

NYUCI

New York University Caregiver Intervention

Implementation Guide

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ROSALYNN CARTER INSTITUTE FOR CAREGIVING

NYUCI Implementation Guide

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Introduction: NYUCI

The Alzheimer’s Disease Supportive Services Program (ADSSP) was created in 1992 to expand the availability of diagnostic and support services for persons with Alzheimer’s Disease or related dementia (ADRD), their families, and their caregivers. Between 2008 and 2011, the Administration on Aging funded 80 ADSSP projects translating evidence-based and innovative caregiver support programs across the nation. Evidence-based ADSSP funded programs closely replicate specific interventions that have been tested through randomized-controlled clinical trials with the results demonstrating improved outcomes for caregivers published in peer-reviewed journals. The NYUCI Implementation Guide shares the experiences and lessons learned from six implementation sites funded by the Administration on Aging to translate the New York University Caregiver Intervention. This guide is intended to serve as a tool for agencies and organizations in selecting and implementing this intervention successfully. This implementation guide addresses implementation procedures that support the delivery of the intervention, not the actual delivery of the services. The appendices include all attachments submitted by the collaborative partners. For more detailed information on actual service delivery refer to *Counseling the Alzheimer’s Caregiver, A Resource for Health Care Professionals* (Mittelman, Epstein, & Pierzchala, 2003).

The implementation sites, located in California, Florida, Georgia, Minnesota, Utah, and Wisconsin, collaborated in the creation of this manual with the leadership of the Rosalynn Carter Institute for Caregiving. A description of each of the six projects is provided below.

California

<i>Project Title</i>	California's ADSSP Evidence-Based Cooperative Agreement to Better Serve People with Alzheimer's Disease and Related Disorders
<i>Lead Agency</i>	California Department of Aging
<i>Project Period</i>	September 30, 2009 – June 30, 2013 (original end date September 29, 2012)
<i>Contact Agency</i>	California Department of Aging

<i>Grantee</i>	Alzheimer's Association, California Southland Chapter
<i>Partners</i>	Alzheimer's Association Northern California & Northern Nevada Chapter Partners in Care Foundation
<i>Area Covered</i>	Alameda County, Contra Costa County, Los Angeles County, Riverside County, Sacramento County, San Bernardino County, San Francisco County, San Mateo County, Santa Clara County

Collaborative Partners

Alzheimer's Association, California Southland Chapter and the Partners in Care Foundation.

Project Overview and Objectives

The purpose of the project is to implement the evidenced-based New York University Caregiver Intervention (NYUCI) to assist family caregivers of persons with dementia. The project goal is to make the NYUCI available to the State's diverse caregiver population and to demonstrate that this can be accomplished at a reasonable cost with outcomes similar to those achieved in earlier research. Project end date changed from 9/29/2012 to 6/30/2013.

Project objectives:

- To develop the capacity of California's dementia service providers to implement the NYUCI;
- To deliver the program and evaluate its impact on ethnically diverse caregivers;
- To develop products to assist with replication, including a lessons learned report, replication manual, cost analysis, and annual data report.
- To disseminate findings through conference presentations and the preparation of an article for submission to a peer-reviewed journal.

In July 2011, a modification was approved to permit the enrollment of adult children of persons with dementia who fit the criteria below:

- live with the parent with dementia
- self-identify as the primary caregiver
- the care recipient has no spouse or partner living in the same residence
- from ethnically diverse communities, specifically, Latino, African American or Asian/Pacific Islanders

The grant continues to evaluate the effectiveness of the intervention in ethnically diverse communities against the original study results while expanding the evaluation to compare the effectiveness of the intervention between adult children and spousal caregivers.

Target Population

Ethnically diverse family caregivers in the designated counties will be the target population for this project.

Anticipated Outcomes

The expected outcomes for participating caregivers are decreased levels of depression; maintenance of better self-reported health; decreased stress reactions to problem behaviors; and delayed institutional placement of their spouse. The expected site-level outcome is that Alzheimer's Association chapters and community partners will adopt the program with the intent of continuing to provide this intervention on an ongoing, sustainable basis.

Florida

Project Title Sarasota Caregiver Counseling & Support Program (SCCSP) - NYUCI

Lead Agency Florida Department of Elder Affairs

Project Period 09/01/2010 - 08/31/2013

Contact Agency Florida Department of Elder Affairs

Collaborative Partners

SCCSP will be implemented by Jewish Family & Children's Service of Sarasota-Manatee, Inc., (JFCS) in partnership with Sarasota Memorial Hospital's Memory Disorder Clinic.

Project Overview and Objectives

The Florida Department of Elder Affairs' (DOEA's) goal is to increase the wellbeing of caregivers of people with ADRD through the use of the New York University Caregiver Intervention (NYUCI). The project has five major objectives: (1) Improve caregiver wellbeing and remove hindrances to the activities required to be effective caregivers; (2) Reduce depressive symptoms to improve caregiver wellbeing and effectiveness; (3) Increase the supports caregivers receive from family and friends to improve their personal wellbeing and enable them to be more effective caregivers; (4) Provide caregiver education about care partners' memory loss and behaviors; and (5) Provide individual and family counseling.

Target Population

Special populations that will be targeted include lower-income individuals who cannot afford to pay for professional services, families of military veterans, and families from minority populations.

Anticipated Outcomes

Outcomes include: maintained caregiver physical health, improved caregiver mental health, increased caregiver social support networks, increasing caregiver understanding of memory loss and behaviors, and increased length of time between enrollment and nursing home placement of the care recipient.

Georgia

Project Title Georgia NYUCI Evidence-Based Project(Georgia Family Support Program)

Lead Agency Rosalynn Carter Institute, Georgia Southwestern State University

Year of Original ADSSP Funding 2009

Project Period September 30, 2009 to May 31, 2013 (original end date was September 29, 2012)

Contact Agency Rosalynn Carter Institute, Georgia Southwestern State

Grantee Partners

University

Georgia Department of Aging Services
Alzheimer's Association, Georgia chapter
Southern Crescent Area Agencies on Aging
Northeast Georgia Area Agencies on Aging

Area Covered

Barrow County, Butts County, Carroll County, Clarke County,
Coweta County, Elbert County, Greene County, Heard County, Jackson County, Jasper County, Lamar County, Madison County, Meriwether County, Morgan County, Newton County, Oconee County, Oglethorpe County, Pike County, Spalding County, Troup County, Upson County, Walton County

Collaborative Partners

The Georgia Department of Aging Services, Alzheimer's Association, Georgia chapter, Southern Crescent and Northeast Georgia Area Agencies on Aging

Project Overview and Objectives

The Rosalynn Carter Institute for Caregiving, in collaboration with the Georgia Department of Aging Services, the Alzheimer's Association, Southern Crescent and Northeast Georgia Area Agencies on Aging, will translate the New York University Caregiver Intervention (NYUCI) to serve a minimum of 150 spouse caregivers of individuals with Alzheimer's disease. Special efforts will be made to recruit rural and African American caregivers. The goal of the project is to support Georgia caregivers providing in-home care to spouses with Alzheimer's disease. The objectives of the project are: 1) to develop a steering committee to oversee project implementation; 2) to install NYUCI in two Area Agencies on Aging in Georgia; 3) to fully implement the NYUCI with fidelity to the model and evaluate its impact on participants; 4) to adapt the program as necessary in light of evaluation results, real work experience, and in consultation with the Administration on Aging; 5) to assure the long-term maintenance and continued effectiveness of the project in Georgia; and 6) to support the adoption and implementation of the intervention by others.

Project end date changed from 9/29/2012 to 5/31/2013.

Target Population

Spousal caregivers of individuals with Alzheimer's disease with an emphasis on enrolling African American families.

In 2012, eligibility was expanded to include adult children serving as primary caregivers of a parent with dementia. Eligibility criteria included: the adult child must live in the home with the care recipient or provide at least four hours of care each day and prepare all meals for the care recipient.

Anticipated Outcomes

Anticipate outcomes for participating caregivers include: 1) reduced burden; 2) fewer depressive symptoms; 3) better health; 4) more satisfaction with their social support network; 5) being less troubled by spouses' memory and behavior problems; and 6) reduced likelihood of nursing home placement. Project products will include: 1) a how-to manual to support implementation of the program by others; 2) presentations at national conferences; 3) articles for publication; 4) yearly data reports; 5) a final report;

and 6) an analysis of program startup and operating costs

Minnesota

<i>Project Title</i>	Minnesota ADSSP Evidence-Based Intervention: New York University Caregiver Intervention (NYUCI)
<i>Lead Agency</i>	Minnesota Board on Aging
<i>Project Period</i>	September 30, 2008 - September 29, 2013 (multiple ADSSP grants)
<i>Grantee Partners</i>	Alzheimer's Association, Minnesota/North Dakota Minnesota Department of Human Services, Aging and Adult Services Division

Collaborative Partners

Alzheimer's Association MN/ND Chapter, Minnesota Department of Human Services Aging and Adult Services Division, five regional Area Agencies on Aging, and several community agencies often partnered with local health care clinics.

