for their responsibilities, the caregivers explained their additional incentive in selecting the Center was to obtain personal respite as a break or to return to work.

Both sets of focus groups favorably compared the Center to other ADS facilities which they had either directly used or had perceived to be less appealing when compared to the Center's offerings of services, activities, and staffing. Aside from the medical or custodial care provided by the Center, the focus group participants revealed no specific services or programs that drew them to the Weinstein Center.

Traditional Group clients appeared to maintain their enrollment with the Center primarily because of their continued need for care and because of the Center's accessibility, either financially or physically through transportation options. In addition, the exploration of retention factors revealed that Traditional Group clients seemed generally satisfied with the Center and specifically satisfied with the help from staff, the physical environment, and the activities for meaningful social or mental stimulation. Caregivers described their satisfaction with the Center in the areas of services, staffing, operations, and overall appreciation or gratitude. The caregivers also credited the Weinstein Center with allowing them to maintain their current care arrangements with their loved ones at home, rather than resorting to an institutional living arrangement.

Traditional Group participants reported the Center programs and activities to be beneficial because they occupied their time or promoted physical, cognitive or emotional well-being. The activities or services that were reported as particularly beneficial were those involving physical exercise and those promoting positive emotional effects such as comfort or improved morale. The participants, however, expressed a desire for more activities for mental stimulation. The social aspects of the Center also produced benefits for the Traditional Group members, by relieving their loneliness and enriching their learning experience.

The Center's positive effects on the caregivers included improved quality of life at home, fewer problems with their caregiving responsibilities, and personal peace of mind. Despite having few concrete details about the daily activities at the Center, the caregivers agreed that the music programs, the physical activity, and the socialization at the Center seemed particularly beneficial for their loved one in the Memory Loss group. Their impressions were that the Center staff work hard to keep the Memory Loss group members happy and busy.

Issues identified by both groups were transportation reliability and a misalignment between expectations and actual experiences with respect to Center facilities or staff. The Traditional Group members were critical of the food, but the caregivers seemed overall to be pleased that the Center provided meals and eating assistance if needed.

The Traditional Group members appeared to focus on their personal limitations and losses in the context of their previous identities. While they often viewed ADS as "going to school or work," the activities offered by the Center did not appear to be viewed as meaningful in light of this strong connection to personal identity. Autonomy, individual choice, and identity were themes that emerged from the evaluation beyond the answers to the research questions.

The exploration of case management revealed that the caregivers were mostly unaware of the scope of case management services that are available from the Center, including opportunities for problem resolution and information referral. Most of the caregivers did not feel they needed the monthly support group offered by the Weinstein Center as currently structured but offered suggestions for alternative ways the Center could meet the needs of their families through more effective communication. Their reported needs included additional feedback or family conferences about their loved one's functioning, help with navigating the elder care network, and behavioral training about how to care for someone with memory loss.

Although the results of the evaluation were not necessarily expected to generalize to other ADS organization, the findings support previous evaluation studies which examined quality and satisfaction measures. For example, the study participants articulated the importance of social interactions, the physical environment, and the caring staff in assessing their satisfaction with the Center, and these factors have been shown to be indicators of high quality care. Significant challenges for the Center include the logistics of transportation and the offering of meaningful, age-appropriate activities that do not hasten the functional decline of participants.

Person-centered care is an approach to delivering services that is gaining in popularity and acceptance in the ADS industry (Meyer-Arnold, 2008). The approach recognizes that many factors contribute to the uniqueness of persons, such as values, interests, and life histories. In addition, fundamental basic human needs such as comfort, occupation, and identity also become more prevalent and intense as functional capabilities decline (Kitwood, 1997). The Center currently offers programs and activities that are designed by the staff based on the medical needs and limitations of the clients. A shift to person-centered care would create program opportunities that take into account participants' backgrounds and interests as well as provide continuity with

past and present identities. Person-centered care would require culture change at all levels -- management, staff, participants, and caregivers – which can pose challenges for any organization with long-standing ways of operating.

Future Directions

The evaluation demonstrated that satisfaction and quality indicators can be elicited from the clients directly, thus helping the Weinstein Center towards developing ongoing quality assurance processes and practices. Nevertheless, the study had several limitations which can be addressed in future evaluations. For example, the focus groups may have limited the number of clients who could participate in the study, so the Center may consider expanding the scope of the evaluation with additional data collection methods, including quantitative measurements.

Quality and satisfaction assessments in community care settings are a continuous and collaborative process. A commitment to this process will be critical for the Weinstein Center in order for the organization to adjust programming to meet the needs of a shifting, increasingly heterogeneous client base.

CHAPTER II

CONCEPTUAL FRAMEWORK

Literature Review

The ADS Industry

National Perspective

For twenty years, the National Adult Day Services Association (NADSA) has provided training, education, and advocacy support to the adult day services industry. According to NADSA, adult day service businesses follow the social model of care and/or the medical model of care. The social model provides a variety of communal and other related support services in a protective environment during the day to functionally and/or cognitively impaired adults through an individual plan of care. The medical model provides health-related services, often combined with social support services. Most adult day centers operate on weekdays, although occasionally centers offer programs and services in the evenings and on weekends (NADSA, 2008).

ADS programs are increasing in prevalence and popularity as an important supplement to the care of frail and cognitively impaired older adults. According to NADSA, ADS organizations now number over 3,400 in the U.S. Approximately 78% of these entities are non-profit or government-based programs. About 52% of attendees have some form of cognitive impairment (NADSA, 2008), and many attendees require some assistance with two or more activities of daily living (ADLs), such as bathing or toileting. Some programs focus solely on the special needs of individuals with dementia.

Since ADS facilities are used by community-living older adults who often are receiving care at home, the ADS industry is also important for their caregivers. Family caregivers are the most common and prevalent form of care provided to the elderly in the nation's long-term care

system (O'Keefe & Siebenaler, 2006). Over seven million Americans provide 120 million hours of care each week to about 4.2 million elderly persons with functional limitations. The estimated economic value of this care ranges from $45-96 billion a year (O'Keefe & Siebenaler, 2006).

Another goal for many adult day programs is to extend the period of time the older adult is capable of living at home, thereby postponing institutionalization in a nursing home. In fact, adult day services offering medical services began in response to rising costs of nursing home care and demand for additional models of community-based care (Lucas, Rosato, Lee, & Howell-White, 2002). The delay in institutionalization is thought to occur for the most part because of the support ADS provides informal caregivers who care for family members with dementia. Caregivers who do not receive respite from the stress and burden of their services may be more likely to institutionalize their care recipients (O'Keefe & Siebenaler, 2006). Institutionalization, however, may not be an appropriate indicator of ADS effectiveness, because research has not consistently demonstrated that ADS programs alone serve as alternatives to skilled nursing care (Gaugler & Zarit, 2001).

While NADSA provides leadership to adult day care organizations, no existing federal regulation governs the adult day services industry. Policy, regulation, and oversight at the state level are tremendously varied in purpose and scope among the states. This absence of consistent regulation creates many variations in programs, services, and standards (Lucas et al., 2002).

ADS programs may obtain accreditation from the Commission on Accreditation for Rehabilitation Facilities ("CARF"), a private, non-profit organization whose mission is to promote quality rehabilitative services in the health care industry. Accreditation is voluntary, and the ADS program must pay CARF researchers for the evaluations required to receive such accreditation (CARF, 2008).

Regulation of Adult Day Services in Georgia

The State of Georgia recently implemented a requirement that ADS centers be licensed, with some exceptions for organizations providing limited respite care. Proposed rules to support the licensure requirement were recently drafted but have not yet been adopted by the State in final form. The rules' section on Quality Assurance provides that "adult day centers must develop and implement an annual quality improvement plan to evaluate and improve the effectiveness of the program's operation and services to ensure continuous improvement in service delivery." Each ADS subject to this rulemaking (which would include the Weinstein Center) must conduct a formal evaluation at least annually. The evaluation will be required to include the following: a review of serious incidents; corrective actions taken; satisfaction surveys or comments from staff, participants, or their representatives; program changes made based on needs of participants; and proposed programming improvements.

ADS Evaluation Research Environment

There is scant literature on the evaluation of ADS programs and services. In their recent guide book written for organizations planning to provide ADS programming, Moore, Geboy, and Weisman (2006) summarize the importance of focusing research and attention on ADS programs. They argue that ADS potential for providing therapeutic care has been under-appreciated, but a collaborative and participatory approach to raising awareness can create model places that will serve well the frail elderly and their families.

The ADS model conceptualized by Moore and colleagues (2006) consists of an organization comprised of people, programs, and physical settings where all three components interrelate in all aspects of service operation. However, ADS centers are complicated community organizations that are not well defined and still unfamiliar to most people, so it is difficult for

them to imagine the possibilities for quality adult day programs. As a result, the optimal integration of people, programs, and physical settings, which is useful in the design and evaluation of ADS, remains unclear. Moore et al. (2006) advocate for raising "consciousness regarding what it is really like to experience the assets and liabilities of the adult day care [sic] environment from the perspective of someone who is elderly, physically frail, or cognitively impaired and from the perspective of the care provider" (p. 7). For example, theoretically, the rehabilitative, social, and medical services offered by ADS should have a therapeutic and beneficial effect on clients' physical and psychological well-being (Gaugler & Zarit, 2001). The ability to measure such effects in an evaluation is critical to the ADS industry.

A starting point for evaluating effectiveness is to define relevant outcomes for participants and family members. Evaluation studies examining the effectiveness of ADS typically review objective clinical outcomes and/or subjective patient attitudes. Satisfaction and quality, from the perspectives of both care recipients and caregivers, are common measures of the effectiveness of ADS.

When CARF evaluates an organization, quality is the primary focus. Relevant factors for determining quality in service providers include the following:

- Recognizing that only the customer can effectively evaluate quality
- Asking customers directly if they are satisfied with services
- Involving customers in service planning, and
- Ensuring customers understand the information they need for quality care (CARF, 2008).

Although CARF incorporates satisfaction as a key criterion for evaluating quality, Applebaum and colleagues (2000) argue that consumer satisfaction and service quality are not synonymous constructs. Quality assessments must relate to the specific nature of the service

being evaluated. Satisfaction assessments can result from any dimension of a service considered important, quality-related or not. In other words, satisfaction is a broader concept than service quality, because "quality is just one of several dimensions that consumers would consider in making satisfaction judgments" (Applebaum, Straker, & Geron, 2000, p. 25). Quality can be expressed from reputation or reviews or general impressions; satisfaction necessarily requires actual, personal experience with the service (Applebaum et al., 2000).

In their guidebook for health care and long-term care practitioners committed to assessing satisfaction, Applebaum et al. (2000) define satisfaction as involving "a comparison of expectations to perceived or experienced attributes of a service, which underscores the importance of using consumer-derived notions of satisfaction to develop service satisfaction instruments" (p. 25). To this end, prior studies have examined satisfaction of adult day services from the perspective of the care recipient, the caregiver, or both.

Buelow and Conrad (1992) examined the relationship of specific ADS program characteristics with client satisfaction. From 74 ADS centers across the U.S., the researchers selected 228 care recipients to interview, disqualifying participants if they had severe memory problems or disorientation. Participants' caregivers also were asked to complete a questionnaire designed by the researchers with some questions borrowed from existing patient satisfaction surveys in health care settings. Multiple regression analyses were used to identify aspects of the ADS that significantly contributed to client satisfaction. Three different program characteristics significantly impacted client satisfaction: (1) staff caring (time spent with clients, rapid response for help, attention, and other factors demonstrating the relationship between staff and clients); (2) general morale (relationships among clients such as rapport, lack of complaining or arguing, and the like); and (3) interior environment (windows, attractiveness of building). The actual services

offered by the ADS centers, however, were not found to relate significantly to satisfaction, although social and recreational activities were reported to be more valued by clients than were health services (Buelow & Conrad, 1992).

Townsend and Kosloski (2002) interviewed 390 caregivers by telephone to assess what factors impact satisfaction with respite services they receive through ADS. The interview questions explored general satisfaction and four variables about caregivers' perceptions of service delivery. The regression model used for analysis demonstrated that clarity of caregivers' expectations about what the respite workers would and would not do had the largest impact on satisfaction. Access to services (schedule, amount of care, availability) also was directly related to satisfaction. Finally, caregivers' difficulties in communicating with ADS staff and the amount of red tape caregivers experienced in using the program were negatively related to satisfaction with services. Since client satisfaction was consistently related to provider characteristics and behavior, providers can respond with program improvements since they generally have control over service delivery (Townsend & Kosloski, 2002).

To respond to the lack of valid tools to measure caregiver satisfaction with adult day services, Balaswamy and Dabelko (2002) conducted a pilot study to test a caregiver satisfaction scale they developed. Their nine-item survey was completed by 143 caregivers associated with Heritage Day Health Centers, a nationwide chain. A factor analysis yielded two major dimensions of ADS: satisfaction with care provided by staff and satisfaction with facility services. Indicators of staff care were such variables as competence and responsiveness. Indicators of facility services were variables such as location, hours, safety, and transportation. The authors suggested that these dimensions of satisfaction should be able to help providers in practical, day-to-day program improvement. One important limitation to their study, however, is

the survey did not include detail about the specific aspects of programs and services offered by the ADS which were valued by caregivers.

Leitsch, Zarit, Townsend, and Greene (2001) surveyed 261 caregivers from 36 ADS centers to explore whether the medical model and the social model differed significantly in caregiver well-being and satisfaction. The survey covered 12 aspects of ADS (e.g., cost, activities, program schedule, and staff) which participants rated on a 5-point scale ranging from very satisfied to very dissatisfied. Principal components analysis revealed three main components of caregiver satisfaction: program features, scheduling and availability, and cost. Caregivers reported being generally very satisfied with their ADS. No significant satisfaction differences between the models of ADS were found except with respect to cost. ADS programs using a medical model typically are more expensive than social services because of the medical care offered.

Warren, Kerr, Smith, Godkin, and Schalm (2003) used a time series design to evaluate the impact of ADS on family caregivers using a variety of outcome measures, including satisfaction. They administered questionnaires and interviewed 140 client-caregiver pairs several times. The Day Program Satisfaction Scale developed by Warren and colleagues (2003) measured seven items on a 5-point Likert scale ranging from 1-Very Unsatisfied to 5-Very Satisfied. Many caregivers reported to the authors that they found the scale difficult to complete, because they did not have enough information about the actual services provided to their family member by the ADS. Open-ended questions administered at the fifth time measurement solicited feedback regarding what the caregivers liked best and least about the ADS program. Socialization and improved health for the care recipient were rated by caregivers as most important, followed by personal respite. Caregivers also reported that their family member's

attendance at ADS seemed to improve their relationships with the family member as well as their own sense of community with health workers.

Baumgarten, Lebel, Laprise, LeClerc, and Quinn (2002) measured objective and subjective outcomes in several Quebec ADS programs that provided clients with individualized care plans for therapeutic activities based on needs and abilities. The treatment group (108 elderly men and women) received immediate access to ADS while the control group (104 elderly men and women) were placed on a 3-month waiting list for ADS services. Using standardized depression, anxiety and burden scales, the researchers found that, over the 3-month time period, the ADS services did not significantly impact objective clinical outcomes of depression, anxiety, functional status or caregiver burden. Interestingly, however, a measurement of the subjective opinions of clients indicated that two-thirds of participants reported the ADS services had relieved their loneliness, and one-half reported feeling less depressed and anxious. Caregivers reported lowered burden with more frequent ADS use. The researchers suggest that, while some differences in depression and anxiety were observed, the changes did not reach statistical significance. The researchers also observe that it may have been unrealistic to expect improvement in functional capacity given the severe frailty of the participant group. In addition, there could be some halo effect on the subjective opinions since participants probably suspected the outcomes desired for the study.

Examining ADS provided to younger adults with disabilities, Ward (2003) used information obtained in focus groups to develop a survey which covered the following areas of satisfaction: personal care, range of activities, communication with staff, education, social activities, food, facilities, equipment, transportation, availability of advice and support, and involvement in decision-making. Open-ended questions included in the survey inquired about the

best and worst aspects of ADS, ideas for change, and additional services desired. Almost 80% of clients reported the social and companionship features were the best part of the program, and most participants did not report any negative features of the program. Suggestions for improvement provided by the participants included increasing staff, activities, and therapy (Ward, 2003).