Project Overview and Objectives

The Minnesota Board on Aging, in cooperation with its community partners, will expand the current AoA-sponsored, evidence-based NYU Caregiver Intervention (NYUCI) to serve additional geographic areas and families. The purpose of this NYUCI intervention translation is to improve spousal caregiver well-being by reducing depression, burden, and the negative impacts of giving care, while strengthening support network effectiveness – thus delaying nursing home placement.

Project objectives:

- Serve 400 families.
- Meet the original NYUCI participant outcomes.
- Demonstrate workability in a range of community settings.
- Maintain fidelity.
- Embed the intervention into the ongoing Minnesota Caregiver Consultant practice.

Target Population

Recruitment efforts will focus on African American communities, families that live in rural areas and those with low socioeconomic status.

Anticipated Outcomes

The project will achieve the following outcomes: ease caregiver burden; reduce caregiver symptoms of depression; improve caregiver's stress reaction to problem behaviors of the care recipient with dementia; strengthen caregiver social support networks; delay premature nursing home placement

Utah

<i>Project Title</i>	NYUCI VA
<i>Lead Agency</i>	Utah Division of Aging and Adult Services
<i>Project Period</i>	September 1, 2010 - August 31, 2013
<i>Contact Agency</i>	Utah Division of Aging and Adult Services
<i>Grantee Partners</i>	Alzheimer's Association Utah Chapter Veterans Administration University of Utah, Utah State University

Collaborative Partners

The Utah Division of Aging and Adult Services, in collaboration with the Alzheimer's Association Utah Chapter, Utah State University, the University of Utah, the Veteran's Administration and specific Area Agencies on Aging will replicate the tools and strategies of the New York University Caregiver Intervention (NYUCI).

Project Overview and Objectives

The goal is to employ this counseling and supportive intervention in a coordinated community-based program to improve caregiver well-being among minority, culturally diverse and rural-based populations. The objectives are to: 1) expand the evidence base by serving 120 families with the NYUCI program; 2) achieve the original NYUCI participant outcomes; 3) demonstrate viability of the intervention with minority populations; 4) maintain fidelity with the NYUCI program; 5) embed the intervention at sites across Utah.

Target Population

Working with identified multicultural populations

Anticipated Outcomes

The project will achieve the following outcomes: ease caregiver burden; reduce caregiver symptoms of depression; improve caregiver's stress reaction to problem behaviors of the care recipient with dementia; strengthen caregiver social support networks; delay premature nursing home placement (and/or caregiver resignation to placement).

Wisconsin

<i>Project Title</i>	New York University Caregiver Intervention in Wisconsin's Rural Northwestern Communities
<i>Lead Agency</i>	Wisconsin Department of Health Services
<i>Project Period</i>	September 1, 2010-August 31, 2013
<i>Contact Agency</i>	Wisconsin Department of Health Services
<i>Grantee Partners</i>	WI State Unit on Aging Greater Wisconsin Agency on Aging Resources Wisconsin Alzheimer's Institute

Greater Wisconsin chapter of the Alzheimer's Association
Area Covered Barron County, Chippewa County, Dunn County, Eau Claire County,
Rusk County, Washburn County

Collaborative Partners

The Wisconsin State Unit on Aging (SUA), in cooperation with the Wisconsin Alzheimer's Institute, the Greater Wisconsin Agency on Aging Resources (GWAAR), and the Greater Wisconsin chapter of the Alzheimer's Association.

Project Overview and Objectives

The Wisconsin State Unit on Aging (SUA), in cooperation with local partners, will oversee this three year Alzheimer's Disease Supportive Services Program evidence-based project to support the spousal caregivers of people with Alzheimer's Disease or Related Dementia (ADRD) living in rural northwestern Wisconsin. This project will translate the New York University Caregiver Intervention, an evidence-based intervention included in the category "Interventions for Caregivers". The overall goal of this project is to enable sustained family caregiving in the community which will lead to delayed nursing home admission for individuals with Alzheimer's disease and related dementias. The objectives of this project are: 1) provide continuous individualized caregiver support counseling throughout the caregiving relationship; 2) ensure participation in the program is as convenient for the caregiver as possible; 3) maximize the impact the project will have in the chosen communities; 4) quantitatively demonstrate successful project outcomes; and 5) incorporate this successful project into the state aging plan.

Target Population

Rural Wisconsin

Anticipated Outcomes

The expected outcomes of this project are: 1) spousal caregivers will maintain or improve their physical and mental health; 2) spousal caregivers will maintain or improve their satisfaction with providing care to their family member; and 3) individuals who are being cared for by spouses will not move into a nursing home as soon as they might have without the support of this project. The products will be a report that describes the project, the translation process, key findings and lessons learned; a manual to guide others in replicating the project; a cost analysis; semi-annual data reporting and an article submitted for publication in a peer-reviewed journal.

Exploration: Is this the right intervention for your agency?

New York University Caregiver Intervention Program History and Overview

The New York University Caregiver Intervention (NYUCI) was originally developed with two goals in mind: to delay the nursing home placement of people with Alzheimer's Disease and to reduce the negative impact of caregiving on their spousal caregiver. (Mary S. Mittelman, 2002)¹ In 1987 a randomized controlled trial was begun in which spousal caregivers who were randomly assigned to the treatment group received services comprised of four components:

- 1) two individual counseling sessions with the caregiver to address his or her specific needs;
- 2) four family counseling sessions with the caregiver and family members as selected by the caregiver to increase support and understanding of the caregivers support network;
- 3) encouraged attendance at weekly caregiver support groups within the community;
- 4) availability of the counselor on an ad hoc basis via telephone.

The caregivers randomly assigned to the control group received resource information and help when they requested it, but no formal counseling.

¹ Mary S. Mittelman, C. E. (2002). *Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals*. American Medical Association Press, page 2

The study enrolled 406 spousal caregivers over a 10.5-year period. This is the largest, longest running study of a counseling and support intervention for spousal caregivers to date. The study had an unusually high retention rate. Only 4.7% of caregivers refused to continue in the study while the patient was still living at home. (Steven H. Zarit, 2012)²

As described in *Counseling the Alzheimer's Caregiver*, a book sharing the experience and knowledge gained during the study, and in publications in peer-reviewed journals, the NYUCI successfully attained their original goals.

“Caregivers in the treatment group have been able to postpone placing patients in nursing homes for about a year and a half longer than caregivers in the control group, with the median difference being 557 days (Mittelman et al, 2006)³

The well-being of the caregivers also improved. While caregivers in the control group became increasingly depressed after they entered the study, caregivers in the treatment group became less depressed, and the effects of depression lasted at least 3 years (Mittelman et al, 1995, 2004).”⁴

With these impressive outcomes, the NYUCI was listed as one of several evidence based caregiver support programs eligible to be funded for translation by the Alzheimer’s Disease Supportive Services Program (ADSSP) grant program beginning in 2008. Six agencies who received grant funding for implementing NYUCI at the community level cited a number of reasons for selecting this intervention over others listed as evidence based interventions:

- Anecdotal experiences with earlier caregiver programs demonstrated
 - a need for both individual and family counseling for families coping with dementia caregiving;
 - spousal caregivers experienced an additional set of challenges related to their relationship and require specialized expertise in addressing those challenges.
- All implementation sites found the delay in nursing home placement, improved mental and physical health of the caregivers, and the focus on increasing the network of support for the caregiver to be the most important outcomes expected from the intervention.

²Steven H. Zarit, R. C. (2012). *Caregiving for Alzheimer's Disease and Related Disorders: Research Practice Policy (Caregiving: Research Practice Policy)*. Springer. page 26

³ Mary S. Mittelman, C. E. (2002). *Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals*. American Medical Association Press.

⁴ Mary S. Mittelman, C. E. (2002). *Counseling the Alzheimer's Caregiver: A Resource for Health Care Professionals*. American Medical Association Press.

- NYUCI seemed sustainable with the possibility of billing Medicare for services provided by Licensed Clinical Social Workers. In some states the potential of net cost savings to a State’s long term care system will provide a compelling case for ongoing State funding.
- Two of the agencies had current staff with the credentials needed to deliver the counseling services.
- Opportunity to further the field of caregiver support research by offering the intervention to a specific targeted population not included in the original study.

The original NYUCI study was implemented in an urban area, the New York City metropolitan area, and the first replication was also in urban areas (New York, New York; Sydney, Australia; and Manchester, England.) The intervention was provided either in home, the counselors’ offices or in another setting, based on the preference of the caregiver. The original study population demographics are as follows:

Age	Gender	Race/Ethnicity
55+	60.1% Female 39.9% Male	90.9% White 6.4% Black or African American 2.5% Hispanic or Latino 0.2% Asian

Furthermore, the original study was implemented in a renowned university memory clinic primarily to white spousal caregivers.

The newly funded implementation sites targeted different races or ethnic groups and was delivered to rural caregivers in their homes or other convenient settings to test if the intervention would derive the similar outcomes. The population or specific area each site chose to target is as follows:

California- included ethnically diverse communities, specifically, Latino, African American or Asian/Pacific Islanders.

Florida- included lower-income individuals who cannot afford to pay for professional services, families of military veterans, and families from minority populations.

Georgia- targeted African American rural caregivers and provided the sessions in-home or at a location of the caregiver’s choice.

Minnesota- first sites served both urban and rural populations, later sites added to the project included rural caregivers with low socioeconomic status and the African American community

Utah- included rural caregivers who are culturally diverse.

Wisconsin- rural caregivers

These changes in venue (serving sparsely populated rural areas) and population, (rural and different races and ethnic groups) posed significant challenges to service delivery that are addressed in this manual. Despite these challenges, it should be noted that outcomes similar to the original study were achieved.

Does NYUCI “ FIT” Your Agency?

Does it fit your TARGET POPULATION?

The New York University Caregiver Intervention was originally developed to meet the unique needs of spousal caregivers. Translations of the original study at the community level have primarily continued their focus on that targeted population. However, beginning in 2011 Minnesota was the first to adapt the intervention to adult children and California modeled their adult children adaptation on Minnesota’s modification of the eligibility criteria. In 2012 Florida, Georgia, and Utah also extended enrollment to include adult children.

The New York University Caregiver Intervention as noted earlier served a primarily densely urban Caucasian population via a renowned university’s memory care clinic. The translation sites served primarily rural and ethnically diverse populations in their home through community based organizations. Outcomes similar to the original study were achieved. These changes posed significant challenges that were surmounted by the implementation sites that are described in this manual and also extensively addressed in the NYCUI/Minnesota Experience Manual.

There were limited numbers of non-white clients recruited in the randomized controlled trials of this intervention, insufficient to assess the significance of the impact on the non-white population. However, counselors working with non-white clients in the translational projects reported anecdotally very positive impact with their non-white clients in terms of increased cohesion with the family members who participated, an increase in service utilization, and a better understanding of the causes of problem behaviors. In Georgia pre and post intervention data supports the observation regarding increased service utilization only.

Does it fit THE NEEDS OF YOUR CONSUMERS?

All services were delivered to individuals in a one-on-one format to help alleviate the isolation family caregivers experience including individual and family therapeutic sessions provided by trained counselors.

These sessions help:

- Increase the caregiver's awareness of how their responsibilities are impacting their physical and emotional well-being.
- Provide education on the condition of their care recipient, how it affects them and what can be expected as the disease progresses.
- Caregivers understand the reasons to involve family and friends and identify potential sources of support from family, friends, and community.
- Improve communication between family members and support for the primary caregiver
- Guide the caregiver through the process of enlisting the assistance of their potential support network.

The individual and family counseling sessions are especially helpful for caregivers who are rural or otherwise isolated from usual sources of support.

NYUCI Provides Education and Information

Caregivers have access to a great deal of information regarding dementia. They receive written materials from many sources. However, caregivers report having someone explain to them in person while answering their specific questions leads to a much better understanding of how to cope with their situation. Counselors deliver a broad education and then pinpoint specific education needs for the caregiver and the family who attend the family sessions.

Information provided during the sessions regarding available resources and enrollment procedures can also lead to increased appropriate utilization of services by the caregiver and care recipient. The multiple session format offers the counselor the opportunity to monitor how effectively the caregiver acts upon identified resources and provide structured support as they learn to seek and accept assistance.

NYUCI Enhances the Caregiver's Support Network

The primary family caregiver often carries the majority, if not all, of the responsibility for care alone for a number of reasons, including:

- they believe it is a societal norm that placed the responsibility on them due to their position in the family.
- they believe no one else is willing to help.
- they believe no one else is capable of providing equal quality of care.
- they don't want to burden other family members and interrupt their lives.

- they believe they shouldn't have to ask other family members for help so they suffer in an unhappy silence.
- There are cultural (especially in Asian Pacific Islander and Latino communities) norms that dictate who is responsible for providing care and not seeking assistance outside of the immediate family.

One of the critical functions of the NYUCI is to explore these caregiver beliefs so they will be open to seeking assistance. The next step is for the counselor to work with the members of the support network to develop a plan that will share the work load and provide emotional support for the caregiver, while ensuring optimal care for the care recipient.

NYUCI Delays Institutionalization

The primary outcome of the NYUCI is the proven delay of placing the care recipient in a residential facility.

The average time from enrollment to nursing home placement of care recipients was 557 days longer with caregivers who received the intervention than with those from the comparison group. Caregivers who received the intervention experienced a 28.3% reduction in the rate of nursing home placement compared with usual care controls.⁵ (Steven H. Zarit, 2012)

It is assumed that most caregivers prefer to keep their care recipients at home as long as possible. Interviews and focus groups might be helpful in assuring this is indeed the goal of the majority of your consumers.

Other Key Outcomes

The caregivers in the treatment group, as compared to caregivers who received resource information only reported:

- Greater satisfaction with the support from their family and friends
- better physical health
- fewer depressive symptoms
- they were significantly less troubled by their care recipients memory and behavioral problems

⁵ Steven H. Zarit, R. C. (2012). *Caregiving for Alzheimer's Disease and Related Disorders: Research Practice Policy*(*Caregiving: Research Practice Policy*). Springer.

Does it fit the ABILITIES OF YOUR STAFF?

Administrative Support

Administrative duties supporting the intervention include fielding inquiries from potential clients, collecting and entering data (referrals, enrollees, service delivery, and other program procedures,) and assisting counselors with scheduling and coordinating sessions.

Does your administrative staff:

- Respect the importance of thorough and accurate data collection and entry?
- Have a team mentality and are willing to engage in new responsibilities?

Data Management

Managing the data collected throughout the process of the intervention includes ensuring uniformity of data collection, accuracy of data entry, and appropriate analysis and application of data trends. Does your agency have someone currently responsible for data management or will the program manager be responsible for this component?

Does that person on your staff:

- Understand how to use data to identify trends and opportunities for process improvement?
- Have technology/software expertise that will enable them to move between data collection to data analysis and reporting?

NYUCI Counselor

As far as the community and the clients are concerned, the counselor you select IS the intervention. There were some differences in how the author sites filled these positions in that some sites hired only licensed mental health professionals or licensed clinical social workers while other sites employed bachelor level professionals with experience in case management and social services. These models are discussed more fully in Section III.

In any case, the NYUCI Counselor should:

- Have a high level of expertise in handling the challenges of caregiving for someone with Alzheimer's disease or other form of dementia.
- Be able to conduct a therapeutic interview and counseling session with an individual and with a family.

- Understand the context in which the targeted population provides care to a family member. Speaks the language? Familiar with cultural stigma and norms?
- Know the theories of family counseling and how to apply them in the field. No specific family counseling theory has been identified as preferred for the delivery of the intervention. The counselor should be able to discuss the theory they have the most experience with in family sessions and why they prefer that one over others. Typically, the theory applied is determined by the counselor's assessment of what would be best for that family.
- Have experience facilitating a family session that may be highly charged with long term conflicts.
- Be committed to the importance of maintaining fidelity to protocol.

Clinical Supervision

Clinical supervision during this program is desired for licensed professionals but is essential for bachelor level professionals, which is an additional expense in operating the program. A detailed discussion of this component is included in Section III of this manual.

Program Manager

The person who provides supervision to the counselors should expect to spend at least 25% of their time during the first six months of the intervention.

They will need to:

- Monitor and motivate the marketing and recruitment activities.
- Conduct team meetings (at least bi-weekly).
- Review referral and session tracker spreadsheets weekly.
- Randomly check client folders to ensure fidelity and thorough documentation.
- Listen to audio tapes (monthly for each interventionist) (Confidentiality issues may limit or even prohibit the counselor's ability to provide these audio files. Each site will determine if this is a tool they will use for supervision.)
- Work with team to identify trends and monitor process improvement opportunities.
- Coordinate and participate in clinical supervision sessions as needed.

The program manager should:

- Have a relationship with community partners who may refer clients for service.

- Have a high level of expertise in handling the challenges of caregiving for someone with Alzheimer’s disease or other form of dementia.
- Have knowledge of available resources to meet the needs of clients expressed during the team meetings.
- Understand how to use data reports and analysis to evaluate the process, consultant performance, and outcome measures.

Does it fit your AGENCY’S SERVICE DELIVERY CULTURE?