Borrowing from popular total quality management (TQM) principles used to improve the quality of goods or services produced, Applebaum et al. (2000, p. 9) identify fundamental tenets that health care organizations should follow to improve quality for consumers, in relevant part:

1. Know the customers
2. Hear the voices of customers
3. Sound decision-making requires information.

Stern and Caro (2004) evaluated quality factors within various ADS programs in Massachusetts by conducting 13 focus groups with consumers of adult day services (7 focus groups with clients and 6 with caregivers, including two groups with caregivers of persons with dementia). The semi-structured group interviews investigated needs of the clients, what was important to them, and how they perceived the ADS programs had impacted them. The authors used content analysis to examine the data from the groups to look for program characteristics that can be monitored for quality. Quality, according to the authors, involved factors such as reliability, consistency, and responsiveness to consumers. The analysis revealed that compassionate staff, availability of nurses, monitoring of health needs, alerting caregivers of problems, activities to fight boredom, and a family environment that was emotionally and physically safe were all features of ADS indicating high quality care. In addition, caregivers reported that activities designed for mental stimulation and increased functional capacity led to

decreased problem behaviors in their care recipients. Areas rated by the study participants as needing improvement were increased communication with caregivers, age-appropriate activities and events, transportation, and meals.

Research Questions

In 2007, the Weinstein Center Advisory Board and Executive Director determined they needed a more in-depth understanding of if, how, and why their services impact clients and family members. For example, in light of client retention statistics recently reported to ARC, management at the Weinstein Center determined they needed a more in-depth understanding of the factors important to clients in their continuing participation. In addition, Weinstein Center management felt an evaluation could provide guidance about how to improve programs and services and to identify programming not deemed important or useful. It is possible that long-standing ways of operating are no longer appropriate, given that a typical client comes to the Center at a younger age and lives longer than clients in the past. In articulating the goals for the evaluation, the Weinstein Center echoed the challenge for most ADS centers today described by Moore and colleagues (2006): "finding the right balance among social services and medical services in light of a changing participant profile" (p 15).

Considering the lack of regulation in the ADS industry and the heterogeneity of the population served, many variations in programs, services and standards have evolved (Lucas et al., 2002). The variations in the characteristics of ADS have made research on the provision, use, and outcomes quite difficult (O'Keefe & Siebenaler, 2006). As a result, adult day service centers must try to understand the needs of their community and to review how their programs support those needs. An effective way to gather this type of information is to elicit customer feedback in order to adjust or correct problems so the organization can ensure relevant, high-quality services

are provided. In addition, the State of Georgia soon will be requiring this reporting as part of the new licensing requirements for ADS.

Therefore, this program evaluation was designed to enrich the understanding of the needs and experiences felt by Weinstein Center clients as well as to gather data for quality assurance reviews under the new rules for ADS licensure in Georgia. The evaluation addressed the following questions:

1. Which programs and services most attract and retain clients?
2. To what extent do the clients or caregivers perceive the activities offered by the Weinstein Center to be beneficial?
3. To what extent is the Case Management Program meeting client and caregiver needs?

This evaluation was formative in nature specific to the Weinstein Center, so its findings were not necessarily expected to be generalizable to other ADS organizations.

CHAPTER III

RESEARCH METHODS

Research Setting

The Weinstein Center

Background

As a division of the Marcus Jewish Community Center of Atlanta (MJCCA), the Weinstein Center provides services to clients who desire to remain in their homes but who need assistance during the day with various medical services (e.g., medication management, nursing care, ambulation, etc.), desire social interaction, and/or suffer from memory loss. The Weinstein Center began operation in 1982 in Sandy Springs, Georgia a community located north of the city of Atlanta, and in 1987 moved to the MJCCA campus in Dunwoody, Georgia, also north of Atlanta. The Weinstein Center's separate building on the MJCCA campus was constructed following the establishment of an endowment for the Center by benefactors Mr. and Mrs. Milton Weinstein in honor of their parents. The Weinstein Center also operates a second adult day program located in Buckhead, an in-town community of Atlanta, in collaboration with Senior Citizens Services.

The Weinstein Center offers two major types of programs: (1) an activity and social program for adults who are mentally competent, but may have some physical limitations, known as the Traditional Group, and (2) an activity and social program for adults with moderate to severe memory loss, known as the Alzheimer's Program or Memory Loss Program. Participants in these programs are referred to as "Traditional Group" and the "Memory Loss Group," respectively. The present evaluation focused on the Dunwoody location only.

An Advisory Board provides leadership and direction to the Weinstein Center staff with respect to programming goals. The Executive Director of the Center provides day-to-day management of the staff and programs. Like many other ADS facilities, the Weinstein Center Advisory Board articulates outcome expectations such as extending the period of time participants can live independently and decreasing caregiver stress.

The Weinstein Center in Dunwoody serves approximately 142 clients per year (unduplicated) with 13 full-time equivalent staff members and averages about 46 clients per day – 21 in the Traditional Group and 25 in the Memory Loss program. Most of the clients who attended during the year 2007 were residents of DeKalb County and over age 60 (see Table 3.1). Although most program participants (approximately 75%) receive some type of funding in order to attend the Center such as Medicaid or the Older Americans Act Title III funding, some participants privately pay the $55-$60 per day fee. As a provider for Title III services, the Weinstein Center is responsible for documenting retention statistics for the Atlanta Regional Commission (the Area Agency on Aging covering metro Atlanta). In May 2008 Weinstein Center management reported to the ARC that 60% of clients attend the Center for longer than one year (see Table 3.2).

Table 3.1:

Select Client Characteristics, 2007

Characteristic	N=142
Sex	
Female	102
Male	40
Race	
Asian	3
Black, incl. African-American	67
Caucasian	68
Hispanic	4
Age	
27 – 36 years old	1
37 – 46 years old	2
47-59	5
60+	134
County	
Cobb	4
DeKalb	111
Forsyth	2
Fulton	11
Gwinnett	16

Table 3.2:

Retention Rates of Clients, 2007

Attendance Duration	Clients N=142	% of Total Clients
≤ 1 year	57	40%
> 1 year	85	60%
> 5 years	8	10%
> 19 years	1 person	.7%

Programs and Services

The Weinstein Center staff describe the Center's core activities by three categories: Creative (e.g., music and art); Cognitive (e.g., thought-provoking games and guest speakers); and Physical (e.g., movement exercises and active games). While the activities provided to both the Traditional Group and the Memory Loss Group fall within these categories, the actual activities vary depending on the functioning level of the groups. For example, the Traditional Group's cognitive exercises may focus on discussion and brain stimulation, such as talking about current events. The cognitive activities for the Memory Loss Group would be designed to maintain elements of memory such as "Completion of the Proverbs" learned as children: "Early to bed, early to _____." For some events, such as entertainment, the two groups occasionally join together. Appendix A is a list of programs and services provided by the Weinstein Center.

The Weinstein Center has a menu of medical and personal care services including health screenings, medication administration, medical education, beauty care, ambulation, and other assistance with ADLs. Management and staff have developed a Case Management Program

which is more informal than a true geriatric care management system. Two staff members perform case management duties in the Dunwoody location. One has a certification as an art therapist and was previously employed with the Alzheimer's Association in communication outreach and education, and the other is a licensed social worker. Their work begins with the clinical assessment of the new client and the establishment of a care plan for the medical services needed by the client. The Weinstein Center staff members are expected to communicate regularly with both the participant and the caregiver and, if necessary, to counsel family members who are struggling to cope with issues surrounding the participant. Information and referral–for example, where to locate other services needed for the family such as home health care–is also a staff job responsibility. They also arrange for transportation to the Center for the client, as needed, and conduct caregiver support groups.

Previous Program Evaluations of the Weinstein Center

While the accreditation process through CARF would involve an extensive client satisfaction evaluation consistent with CARF's mission to promote quality rehabilitative health care, the Weinstein Center has not sought such accreditation. Instead, the Weinstein Center has conducted evaluations using a two-page survey completed by clients and family members. The survey asked participants to rate the Weinstein Center with adjectives of "Excellent," "Very Good," "Fair" or "Unsatisfactory" and provided space for survey respondents to explain their answers. The survey covered the following areas: activities in general, quality of nursing services and personal care services, quality of meals, case management, quality of transportation, courtesy and professionalism of staff, hours of operation, safe and clean facilities, convenience of location, monthly newsletter, and support group. The Weinstein Center used this survey (included as Appendix B) from 2005 – 2007.

Survey respondents overwhelmingly reported the services and activities to be "excellent" or "very good." Two survey questions soliciting Yes/No responses had mostly affirmative responses: "Has your family member's quality of life stabilized or improved due to coming to the Center?" (93% answered "yes"), and "Has adult day services for your family member helped to reduce the stress of caregiving for you?" (98% answered "yes").

Very few survey participants provided any elaboration on their answers. Although several items asked respondents to rate the quality of the service, the survey did not explain or define the term "quality." Finally, many respondents checked "N/A" or left blank the question about case management, even though the Weinstein Center staff believed they regularly provided case management services to such families.

Design

The present evaluation focused on the existing programs and services at the Weinstein Center and their impact on currently-enrolled care recipients and caregivers. As a result, a naturalistic inquiry (no control) was appropriate rather than an experimental or quasi-experimental design. As suggested by Patton (2002), the evaluation intended to capture and document the day-to-day reality of participants in the program. In order to achieve a rich and thorough understanding of the programs and activities of the Weinstein Center, this field study used data triangulation (a variety of data sources), including two different types of participants.

Procedures

Recruitment

As a prerequisite to requesting approval of the research protocol from Georgia State University's Institutional Review Board, I obtained written permission from the Director of the Weinstein Center to perform research on-site at the Dunwoody location (attached as Appendix

C). Next, following approval of the research protocol from the Institutional Review Board, I began recruiting participants from the Weinstein Center's Traditional Group members and from family member caregivers of the Weinstein Center's Memory Loss Group members. To recruit Traditional Group members I went to the Dunwoody location of the Weinstein Center on 4 separate days of one week. Prior to the start of the Traditional Group's 11:00 activity each day, I made an announcement to the members in attendance that day. For those group activities, the members assemble in a large room, with chairs and couches in a square pattern along the perimeter walls with room for wheelchairs to be placed next to some of the chairs. Using a script for guidance (see Appendix D), I explained the purpose of the research study and the voluntary nature of participation. I then invited each member to meet with me individually in one of the private offices to discuss the evaluation in more detail. When I met with Traditional Group members individually, I explained the research again, emphasized the voluntary nature of it, answered their questions and solicited a response about whether they desired to participate. Their response was recorded on a form I designed on which I could collect their name, assign a unique identification number and document their regular days of attendance at the Weinstein Center (included in Appendix D). While most of the individuals agreed to participate, five declined after discussing it further. They cited reasons of recent brain tumor surgery, fear of being unable to hear in the meeting and the desire to receive permission from family first. Two people said the activity did not sound like "their cup of tea." A total of 23 Traditional Group members agreed to participate. Two individuals did not attend a focus group meeting as they were not in attendance on any of the days on which the meetings were held. A total of 21 individuals participated in the Traditional Group focus groups.

I recruited caregivers of Memory Loss Group clients by calling the caregivers at telephone numbers supplied to me by the Weinstein Center. I used a script for guidance (see Appendix D) to introduce the research and invite them to one of several focus group meetings arranged for the following week. Of the 40 family members names provided to me, I was able to speak with or leave a message for 28. A total of 10 caregivers participated in the focus groups, and 4 others indicated a willingness to be in a focus group but could not participate during the week the meetings were scheduled. Three family members expressed the desire to help, but stated their schedule would not permit an in-person interview and offered to participate in an evaluation in the future by telephone. Four phone messages were not returned.

Data Collection

Planning and Conducting the Focus Groups

In order to collect the data, I scheduled focus groups during the two weeks following recruitment and assigned participants to a specific focus group. I randomly assigned Traditional Group participants to focus groups based on their regular day of attendance and the desire to have no more than four members in a group or to conduct no more than two group meetings per day (at 11:00 a.m. and 1:30 p.m.). I made an appointment with caregivers for a scheduled focus group during the recruitment phone call. Each caregiver focus group was held at 10:00 a.m. or 3:30 p.m. during the week following the week of data collection from the Traditional Group.

I held six group meetings with clients in the Traditional Group. Each such meeting contained two, three or four people, and may have included a member assigned initially to another focus group, depending on who was unexpectedly absent and who was in attendance on the day of the focus group. Prior to each meeting, I greeted each Traditional Group participant in

the main meeting room or dining room, invited him or her to the focus group meeting and escorted the participant to the Weinstein Center conference room where the meetings were held.

After the focus group members had settled into the room, I read the Informed Consent (see Appendix E) to the group, solicited questions, and obtained the signature of each participant. I gave a copy of the Informed Consent to each participant to keep for his or her records. I also reiterated the importance of keeping what was said in the meeting confidential and requested the participants not to talk about our conversations with those not in our meeting. The second researcher from the University, present in all but two of the focus groups, assisted with collecting the Informed Consents, answered participant questions as needed, helped with wheelchair maneuvers, and obtained water or other requirements necessary for the participants' comfort during the meeting.

Only the two researchers were present in the conference room during the interviews with the participants. No member of the Weinstein Center staff was present during the focus groups, although two of the Traditional Group meetings held in the afternoon were interrupted briefly when a staff member entered the conference room to deliver the candy jar for participants to choose their after-lunch snack. The interview ceased while the staff member was in the room and resumed after the conference room door was closed again. The focus group meetings ranged from 35 minutes to 62 minutes, with an average length of 48 minutes (see Table 3.3).

I held four caregiver focus groups, and each meeting contained either two or three participants. Prior to the start of the interview, I reviewed the Informed Consent (see Appendix E) with the caregivers, answered questions, obtained their signatures and gave them each a copy of the Informed Consent to keep for his or her records. The meetings ranged in length from 59 to 82 minutes, with the average length 69 minutes (see Table 3.3). All caregiver meetings were also

held at the Weinstein Center in the conference room for the convenience of the caregiver, since several of them routinely bring their family members to the Weinstein Center Memory Loss room in the same building.

Table 3.3:

Characteristics of Focus Group Meetings

Focus Group Type	Date	Time	N=31	Duration
Traditional Members	May 12, 2008	1:30	3	50min 30sec
Traditional Members	May 13, 2008	11:30	3	35min 15sec
Traditional Members	May 13, 2008	1:30	4	49min 52sec
Traditional Members	May 15, 2008	11:30	4	43min 21sec
Traditional Members	May 15, 2008	1:30	4	47min 28sec
Traditional Members	May 16, 2008	11:30	3	62min 14sec
Caregivers	May 20, 2008	10:00	3	82min 02sec
Caregivers	May 20, 2008	3:30	2	69min 23sec
Caregivers	May 21, 2008	10:00	2	59min 38sec
Caregivers	May 21, 2008	3:30	3	65min 28sec

Recording and Field Notes

A digital voice recorder was used to record each meeting. The recorder was placed on the conference room table around which the participants sat either in the conference room chairs or in their wheelchairs. Recording began after the Informed Consents were signed by all

participants and collected by the researchers, since the final part of the consent included the agreement to have the interview recorded.

The second researcher took notes during each meeting she attended. Her notes indicated which participant (by ID code) was speaking and documented key phrases that addressed the interview questions. I took notes each day after the meetings to document my impressions about what happened in the meetings, my interpretations of participant statements in light of the research questions, and group dynamics.

Over the several weeks following the focus group meetings, I transcribed the interviews verbatim using the second researcher's field notes as a guide to attribute statements to specific participants by ID code. The second researcher then checked the transcriptions and made any necessary changes into the transcript documents using the "track changes" feature of Microsoft Word. This procedure allowed for an additional review of the transcripts at several points during the coding phase. The only exception to the verbatim transcriptions occurred when foreign accents of several participants prevented an interpretation during transcription. In these instances, the notes taken by the second researcher supplemented and assisted the interpretation.

Instruments

Interview Guides

Interview Guides were used for all group interviews in order to keep the interactions focused while permitting individual perspectives. The Interview Guides contained three parts, (a) a script to provide guidance in starting the focus group with an introduction to the research study, (b) a script to begin the Informed Consent review, and (c) the list of interview questions. The Traditional Group interviews and the caregiver interviews required slightly different Interview Guides, because questions of the caregivers addressed their family member's experience with the

Center. Thus, the same basic lines of inquiry were possible with different types of participants. Appendix F includes the Interview Guides for the Traditional Group members and for the primary caregivers of the Memory Loss group.

Interview Questions

The Interview Guide questions were open-ended and included a series of probes intended to help document the complexity of the experience of the Weinstein Center from the perspectives of different types of participants and to explore the research questions for evaluation purposes. For example, after rapport building, each focus group began with an exploration of the first research question "Which programs and services most attract and retain clients?" The interview question posed to each focus group was "What are some of the reasons you started coming to the Weinstein Center?" Further probes sought to elicit what they had looked for in choosing an adult day facility. To investigate client retention with the Weinstein Center, the next several interview questions asked, for example, "What keeps you coming to the Center?" and "How would your life be different if you weren't coming to the Center?"