The NYUCI was originally provided to caregivers in an office setting within a memory clinic, in the caregiver’s homes, or another location convenient for the caregiver. More than 50% of the caregivers were referred by community agencies, medical professionals, or other caregivers. In the community translations, the sessions have been delivered primarily in the home of the caregiver. In deciding if this program is a good fit for your agency, you should determine now how you will deliver the intervention.

In-Home delivery Advantages:

- Eliminates the barriers of transportation needs and time constraints for the caregivers.
- Counselors gain helpful insights from observing the home environment and interactions between the caregiver and care recipient.

In-Home delivery Disadvantages:

- Costly in terms of NYUCI Counselor time and cost of travel expenses.
- The presence of the care recipient in the home during the assessment and sessions can be a challenge for the counselor. Providing respite when possible or having the family make arrangements for a companion to be there during this time is helpful.
- It is not unusual for caregivers to forget the appointment and not be available leading to lost time and frustration for the NYUCI Counselor.
- Reduces the number of clients the NYUCI Counselor can reasonably carry on their caseload.
- Some caregivers seem to place a greater value on sessions held in a professional setting.

Does it fit your BUDGET?

Budget considerations should include:

- Cost of credentialed NYUCI Counselors
- Cost of training

Visit www.hcinteractive.com/NYUCI or contact sales@hcinteractive.com for information about the NYU Caregiver Intervention Online Training Program for your counselors. (The online training program is currently under development and scheduled for completion by September 30, 2013.)

- Cost of delivery of sessions outside the office (if that is the model you selected)
- Cost of clinical supervision.
- Cost of program supervision, administrative support, and data management.
- Cost of equipment, office space, etc.
- Cost of marketing the intervention, marketing to ethnic communities may cost more for personalized materials and translation of documents, as well as time spent networking with agencies that serve these communities.

Delivery of this counseling intervention in rural settings proved to be challenging in terms of client recruitment and retention and costly in terms of travel expenses and limited caseloads. However, strategies that ameliorated these challenges were employed at the rural author sites and included:

- In rural areas, word of mouth and personal testimony is the best recruitment strategy. Knowing that it will take time for people who receive the service to share their endorsement helps the agency better plan for staffing needs.
- Counselors were assigned cases by their location so that visits could be combined to reduce mileage costs.
- Counselors made reminder calls prior to the visits to reduce “no one at home” visits. It was found that the calls the day before and just prior to leaving for a visit were needed.
- In some cases, the caregiver and care recipient was transported to the adult day care center where the care recipient was served as a day care client while the caregiver and their support network attended a session. In other cases a respite

volunteer or companion attended to serve the care recipient during the home visit.

- If transportation is not an issue for the caregiver, sessions can be held in the office setting which will reduce the cost of travel for the counselors as well as time spent in transit.
- If the service is embedded in a network such as a caregiver consultation network or in sparsely populated rural areas significant cost savings can be achieved by having a centrally located counselor receive warm handoffs from their partnering caregiver consultants.
- Building collaborative relationships with memory care clinics, neurology centers or Health Care Homes can result in a steady stream of caregivers via a warm handoff. One state is piloting an Alzheimer's Health Care Home that includes a warm handoff to this service.
- Establishing an ADRC protocol for identification of potential participants and a warm handoff to the counselor is another important strategy.
- Counselors and host sites that had strong referral relationships with both community providers, county human services and the medical community experienced higher participation and lower costs than other sites.



Readiness Assessment:

What is in place and what is needed to implement this intervention?

Although consideration of readiness is part of the decision making in selecting this intervention for implementation, a more in-depth assessment must be performed in preparation for actual service delivery.

Assessing Readiness: MARKETING AND RECRUITMENT

- Access to clients
 - In-house or partner agencies should be polled to be determined exactly how potential clients will be identified, contacted, and enrolled and the projected number of clients eligible for and interested in the project.
 - Service delivery – will you provide the service at the caregiver home, the agency office, or other location chosen by the caregiver?
 - What policies are in place for the delivery format you have chosen?
- Do you have a history of success with receiving referrals from other agencies in your community?
- How will you alert your community that this new service is going to be available?
- What are the opportunities for free publicity through the local paper, television stations or radio stations?

- What marketing campaigns have been successful in the past and how may they be utilized for this program?
- If you already have an active outreach staff, what materials and training will they need and what venues will they pursue to begin marketing this service?
- Develop all printed marketing materials now for a media blitz to be conducted immediately upon implementation. Arrange to speak at community meetings, participate in health fairs and other community events coming up over the first six months of the project.

Assessing Readiness: STAFFING

- Have the education/skills been clearly outlined for the hiring/assigning of staff to this particular project?
- What is the time line for hiring/assigning the staff for administrative support, data management, service delivery, and program supervision as explained previously?
- Has sufficient time been built into the time line for training and mentoring of staff into this intervention?

Assessing Readiness: TECHNOLOGY

- Will your counselors complete documentation with pen and paper or are there laptops or tablets available for data entry in the field?
- Data storage:
 - What type of software can be used for easy data entry by staff involved in data entry?
 - What type of software can be used for reporting purposes?
 - How will the files be maintained with confidentiality yet be readily accessed by all staff involved in data entry and analysis?
 - Do you have a shared drive that can contain password protected files? If not, how will you ensure everyone is working from the most recent spreadsheet?
 - Do you have encryption capabilities for emailing confidential files?

Assessing Readiness: STAKE HOLDERS

The Minnesota site implemented this intervention in partnership with other community stakeholders. From their experience they developed “Readiness Checklists for Stakeholders” (Attachment A). For agencies intending to implement the

intervention with staff housed within multiple agencies, this document will be very useful.

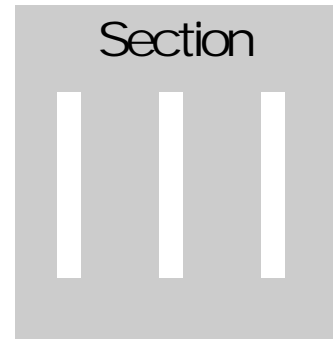
Lessons learned regarding READINESS:

- Orchestrating hiring and training counselors while building client caseloads proved challenging to current implementation sites.
- **Well-known, trusted agencies that already work with the dementia caregiver population will have a much easier time recruiting participants than agencies new to this population.** This seems to be an obvious statement, but sites found if they did not already have access to clients in their agency's service delivery, it was much more difficult than expected to enroll the number of clients needed to maintain full caseloads for the counselors.

After considering all of the needs mentioned above many agencies reflect on what they wish they had known now in terms of readiness when they started out with the program.

The author sites would have:

- Intensified and funded their marketing and recruiting efforts,
- established a stronger network of referral sources,
- researched the demographics of their family caregivers,
- been more proactive in coordinating the training schedule to facilitate an earlier start date for service delivery.



PRE-Implementation

Once it is decided NYUCI is a fit for your agency and you have fulfilled the readiness checklist, you will focus on pre-implementation activities for launching this program. The steps involved in the pre-implementation stage lay the foundation for the ultimate success of the program. Remember success in evidence based implementation means delivering the services with fidelity to the original research intervention which results in achieving similar positive outcomes for those served.

CREATE IMPLEMENTATION TEAM

An Implementation Team provides the internal capacity within an organization to support systems change and effective implementation of a practice, policy or program.

An Implementation Team is more than a name. Implementation Team members have special expertise regarding programs, implementation practice, improvement cycles, and organization and system change methods. They are accountable for making it happen; for assuring that effective interventions and effective implementation methods are in use to produce intended outcomes for persons with dementia and caregivers of persons with dementia.

Team members should bring differing perspectives on how the intervention plays out within the agency. It should include those directly involved in the delivery of the service as well as staff members who support the delivery and who provide the referrals and adjunct services to the clients enrolled.

The implementation team should include (at a minimum):

- The agency decision maker who can approve any changes needed in policies, procedures, and/or funding allocations.
- Program supervisor (supervises all available programs to enrolled clients)
- NYUCI Counselors
- Supervisor of the agency intake staff (source of referrals to the program)
- Data manager

Although there is much to be said for keeping working groups small, in this case it is important to include representatives from each group of staff and all community partners who will be involved in the project.

MAP THE PROCESS

A process map is a tool to visually illustrate how the work flows within the NYUCI Program in your agency. The exercise of creating the process map and referencing it during the implementation also facilitates communication across your agency, serves as a planning tool and will be useful in the supervision of the program as well as in decision making as new situations arise during the implementation.

Set aside time for a brain storming session with the full implementation team, your full staff and, when appropriate, partner agencies to create the step by step map illustrating how clients would be referred, screened for eligibility, enrolled, served, and evaluated.

Identify each action step and decision made from the first contact with the client through the evaluation of outcome data and client satisfaction. The key phrases for this exercise:

- And then what?
- Who is responsible for that?

You can expect the process map will need revisions along the way but this exercise serves two important purposes.