With interview questions covering favorite activities, undesirable activities, feelings about the environment, probes about medical services and suggestions for changes at the Center, the second research question was addressed to investigate the extent to which clients and caregivers perceive the Center's activities to be beneficial. Finally, to explore whether the Case Management Program was meeting the needs of the clients, interview questions and probes of the caregivers directly addressed their understanding of the term "case management" in general as well as their perceptions of the current Weinstein Center program and their needs.

The research proposal for this evaluation included a provision whereby the first two focus group meetings with Traditional Group members would be considered practice sessions to test

the interview questions, format, order, and meeting duration. These two focus groups appeared to understand and respond to the interview questions and any follow-up questions based on the probes without incident and within the time period expected.

Sampling

I read the transcripts of all focus groups several times in their entirety as well as the field notes taken during and after each focus group meeting. Based on the transcripts and notes, I used purposeful sampling to select four of the six Traditional Group focus group meetings to analyze in detail, because these groups yielded information rich discussions important to answering the research questions (Patton, 2002). The participants represented diverse demographics such as sex, race, level of physical functioning, financial means, and countries of origin. While such heterogeneity within a small group of participants could yield cases that are quite different and extreme, I selected the groups that appeared to have detailed descriptions which addressed the interview questions and revealed shared patterns (Patton, 2002). In addition, if one participant appeared to dominate the focus group discussion to the exclusion of the opinions of the other participants or if the participants provided only yes/no responses or answers lacking in specifics, purposeful sampling supported the exclusion of those focus groups from the analysis. Because of the small number of caregivers able to participate in this study, I chose not to sample the groups and used all caregiver participants instead. Therefore, the analysis reflected 14 Traditional Group members and 10 caregivers of Memory Loss group members.

Data Analysis

Data collected from the focus group interviews were analyzed qualitatively using content analysis (Weber, 1990). In order to analyze the data inductively, I designed and implemented a coding scheme using open coding techniques. Because the interview questions in the focus

groups were open-ended, the transcripts contained participant responses in the form of phrases, sentences or entire paragraphs. I chose to examine the participants' responses by sentence or phrase units in order to examine closely the data and to create codes or categories for the phenomenon represented by each unit. Long, complex sentences at times had to be broken up into multiple sentences, and parts of speech added back manually in order to label the units with a category (Weber, 1990). In addition to the manifest content of the participants' statements, wherever possible, I also examined latent content, such as clapping, laughing, nods of agreement, sighs, etc. (Strauss & Corbin, 1998). With multiple reviews of the sentences in one transcript, the categories were further refined to create a stable, reliable system that could then be applied to label the sentences and phrases in the other transcripts.

Specifically, I read each transcript several times and made notes in the margins to describe the content of the participants' statements. The notes and codes came from sources such as: (a) the codes that emerged from the initial reading of the transcripts as a whole, (b) the open-ended focus group questions and the probes for information intended by the questions, (c) ideas to be examined as demonstrated by the literature on ADS, and (d) new concepts that emerged if other existing codes did not seem to apply to passages. I continued reading the transcripts to refine the notes and codes. I then extracted the notes from the margins, along with corresponding sentences and phrases from the transcripts and placed them in a table format to create a coding sheet. After this open coding, I grouped the data together when the codes seemed to fit together or create similar patterns and identified diverging data patterns. These patterns demonstrate how the data can be represented through higher-level categories, dimensions or themes. The interpretation of the findings, also known as abstraction, should offer explanations, make inferences and otherwise be illuminating within the context of the participants' experiences

with the Weinstein Center, the research questions posed under this evaluation and other important information the Weinstein Center should know.

Figure 3.1 illustrates the coding procedures used in the evaluation. For example, using open coding techniques I examined participant responses and discovered they expressed positive, and sometimes negative, effects from being at the Center. I then could group the effects that appeared to be similar by type of effect such as emotional, cognitive, and physical. Grouping on a higher level permitted a comparison to other data and observations that were similar and dissimilar. Thus, through abstraction, I formulated a description of whether the clients view the activities as "beneficial."

Subcategory Phrases		Generic Category		Main Category
Enjoyed activity Felt happy Felt comforted or safe Calmed down	→→	Positive Emotional effect	→→	Beneficial effects on participant
Experienced outdoors Exercised Played game with movement	→→	Positive Physical effect	→→	
Learned new thing Stimulated mentally	→→	Positive Cognitive effect	→→	

Figure 3.1: *Example of Content Analysis Coding Structure for Positive Effects Reported by Participants*

Guiding Principles for Program Evaluation

This evaluation followed the guiding principles for ethical conduct of evaluators (AEA, 2008). In addition to personal performance requirements such as working with competence, displaying integrity/honesty, and respecting the security and dignity of participants, the evaluation used a systematic, data-based inquiry. The Weinstein Center management was aware of the strengths and weaknesses of the research project during all aspects of the work, including during the conceptualization phase and the analysis of findings and recommendations.

For example, during the planning phase of the evaluation, Center management expressed their preference to include all staff members, a sample of former clients and referral agencies in interviews about the Center programs, in addition to participants and caregivers in both groups. The scope of the evaluation, however, would not have been feasible given the amount of researcher time and resources that such a broad scope would require. As a result, the evaluation of the Center's programs and services represent only two types of viewpoints, Traditional Group members and caregivers of Memory Loss group members.

When the Weinstein Center Advisory Board and management articulated its goals for the evaluation, one question they hoped the research would answer was whether the programs they offer are "therapeutic." I explained that the evaluation would not be able to assess whether activities were therapeutic, in the curative or treatment sense, for several reasons, including the heterogeneity of the client population, the lack of baseline quantitative measurements, the feasible time period for the evaluation, and the experience level of the researchers. As an alternative, I recommended that the evaluation cover the subjective perspectives of clients and caregivers to allow the meaning of "beneficial" to be inducted from the participants' responses.

We discussed the advantages and disadvantages of the focus group as a data collection method. Some Traditional Group individuals would likely not be comfortable in a group format to offer candid opinions. Furthermore, the caregivers presented recruitment challenges for in-person interviews. Despite the sample sizes, the Weinstein Center desired to obtain data using a method that would reveal significantly more information than would be possible through a written survey.

CHAPTER IV

RESULTS

Sample Characteristics

Table 4.1 shows the demographic makeup of the entire population of evaluation participants as well as the purposive sample. Both of these groups had very similar basic demographic characteristics to the total client population during 2007. The participants' attendance at the Weinstein Center ranged from under six months to over 5 years, so opinions represented both newcomers and long-term attendees. Representing a range of economic backgrounds, the study included members who attend the Center at no cost (Medicaid benefits) or at a reduced cost based on their income (Title III benefits) as well as individuals who pay the full regular daily rate.

The caregivers who participated in the evaluation were predominantly female and Caucasian (see Table 4.2). In fact, three-fourths of the individuals listed as "primary caregiver" for the total population of Memory Loss members were female which is similar to the population as a whole. Most of the caregivers who participated in the study had been associated with the Weinstein Center for less than one year. In addition, these families also represented both Medicaid recipients and private payers thereby providing some diversity in economic background.

Table 4.1:

Select Traditional Group Sample Characteristics by Sample Group

Characteristic	Purposive Sample N=14	Total Study N=21
Sex		
Female	9	13
Male	5	8
Race		
Asian	2	2
Black, incl. African-American	7	10
Caucasian	5	9
Hispanic	0	0
Age Group (years)		
$\leq$ 59	1	1
60-79	8	12
$\geq$ 80	5	8
Mean Age	73.8	73.6
Median Age	75.0	75.0
Payment Method		
Medicaid Benefits	6	10
Title III Funding	4	6
Private pay	4	5

Table 4.1 (continued):

Characteristic	Purposive Sample N=14	Total Study N=21
Living Situation		
Alone in home	4	6
Alone with in-home care	1	2
Assisted living facility	1	1
With spouse/partner	2	4
With sibling	2	2
With adult child	3	5
With parent	1	1
Duration of Attendance at Center		
Less than 6 months	2	3
6 to 12 months	2	3
13 to 24 months	2	3
25 to 36 months	3	3
37 to 60 months	2	5
61 months or longer	3	4

Table 4.2:

Select Characteristics of Memory Loss Group Caregivers

Characteristic	Participants N=10
Caregiver Sex	
Female	8
Male	2
Caregiver Race	
Asian	0
Black, incl. African-American	1
Caucasian	9
Hispanic	0
Relative Attending Weinstein Center	
Parent	5
In-law	1
Spouse/Partner	4
Payment Method	
Medicaid Benefits	3
Title III Funding	1
Private pay	6

Table 4.2 (continued):

Characteristic	Participants N=10
Frequency of Attendance	
2 days/week	3
3 days/week	3
4 days/week	1
5 days/week	3
Duration of Attendance at Center	
Less than 6 months	4
6 to 12 months	3
13 to 24 months	2
25 to 36 months	0
37 to 60 months	1
60 months or longer	0

Attracting and Retaining Clients

As a combined medical and social model of care, the Weinstein Center served families representing diverse demographic characteristics and care recipients with a variety of medical conditions. Traditional Group members and caregivers articulated similar reasons for selecting the Weinstein Center and continuing their enrollment. As predicted, the medical services and social environment provided by the Weinstein Center were major factors in the selection of the Center reported by both study groups, particularly in light of professional recommendations and the lack of other viable ADS alternatives. Although the Traditional Group members and the caregivers provided few precise details about specific programs and services to which they

attribute their continued participation with the Center, they did express an overall satisfaction with the Center. The two study groups also shared similar problems and concerns concerning communicating with staff and transportation, but the Traditional Group members were able to report on several more specific program elements that contributed to dissatisfaction.

Traditional Group

Initial Selection of the Weinstein Center

Analysis revealed three key factors underlying Traditional Group members' initial selection of the Weinstein Center: specific participant needs met by adult day care, professional or family initiation, and favorable comparison of the Center to other facilities.

Participant needs

The participants described their attraction to adult day care centers in general based on their daily needs, such as needing help (n=5), wanting to have "something to do" (n=4), needing or wanting to be around other people (n=5) and requiring physical exercise (n=1). Additionally, over half of the participants (n=8) mentioned a specific health reason, such as stroke, surgery, memory loss, and vision loss, that led to increased needs for daily physical and emotional support. Almost half of the participants (n=6) reported that medical services were an attractive feature of the Weinstein Center.

Source of initiative to attend

Participants also indicated that other people often initiated the exploration of ADS facilities in general, and the selection of the Weinstein Center, in particular. Specifically, some participants cited family members (n=7) as instrumental in seeking adult day services and choosing the Weinstein Center. Participants reported that their families seemed to be searching for a well-run center with a good environment. Other participants (n=5) referenced a social

worker, caseworker or Wesley Woods Hospital as the source of referral to the Weinstein Center. Only two participants reported that their decision to attend adult day care and the Weinstein Center was personally initiated.

Comparisons to other ADS centers

The final theme revealed in the selection of the Weinstein Center was comparisons. Several participants indicated that they compared the Weinstein Center to other facilities and found it preferable because of the services and environment. Participants who had either attended other facilities or considered adult day center alternatives reported perceiving those other facilities as offering significantly fewer activities. One female participant contrasted her experiences with ADS, saying "The first one I went to wasn't so good. Nothing was going on there. All day long, tired, just sit there and listen to the radio and that's about it."

Ultimately, the Weinstein Center's programs, services, and activities are factors that attract clients. Apart from the medical or custodial supervision, however, participants did not cite any particular services or activities that were responsible for the initial draw to the Weinstein Center.

Maintaining Participation

Since many of the participants who attend the Weinstein Center have chronic illnesses or other serious medical conditions, the medical services offered by the Weinstein Center continue to play an important part in client retention. Analysis of interview responses indicated several other factors that seem to contribute to retention, including accessibility, client satisfaction, and relief from boredom.

Accessibility of the Center

Several Traditional Group members (n=6) cited the Weinstein Center's transportation assistance and/or financial aid as helpful to their continuing participation. I labeled these factors as accessibility. Several of the participants identified the Weinstein Center buses or an outside transportation service arranged by the Weinstein Center as their mode of transportation. A few participants compared the cost of the Center to in-home paid caregivers and concluded the Weinstein Center to be less expensive. Other participants acknowledged the government and Medicaid funding as making it possible for them to continue with the Center. Indeed, in the sample of 14 participants, 10 qualified for either Medicaid benefits or financial assistance under Title III of the OAA to attend the Weinstein Center.

Client satisfaction

The majority of participants reported an overall satisfaction with or general gratitude for the Center. For example, one female participant said, "I don't have words for my appreciation." The participants also expressed their satisfaction with the Weinstein Center in comparison to their perceptions of other adult day facilities. Another female participant who had previously described another adult day program she had attended commented, "There are many more places around that nobody wants to go to. For me, I have nothing to give this place but an A+."

Finally, participants seemed to indicate their satisfaction with respect to specific Weinstein Center features. Examining the patterns in participant responses revealed client satisfaction in the areas of activities, Center environment, and staff interactions. The focus group participants listed numerous examples of activities they found enjoyable in the past, including lectures, entertainers, games, field trips, Trivia, and intergenerational social visits. Responses indicated that the most favored or preferred activities were those involving physical exercises,

engaging social encounters and opportunities for mental stimulation. Participant suggestions for additional programs also fell into these three categories. While one female participant reported crafts as an activity she enjoyed, calling herself "a crafts person," no other participant mentioned arts or crafts.

Most of the participants neither criticized the programs nor identified any overwhelmingly undesirable activity, although several did express negative opinions about Bingo. For example, one participant called it a "dumb game," and another member said that she has "never liked Bingo her whole life." Further probes elicited perceived control in activity participation as an important aspect of satisfaction with the programs. Some of the participants reported that while the staff encouraged participation, they believed they had the choice as to whether to join in on a specific activity or not. Commenting on the Weinstein Center approach to permitting members to opt out of activities, in comparison to the way they perceived other facilities operated, two members agreed that the Weinstein Center has "a lenient policy that way." This control over choice to participate appears to be an important component to satisfaction with the activities.

The discussion on retention also revealed the importance of certain environmental variables. Several participants commented on the comfortable and clean interior and grounds at the Center. In addition, participants specifically referenced enjoying the flower and vegetable garden adjacent to the Center while others mentioned the former resident canine companion. One participant said that she considers the Center as her "home away from home."

Analysis of the transcripts revealed that the kind and caring attitudes of the staff and the staff's helpfulness and responsiveness were two important factors in client satisfaction related to staff. Participants explained that there is staff follow-up if someone is sick. For instance, one

client said that, “the following day, if I don’t come, they call and ask ‘how are you doing?’” Another participant added, “They go out of their way to help you here. They’re really great that way.”

Relief from boredom

Finally, the focus group participants reflected on what they believed life would be like for them if they were not attending the Weinstein Center. “I would keep eating, sleeping all day, and watching TV and I would be very bored. Very bored,” reported one participant. Another female client said, “I am at home by myself and lonesome.” Similarly, most of the other participants said they believed they would be much more lonely and bored were they not attending the Weinstein Center. As one male participant contrasted it with staying home, “it’s better than staring at the four walls.” The social interactions and activity levels at the Center further contribute to client retention.

Problems or Concerns

The participants discussed several concerns with the Weinstein Center that represented diverging patterns from the factors found to contribute favorably to client attraction and retention. Personal resistance and family pressures about attendance, perceived retention problems at the Center and client dissatisfaction in several areas were issues that deepen the understanding of clients’ experiences with participating at the Weinstein Center.

Resistance to attendance

Almost half the Traditional Group members cited some degree of resistance to attending the Weinstein Center. One individual expressed it as her regular desire to take “a day or two off.” Several members described their family members’ encouragement to attend but their resistance to the perceived pressure, as one member explained, “I can take care of my own business. If I say

I'm not going, I'm not going." One individual explained that he does not live alone but rather his family is always with him; he then added, "outside of when they dump me off here." The two female focus group members reiterated the importance of choice to attend then suggested to the participant who reported being "dumped off here" that he not attend the Center if he did not want to. The other male participant in the focus group responded with, "It's not that easy." Just like with activities, perceived control in attendance at the Center seems to be an important factor in perceived satisfaction.