- It forces the team to identify in detail the procedural flow (with documentation along the way) and the responsibilities of everyone involved in the project.
- It gives those involved a very clear picture of how they will be supporting the success of the new program. (See attachment B) for an example of a process map.

DESIGN THE CLIENT RECRUITMENT CAMPAIGN

Unless you know you have access to the number of clients needed to maintain full caseloads for your counselors, you will need to market this program to new clients. These steps will begin that work for your agency.

- Develop “elevator speech”. Everyone on your team should have a three to four sentence explanation of what the program is and how it benefits the caregiver. This is referred to as “elevator speech” because you should be able to give it in the span of an elevator ride. This speech should be tailored to your regional culture. Some areas may need a more academic sound, others may need a grassroots, “git er done” tone. This is why it should be developed during the process mapping with the entire team. If they helped create it, they will be more likely to remember and use it. Practice the elevator speech until it can be comfortably delivered in any setting. Include a personal story if time will permit.
- Develop recruitment/marketing strategies, recruitment materials and role played recruitment. Determine where recruitment will take place. Do not let “business as usual” be the mantra here. Challenge them to think creatively about where potential clients can be reached and what means is most effective in your area.

Client recruitment among persons of color needs to include marketing materials that reflect their ethnicity; understanding of the familiar patterns; and significant presence in communities of color. (See attachment C)

DATA COLLECTION AND MANAGEMENT

Established parameters and procedures for data collection must be in place before any other work is begun for the implementation of the project. Careful planning will help avoid crossing the fine line between ensuring the collection of data important to the

success of your project and creating undue burden for staff. Remember that data is used in evidence-based implementation to:

- justify adaptations for site specific process improvement,
- identify possible fidelity issues,
- support continuation of the program to potential funding sources.

Staff members with a history of attention to detail and accuracy in record keeping should be selected for the data entry and management of the data spreadsheets. The program manager or the data manager should be responsible for regularly checking files that have been randomized for accuracy of data entry.

Spreadsheets may be maintained in Excel, Access, SharePoint, or any other software your agency uses for this purpose. If you intend to conduct statistical analysis on your outcomes measures, you will need to employ a program that imports/exports easily with the analysis software that will be used. SPSS is a program used by at least two implementation sites for data analysis. Beta test the collection system with potential users to improve the tool; be certain to create a tool that can readily export information when needed; be able to cross tabulate different ethnic populations.

One implementation site used a propriety software for their data in the project that would allow the project to intersect with other programs. However, the counselors found the software's structure cumbersome and the administration had difficulty generating reports.

Training and discussions on all areas of the program are needed prior to implementation and on an ongoing basis to assure that criteria for data collection were operationalized; i.e., that all staff were interpreting and recording data in the same manner.

The data manager should be able to provide the Implementation Team with a “dash board” of data points which can be used as a snapshot of the caregiver's status and results.

Recruitment and Enrollment Data (Referral Tracking Spreadsheet)

- Track how each referral is obtained (and in outreach you may want to note the specifics such as church, grocery store, word of mouth, web site etc.) This will help you know which method of recruitment is working best.
- Any individual who expressed an interest in the program whether enrolled or not is listed in the Referral Tracking Spreadsheet which documents their name, contact information, how they heard about the program, agency referred by, their ongoing status in relationship to enrollment (not eligible, not interested,

referred, screened, active, completed, discharged) and a column for notes pertaining to that client. If the client was eligible but refused to participate, their reason for refusal should also be documented in a column on this sheet.

The Referral Tracking spreadsheet is maintained by the intake staff or administrative assistant. It is reviewed prior to and during all team meetings to gauge the number of referrals available for enrollment, the effectiveness of outreach efforts in stimulating inquiries about the program, and to ensure potential clients are not lost in the process.

The Georgia site discovered having clients on the referral list for too long often resulted in the caregiver losing interest in participating. However, restricting outreach efforts to maintain a limited number of referrals waiting may result in counselor caseloads falling below productive and cost effective levels. The program manager should regularly monitor the list and learn with experience the range that serves best for your agency.

Caregiver Status Spreadsheet

The Caregiver Status sheet is an Excel document that provides a snapshot of progress through the NYUCI program with each caregiver and family. The NYUCI Care Consultant or administrative assistant completes the Caregiver Status Sheet after each contact with the caregiver and family.

The following information must be documented on the Caregiver Status Sheet for each caregiver:

- Caregiver ID
- Screening date
- Assessment #1 date
- Assessment #2 date (fill this cell in if it takes more than 1 meeting to complete the assessment)
- 1st Individual session date
- AS+ (dates of any additional sessions before the family sessions)
- 1st - 4th family session dates
- Ad hoc contacts (enter number of contacts, not dates)
- Support group participation (enter number of groups caregiver has participated in, not dates)
- 4, 8, 12, 18, 24 month reassessment dates
- Placement date
- Bereavement date
- Dropped (date dropped from NYUCI)
- Reason for dropping
- PUC? (If dropped, is your agency **Providing Usual Care** to the caregiver? Answer Yes or No)

- “Notes” is used for any explanations needed such as reasons for pre-mature termination, number of attempts made to contact client or off-protocol session delivery.

The Caregiver Status Spreadsheet is reviewed at all team meetings and is used:

- to ensure the intervention is delivered within the protocol timeline,
- to identify clients who are at risk of attrition or should be closed so more compliant clients can be enrolled,
- to determine counselor availability for next enrollees,
- to alert for program evaluation survey to be conducted.

This spreadsheet includes **only the clients who have been enrolled** and is maintained by the interventionist or administrative assistant. The spreadsheet is often shared via email therefore clients are identified by client ID only.

Assessment Measures Spreadsheet

The Assessment Measures Spreadsheet contains the pre-intervention and post intervention responses to the assessment that indicate the impact of the intervention on the caregiver. Accuracy of data entry should be checked regularly by a member of the management team so that needed corrections are caught in a timely fashion.

The data entered into the spreadsheet is used to analyze how effective the program is in achieving outcomes similar to the original study. Closely monitoring the changes in caregiver burden, depression, and satisfaction with support will inform the team of possible fidelity issues or how well the intervention does fit with the population served.

If all other process indicators show the intervention has been delivered with fidelity to the original study and the counselor has conducted the assessment and intervention according to protocol but the outcome measures are not in line with expectations, it may mean the intervention is not successful with-- your caregiver demographics.

PROCESS INDICATORS

It is not prudent to wait until the outcome data is secured to determine the success of the project in achieving its goals. Process indicators can provide interim feedback on individual steps of the process map created in the early stages of pre-implementation.

Some process indicators are:

- Number and locations of marketing activities
- Number of referrals received from partner agencies and from outreach efforts

- Percentage of eligible referrals that enrolled
- Reasons eligible enrollees did not enroll
- Timeline of service delivery
- Client participation and completion
- Counselor challenges and lessons learned from service delivery
- Attrition rates and reasons
- Ad hoc contacts
- Number of clients completing within prescribed timeline

OPPORTUNITIES FOR FEEDBACK

Communication up and down the chain of command is essential for successful implementation. The staff conducting outreach, taking inquiry calls, processing eligibility, the counselors delivering the sessions and the management staff conducting caregiver satisfaction surveys will have extremely valuable insights into the nuts and bolts of process improvement.

Establish opportunities for feedback, indicating who, when and how feedback will be gathered and the process for response. These opportunities can include:

- Small group meetings with clinical supervisor.
- Cross-site teleconferences or face to face meetings with all counselors.
- Regular team meetings with all members of the implementation team. Develop an agenda that will include staff input from each component of the process map.
- Brief surveys to be completed by the staff that poses questions regarding possible improvements, most annoying challenges, most rewarding aspects of the project. These could be completed quarterly or semi-annually.
- One on one conversations between the management team and other team members.
- Staff meetings with this project as an agenda item.

STAFFING OVERVIEW

Program Supervision

The NYUCI is best delivered under supervision at two levels, the program manager who oversees the delivery of the services according to protocol and the clinical supervisor who oversees the delivery of therapeutic and clinical services according to the ethical and clinical requirements of that profession. (For an example of the Georgia Program Manager Job Description see attachment D)

Program Manager Overview:

- Experience and understanding of the rigor required to implement an evidence-based intervention
- Advanced understanding of the specific intervention and the research behind it
- Commitment to ensure fidelity to the original intervention
- Time commitment
 - Participate in NYUCI training
 - Meet weekly (first six month to a year) and then bi-weekly with counselors to discuss progress, solve administrative problems, provide support and guidance with outreach/recruitment, support in implementation of NYUCI with fidelity
 - Available for one on one support as needed
 - Liaison with AAA/State Coordinator if possible
 - Coaching model of supervision: Must be experienced in the coaching model of supervision which includes regular observation, positive reinforcement and constructive course correction of staff.
 - The coaching model that worked most effectively at one site was the original mutual support group model. Each group formed a cohort during their initial rigorous training program; contact between meetings was/is fostered. We learned that is best for the counselors to choose their own coaches and it was always a mutual support model.
 - As new counselors were hired and trained, providing time with an experienced counselor as their mentor proved very helpful in the learning process.