Retention issues

Several participants referenced disappointment in not knowing why some of the interesting clients they had met in the past did not continue participating with the Center. One male participant described his perception of a new member's orientation:

> A new person will show up. They'll introduce him in the morning. And I maybe get to meet him when he's eating lunch. But they don't show up two days later. After the activity of putting a golf ball, we're going to impress him? Here's the kind of activity we do here, buddy! And he sees that and says 'I'm not coming back anymore'.

From this client's perspective, the current offerings of activities and games are insufficient to retain the interest of new members.

Client dissatisfaction

A few participants described how their initial expectations about the Weinstein Center did not match their actual experiences. For example, one participant expected more rehabilitative services such as exercise machines and a pool, which are not available at the Weinstein Center building. Another participant, who had volunteered that he had participated actively in the selection of the Weinstein Center based on his own health issues, revealed that he sometimes

wonders why he continues to attend. Further probes about what he was looking for from the Weinstein Center led to a series of comments: “I don’t know what I expected, but I expected more.” “They say, ‘take care of yourself.’ But no one is telling me how to do that.” Finally, he added “Some people say ‘you going to your babysitter place?’ And I guess that’s why we’re here. Four or five hours a day.” This individual appears disappointed by the program offerings, his unmet needs, and the apparent public sentiment or stigma about day services.

The analysis also revealed the clients appeared to be dissatisfied with several other areas related to the Center’s operation and environment. When discussing how important transportation options are in making the Center accessible to them, several participants acknowledged some deficiencies in the transportation as to reliability of schedules and drivers. Since the Weinstein Center serves two meals and occasional snacks, food is also an important component to the overall environment at the Center. Most of the focus groups included criticisms about the taste and quality of the food. For instance, one individual said, “They could use some help in the kitchen.” However, several participants credited the Weinstein Center with responding to their wishes about food changes, albeit slowly, when they described their successful removal of tuna casserole from the menu and then agreed, “now we need to work on those cheese sandwiches.”

While overall, the participants seemed satisfied and appreciative of the staff, a few participants reported on incidents involving staff-client conflict. One participant cited pressure from staff to participate in activities he did not enjoy. Another client explained that she felt a staff member had yelled at her, and decided to retaliate: “I said ‘drop dead!’ I just wanted to give her a dose of her own medicine.”

Caregivers of Memory Loss Group Participants

Initial Selection of the Weinstein Center

Explaining their initial involvement with the Weinstein Center, the participants discussed the progression of their loved ones' illnesses and their own responsibilities as caregivers. They described a variety of conditions ranging from more mild memory loss (e.g., a mother who is aware of activities and recognizes people) to more severe memory problems (e.g., family members who are unable to report on their daily activities). Most of the caregivers reflected on their own feelings and experiences, such as being unprepared, over-worked or burned out. In one focus group, the participants seemed to empathize and relate to one caregiver's description of her adaptation: "this has been kind of hard for me, though, because I've always been a go-with-the-flow person…but I've discovered life is much nicer if we follow a pretty close schedule."

Examining the participant responses, I identified the patterns that emerged regarding the interest in ADS and the selection of the Weinstein Center. The primary themes were the perceived care recipients' needs for a structured, social environment, the caregivers' needs for relief from their duties, recommendations from a trusted referral source, and comparisons.

Care recipient needs

The caregiver study participants reported that social interaction was a major factor in choosing ADS as a care option. The majority of caregivers indicated they viewed adult day care as fulfilling the perceived need for their family member to be in a social setting. One daughter stated, "I was very concerned about the socialization." Other participants described the importance of having their care recipient in a place with structure and supervision. For example, one caregiver said, "Doctors had said she should not be left alone, nor should she stay at home

all the time." Another caregiver observed, "Things started to change for her. And so she needed to be in a more supervised setting."

Caregiver respite

In addition to the needs of their loved one, most caregivers identified their own personal needs as an additional factor in choosing ADS as a care option. Specifically, personal respite was an important factor in choosing ADS. The category of personal respite included participants who said they needed a break from the loved one or that they needed to earn a living. A daughter caring for her mother cited her need for personal relief and observed, "I realized back in November that I needed to do something to give me a break." Another participant explained why she chose ADS for her husband as, "I would have gone crazy if he didn't have something to occupy his time." Participants also cited financial reasons for choosing ADS, including, "Finances, first of all were very tight, so I needed to get back to work…" and "I was having a real difficult time. I haven't worked for a year now, taking care of them."

Referral sources

In terms of choosing the Weinstein Center over another ADS center, most of the caregiver participants reported receiving a recommendation from a medical professional, previous clients of the Center or members of the MJCCA. Several families credited other ADS facilities as the recommendation source. One participant, whose family member needed medication assistance, recalled, "I did call one place, and [was told] 'you should check out the Weinstein Center if that's what you are looking for'."

Comparisons to other facilities

Comparison with other ADS facilities was the final factor related to the selection of the Weinstein Center. All but one of the caregivers discussed their negative experiences and

impressions with other adult day facilities. These comparisons suggested they found the Weinstein Center superior in two dimensions: the environment and the staff. One caregiver described her search for the appropriate environment for her father saying, "It reminded me of looking for day care for our kids. Some places you go in and go 'ugh' [*holding her head in her hands*]. 'How can I leave them here'?" A daughter caring for her mother commented on another facility she researched by saying, "They just don't do that much with them. They basically vegetate."

Several participants commented on the importance of professional staff. For instance, one caregiver said, "I liked the fact that the staff was all trained, professional staff, not volunteer staff." Another staff-related feature of the Weinstein Center cited by the participants was the nurse, as one participant put it, "That [a nurse] was definitely one of the things we were looking for." Another caregiver recalled her experience with a rehabilitation day center, where the staff permitted her mother to refuse the physical exercises, to remain non-participatory, and as a result, to decline in her functioning capabilities. In contrast, the caregiver expected the Weinstein Center's staff to be more competent and professional, saying "We decided we know Mother and you present it to her one way and she says "no" and you wait a few minutes and present it to her another way, usually she will do it." A final example that touches on both environmental and staff dimensions came from a participant who said she and her son had considered a variety of factors in choosing the Weinstein Center, including "What are their goals? What is the physical set up of the place? What is the ratio of helpers to attendees? Things like that."

Maintaining Participation

During analysis, I identified the factors that contributed to retention for the caregivers as the preference to maintain the existing care scenario, personal/medical care services, staff relations, and general caregiver satisfaction.

Maintaining the existing care scenario

The importance of maintaining their current arrangements appeared to be a factor contributing to the retention of clients, because the caregiver could keep his loved one at home or preserve an existing routine. For example, several caregivers articulated their reasons for staying with the Weinstein Center to include the desire to maintain the current living arrangements for their family. One caregiver stated, "I had thought that coming here, I could keep taking care of him." Other comments focused on the desire to keep things the same. That is, several caregivers described reluctance to change from the Weinstein Center, because it would disrupt their loved ones' routine.

Medical and personal care services

Similar to the results found with the Traditional Group members, the medical and personal care services were the only specific programming components participants described as being a factor for initiating and retaining their enrollment in the Weinstein Center. The caregivers referenced blood pressure monitoring, the nurses, and the podiatrist in the list of important features of the Weinstein Center. Two caregivers, however, were not aware of the medical care available at the Center.

Staff relations

Caregivers also reported that staff relations were important in their decision to continue bringing their family member to the Weinstein Center. Most of the comments made in the focus

groups about the staff were positive and represented dimensions of staff caring and personal service. Specifically mentioned in terms of staffing were oversight and specific attention paid to individual care recipients. With respect to staff caring, the participants made several references to specific staff members who are "very good" or "excellent." There were also general comments about the staff and, as one caregiver put it "the whole caring atmosphere." Other participants observed "the ladies are patient" and "I believe these people care about their patients." Several caregivers mentioned the close supervision provided by the staff. For instance, one caregiver said that, "One thing they are very good about, it is almost one-to-one oversight." Finally, several caregivers illustrated the personal service approach taken by staff. For example, a daughter whose mother recently entered the Memory Loss group described her experience:

> One thing I like about coming here is that they greet Mother at the door, they call her by name, they set her down, they ask her if she wants some coffee – she says 'Yes!' They provide her with coffee; they take her coat. In the afternoon they always say goodbye, if she has a jacket they get it themselves, it's not me going looking for it.

Another daughter agreed, saying "Yes, they're always escorting Dad out, giving him a salute. Just make him feel he is valued. In between, I know he sleeps a lot and gets uninterested, but that personal touch is great."

Satisfaction

Most of the participants indicated their satisfaction or gratitude in general terms, such as "I am satisfied here," or "The Weinstein Center is a wonderful place." In addition, most of the participants referenced some element of Weinstein Center operations and processes as contributing to their satisfaction with the Center. For instance, the duration of open hours and flexibility of drop-off/pick-up times were mentioned as features contributing to their continued

satisfaction and retention with the Center. In addition, several caregivers cited specific instances where the Weinstein Center worked with them financially so the family member could continue participating.

Problems or Concerns

One important issue that emerged during coding was that the caregivers knew little about the actual day-to-day functioning of their loved one while at the Center. One possible reason for this is that many of the care recipients have memory problems which leave them unable to report accurately on their days. This lack of quality reporting appears to leave caregivers with little concrete information to make judgments about specific activities or the quality of care being received. For example, as one caregiver stated, "As far as Mother is concerned, all she does is sit there all day long. She doesn't do anything." Most of the caregivers said they did not have specific knowledge about many of the activities conducted by the Weinstein Center. For example, one caregiver commented, "I don't really know what goes on during the day." Another caregiver explained, "Not that I know they don't do it, but I don't see it on the activity chart." Although the lack of detailed information about the Weinstein Center was almost universal in the caregivers interviewed, it did not appear as a major concern for the caregivers. However, several caregivers reported a desire for more feedback, a topic covered in detail in the research question concerning case management.

Families (n=5) who indicated they used transportation, either on the Weinstein Center buses or with an outside service arranged by the Center, seemed to consider it a factor in the selection and retention with the Weinstein Center. Most, however, identified some problems with the transportation services, either in mechanical or scheduling reliability. One participant described the solution to one transportation problem at the Center was the Director's willingness

to drive her own car to pick up clients when the Weinstein Center bus broke down. Several other anecdotes from the focus groups indicated problems with reliable scheduling of departure and arrival times. One caregiver observed, “I must say the Weinstein Center has been wonderful, but the transportation company, I’m not too happy with.” The same participant later elaborated, saying “Now she would really like to come 5 days but it is hard for me to let her come 5 days because of the transportation situation. You never know what time they will come – 15 after, then it’s 10. They might bring her home at 4:00 or they might bring her home at 7:00. So it’s kind of difficult.”

Perceptions of Activities as Beneficial

The second research question sought to determine the extent to which Traditional Group participants and caregivers of the Memory Loss program members perceive the activities offered by the Weinstein Center to be beneficial. To determine what was considered “beneficial” for the participants, I examined the data for patterns and themes related to positive impacts and outcomes.

Overall, both sets of focus group participants reported perceiving the activities at the Weinstein Center as beneficial. The benefits of the activities included occupying time and promoting emotional, physical or cognitive well-being. The extent to which the activities were felt to be beneficial was related to the nature of the activities and the expected and actual perceived outcomes.

Traditional Group

During the analysis, I coded the responses in terms of positive or negative effects on the participants. Three central themes emerged with regard to the way the activities and environment at the Center positively benefit participants: occupying time, well-being promotion, and social

engagement. Other important themes revealed in the data were personal identity, perceived influence, and resignation.

Occupation

Most of the participants (n=9) described the Weinstein Center activities in terms of occupying their time through keeping them busy, or giving them something to do or somewhere to go. This outcome is consistent with some of the previously mentioned expectations in choosing ADS in the first place. Some examples of participant comments on this effect of occupation include: “If you can’t stay alone, and they have to go to work, you have to be someplace,” “Life here is very busy,” and “Usually we are active most of the time, and time passes so fast.” One female participant said, “Each of us has a problem. Yours might be the same or different. During the time that we are here, our problem is not in front of us.” For this participant, the Weinstein Center appears to provide a distraction from the medical conditions or other problems of the Traditional Group members.

Well-being Promotion

Participant responses also indicated that members experience the Center activities as promoting physical, cognitive or emotional well-being. Activities involving physical exercise or movement appeared to be viewed by the participants as highly beneficial. Referenced either as “exercises” or “games to keep us active,” participants (n=7) related tangible benefits from participation in the activities. The benefits ranged from general terms, such as “I like exercise because that’s helpful,” to more specific effects such as “when I move around before lunchtime, it helps me digest.” Several participants with limited mobility credited the Center-provided activities as helping them physically. One female participant said that “I couldn’t walk and this

[the Weinstein Center] is where I took my first step," while a male participant said, "movement of limbs, bend the legs – whatever we can do – they help us, they help us."

In terms of promoting or enhancing cognitive well-being, the participants did not report the activities as highly beneficial. In fact, only one, Trivia was specifically mentioned as cognitively enhancing or mentally stimulating. One client provided detail about his experience with Trivia:

> I like trivia. And I find that all the people here, the participants, they get involved in it. I think we stir up their energy and they become alive as the game progresses. When they start up they say 'ho hum, ho hum, just another game' and as soon as they find they can take part and they do have information in that noodle of theirs, and by the time it's time to go home or get a treat for the day, they may want to continue, but our schedule says we're done. And they start getting wrapped up in it and they say 'hey, maybe I'm not as dumb as they say I am'.

Excluding comments about Trivia, only three participants mentioned the Center's activities as educational or helpful for mental stimulation. One participant described her expectations of the Center as a place to learn and added, "That's exactly what it's turned out to be."

Analysis revealed the participants viewed the Center's activities and environment as beneficial by enhancing emotional well-being. Several participants expressed feeling good or comforted by the Weinstein Center, including one participant who said, "the atmosphere of this place is very comfortable." Another participant described her home life as "sad, lonely, boring" and said that coming to the Weinstein Center helped with that. Another common response was that attendance at the Center resulted in improved mood. Emotional benefits of happiness, fun, and enjoyment consistently emerged from the majority of participant comments about the

activities and the environment of the Center. In addition, many of the participants mentioned the outings or field trips as activities they enjoyed. Heightened self-confidence and sense of safety were additional emotional effects experienced by several of the participants. Some examples of how participants reported about confidence and safety were "[coming here] give[s] you things to think about. You can do better," "we feel safe coming here," and "we have a nurse every day. It makes me feel better."

Social Engagement or Interaction

Socialization was a prevalent theme throughout the focus group discussions. Several participants commented that being at the Weinstein Center enabled them to meet, interact, and converse with people. The more specific beneficial effects reported by the participants ranged from relief from loneliness, to the enjoyment of the people ("I just think it's fun to interact with everybody"), to educational enrichment ("People get together and come here and do things together. You learn a lot like that."). One participant articulated specifically what he would like to experience with the participants with whom he shares his days: "I'd like to hear these women, when they talk about their life, when they were younger, how they lived, how they played. I'd like to hear about things they did I never even thought about doing." Finally, participants described the importance of relationships among clients. For instance, citing a Bible story about Jacob's dream, a female participant described feeling that, "We're climbing the ladder together."

Personal Identity

Personal identity was a theme I identified when participants described their interactions and associations with other clients. While the clients represented a variety of professions, cultures, and hobbies, during the interviews, the participants often discussed common interests with their fellow group members. One participant observed, "we tell each other about our lives,

and there are so many things we have in common." Another participant expressed his desire for more interaction with others, saying, "I could be very interesting, I've been all over the world."

Personal identity was a strong, relevant theme when participants described their attitude towards their attendance at the Center. Some female participants viewed the Weinstein Center as similar to going to school, for example, a participant reported, "My sister says, 'Got any lessons? Got any homework? What did you do today? Did you make anything?' I say 'yes, but I don't have any homework'." Others participants, both male and female, compared their routine with the Weinstein Center in terms of work, as one female participant said, "Sometimes I feel like I'm going to work. I've worked so many places my whole life." I coded both the role of student and the role of worker as falling under the theme of personal identity.

Losses and/or limitations experienced by the participants also fit within the personal identity theme. Most of the participants (n=10) disclosed their health condition and physical or cognitive limitations, and many compared their current situation with their past. During the discussion about the Center's garden, one client shared with other participants in his group his knowledge of tomato varieties, adding, "I used to put out a garden before I got screwed up." Another client in the focus group added, "I've cooked my whole life. I can't go in the kitchen now." Comparing her past and present, a client said, "As a younger person, I had to have a very busy life. I was into everything. I felt nothing happens without me. I volunteered for everything. And I think this is the way the Lord stopped me. No you're not. Leave things to me." Being at the Weinstein Center because of these age or health-related changes had become part of their new identity.

Despite the participants' reporting a connection between the Center with their previous work or school experiences, personal identity was not an important variable in terms of the actual

activities offered by the Center. Instead, the participants appeared to view the benefits derived from the activities as filling their time at the Center rather than being personally relevant or fulfilling their current or prior individual interests in terms of personal identity.

Problems or Concerns

Areas of concern for several participants included their perceived lack of influence or control over the activities available from the Center as well as the lack of variety. For example, a participant complained, “I’m not getting anything out of it if I see the same thing over and over.” Another participant agreed, “It happens all the time. The same thing. Like she said, we want something different.” Contrasting her current and past experiences at the Weinstein Center, a participant explained, “Some things we used to do, we used to be asked. Places we want to go. We used to have a say in it.” She later added, “We would like to have a say in where we go.” Some clients commented that traveling outside the Center sometimes created difficulties for the less mobile individuals and potential frustrations for those with greater physical abilities.

While other participants criticized the food in general, one participant felt that Center meals negatively affected physical well-being. Her concern was the meal schedule, observing that lunch closely followed breakfast, thereby preventing the proper digestion of breakfast. She also expressed her desire to “encourage the Center to have [a] more healthy lifestyle.”

Most participants expressed the desire for the Center to offer a more mentally-stimulating, learning environment. While some participants reported the Center to be a place to learn, two participants expressed a different experience with the Center activities. Referring to her perceived lack of opportunity to learn new things, one female participant said, “I’ve felt a loss with that.” Another male participant observed, “there’s no challenge.”

While many participants found the social environment beneficial, other participants (n=6) referenced the challenges of putting large groups of people together for activities. For example, one female client observed, “everybody tries to be very accepting, to love each other and try not to hurt each other’s feelings.” Another participant reported noticing that, “some people associate with certain people and certain people don’t.” Finally, a participant described her views on the social environment at the Center as, “sometimes there are, [*pausing*] well, group dynamics. Mostly we get along.”

Finally, when asked about anything they would change if they could and anything else they would like to tell about their experience at the Center prior to concluding the focus group, several members’ reflections, tone of voice, facial expressions, and body language suggested an ambivalence or resignation to their situation at the Weinstein Center. The participants offered few suggestions for Center improvements, as one participant summarized, with a furrowed brow and a heavy sigh, “they take care of needs.” After additional probes to obtain a deeper understanding of the participant’s feelings, she reflected, “I don’t know what I would change here. From the outside looking in, I see that everything is OK. I don’t know from the inside looking out.” Another participant, who had previously reported that he was not getting what he had expected from his participation at the Center, said, “I don’t want to be negative. I think what we’re getting is good.” He later added, “I don’t feel forced to be here,” to contrast his experience with the focus group member who felt “dumped off” at the Center. These seemingly incongruent comments and others suggest some participants may feel resigned to their situation and unable to influence their personal experiences with the Center.

Caregivers of Memory Loss Group

Analysis of the caregiver focus group data revealed two distinct categories of beneficial effects relating to enrollment with the Weinstein Center: personal benefits and perceived care recipient benefits.

Effect of the Weinstein Center on Caregivers

Two themes of personal caregiver benefits emerged: improved quality of family life and personal peace of mind. The specific effects reported were focused on the time the caregivers and care recipients spent together. This is an interesting phenomenon, because an important initial factor in deciding on ADS was to provide respite from caregiving responsibilities, but no caregivers referenced any positive respite effects. Instead, the caregivers reported feeling that because of the time the care recipient spent at the Center, they were able to enjoy an improved quality of family life. The caregivers tended to attribute the improved quality of family life either to participating with the Center generally or to specific changes in the behaviors of the care recipient. Some examples of participants' comments about improved family life are: "This has been very good – one of the best things that's happened to us, once we got established," and, "Our time with Mother is more quality time."

In addition to identifying behavioral changes as positive effects on the loved one, which will be discussed in the next section, the caregivers observed personal benefits in the form of improved caregiving responsibilities. For example, a daughter caring for her mother observed, "I've seen her pretty out of control. When she comes here, she comes home, she's manageable…. The difference is night and day." Another caregiver explained, "When she comes here, she's up even though she says she does nothing here, at least she's not in the bed and we're not fighting constantly to keep her out of the bed."

Several caregivers indicated experiencing a sense of trust and peace of mind about the loved ones' care at the Weinstein Center. Two participants described the experience at the Center "reassuring." One daughter noted that the family, "look[s] forward to Mondays through Fridays, coming to the Weinstein, because we know that, number one, she's getting meals…"

Effect of the Weinstein Center on Care Recipients

Because of the issue with lack of knowledge of daily activities of the care recipient, the caregivers were unable to provide many examples of specific activities or events that directly affected, positively or negatively, the care recipient. As one caregiver put it, "Early on, I thought that if his disposition went down, I automatically assumed something happened here, and I realized that's not the case. It can change on an hourly basis." Similarly, a caregiver commented her husband "seems to come home in the same mood every day." The caregivers, however, were able to provide several specific anecdotes as well as general impressions to illustrate the benefits they believe their family member experienced by attending the Weinstein Center. Occupation of time, emotional and physical well-being, and socialization were the major categories of benefits to the care recipient.

Occupation

Half of the caregivers identified the activities and the environment of the Weinstein Center as keeping their loved one busy and giving them somewhere to go and something to do, hence, occupying their time. For example, a caregiver described her mother saying, "She likes having stuff to do, she likes being busy, so it was something to look forward to." In addition, a wife described her husband's patterns, "At home, I know all he'll do is sit and watch TV."

Emotional and physical well-being

The caregivers also reported positive emotional effects on the care recipients, as evidenced by their improved moods, behaviors, or both. Many caregivers attributed the improvements to the environment in general and to the creative therapy programs of the Center. A caregiver reflected on the apparent effects of the Center on her mother as "she hasn't been depressed coming here. She doesn't complain." Another caregiver said she has been able to postpone the administration of tranquilizers to control her husband's behaviors since he started attending the Center. Some caregivers suggested the effects on care recipient mood related to the approach taken by the Center staff. In terms of the staff, one caregiver observed that, "They do concentrate on keeping them happy and stimulated, which I think is good."

The Creative programs of the Center were viewed as beneficial. Many of the caregivers also referenced the music programs as highly beneficial to the care recipients. For instance, "It [music] will change his attitude if he's feeling negative or scared," observed one caregiver. Another caregiver reported that, for her family member, music "is one of the few things that he responds to immediately, it's music, singing." Several caregivers referenced the Center's arts and crafts program, not in terms of the specific benefits to the care recipient but rather as evidence their loved one is participating in activities. One caregiver, however, did credit the crafts as improving her mother's emotional confidence, saying, "Sometimes she's like a little child. She's proud of what she's done and she shows me."

All of the caregivers noted that the physical activities, such as chair exercises and moving a ball back and forth, were highly beneficial for care recipients. They also expressed a preference for the Center to create more opportunities for physical activity, including being outdoors in the fresh air. When discussing the benefits of physical exercise and being outdoors, several

caregivers mentioned the field trip to Azalea Park as a specific activity enjoyed by the care recipient. One daughter articulated the benefits she perceived the outing had for her mother, saying "She really enjoyed the outing to Azalea Park. She had a really good day; she talked about it and with a lot of clarity for several days after that." Several of the caregivers suggested the Center could help the care recipients to be outdoors more by utilizing the adjacent garden or other parts of the MJCCA campus.

Social interaction or engagement

Regardless of the care recipient's level of functioning, the opportunity for socialization was a perceived benefit by all the caregivers. Caregivers with family members in advanced stages of memory loss observed their loved ones' experiences, saying "She really does much better with the interaction here," and "The camaraderie of the group, seeming to have a good time – he really picks up on that." One caregiver described her mother-in-law as functioning on a level where she could remain at home:

> But she likes to be around people her own age. And I joke, she's like my teenager, she likes hanging out with her own age group. So she gets that around here, she's around her peers. So that's definitely one of the pluses -- getting her out of the house, going to a senior day.

Problems or Concerns

Not all caregivers, however, found peace of mind from having their loved ones attend. Three participants admitted to worrying about their loved ones' experiences at the Center. One daughter caregiver revealed her impressions of the Memory Loss unit: "Sometimes I look to see who is in the room, and if I see nothing but blank stares, my stomach is in knots the rest of the day. But if I see other people that appear to be like she is, then I leave feeling good." Another

caregiver worried about the care his loved one receives during the day, admitting his expectation for the Center was "I wanted someone to give him the care I would give him at home." The caregiver appeared to need better communication with the staff than he felt he was getting, as he described, "I find they sort of blow me off when I ask questions. They just kind of blow it off. Like that was just a silly question in the first place. They get very defensive." He later added, "One day, they said 'y'all are just too protective.' I just shrugged it off." He later summed up his feelings about the Center:

> I'm sorry I don't mean to complain. The Weinstein Center is a wonderful place. It's one of the best in the city, of the few there are. But nothing's perfect. I'm trying not to be negative. But there are things I worry about. And I want y'all to realize that I'm just overprotective.

Suitability of the programs, given the functioning capacity of the memory loss patient, was the primary theme indicated by the caregivers who volunteered concerns or suggestions. Three of the caregivers discussed their desire for the activities to be responsive and suitable to the physical and cognitive changes experienced by the individual with memory loss. One participant felt that history discussions were "not the best use of what faculties they have left." Focusing on the importance of engagement, she explained in detail her expectations from Center activities for her father and others:

> I think they rely too much -- at least in the Memory Impaired Group – on talking about things. Rather than showing, pictures, dancing, illustrations, whatever, especially in a group, someone who is confused, can't follow it… put him [Dad] in a group with 10 people, and I've seen him drifting and everybody else is drifting, because of the medication. I think a lot of it is it is not an engaging activity. An engaging activity is

> they have hand bells, lessons on how to do that, different colors, something that engages that is not just talking… I'd really like to see them doing more engaging things.

This same participant later acknowledged the challenges of programming for a group of people whose physical and cognitive functional capacities are very diverse, admitting, "even as I think the program could be stronger and more engaging, I don't know how I would go about designing that."

In discussing the Azalea Park field trip, a caregiver expressed concern over the lack of information she felt she had with respect to the outing. This concern, a need for information, will be explored in more detail in the third research question. Some caregivers did speculate about whether outings and field trips resulted in overstimulation and confusion in the care recipient compared to the benefits likely to be experienced by the loved one.

Case Management Program

The discussion of the case management program in the caregiver focus groups began with identifying the participants' impressions of case management in general terms. Each caregiver seemed to have a slightly different understanding of it. Some representative comments are as follows: "Case management – it's a fuzzy area," "I don't know what case management is," "I'd say it is matter of making sure that the billing is done right, the money is collected, and if you have a problem," and "Someone who monitors the situation and maps it out. Not a caregiver."

I analyzed the data to identify themes relevant to evaluating the current case management system at the Weinstein Center. The major themes were lack of awareness, inadequacy of the current support group meeting, and unmet needs with respect to caregiver information and training.

As additional probes surrounding case management were offered in each focus group, typical components of case management programs, such as information referral and individualized care plans, emerged in the discussions. Most of the participants, however, did not identify those types of services to be provided currently by the Weinstein Center. For example, follow-up questions about problem resolution and information referral tested caregivers' awareness of such services as accessible through the Weinstein Center. They unanimously indicated that the Center did not provide such services as a regular service to families.

When questioned about the support groups offered by the Weinstein Center, only one caregiver had attended a meeting, found it "reassuring" and reported on its content, saying, "Here it is very informal. Do you have questions? Do you have something you want to bring up? Do you have issues with anything here?" Most of the other participants were either not aware of the support group or not in favor of the group as they perceived it. Held on the third Thursday of every month at 3:00 p.m., the meeting was not feasible for some of the caregivers because of conflicts with employment or personal commitments. Other participants cited perceived lack of substantive content or agenda and dominance by individual caregivers as reasons for their lack of interest. Finally, the caregiver who reported some conflicts with the staff, when probed further about seeking support from others at the Center, stated, "I don't have an outlet."

Half of the caregivers had attended educational or support meetings outside of the Weinstein Center. All who had attended these other meetings identified features they found favorable in comparison to the Weinstein Center meetings: evening or weekend schedules, existence of an agenda, and facilitation of discussion among attendees. They suggested that the Weinstein Center either promote the outside meetings to clients or conduct their own meetings with similar formats and content.

The information needs comprise four main categories: feedback on the daily activities of the loved one, emergency protocols at the Weinstein Center, available services to provide additional help to the caregivers and families, and caregiver training. Most participants (n=8) discussed the desire for regular feedback about how the loved one is doing, such as a regular report or assessment, or as one caregiver called it, a meeting analogous to a "teacher conference." Several caregivers suggested the use of electronic mail might improve communication with a minimal amount of extra work for staff. In contrast, a couple of participants provided an alternative view by stating that they did not want to focus on the day-to-day progression of the disease or follow each identifiable milestone of decline.

Several caregivers were unclear about emergency procedures in place at the Center. One caregiver, the sole provider of his loved one's care, wondered if he were to become incapacitated and unable to pick up his loved one, what would the Weinstein Center do? The caregivers in that focus group all agreed they would like to receive more guidance on establishing emergency care procedures.

The caregivers all agreed on the difficulty of navigating the elder care system. The third type of information need participants indentified was reliable service referrals. The caregivers who had sought out the Weinstein Center for assistance with additional external resources found that staff members were, as one long-term client put it, "a wealth of information." Specifically, the services had covered transportation assistance and referrals of medical and legal services. On the other hand, some caregivers felt these types of needs were not being met by the Weinstein Center and suggested this to be an area warranting improvement. One caregiver summed up her expectation of the Center, saying,

> I have great faith in this place. So, I know they're not going to make a recommendation to someplace where they'll just sit and vegetate or not be taken care of. I would trust a recommendation from here more than me going on the internet.

Finally, all participants agreed on the need for training for themselves, specifically identifying behavioral training as a caregiver and education on patient experiences with dementia or memory loss. One caregiver explained her need for such training, saying, "So you know what to do and what not to do." A caregiver who had received some behavioral training at an assisted living facility described her experience, saying, "She [an outside speaker] did something on techniques, and actually acted out for us, to see what our response is …Your initial response you give is totally wrong. 'Calm down!' Now what would you do if someone told you to calm down?" Finally, one focus group discussed how they would like to draw upon the experience of the staff at the Center who work directly with the patients. They speculated that the staff could describe their techniques of coping with behaviors and moods of the patients, and the families could adopt such strategies into their daily interactions with the loved one.

CHAPTER V

DISCUSSION

This program evaluation of the Weinstein Center was an effort to capture and understand the experiences of Traditional Group members and caregivers to Memory Loss Group members. In line with Applebaum and colleagues' (2000) suggestion that quality assessments include "knowing the customer," this evaluation was designed to answer the research questions desired by Weinstein Center management and thereby further their understanding of client needs, perceived outcomes, problems and concerns.

This study also adds to the existing evaluation research environment in several important ways. Most of the previous evaluations of ADS used satisfaction surveys, questionnaires or telephone interviews and were often limited to the perspective of the caregivers only. This evaluation indicated that the open-ended interview questions, the focus group format, and the participation of care recipients as well as caregivers, provided detailed descriptions of the client experience. The analysis revealed not only satisfaction and quality indicators but also concrete recommendations for paradigm shifts and programming changes that can help the Weinstein Center, and possibly other ADS facilities, better meet client needs and provide very high quality care.

Contribution to ADS Evaluation Research

The results of this evaluation support the findings of previous evaluations of ADS programs and other long term care environments. As Warren and colleagues (2003) found, the opportunities for social interactions and relationships were very important to the participants and caregivers and a key component to their selection of ADS. Like the findings by Baumgarten and colleagues (2002), the Traditional Group members reported attendance at the Center helped to

relieve their boredom and loneliness. The Weinstein Center's interior environment contributed to client satisfaction, which is similar to the findings of Buelow & Conrad (1992). Participants also appreciated the surrounding grounds at the MJCCA, including the garden adjacent to the Center. Staff caring, defined as competence and responsiveness by Balaswamy & Dabelko (2002), was a key factor for caregiver satisfaction. This evaluation also demonstrated that not only the caregivers but also the care recipients reported the staff as caring, helpful, responsive and competent. As in Townsend and Kosloski's (2002) study, when the participants reported negative interactions with staff, their difficulties in communicating contributed to client dissatisfaction. Finally, the emotional, functional, meaningful activity, and individuality needs, among others, revealed by the participants in describing the effects of attending the Center were similar to most of the needs and desired outcomes compiled in a list of quality-of-life indicators used for evaluating nursing home environments (Lawton, 2001). The list of outcomes for quality of life in the nursing home environment demonstrate environmental factors and staff behavior that should be congruent with meeting the basic human needs for quality of life (Lawton, 2001), so those environmental and behavioral factors are instructive to an analysis of Center policies and practices in programming and service delivery.