Clinical Director

The Minnesota Site found regular meetings (teleconference and face to face) with the counselors and the clinical director was extremely helpful. The counselors gained insights and tools to address the issues they were facing in the field and the program manager identified themes and resolutions to be shared across sites. The role of the clinical director in their work is outlined in more detail in Attachment E.

- Expertise needed:
 - Advanced counseling experience with families of people with Alzheimer’s disease
 - Advanced knowledge of Alzheimer’s disease and related disorders, the disease progression and caregiving issues.
- Procedures:
 - Monthly small group meetings (3 to 4 counselors with clinical supervisor)
 - Email whenever there is a question
 - One-on-one in person or phone meetings as needed for more in depth guidance on individual or family sessions/issues

Counselor/ Care Consultant / Interventionist

There have been several models for staffing the NYUCI:

- Full-time dedicated counselors:

Pros: credentialed clinician focused on promoting and delivering the intervention.

Cons: licensed clinicians are expensive, especially costly if lulls in enrollment causes down time for the counselor.
- Part-time shared counselors:

Pros: the program pays a portion of the salary of several counselors leading to flexibility in enrollment as referrals are received; if enrollment lags, cost per client could be prohibitive.

Cons: counselor attention is shared with competing projects; time paid for by this program may be actually used on other programs; more counselors to serve the same number of clients means more people to train and supervise.
- Contracted “free lance counselors - Pay per service:

Pros: payment only for services rendered, may be able to negotiate a competitive rate; keeps costs down when referrals lag. Counselor may have clinical supervision in place.

Cons: provider may hold multiple contracts which will compete for time availability.

- Stipend contracted: set monthly rate based on deliverables:

Pros: a fixed monthly income may attract premium talented counselors.

Cons: if enrollments lag, cost per client becomes prohibitive.

Requirements for Counselors/Memory Care Consultants

Job descriptions from Georgia and Minnesota are included in Attachment F however, these skills are the basics that were sought at all sites for their counselors.

- Advanced education – graduate degree
- Experience in working with families and older adults
- Strong knowledge base in Alzheimer’s disease and related disorders
- Confidence
- Strong listening skills
- Willingness and ability to learn from families, peers and clinical director and apply learnings
- Therapeutic counseling experience

Data Manager

Creating and managing spreadsheets for the data collected in the intervention can be the work of the Program Manager or Administrative Support staff, but ongoing data analysis usually required specialized expertise. The job description used at the Georgia implementation site when selecting a Data Manager is Attachment G.

The Data Manager should have:

- An extensive background with the software packages your agency used for data management.
- experience in creating and utilizing spreadsheets, importing and exporting data into the data analysis software.
- Ability to generate charts and reports to be shared with the implementation team.

Program Assistant (Administrative)

Depending on the number of NYUCI Counselors you intend to employ, administrative support can be complicated. Providing support to the Counselors can free their time for service delivery and be a more cost effective staffing structure. Attachment H provides the job description used in Georgia for this staff member.

The person selected to provide this support should have:

- Proven attention to detail and accuracy of data entry
- Ability to coordinate schedules between multiple parties
- Communication skills needed to present and “sell” intervention to potential enrollees and to retain current participants.

Providing an orientation presentation to the entire staff ensures everyone has the same information regarding the program and helps generate ownership or buy-in by staff members who otherwise would not be included. The orientation should include:

- Background information on the program and its effectiveness in serving caregivers.
- How the program fits into current agency operations.
- Roles and responsibilities of the staff

TRAINING IN THE INTERVENTION

- The online training program is currently under development and scheduled for completion by September 30, 2013. Visit www.hcinteractive.com/NYUCI or contact sales@hcinteractive.com for information about the NYU Caregiver Intervention Online Training Program for your counselors.
- These web based training modules will prepare the counselors and their supervisors for delivery of the intervention. This implementation guide addresses implementation procedures that support the delivery of the intervention, not the actual delivery of the services.
- Counselors are expected to prepare for the training by reading the journal articles of the original study and reading Dr. Mittelman’s book, *Counseling the Alzheimer’s Caregiver*. Sites found it helpful to hold “book club” style

discussions among the team, dividing the book into three segments, one for each discussion.

- Best practices in evidence based implementation require training and certification of both the counselors and the program supervisor.
- The author sites found that supplemental training was needed to ensure the success of the project. Topics for these additional training events included:
 - Group dynamics
 - Family systems theory
 - Alzheimer's disease (one site required attendance of various Alzheimer's Association classes)
- Booster training for the entire staff was also provided
 - review of the procedures and benefits of the intervention
 - updates on the counselors' ongoing experiences in the field
 - report results of preliminary data analysis
 - opportunities for constructive feedback.

Lessons learned regarding NYUCI Counselors:

- Graduate level counselors (preferably MSW's) require less training and support and in general have more relevant counseling experience and a higher level of confidence in delivering NYUCI
- The cost of staff with these credentials may impact the number of clients that will be served.
- When adding NYUCI as a component of regular caregiver consultation practice, caregiver consultants do not have enough time to recruit or serve many NYUCI participants. Because of insufficient time for recruitment, they receive few and sometimes no referrals. When they do serve more than a few, it jeopardizes their regular caregiver consultant practice because of the time consuming nature of the intervention. Centralizing this service helps to ameliorate this effect, with one specialized caregiver consultant receiving referrals from their partnering caregiver consultants who provide usual care.
- Role plays during the job applicant interview process are an excellent way to cull the candidates who can actually deliver the skills they claim to have.



Implementation

In this chapter we will discuss the tools and strategies the author sites found useful in the implementation activities around the delivery of the intervention.

INTAKE

Agency frontline staff that are responsible for client inquiries will need regular reminders of the availability of the program. Most intake staff have many program options available to clients according to their eligibility criteria. Expecting them to immediately include a new program in that list is not realistic. Strategies for reminding them of the new program have included:

- Provide a one page summary listing the eligibility criteria and the agreed upon language to be used in promoting the program to potential clients. Printing on brightly colored paper and asking staff to keep it on their desks will be helpful as a reminder.
- Creative reminders to have on their desks like magnets, postcards, a sign on their wall, etc.
- Discuss the program at every staff meeting, providing data regarding number of clients referred through the intake desk.
- Consider a contest with a small reward for the intake staff member who provides the most referrals in a certain time frame.
- Potential participants may already be known to the agency, may be referred by another agency or may respond to brochures and other outreach mechanisms. They may make the initial contact by phone, mail, email or in person. You should record the referral source and method of contact in your records. The main purpose of tracking the many aspects of implementing the intervention is to learn as much as possible about how to most effectively offer the service.

- A candid approach that is neither defensive nor overly eager, but rather open to questions and concerns may be most effective in helping caregivers to move at their own pace towards a decision about whether to participate in the program. The need to recruit participants should not create a pressure on either the counselor or the caregiver. The description of the program should include the eligibility criteria so that the listener will know whether he or she qualifies or if the person on whose behalf the inquiry is made will qualify. In all cases the option to receive usual care if the person decides not to participate in the program should be made clear.

INITIAL CONTACT WITH COUNSELOR

- When there is no prior relationship between the caregiver and the counselor, the initial contact sets the stage for the engagement of the participant. The counselor should convey the idea that the intention of the program is to be supportive and be sure that the potential participant understands what is being offered.
- The counselor should explain that the program includes individual and family meetings as well as periodic formal evaluations of the participants and of the program itself. Thus, from the start, participation involves a collaboration in which we will be offering services not usually available and in turn, requesting that caregivers provide us with feedback about their experience and whether the program met their needs. We begin with an assessment of eligibility of potential participants and a clear explanation of what will occur.
- The counselor should respond to e-mail or telephone inquiries with an offer to send written informational materials and to discuss the program further in person if after reviewing the information the caregiver is interested and appears to be eligible for the program. An important aspect of this intervention is the supportive relationship with the counselor so the ability to engage face to face is essential.

ELIGIBILITY

The original study was conducted with spousal caregivers who lived at home with the care recipient. Translations of the intervention later expanded these criteria to include adult children who were either living in the home with the care recipient or who prepared meals and provided at least four hours of care per day. A recently completed clinical trial has shown positive outcomes for adult children in regards to delayed institutionalization of the care recipient.⁶ Your agency will determine whether expanding the eligibility to include adult children is appropriate. (See Attachment I)

⁶ Effects of the NYU Caregiver Intervention-Adult Child on Residential Care Placement
Joseph E. Gaugler, PhD¹, Mark Reese, MA² and Mary S. Mittelman, DrPH³

- Eligibility screening can be done in one or two stages.
 - Intake staff may conduct the full screen and assign only clients who meet all criteria to the counselor or administrative assistant for enrollment.
 - Intake staff may refer any client who has been identified as caring for someone with Alzheimer's/related dementia to the administrative staff assigned to the project or directly to the counselor for further eligibility screening and “selling” the program to the client.

The eligibility screening process selected should depend on how much time intake staff has to fully screen and discuss details of the program with potential clients, how skilled the intake staff is in “selling” the program, the availability of administrative support for completing the eligibility screen, and the availability of the counselors to complete the screen.

Some implementation sites found it beneficial for the counselor to complete the screening and “sell” the program to potential clients. The relationship between the counselor and client will actually begin during this process and may help ease the client’s anxiety about enrolling in a program with someone they have not met.

During screening:

- Explain the purpose of the intervention, focusing on the importance of family involvement.
- Ask the screening questions (“Original Assessment Forms–Screening Questionnaire”).
- Describe the process of the intervention: An assessment meeting that will last about two hours, 6 counseling sessions (2 individual sessions, one prior to the family sessions and one after, and four sessions with family members); able to call the counselor at any time for issues or concerns; opportunity to participate in support group; phone contacts from the caregiver counselor from time to time with those participants with whom there has been no other contact.
- Assure the caregiver that his/her privacy is important to the project and all information will be confidential and used for evaluation of the program only.

ENROLLMENT

Agencies could consider a client enrolled once they are determined to be eligible and have agreed to participate in the program. However, your agency may decide to delay declaring a client to be “enrolled” until there has been a face to face contact between the counselor and the client. If the client appears to be a good candidate for the program and agrees to participate, they would be told so but not guaranteed enrollment at that point. Situations that have been found by counselors that would nullify enrollment include:

- The person who agreed to participate may not actually be the primary caregiver.
- The care recipient may be too ill or too progressed in the disease to enable the caregiver to complete a four to six month program due to impending placement.
- The caregiver may exhibit mental health issues that would preclude their ability to successfully complete the program.
- The caregiver may be unable to identify friends and family who can participate in the program which is a critical core component of the intervention.

If the caregiver is determined to be appropriate for enrollment during this initial contact, the counselor would then proceed with the assessment.

ASSESSMENT

A detailed caregiver assessment is essential. The purpose of the initial assessment is to gather information about the caregiver and his or her family that will help you to understand their current situation and challenges and be helpful to him or her. By doing the assessment, you will learn about the caregiving environment, the cognitive status of the ill spouse, and problems that require immediate or subsequent attention. Severe depression, for example may require a referral to other services before the caregiver enrolls in the program. The initial assessment also provides the data against which data obtained in follow-up assessments can be compared so that changes in the caregiver can be identified, documented and if necessary, addressed.

The assessment can be conducted in a variety of ways depending on what is most comfortable for the caregiver. Some ways that have been used successfully include reading the assessment with the caregiver or simply asking the questions. Some caregivers may prefer to complete portions of the interview on their own. Some caregivers may even prefer to complete the entire assessment on their own and later discuss it with the counselor.

The sections that are often completed by caregivers alone are:

- Time Expenditure
- Caregiver Physical Health
- Social Support

If the caregiver will complete portions of the assessment her/himself, they should review the instructions carefully and review the sections to be sure the items are completed appropriately.

During the pre-implementation stage, your agency may have decided to exclude some of the data collection instruments thereby reducing the length of the assessment. It is important however, to gather pre and post data on the outcomes measures that are most important to your agency in serving caregivers.

In order to be helpful to the caregiver and family, the counselor should know whether the person with dementia is in the early, middle, or late stage. This is determined by using the Global Deterioration Scale (GDS). The stage of the illness is a sensitive issue for many caregivers. Discussion of the meaning of the symptoms during the initial assessment should be handled carefully, with the caregiver's perspective in mind. It is possible that the counselor will have met the person with dementia previously and so will have firsthand information. The person with dementia should not be present at the initial assessment. If the care recipient is in the early stages of dementia then it is okay for them to attend one of the sessions but would not be an effective protocol for them to attend all sessions.

SESSIONS

If the counselor feels the assessment has not been too burdensome, they may choose to continue with the first individual session at this time. Otherwise, they will schedule that first official session at a later date.

Some counselors have found scheduling future visits at this time can be helpful. However, it may be impossible to schedule the sessions involving friends and family without their direct input. Identifying dates and times that would work for the caregiver and could be offered as alternatives to the others is a good first step in coordinating these sessions.

Fidelity checklists must be completed after each session and reviewed regularly by the program supervisor. The program manager will also randomly select files to review the assessment and session notes to ensure appropriate completion.

AD HOC CONTACTS

Ad hoc contacts can be made by phone, e-mail, or in person. The caregiver and all family members who have participated in the family sessions should be told that they have the option of contacting the counselor with questions and concerns related to changes in the person with AD, the care of the person with AD, the wellbeing of the caregiver or family interactions around caregiving and information about community resources.

Family members who did not participate in counseling sessions may also call the counselor if they wish. If there has been reluctance to use this service, the counselor can ask the spouse caregiver if it would be acceptable for him/her (the counselor) to initiate contact.

Ad hoc counseling is ideally offered by the counselor who originally worked with the caregiver and family and thus has developed a relationship with them, but in his or her absence another knowledgeable staff member may be able to fill in. The results of the assessments and the counselor's notes will help remind the original counselor of the caregiving circumstances, and provide information for another counselor who is responding to the call.

Because ad hoc counseling is an important component of the NYUC Intervention, it is essential that this service be clearly explained early in the program. Families need to know that

- Ad hoc counseling is available for all family members
- There is no limit to the number of contacts
- The counselor will be available to take calls at specific hours or will return them as soon as possible.

The protocol requires that all contacts be tracked for frequency and content. This process can call attention to an increase in contacts that may suggest a potential crisis or that the underlying reason for the calls has not yet emerged and further inquiry is necessary.

ALZHEIMER'S CAREGIVER SUPPORT GROUPS

The NYUCI protocol encourages the spousal caregiver to participate in a support group after the conclusion of the individual and family counseling component of the intervention (4 months after enrollment). Some spouses may decide to join support groups at an earlier or later time than is suggested by the protocol. This should be documented in the record. If spouses and other family members are reluctant to join a group, counselors can try to help them work out their issues. However people who continue to feel uncomfortable with the idea of joining a group should not be

pressured to join. We have observed that many who were initially unwilling will decide to join a group at a later time.

THE FOLLOW-UP ASSESSMENT

The follow-up assessment of the caregiver should take place after the individual and family sessions have been completed. It includes the same scales that were in the initial assessment.

According to the protocol, all individual and family sessions should take place within four months of enrollment. On some occasions, travel, illness or other events can interfere, but the first follow-up assessment must occur no later than six months after enrollment. If it has not occurred by then, the first follow-up will be counted as missing, and the next assessment should occur eight months after enrollment.

PLACEMENT PROTOCOL

Most caregivers do not want to place their husbands or wives in a nursing home. However, it is not clinically sound, nor do the data substantiate evidence for the interventionist to focus his or her treatment efforts directly towards avoiding nursing home placement. Indeed, there are circumstances that call for placement for the wellbeing of both the care recipient and the caregiver.

Regular assessments and ad hoc contact continue even after the person with AD is placed in an assisted living or nursing home. The date of placement is noted on the Change of Status Form, and a modified reassessment protocol is implemented according to the regular schedule.

BEREAVEMENT PROTOCOL

AD is a terminal disease. That means that the person with dementia will ultimately die from the effects of the disease unless he or she dies earlier from some other cause. The date of death is noted on the Change of Status Form. (See Attachment J)

A modified protocol is implemented in which the counselor is available for two years after the death of the person with dementia. Counselors can provide emotional and practical support for caregivers throughout the grieving process.

TOOLS FOR SUPERVISION AND FIDELITY ASSURANCE:

Caregiver Status Sheet

The Caregiver Status sheet is an excel document that provides a snapshot of the progress through the NYUCI Program with each caregiver and family. The NYUCI consultant completes the Caregiver Status Sheet after each contact with

the caregiver and family. The information to be documented on the Caregiver Status Sheet is described in Section III page 28.

The supervisor reviews the spreadsheet regularly to monitor:

- Status of caseloads/ waiting lists: Are marketing and recruitment maintaining enough referrals to provide full caseloads for the counselors?
- Timely delivery of each session: Are there valid reasons listed for each client whose sessions are not being delivered according to the protocol timeline?
- Outcome measure assessment and Client satisfaction surveys: Are they being conducted according to the established time line?
- What is the attrition rate? Is the attrition rate similar across all counselors or compared to other implementation sites?
- Are all referrals being monitored to ensure no potential client is lost through the process?