This evaluation shared a number of similar results with Stern and Caro's (2004) study that examined characteristics of high quality care in the ADS setting. The focus groups in their study identified compassionate staff, availability of nurses, monitoring of health needs, alerting caregivers of problems, activities to fight boredom, and a family environment that was emotionally and physically safe as indicators of high quality care. Similarly, this evaluation revealed those factors to be important to the Weinstein Center clients. Their study observed that transportation and food are commonly identified problems with ADS which were similarly

reported frustrations about the Weinstein Center. These problems are likely to remain a continuing challenge, particularly in light of fluctuating costs of food and fuel.

By expressing their desire for more activities involving mental stimulation and meaningful social interaction, the Weinstein Center participants also may have been implying a need for more age appropriate events and activities, as found by Stern and Caro (2004). Programming for older adults is often criticized by the participants and experts alike because of the similarity to children's games or activities. Our society tends to infantilize older adults when communicating with them (Kitwood, 1997), and if activities are not age appropriate, the Center risks perpetuating that approach, thereby furthering the gap between the participants' expressed needs for personally meaningful activities and the programming provided to them.

Current Limitation-Based Approach to Programming

The Traditional Group clients themselves identified no specific program, activity or service, beyond the medical or custodial care other people said they needed, as important to their specific choice of the Weinstein Center. This suggests that the programs and services that attracted clients to the Center likely represent what the family, physicians, and caseworkers want for these individuals, rather than what the clients would choose for themselves. Furthermore, when discussing the beneficial effects they experienced, the Traditional Group participants provided numerous examples of how the staff helped them and made them feel better and comforted given their medical condition or other problems. The participants also acknowledged the Center's goals to promote a social environment and personal well-being, but also expressed concern over maintaining control, choice, and personal identity, at times demonstrating an apparent ambivalence or resignation to their experience at the Center.

When a participant expressed her inability to influence or change things there, she explained her perception of the Center's purpose as "they [Weinstein Center] take care of needs." This sentiment reflects the limitation-based program design that is common in adult day centers, whereby the programs and services are designed primarily for the medical diagnoses of the attendees and attempt to be safe and therapeutic based on their functional and cognitive needs. Programming derived from an orientation based on losses and limitations tends to be what the staff wants to do and feels is best for the participants rather than what the clients themselves want to do (Meyer-Arnold, 2008). Considering the clients' past and present identities and interests but perceived lack of influence over their environment could explain why participants exhibited this sense of resignation with the Weinstein Center experience.

Recommendations

Person-Centered Care

A sustained commitment to an approach called "person-centered care," would improve the subjective experience of clients at the Weinstein Center. Kitwood (1997) calls this a shift in thinking from person-with-DEMENTIA to PERSON-with-dementia (p. 7). Reid, Ryan, and Enderby (2001) advocate for a "change in emphasis, from pathology to people and their potential" (p. 377). This type of shift in care focus is important not just for the Memory Loss group members but for any client regardless of medical condition or other event that precipitated utilization of the Weinstein Center.

Conceptual Background

When the needs of autonomy, individual choice, and identity expressed by the Traditional Group participants are integrated into their basic age and health-related needs, Kitwood's (1997) concept of "personhood" is suggested. He acknowledges that numerous factors such as

personality, abilities, beliefs, values, interests, biography, and demographics contribute to the uniqueness of persons. He also identifies the basic psychosocial needs that apply to all people as love, comfort, attachment, inclusion, occupation, and identity. He posits that the pattern of the psychosocial needs varies with personality. In addition, he argues the needs are more evident and more intense in people with cognitive impairment as they may be less able to function in ways that would fulfill those needs.

Specifically, Kitwood's (1997) construct of identity as a desire to maintain a sense of consistency across the life course and a connection with the past was evident as important to Center participants. The Traditional Group members expressed a sense of loss brought on by declining health and a change from a long-established way of life, which Kitwood argues heightens the need for comfort. In addition, unlike Kitwood's concept of "occupation" which takes into account individual backgrounds and interests, for the most part, the Center clients did not often report the activities as personally relevant or connected to current or prior interests.

Implications for Programming

A shift to person-centered care could help to match expectations and actual experiences at the Center. More choice, personal engagement, and involvement in the activities may help to reduce the personal resistance to day care. Person-centered care requires culture changes, environmental considerations, and programming changes, all of which, however, can pose challenges to an organization with long-established ways of operating.

Culture changes

Culture change would involve all the people at the Center, including management, staff, and participants migrating from an emphasis on loss of ability to the support of retained abilities. For example, Lawton (2001) described best practices to promote autonomy and individuality,

key dimensions to quality of life in a nursing home environment, as follows: staff encouraging clients to direct their lives and to take initiative and providing an environment sensitive to clients' backgrounds, current interests, and preferences.

The results indicate that the Weinstein Center Traditional Group members are ready and equipped to embrace a culture change. The participants themselves can provide the "social capital" to fund the paradigm shift to person-centered care (Meyer-Arnold, 2008). For example, the focus groups in this evaluation provide evidence of the social capital at the Center. On numerous occasions, the focus group participants seemed to support their peers by asking follow-up questions, signaling agreement with their comments, and offering suggestions and comparative personal experiences. Their responses in the interviews indicated that while the Center population is quite diverse, ranging from adults with very severe disabilities to persons who are highly functioning, the members appear to enjoy being together and to feel enriched by the life histories of fellow members. Diverse individuals come together into teams of people in community, and an ADS environment can cultivate that as well.

Importance of environment

Both groups of study participants identified features of the Center environment, such as the staff, the physical surroundings, and the social structures, as important to their selection, retention and perceived benefits. Lawton (2001) promotes the importance of evaluating the environment based on the outcomes sought, because understanding the relationship of person, environment and outcomes is critical to delivering high quality services (Lawton, 2001).

When people experience declines in health, physical strength, cognitive skills, and other areas of competence, their environment becomes increasingly more important to their well-being (Calkins, 2004). A person's particular functional competence level and the demands placed on

him by his environment can result in adaptive or maladaptive behavior and positive or negative affect (Cavanaugh & Blanchard-Fields, 2006). Although the competence-press model is typically discussed in the context of long-term care for severely cognitively impaired individuals, the same principles and strategies can apply to community care settings, such as ADS centers, which serve higher functioning older adults.

Using the competence-press model, Calkins (2004) discussed ways that the environment can be structured to help people with dementia function better, recognizing that people have diverse backgrounds and experiences along with changing functional and cognitive abilities and needs over time. A person may perform better in an environment that is able to respond to these diverse variables and create relevant programs and services based on each person's own unique experiences. Indeed, the caregivers in this evaluation expressed their concerns about whether the Center environment, including programs, appropriately suited the functioning levels of the individual Memory Loss members. The caregivers of family members with moderate memory loss wondered whether there was enough challenge at the Center to avoid accelerating their functional decline. In addition, many of the Traditional Group members sought more challenge from their participation in the Center, greater control and autonomy, and more personally relevant activities recognizing their unique identities, suggesting the current environment at the Center does not fulfill consistently their functional competence levels.

Suggestions for program changes

It will be important for Weinstein Center management to respond to the evaluation results, ideally with enhanced activity programming for the Traditional Group and further review about the activities provided to the Memory Loss Group. While it may not be realistic or even necessary to make major changes in the existing structure, small changes where possible will

demonstrate to participants that their unmet needs and suggestions are important to Weinstein Center staff and management. Small successes can often have a major impact in a shift toward a person-centered environment. (Meyer-Arnold, 2008).

A detailed review of specific programs and activities would be required for specific program change recommendations. Using the principles of person-centered care, however, general recommendations are possible. For example, where the activities structure currently appears to be determined solely by staff using ideas from the internet and holiday events, the Weinstein Center could begin to harvest ideas from participants, through interest inventories and personal background questionnaires. While the current physical environment allows for only one activity at a time in the large living area, the Center should consider whether the participants can be divided into smaller groups by common interests or activities. Some participants may desire to even lead and direct the activities. The addition of more age-appropriate décor and activities may be warranted, along with activities or outings that may appeal primarily to the male members of the Traditional Group who seemed to be particularly dissatisfied with the current activity offerings. Finally, a review of the approach to enhancing choice and independence among the attendees will be important.

Challenges

Inveterate to health and long-term care settings including ADS is the loss/limitation paradigm, which presents challenges for a culture shift to person-centered care. At the core of culture change must be a clear mission and set of values which guide all decisions. The values pertain to both participants in the program as well as staff and management. Ideally, the values will reflect a care model that management and staff would design for themselves, but people rarely envision themselves as needing chronic care or other elder care services. Staff may not

readily see the reason to change processes and procedures that they believe have been working for a long time. It is critical to acknowledge staff's prior contributions yet enroll them in the new mission and values, a sense of urgency, and the teamwork which culture change requires. Framing all changes as focused on the participant assists with encouraging staff to revise their approach (Meyer-Arnold, 2008). As for participants, they must also adopt the values, which may require a shift in thinking from aging as decline, to instead, a potential for growth and time of engagement and satisfaction.

Culture change will lead to programming changes which could also prove challenging to resources. A person-centered approach to programming suggests that the number of activities and routines may potentially increase to serve such a heterogeneous population as the Weinstein Center maintains. Achieving such programming goals could increase operational costs, for additional staff and other material resources. Alternatively, if the participants can lead and direct many of the activities themselves, the additional cost may be mitigated.

Finally, the integration of the physical structure into programming is critical to the design and evaluation of optimal ADS centers (Moore et al, 2006). Environmental changes can be expensive if major enhancements are desired for the existing physical structures of the Center. Nevertheless, the physical environment should be analyzed concurrently with programming changes, so that the space can be most effectively utilized given the programming goals. How the clients will engage in activities will be a major factor in determining the physical structure. For example, the Center's existing perimeter seating arrangement, where all chairs and couches are lined against walls, would likely need to be modified if smaller group activities were regularly conducted. Small environmental changes may often yield highly positive results.

Case Management Program

The caregivers' lack of awareness about the Weinstein Center's case management program as revealed in the findings helps to explain the Center's prior survey results where most respondents either left blank or indicated "N/A" on the case management query. As may be expected, the caregivers who had been utilizing the Weinstein Center for a longer period of time are more aware of the services available and appear more comfortable accessing help through the case managers than are the newcomers to the Center.

The results suggest several ways the Weinstein Center can better meet the needs of client families. At a minimum, the Center may embark on a communication campaign to reiterate to caregivers what services and information sources are available from the Center. Additional feedback to families who want the information may help to manage expectations and allay worries. The case management process should recognize that newcomers to ADS may be experiencing a phase of adjustment, and careful attention by staff may help to ease the transition (Reid et al., 2001).

Finally, the Center may want to consider alternative approaches to caregiver support groups. Although most of the caregivers said they did not feel like they needed a support group, during and after the focus groups for this study, they seemed to resonate from the interactions with the other caregivers. They asked each other follow-up questions, signaled understanding and empathy, and offered suggestions and peer support.

Evaluation of Satisfaction and Quality

Applebaum and colleagues (2000) identify a key component to satisfaction in health care models is an alignment of expectation to actual experience. This may be an area of improvement for the Weinstein Center. A source of reported dissatisfaction in the Traditional Group was

unclear expectations about what the Center provides in terms of programs and services to fit individual needs. In addition, the caregivers reported not being sure their loved ones' needs are met, because they receive little information about the daily functioning at the Center. Consequently, the management at the Center may want to be vigilant about the importance of establishing, managing, and adjusting clear expectations of clients, family members, and professionals who choose the Center.

Several healthcare quality improvement initiatives, such as TQM and the criteria under CARF accreditation, also focus on client satisfaction. The Malcolm Baldridge performance excellence criteria are used by some health care organizations to provide a practical framework for implementing quality initiatives and to evaluate best practices for quality improvement (Barber, 1996). Two of the seven Baldridge processes for excellence are (a) information collection and analysis and (b) focus on satisfaction of patient and other stakeholders (Barber, 1996). By using those same methods, this evaluation may help the Center to progress towards a establishing an ongoing process and practice for achieving excellence in the ADS marketplace.

The Baldridge category of focus on client satisfaction covers how well the organization understands its market, the customers and their needs. This category also evaluates how well an organization (a) manages relationships to meet ongoing needs, (b) incorporates consumer needs into programming, and (c) resolves problems. By designing its programming primarily on the medical limitations of the population, the Weinstein Center has met for the most part the basic needs of medical care and a safe, social environment, particularly in light of the apparent lack of attractive alternatives for clients in the ADS marketplace. The present evaluation, however, indicates that the Weinstein Center has under-developed the relationships with its own clients

that would sustain satisfaction longer term. Programming designed as person-centered care may contribute to meeting this quality and satisfaction criteria.

This present evaluation assists the Weinstein Center to satisfy portions of the pending quality assurance requirements in the state of Georgia. Section 290-9-11.24 of the Rules and Regulations for Adult Day Centers promulgated by the Department of Human Resources' Office of Regulatory Services, as currently proposed, is the Quality Assurance requirement that all ADS centers subject to the rules must follow. The rules require centers at least annually to "develop and implement an annual quality improvement plan to evaluate and improve the effectiveness of the program's operation and services and to ensure continuous improvement in service delivery." Satisfaction of clients is one of the evaluation criteria. The rules also require the centers to produce a written report with evaluation findings, improvement goals, and implementation plan for such goals. This evaluation provides the Center with satisfaction results, demonstrated progress towards quality assessment initiatives, and concrete improvement goals using a person-centered approach to care delivery.

Future Evaluations

The Center may benefit from a number of other evaluation and research studies. For example, a more thorough understanding of retention statistics (40% of clients do not continue participation beyond one year) by interviewing former clients or family members may illuminate more specific unmet needs or concerns regarding programming. Since the caregivers in the study represented only 25% of the total primary caregivers at the Center, additional data from other caregivers of the Memory Loss Group may enrich the results. Telephone interviews, however, may be a more feasible data collection strategy than focus groups, given their time constraints with caring for their family member. The Traditional Group members were not asked to provide

specific feedback on case management, so their viewpoints may be needed to complete the data gathering on the case management program.

Center management had considered including the higher functioning participants in the Memory Loss Group in the study, rather than their family caregivers only. While it has been found that dementia patients can communicate preferences or opinions about services (Reid et al., 2001; Stern & Caro, 2004), it will be important to use or develop an appropriate tool to gather data from people with memory loss with special sensitivity to the vulnerabilities of that population. For example, Carroll, Vetor, Holmes, and Supiano (2005) tested a consumer satisfaction interview using primarily closed-ended questions on persons with mild to moderate dementia who attend ADS.

During the intake and orientation process for a new client, the Weinstein Center may consider including some quantitative measurements such as anxiety, depression, caregiver burden, or other outcomes on which Center management desires to evaluate the impact of their programming interventions. Obtaining the measurements prior to attending the Center (base-line), then performing follow-up measurements at some time interval(s) may permit an objective assessment of the impact of programs and services, recognizing that external conditions outside of the Weinstein Center's control may confound the results.

Finally, it is important for Center leadership to recognize that quality and satisfaction assessments in health and long-term care settings are a continuous and collaborative process including at a minimum the following requirements (Applebaum et al., 2000, p. 113-119):

1. Commitment to hear client voices
2. Agreement to respond to consumer feedback and other data with changes or improvements

3. Development of specific data collection tools and approaches
4. Overall strategy for collection of information – type, outcomes, frequency, etc.
5. Systematic processing of client-level data
6. Linkages of information to a quality improvement process

Adopting processes to permit the Center to assess its programming on a regular basis should improve the Center's ability to adjust programming to meet the needs of a shifting, increasingly heterogeneous client base.

Community Challenges for Adult Day Care

The study participants credited the Weinstein Center as helping them or their loved one to remain in their current living situation. This is a common contributing factor in the decision to choose ADS programs for families (Gaugler & Zarit, 2001). Aging-in-place is generally recognized as the preferred living arrangement for the older adult population in the U.S.

Both groups of study participants also referenced a perceived lack of viable alternative adult day programs as contributing to their selection of and retention with the Center. While the apparent lack of alternatives has apparently served to help the Weinstein Center in maintaining a loyal and satisfied client base, this factor potentially has significant implications for the community.

Currently, there are 34 other ADS facilities within the counties represented by Weinstein Center attendees, but only 9 facilities located in DeKalb County where most of the Center participants reside (ARC, 2008). With the increasing size of the elderly population, the need for ADS as a care option will likely increase, but it is unclear how current ADS practices will be able to fulfill the community needs. For example, ADS programs must compete for increasingly tight financial resources shared among many other needed social programs.

O'Keefe and Siebenaler (2006) observe that some experts feel that public knowledge about ADS has improved but argue that awareness and understanding continue to lag far behind public understanding of other long-term care options. Even though ADS programs can allow significantly impaired people to remain at home or living with family, the public, including some of the caregivers and participants, still views ADS as the adult equivalent of child care (O'Keefe & Siebenaler, 2006). If the community perception of ADS is, as one Traditional Group member put it, "your babysitter place," it is not surprising that older adults present some resistance to attendance or resignation with the experience. The familiar stereotype of old age, articulated by one Traditional Group member who declined to join the research study, as "once a man, twice a child," deserves to be challenged, and new approaches to ADS as a community care alternative are needed.

Limitations

While the results of the evaluation were not expected to be generalizable to other ADS organizations, the evaluation has several limitations that are important for the Weinstein Center. Management of the Center were notified of these possible limitations during the planning and implementation of the evaluation. Most notable is that the evaluation covered the Dunwoody location of the Weinstein Center only and did not include the Buckhead center which has its own staff and potentially different participant demographic characteristics and activity and programming features.

Researchers risk bringing personal and professional biases into a study. In an effort to minimize personal bias, my goal was to facilitate the participants in educating me about the Weinstein Center and helping me to conceptualize their experience with the Center's environment. I did not observe any services or activities directly or discuss the program details

with Center staff or management prior to the evaluation. I attempted to document the spontaneous and meaningful expressions of the informants and to use such statements to illustrate an accurate description and interpretation of their experience at the Center. The background information I did have was necessary in order to develop an appropriate approach to and scope for the evaluation. Since the data was single-coded, however, the analysis has a degree of researcher subjectivity. The coding reliability was enhanced by a subsequent review of the transcripts which resulted in consistent coding between the two coding times.

The sample of participants was small in number compared to the total participant population. The approach to sampling excluded seven of the Traditional Group participants from the analysis. In addition, two Traditional Group members who had agreed to be in the study were not interviewed due to scheduling conflicts. Finally, to investigate the research questions about retention and benefits fully, it would have been helpful to interview former clients of the Center to determine why they had chosen to terminate their participation.

The results may reflect a selection bias. The Traditional Group members who participated volunteered to do so and possibly were higher functioning, healthier, or more satisfied with the Center than others who did not volunteer. The caregivers who participated also volunteered and had schedules which permitted attending a focus group at the Center. Although the Weinstein Center management predicted that the participants would be forthcoming and candid with criticisms, the data may reflect some bias from the Traditional Group members if they feared programs and services would be terminated or other negative ramifications if they were overly critical.

Focus group dynamics may have impacted the nature of the data. Some participants could have been reluctant to share opinions in a group setting despite the agreement to keep the

meeting discussions confidential. In fact, one individual who declined to join the study indicated she would be willing to share her concerns in a private interview.

Conclusion

The Weinstein Center evaluation revealed the integral role the Center plays in the lives of its family constituents and the fundamental impact their programs have on well-being and quality of life. As a result, the Center's leadership and staff have a continuing responsibility to understand its clients and listen to them as individuals with unique backgrounds and identities.

NADSA recognizes the challenges and the opportunities of the ADS model of care. There is a "tremendous chasm between the elder care we have and the care we could have" (Meyer-Arnold, 2008), because generally, the leaders in ADS and other elder-care businesses often never view themselves as eventually being a part of that environment. Person-centered care is major step towards lessening the gap. Programming can involve the participants in design, decision-making and facilitation. This level of commitment to the client will help the Center satisfy key components of any quality improvement initiative and continue striving for excellence.

REFERENCES

American Evaluation Association (AEA) (2004). *Preface: Assumptions concerning development of principles*. In American Evaluation Association Guiding Principles for Evaluators. Retrieved October 18, 2007, from http://www.eval.org/Publications/GuidingPrinciplesPrintable.asp

Atlanta Regional Commission (ARC) (2008). On-line database. Retrieved July 22, 2008, from: http://agewise.atlantaregional.com/agewise/forms/Search/results.asp

Applebaum, R. A., Straker, J. K., & Geron, S. M. (2000). *Assessing satisfaction in health and long-term care*. New York: Springer Publishing Co.

Balaswamy, S. & Dabelko, H. I. (2002). Assessing the satisfaction of caregivers of adult day services participants: A pilot study. *Activities, Adaptation & Aging, 26*(3), 1-14.

Barber, N. (1996). *Quality assessment for healthcare: A Baldridge-based handbook.* New York: Quality Resources, A Division of the Krause Organization Limited.

Baumgarten, M., Lebel, P., Laprise, H., LeClerc, C., & Quinn, C. (2002). Adult day care for the elderly: Outcomes, satisfaction, and cost. *Journal of Aging and Health, 14*(2), 237-259.

Buelow, J. R. & Conrad, K. J. (1992). Assessing the influence of adult day care on client satisfaction. *Journal of Aging and Health 4*(2), 303-321.

Calkins, M. P. (2004). Articulating environmental press in environments for people with dementia. *Alzheimer's Care Quarterly, 5*(2), 165-172.

Carroll, A. M., Vetor, K., Holmes, S., & Supiano, K. P. (2005). Ask the consumer: An innovative approach to dementia-related adult day service evaluation. *American Journal of Alzheimer's Disease and Other Dementias, 20*(5), 290-294.

Cavanaugh, J. C. & Blanchard-Fields, F. (2006). *Adult Development and Aging* (5th ed.). Belmont, CA: Thomson Learning, Inc.

Commission on Accreditation for Rehabilitation Facilities (CARF) (2008). *What is quality?* Retrieved January 3, 2008, from: http://www.carf.org/consumer.aspx?Content=Content/ConsumerServices/cs03en.html&ID=3

Gaugler, J. E. & Zarit, S. H. (2001). The effectiveness of adult day services for disabled older people. *Journal of Aging & Social Policy, 12*(2), 23-47.

Kitwood, T. (1997). *Dementia reconsidered. The person comes first.* Buckingham, U.K.: Open University Press.

Lawton, M. P. (2001). The physical environment of the person with Alzheimer's disease. *Aging & Mental Health, 5*(Suppl. 1), S56-S64.

Leitsch, S. A., Zarit, S. H., Townsend, A., & Greene, R. (2001). Medical and social adult day service programs. A comparison of characteristics, dementia clients, and their family caregivers. *Research on Aging, 23*(4), 471-498.

Lucas, J. A., Rosato, N. S., Lee, J. A., & Howell-White, S. (2002). *Adult day health services: A review of the literature*. Retrieved July 17, 2007, from Rutgers University, Rutgers Center for State Health Policy Web site: www.cshp.rutgers.edu/PDF/AdultDaycareLitRev.pdf

Meyer-Arnold, B. (2008, May). Elements of success: Adult day services industry leaders work on a blueprint for transformation. Paper presented at Georgia Adult Day Association Meeting, Atlanta, GA.

Moore, K. D., Geboy, L. D., & Weisman, G. D. (2006) *Designing a better day. Guidelines for adult and dementia day services centers.* Baltimore: The Johns Hopkins University Press.

National Adult Day Services Association (NASDSA) (2007). *Adult day services: Overview and facts*. Retrieved July 24, 2008, from NASDA Website: http://www.nadsa.org/adsfacts/default.asp

O'Keefe, J. & Siebenaler, K. (July, 2006). *Adult day services: A key community service for older adults: Executive summary.* Retrieved December 12, 2007, from: http://aspe.hhs.gov/daltcp/reports/2006/keyADSes.htm

Patton, M. Q. (2002). *Qualitative Research & Evaluation Methods,* 3rd Ed. Thousand Oaks, CA: Sage Publications, Inc.

Reid, D., Ryan, T., & Enderby, P. (2001). What does it mean to listen to people with dementia? *Disability & Society, 16*(3), 377-392.

Stern, A. L. & Caro, F. G. (2004). *Consumer perspectives on quality in adult day car*e. *Working paper.* Retrieved October 12, 2007, from University of Massachusetts, Gerontology Institute Web site: www.geront.umb.edu.

Strauss, A. L. & Corbin, J. (1998). *Basics of qualitative research: Techniques and procedures for developing grounded theory.* Thousand Oaks, CA: Sage Publications.

Townsend, D. & Kosloski, K. (2002). Factors related to client satisfaction with community-based respite services. *Home Health Care Services Quarterly, 21*(3/4), 89-106.

Ward, M. (2003). The views of people with a physical disability on day activity centers in the Eastern Region of Ireland. *Disability and Rehabilitation, 25*(10) 527-531.

Warren, S., Kerr, J. R., Smith, D., Godkin, D., & Schalm, C. (2003). The impact of adult day programs on family caregivers of elderly relatives. *Journal of Community Health Nursing, 20*(4), 209-221.

Weber, R. P. (1990). *Basic Content Analysis* (2 ed.). Thousand Oaks, CA: Sage Publications.

APPENDICES

Appendix A

PROGRAMS AND SERVICES OF THE WEINSTEIN CENTER

PROGRAMS AND SERVICES OF THE WEINSTEIN CENTER

NURSING (RN) SERVICES/PERSONAL CARE

Nursing (RN) Services

- Medication Monitoring (giving out meds, monitoring for changes in behavior, coordinating with caregiver/physician on med changes, etc.)
- Blood Pressure checks at least monthly or more if needed
- Blood Sugar Monitoring – For Diabetics – check blood sugar regularly and give insulin, as directed by physician, if required.
- Wound care and dressing changes
- Oxygen Therapy – monitor oxygen level, and change oxygen tanks, as needed. Coordinate with family/physician on any changes in oxygen level.
- Catheter Care/Colostomy Care – empty/change catheter/colostomy bag
- Tube Feeding – Assist participant with tube feeding daily, if needed.

Personal Care Services

- Assist with toileting - give direction, assist with clothing, assist with transfer, incontinence care – change depends, hygiene care)
- Dressing/grooming – Assist with clothing changes (due to incontinence issues), comb/brush hair, if needed.
- Bowel/Bladder program – Encourage, remind, and assist clients to use the bathroom on regularly scheduled times to help with incontinence issues.
- Gait training/Ambulatory Assistance – Assist clients with ambulation (cane, walker, wheelchair), and help with transfer from wheelchair to chair and chair to wheelchair. Encourage clients to ambulate frequently throughout the day, if able to, to keep physically active.

THERAPEUTIC ACTIVITIES

Music

- Sing-alongs
- Name that Tune
- Musical Bingo
- Dancing to Music (circle dances, line dances, chair dancing)
- Education and the History of different types of Music (musical theme days)
- Entertainers (piano players, bands, vocalists, chime/handbell groups, dancers)
- Musical Memories
- Music Trivia
- Music Appreciation Day
- Songwriting

Art

- Crafts that relate to a certain holiday (make/color flags on the 4th of July, pinecone turkeys for Thankgiving, etc.)
- Create get well cards for ill participants or create cards for family members
- Make centerpieces for the dining tables (use flowers, beads, feathers, wood, etc.)

- Collages (using magazines – these can be based on a theme or holiday)
- Wood art
- Bead art or fruit look art (necklaces, bracelets, etc.)
- Create recipe books
- Color (free form or with coloring books)
- Painting
- Bookmarks

Exercise/Active Games

- Daily chair exercises
- Bean bag toss
- Bowling
- Golf
- Horseshoes
- Indoor hockey
- Baseball
- Punch-ball volleyball
- Basketball
- Outdoor walking (around butterfly garden)
- Dancing
- Parachute

Cognitive Games/Programs

- Trivia
- Finish the proverb
- Current event discussions
- Medical education talks with speakers
- Poetry writing
- Crossword puzzles
- What's in a Word
- Puzzles
- Who Am I
- Charades/Taboo/Scattegories/Pictionary
- Hangman
- Spelling Bee
- Geography Bee
- Tic Tac Toe
- Jeopardy/Who Wants to Be a Millionaire
- Price is Right
- Speakers on various topics

Source: MJCCA Weinstein Center for Adult Day Services

Appendix B

WEINSTEIN CENTER CAREGIVER/PARTICIPANT SATISFACTION SURVEY – 2007

Weinstein Center
For Adult Day Services

CAREGIVER/PARTICIPANT SATISFACTION SURVEY 2007

The MJCCA Weinstein Center wants to provide the highest possible quality services to you and your loved one. If you will take a few moments to provide your feedback on the performance of the center, it will be very much appreciated. Any additional ideas for improving our services and responsiveness are also welcomed. Please contact Georgia Gunter at (770) 458-3614 if you have any questions.

How is the Weinstein Center doing on …

	Excellent	*Very Good*	*Fair*	*Unsatisfactory*
1. Activities Please explain:	O	O	O	O
2. Quality of Nursing Services & Personal Care Services Please explain:	O	O	O	O
3. Quality of Meals Please explain:	O	O	O	O
4. Case Management Please explain:	O	O	O	O
5. Quality of Transportation (if applicable) Please explain:	O	O	O	O
6. Courtesy & Professionalism of staff Please explain:	O	O	O	O
7. Hours of Operation Please explain:	O	O	O	O
8. Safe & Clean Facilities Please explain:	O	O	O	O
9. Convenience of Location Please explain:	O	O	O	O
10. Monthly Newsletter Please explain:	O	O	O	O

	Excellent	*Very Good*	*Fair*	*Unsatisfactory*
11. Support Group (if applicable)	**O**	**O**	**O**	**O**

Please explain: _____

12. Has your family member's quality of life stabilized or improved due to coming to the center? Yes _____ No _____

Please explain: _____

13. Caregivers: Has adult day services fro your family member helped to reduce the stress of caregiving for you? Yes _____ No _____

Please explain: _____

14. Which **one** of the above 11 (or any other aspect not listed) is **most important** to you and why?
_____
_____
_____

Which group do you or your family member participate in?

Traditional Group _____ **Memory Loss Group _____**

Which center do you or your family member attend?

Dunwoody (Tilly Mill Rd.) location _____

Buckhead (Commerce Dr.) location _____

Would you like Georgia Gunter, Director, to contact you to discuss your feedback ideas?

_____ Yes _____ No

Name (optional) _____
Telephone _____

Thank you for your feedback – and for choosing the MJCCA Weinstein Center

Appendix C

PERMISSION TO PERFORM RESEARCH ON-SITE

Georgia State University
Gerontology Institute
Documentation of Agreement

Title: Program Evaluation of MJCCA Weinstein Center for Adult Day Services

Principal Investigator: Ann Pearman, Ph. D. (faculty advisor)
Dianne O'Donnell, J.D. (student Principal Investigator)
Tiffany Young (student researcher)

I, Georgia Gunter, Director of the MJCCA Weinstein Center for Adult Day Services (the "Weinstein Center") grant the above-named investigators permission to enter the Weinstein Center for the purpose of conducting research.

- I acknowledge that the study, a Program Evaluation of the Weinstein Center, has been explained to me and all questions have been answered to my satisfaction.

- I agree to permit the investigators to recruit clients of the Weinstein Center's Traditional Group and caregivers of our Memory Loss Group members.

- The research may be conducted on the following premises:
    - 5300 Tilly Mill Road, Dunwoody, GA 30338

- The expected duration of this research will range from one (1) to two (2) months.

The Weinstein Center looks forward to working with Georgia State University on this important research project.

Signatures:

_____ _____
Georgia Gunter, Date
Director of the Weinstein Center

_____ _____
Faculty Advisor Date

Appendix D

MATERIALS FOR PARTICIPANT RECRUITMENT

SCRIPT TO RECRUIT – TRADITIONAL GROUP MEMBERS

Date: _____ Day of Week: _____

Announcement Completed? ___ Yes ___ No

My name is Dianne O'Donnell. I am a student at Georgia State University. I'm earning a master's degree in Gerontology, the study of aging. It is nice to be here with you today.

I am doing a research project for my master's degree program here at the Weinstein Center. I would like to tell you about the project then see if you would like to participate in the project.

The Weinstein Center has been here for a long time. Some programs and services work very well. Others may need improvement. I would like to get some small groups together (we call them focus groups) to find out more information about how the Weinstein Center is doing and how it affects your life. I want to understand your experience here from *your perspective*.

In the focus groups, I'll ask questions, listen to your answers, then later analyze them. I will need to tape record the focus group so I don't have to remember everything that was said or rely on my notes. However, your name will not be reported on any results to the Weinstein Center or in any research report. I'll ask everyone in the group to keep what is said confidential as well. I will analyze everything from what the ***focus groups*** say.

On the day of the focus group, I'll give you clear instructions about what to do. There will be a Consent Form for us to discuss and you to sign even before we begin the focus group. I will make it very clear to you what we will do.

I really want to emphasize a couple of things. We want everyone to have the chance to give their input and ideas. *But, you do not have to participate in these groups if you don't want to. This research is absolutely voluntary for you.* And, if you decide to participate with us, and later change your mind, you may. You do not have to attend the focus group or you can leave the focus group if you need to. All you have to do is let me know.

Does this make sense? Does anyone have any questions? *[Answer any questions.]*

THANK YOU everyone for your time today. I look forward to working with you!

[Interested members to meet in private office to indicate whether they desire to participate in the research – see Confidential Participation Form – Traditional Group.]

GEORGIA STATE UNIVERSITY
RESEARCH STUDY
PROGRAM EVALUATION OF THE WEINSTEIN CENTER
Dianne O'Donnell, Student Investigator

CONFIDENTIAL PARTICIPATION FORM –TRADITIONAL GROUP

My name is: _____
(Please print)

Please check one:

☐ **YES.** I would like to be in the research study. I will join the Focus Group. (We will give you a letter with the day and time of your Focus Group.)

☐ **NO.** I do not wish to be in the research study.

THANK YOU FOR YOUR CONSIDERATION!

TO BE COMPLETED BY RESEARCHER:

Participant's Regular Days of Attendance (check all that apply):

____ Monday ____ Wednesday ____ Friday
____ Tuesday ____ Thursday

Participant ID# _____

Focus Group Assignment:
Day_____ Date_____ Time_____

TELEPHONE SCRIPT TO RECRUIT
CAREGIVERS OF MEMORY LOSS GROUP MEMBERS

Caregiver Name/Phone no: _____

Ms./Mr. _____. My name is Dianne O'Donnell. I am a master's degree student at the Gerontology Institute of Georgia State University. I am conducting a research study for my thesis project. The research study is a Program Evaluation of the MJCCA Weinstein Center for Adult Day Services.

In the past, the Weinstein Center has sent a survey home to ask you and your family members about how the Weinstein Center is doing in areas like activities, personal care services, transportation, and other areas. It's now time to learn more about how the Center is doing through a formal program evaluation.

I will be conducting focus groups that will cover about 10 different topics ranging from the reasons you chose the Weinstein Center, satisfaction with activities and services, the impact the Center has had on your home life, care management, and suggestions for improvement.

The focus group will last about 1 to 1½ hours and will be held at the Weinstein Center.

* * *

Would you be interested in participating in a Focus Group? ___ Yes ___ No
[If yes, continue with script below. If no, thank them for their time.]

* * *

[Discuss date and time for meeting to work best with their schedule. Assign individual to a focus group date and give them the date.]

At the start of the focus group, I'll give you clear instructions about what to do. There will be a Consent Form for us to discuss and you to sign even before we begin the focus group.

Does this make sense? Do you have any questions? *[Answer any questions.]*

THANK YOU for your time today. I look forward to working with you!

Assigned Focus Group Date/Time: _____

Appendix E

SAMPLE INFORMED CONSENT FORMS

Georgia State University
Department of Gerontology
Informed Consent – Traditional Group Members

Title: Program Evaluation of the MJCCA Weinstein Center for Adult Day Services

Principal Investigator: Ann Pearman, Ph. D. (faculty advisory)
Dianne O'Donnell, J.D. (student Principal Investigator)

I. Purpose

You have been asked to participate in a research project about adult day services. Our goal is to determine whether the Weinstein Center services meet client needs. From this study, we hope to gain ideas about how to improve its programs and services. This research will also help to design future evaluations. All clients in the Traditional Group will be invited to participate in this study. Caregivers of the Memory Loss members will also be asked participate. A total of 60 people will be asked to be in the study.

II. Procedures

If you participate, here is what you can expect. We will invite you to a focus group meeting. We will tell you the day and time of your focus group. The meeting will last 1 to 1 ½ hours. In the group, we will ask you to tell us about what it is like for you to come here. We will ask about what you like here. We also will ask about what you do not like here. We welcome your ideas. We will ask you if we can audio tape record the focus group meetings. We want to tape the focus groups so we do not have to rely solely on memory or notes. We will also ask that you do not discuss what is said in the focus group outside of the group. At the end of the focus group, we will ask you to complete a simple form with basic data about yourself such as age, sex and education.

III. Risks

In this study, you should not have any more risks than you would in a normal day of life. You will receive clear instructions before each part of the study. You may find questions about your mood or being in the focus group is stressful for you. You can stop at any time. If you become upset, we will stop the work. If you remain upset, you will receive a referral to a local counseling center.

IV. Benefits

You may not receive any direct benefits from this study. What you tell the researcher may help her with ideas about how to improve the programs of the Weinstein Center. Our goal is to gain knowledge through our research. Overall, we hope to learn how the Weinstein Center can improve its ability to meet the needs of clients, caregivers and the community.

V. Voluntary Participation and Withdrawal

Participation in research is voluntary. You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop participating at any time. If you choose not to participate, it will not affect you in any way.

VI. Confidentiality

We will keep your records private to the extent allowed by law. Ms. O'Donnell will store all information from the interview in a locked cabinet in a locked office at all times. Dr. Pearman and Ms. O'Donnell only will have access to your information. Your name and other facts that might point to you will not appear when results are presented or published. The findings will be summarized and reported in group form. You will not be identified personally.

VII. Contact Persons

Ms. O'Donnell will answer any questions you have about participating in the study. You may reach her at 678-429-6954 or dodonnell3@student.gsu.edu. Contact Dr. Pearman if you have further questions at 404-413-5214. If you have questions or concerns about your rights as a participant, you may contact Susan Vogtner in the Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu.

VIII. Copy to Form to Participant

If you wish to participate in the study and agree to be audio taped, please sign and date below. A copy of this form is yours to keep.

Signatures:

_____ _____

Participant Date

_____ _____

Student Principal Investigator Date

Georgia State University
Department of Gerontology
Informed Consent – Caregivers of Memory Loss Group Members

Title: Program Evaluation of the MJCCA Weinstein Center for Adult Day Services

Principal Investigator: Ann Pearman, Ph. D. (faculty advisory)
Dianne O'Donnell, J.D. (student Principal Investigator)

I. Purpose

You have been asked to participate in a research project about adult day services. Our goal is to determine whether the Weinstein Center services meet client needs. From this study, we hope to gain ideas about how to improve its programs and services. This research will also help to design future evaluations. Clients in the Traditional Group and family member caregivers of clients in the Memory Loss Group will participate in this study. A total of 60 people will be asked to be in the study.

II. Procedures

If you participate, here is what you can expect. We will invite you to a focus group meeting. We will tell you the day and time of your focus group. The meeting will last about 1 ½ to 2 hours. In the group, we will ask about your experience with the Weinstein Center. We want your impressions and opinions of the case management process. We welcome your ideas. We will ask you if we can audio tape record the focus group meetings so we do not have to rely on memory or notes. We will also ask that you do not discuss what is said in the focus group outside of the group. At the end of the focus group, you will be asked to provide some basic personal data about yourself.

III. Risks

In this study, you should not have any more risks than you would in a normal day of life. You will receive clear instructions before each part of the study. You can stop at any time.

IV. Benefits

You may not receive any direct benefits from this study. What you tell the researcher may help her with ideas about how to improve the programs of the Weinstein Center. Our goal is to gain knowledge through our research. Overall, we hope to learn how the Weinstein Center can improve its ability to meet the needs of clients, caregivers and the community.

V. Voluntary Participation and Withdrawal

Participation in this research is voluntary. You do not have to be in this study. If you decide to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop participating at any time. If you choose not to participate, it will not affect you in any way.

VI. Confidentiality

We will keep your records private to the extent allowed by law. Ms. O'Donnell will store all information from the interview in a locked cabinet in a locked office at all times. Dr. Pearman and Ms. O'Donnell only will have access to your information. Your name and other facts that might point to you will not appear when results are presented or published. The findings will be summarized and reported in group form. You will not be identified personally.

VII. Contact Persons

Ms. O'Donnell will answer any questions you have about participating in the study. You may reach her at 678-429-6954 or dodonnell3@student.gsu.edu. Contact Dr. Pearman if you have further questions at 404-413-5214. If you have questions or concerns about your rights as a participant, you may contact Susan Vogtner in the Office of Research Integrity at 404-413-3513 or svogtner1@gsu.edu.

VIII. Copy of Consent Form to Participant

If you wish to participate in the study and agree to be audio taped, please sign and date below. A copy of this form is yours to keep.

Signatures:

_____ _____
Participant Date

_____ _____
Student Principal Investigator Date

Appendix F

INTERVIEW GUIDES

FOCUS GROUP INTERVIEW GUIDE – TRADITIONAL GROUP

Date: _____

Time: _____ (begin/end)

Focus Group # _____ Number of participants in group: _____

INTRODUCTION TO THE STUDY [SCRIPT]

My name is Dianne O'Donnell. I am a student at Georgia State University. I'm earning a master's degree in Gerontology, the study of aging. It is nice to be here with you today.

[Develop rapport around the introduction -- follow the lead of the participants.]

First, I am going to tell you about the research project I am doing here at the Weinstein Center. Then I will need your consent to participate in our group before we get started. Does that make sense? Ok, then let's begin.

The Weinstein Center has been here for a long time. As with any place, some programs and services work very well. Others may need improvement.

Some of you may know, each year the Weinstein Center sends a survey home to ask you and your family members this question: How is the Weinstein Center doing in areas like activities, personal care services, transportation, and other areas? Possible answers are Excellent, Good, Fair and Poor.

The Weinstein Center wants to learn more than just answers to a survey. They want to hear from you, the people who come here, what you think about the Weinstein Center.

I've been asked to do a research project for my master's degree program. The project is to do focus groups like this, to ask questions, listen to your answers, then analyze them. I want to understand your experience here from *your* perspective.

My job is to manage our group here so I can represent your points of view accurately and thoroughly. Please feel free to give your opinions and feelings on each topic. This is all voluntary – you don't have to answer any questions you don't want to. I do encourage everyone here to give each person an opportunity to talk and participate.

FOCUS GROUP INTERVIEW GUIDE – TRADITIONAL GROUP

INFORMED CONSENT [SCRIPT]

Before I start, I have a letter that outlines the study and if you agree to participate, what your rights are and what you can expect to happen. It also lets you know that everything you tell me is completely confidential and your name will never be used. It also allows us to audio-tape this meeting, so that I can focus on the meeting and do not have to remember everything or rely solely on my notes.

Introduce the Informed Consent to participant. Read it aloud to participants.
Answer any questions.
Obtain signature if participant is willing, then proceed with the Focus Group.

Participant ID # in Focus Group:

_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____

FOCUS GROUP INTERVIEW GUIDE – TRADITIONAL GROUP

QUESTIONS/TOPICS FOR FOCUS GROUPS

What are some of the reasons you started coming to the Weinstein Center?

- Probes: Understand needs, expectations, preferred services and activities, indications of quality

Please tell me about some of your favorite activities you do here?

- Probes: Preferred activities, timing and scheduling, age appropriate activities, mental stimulation, satisfaction, structure, process, indications of quality

Can you describe any activities here you do <u>not</u> do or <u>do not want</u> to do?

- Probes: Preferred activities, timing and scheduling, autonomy/freedom to choose, age appropriate activities, indications of problems or concerns, ideas for improvement

How would you describe how the environment here feels to you?

- Probes: Structure, needs met, therapeutic effects – morale, social interactions, friendships, environment, boredom, depression

If you receive medical services here, please tell me your opinions about such services.
What kinds of things has the staff taught you about healthy living?

- Probes: needs met, indications of quality, therapeutic effects, staff caring (timeliness/responsiveness), autonomy and respect, problems or concerns, suggestions for services not currently offered

How would your life be different if you weren't coming to the Weinstein Center?

- Probes: behavior changes, therapeutic effects

What keeps you coming to the Center?
What are some of the reasons you may think about going to another adult day facility?

- Probes: understand needs, preferred services and activities, needs being met, indications of quality/excellence, structure

If you could change anything about the Center or the services it offers, what would you change?

- Probes: other areas of problems or concerns, suggestions for improvement

We've talked about a lot of different topics today. Is there anything you'd like to add that you think is important for me to know about your experience with the Weinstein Center?

- Probes: other areas of problems or concerns, suggestions for improvement

FOCUS GROUP INTERVIEW GUIDE – CAREGIVERS

Date: _____

Time: _____ (begin/end)

Focus Group # _____ Number of participants in group: _____

INTRODUCTION TO THE STUDY [SCRIPT]

My name is Dianne O'Donnell. I am a student at Georgia State University. I'm earning a master's degree in Gerontology, the study of aging. It is nice to be here with you today.

[Develop rapport around the introduction -- follow the lead of the participants.]

First, I am going to tell you about the research project I am doing here at the Weinstein Center. Then I will need your consent to participate in our group before we get started. Does that make sense? Ok, then let's begin.

The Weinstein Center has been here for a long time. As with any place, some programs and services work very well. Others may need improvement.

Some of you may know, each year the Weinstein Center sends a survey home to ask you and your family members this question: How is the Weinstein Center doing in areas like activities, personal care services, transportation, and other areas? Possible answers are Excellent, Good, Fair and Poor.

The Weinstein Center wants to learn more than just answers to a survey. They want to hear more detail about what you and your family member need, what's working and not working, and what is important to you about these programs and services. How has your family been impacted by the ability to bring your family member here?

I've been asked to do a research project for my master's degree program. The project is to do focus groups like this, to ask questions, listen to your answers, then analyze them. I want to understand your experience with the Weinstein Center from *your* perspective.

My job is to manage our group here so I can represent your points of view accurately and thoroughly. Please feel free to give your opinions and feelings on each topic. This is all voluntary – you don't have to answer any questions you don't want to. I do encourage everyone here to give each person an opportunity to talk and participate.

FOCUS GROUP INTERVIEW GUIDE – CAREGIVERS

INFORMED CONSENT [SCRIPT]

Before I start, I have a letter that outlines the study and if you agree to participate, what your rights are and what you can expect to happen. It also lets you know that everything you tell me is completely confidential and your name will never be used. It also allows us to audio-tape this meeting, so that I can focus on the meeting and do not have to remember everything or rely solely on my notes.

Introduce the Informed Consent to participant. Read it aloud to participants.
Answer any questions.
Obtain signature if participant is willing, then proceed with the Focus Group.

Participant ID # in Focus Group:

_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____
_____ Informed consent signed: Yes_____ No_____

FOCUS GROUP INTERVIEW GUIDE – CAREGIVERS

QUESTIONS/TOPICS FOR FOCUS GROUPS

What are some of the reasons you started bringing your family member to the Weinstein Center?

- Probes: Understand needs, expectations, preferred services and activities, indications of quality

Can you please describe some of the activities your family member enjoys here.

- Probes: Preferred activities, timing and scheduling, age appropriate activities, mental stimulation, satisfaction, structure, process, indications of quality

Can you please describe any activities he/she will not do or does not want to do?

- Probes: Preferred activities, timing and scheduling, autonomy/freedom to choose, age appropriate activities, indications of problems or concerns, ideas for improvement

Let's discuss the Case Management services offered by the Weinstein Center.
How would you define Case Management in general? What does that term mean to you?
Do you have those types of services here at the Weinstein Center?

- Probes: expectations; met/unmet needs; indications of quality; therapeutic effects; problems or concerns, suggestions for services not currently offered

What keeps you with the Weinstein Center? Have you ever considered another adult day facility?

- Probes: understand needs, preferred services and activities, needs being met, indications of quality/excellence, structure

What role do you feel the Weinstein Center plays in your family member's life?

- Probes: Structure, process, needs met, therapeutic effects – morale, social interactions, friendships, environment, boredom, depression; staff caring (timeliness/responsiveness), autonomy and respect

What would your home life be like if you didn't have the Weinstein Center?

- Probes: behavior changes; therapeutic effects

Can you think of any programs or services that would help you or your family member that are not currently offered?

- Probes: expectations; met/unmet needs; indications of quality; therapeutic effects; problems or concerns; suggestions for services not currently offered

If you could change anything about the Center or the services it offers, what would you change?

- Probes: other areas of problems or concerns, suggestions for improvement

We've talked about a lot of different topics today. Is there anything you'd like to add that you think is important for me to know about your experience with the Weinstein Center?

- Probes: other areas of problems or concerns, suggestions for improvement