File Checklist

The File Checklist is a very low tech tool but serves an important purpose to ensure all documentation is provided within each case file. A checklist should be included at the front of each folder and checked off as each document is added. Supervisors should also use this checklist and personally check off each item when they conduct random folder audits. The Checklist includes the dates of completion for each component of the intervention. (See Attachment K)

Monitoring Session Delivery

The Fidelity Checklists (See Attachment L) are a self-reporting tool for counselors to complete after each session. It is important the counselors know this is not a punitive tool but one that will help alert the implementation team of protocol activities that are not easily managed in this setting. If counselors are having problems completing a protocol activity regularly, this should be discussed with the team. Perhaps an adaption is in order that should be discussed with the full implementation team and with the developer of the intervention.

Another tool used for supervisory observation at one site was to have each counselor audio tape one session per month. After securing the consent of the caregiver and those present, the session is taped and then provided via password protected email to the supervisor. The supervisor will review the tape with the fidelity checklist for that session and discuss any concerns with the interventionist.

Regular Team Meetings

Each team meeting is an opportunity to review operational or procedural changes. More importantly it is a time for counselors to debrief from their experiences in the field and seek advice and support from the team. During these discussions, supervisors have a window into the conversations and challenges the counselors have with the clients. Sometimes, deviations from protocol will be revealed, giving the supervisor a chance to guide the staff back on course. Despite the difficulty in carving out the time for these meetings, weekly or biweekly, they are critical to the success of the project.



Evaluation

Because evidence based programs have been proven to be effective through very rigorous analysis, people may question the need for further evaluation when it is implemented in the field. After all, they may reason, isn't that the point of using evidence-based programs? However, ongoing evaluation is a critical tool to be used to ensure successful implementation with fidelity (process evaluation) and achieving positive outcomes for the client served similar to those achieved by the original study (outcome evaluation).

Process Evaluation

- Exposes possible problem areas early so they can be corrected before they impact the ultimate success of the project.
- Monitors fidelity to protocol to identify possible drift from protocol.
- Identifies and justifies adaptations to protocol needed to better serve the clients of the agency.
- Can reveal why an agency does not achieve the expected outcomes from their implementation efforts. Process evaluation data may help determine if there were errors in implementation or if the intervention was not suitable for the population served.

Outcome Evaluation

- Indicates how well the agency was able to replicate the outcomes of the original study within their agency and with their clients.
- Provides tangible evidence of effectiveness of the services provided to the community.

- May help justify ongoing funding and resources for the continuation of the project.

Most of the tools used for the evaluation of the project have already been discussed as components of implementation, data management, and supervision. Process and outcome evaluation is often the responsibility of the site program manager and the data manager. This chapter will further illustrate how these tools were used in the author sites as recommendations for your agency.

TOOLS FOR PROCESS EVALUATION

This list of process evaluation tools is compiled from all of the author sites. No one site used every one of these tools. Your agency should think carefully about which tools will work best for your staff.

- **Recruitment and Enrollment Data Spreadsheet**
 - Why: Monitors rate of referrals / enrollees; monitors the effectiveness of marketing strategies; ensures all clients who have expressed and interest proceed through the eligibility and enrollment process.
 - How: an excel spreadsheet (see Section III, page 27) is maintained and updated as potential clients are introduced to the program. This sheet is reviewed during team meetings.
 - Who: Intake staff enter all client information when offering the program and the counselors provide updates such as eligible/ineligible/enrolled/refused. Program supervisor reviews and prepares to discuss at each meeting.
- **Caregiver Status Spreadsheet** (described in Section III page28)
 - Why: provides a snapshot of caseloads, timeline for delivery of sessions, indicates attrition rates, and highlights clients at risk of attrition for extra attention. Ensures that clients are not “lost” in the process since this sheet is reviewed at all team meetings and by the supervisor on a regular basis.
 - How: An Excel spreadsheet that is password protected and updated on a daily, weekly or bi-weekly basis. Reviewed by supervisor to monitor timeline of session delivery, attrition rates, potential missing in action clients and availability of counselor to receive new referrals.
 - Who: Can be maintained by the interventionist(s) or by an administrative assistant who is supplied the information by the interventionist(s). If more than one interventionist, it may be a good

idea to have a third person responsible for a single spreadsheet updated with the information coming from the multiple interventionists. Supervisor should review and prepare to discuss at all meetings.

- **RE-AIM Counselor Report**

- Why: requires thoughtful review and communication from the field which may reveal what is most effective and what may need adjustments.
- How: Counselors write quarterly reports using RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance). Template provided: See Attachment M.
- Who: Counselors submit reports to the supervisor; supervisor reviews, summarizes, and identifies cogent points for project improvements.

- **Quantitative Cost Data Reports**

- Why: This quarterly report tracks time and money spent on the program by all staff/volunteers who were directly involved in implementing the program.
- How: A spreadsheet in Excel works well for keeping track of this data. Categorization should be “indirect”, “direct”, and “outreach”.
 - Indirect is administrative tasks and data entry
 - Direct is used to describe any contact between the caregiver and the family members. Assessments, screenings, meetings, follow-up etc...
 - Outreach is any time used in promoting/discussing the program
- Who: Program Manager/Data Manager uses the spreadsheet to run analysis on the different categories. Outliers can be identified, for instance, if one counselor is allocating substantially more time for a specific task than the other counselors, a discussion may reveal they need additional training or suggestions from the other counselors.

- **Four Month follow up interviews with Counselors**
 - Why: to understand the counselor’s experience in implementing the intervention and seek feedback for possible improvements to the process.
 - How: Counselors were interviewed at four months or when they have completed the program with their initial enrollees. See Attachment N.
 - Who: The Counselors interviews were conducted by the supervisor.

- **Cross- site teleconferences or meetings**
 - Why: These periodic calls or meetings provide the opportunity for counselors to share the techniques of providing the NYUCI intervention (e.g., tips for communicating with caregivers, how to work with difficult families, how to address certain situations that might arise, etc.)
 - How: quarterly, monthly, bi-monthly meetings. Some sites held majority by teleconference with face to face meetings held every 3 to 6 months. Agenda items could be drawn from suggestions made by counselors prior to meetings.
 - Who: Supervisor, clinical supervisor and counselors.

- **Review of state reports**
 - Why: provided additional information about the project implementation from the vantage point of the state.
 - How: Periodic conference calls or telephone calls with state staff were conducted informally to discuss the program.
 - Who: State staff, counselors, supervisors, and sometimes an AAA staff member participates in these calls.

TOOLS FOR OUTCOME EVALUATION:

- **Pre and Post intervention assessment**
 - Why: to measure the impact of the intervention on the client for improvement in certain areas of concern such as depression,

health, burden, and strain; to compare outcome measures to other sites and the original clinical trial. The pre and post assessment is included in the training in delivery of the intervention.

- How: the counselor and caregiver complete the assessment during the first face to face visit and again during the last face to face visit. The assessment is then provided to the data manager for entry onto an excel spreadsheet that can then be analyzed for statistical significance.
- Who: Counselors conduct the pre-post assessments, data manager or program supervisor enters into spreadsheet.

- **Caregiver Experience Survey**

- Why: to understand the caregiver's experience with the process of the intervention and to gather feedback and suggestions from those who participated. This survey is included in the training provided in delivery of the intervention.
- How: Two survey instruments are used: one for the caregiver (*Caregiver Experience Survey*) and one for family members (*Family Experience Survey*) participating in the NYUCI program.
- Who: The counselor leaves these surveys with the participants and either the administrative support staff or the program manager will then call and complete the survey with the caregiver responses.

Each agency will develop their own way of evaluating experiences with the program but ultimately each agency will want to know the same information and that is that the program did reach the intended audience and the program was delivered according to protocol.

Some key factors you would like to keep in mind during your evaluation are:

- Ease or difficulty of implementing the intervention at the program site
- Acceptance and perceived value of the intervention by the NYUCI counselors based on experiences
- Perceived value of the NYUCI program by spousal caregivers and family members who completed the program

- Cost of the intervention and likelihood of reimbursement or funding to cover the cost going forward
- What marketing efforts to introduce the program worked and didn't work

RECRUITMENT AND OUTREACH

Some ways that were found most useful in advertising the program to obtain referrals were:

- Placing articles in local newspapers, presenting at local meetings and health fairs, and attending local support groups
- Partnering with local Aging and Disability Resource Centers, developing relationships with doctors and pharmacists while distributing flyers at their business. Having an agreement with medical clinics or doctors to make referrals that includes follow-up communications.
- Placing flyers about the program at any business in your community etc. grocery stores, churches, health departments, senior centers

Each agency should keep track of how each referral hears about the program. Keeping track of outreach will contribute to the success of the program in knowing which marketing efforts worked best.



Maintenance & Sustainability

Maintenance and sustainability in evidence based interventions not only refers to the financial support needed to continue the program in your agency, but also maintaining and sustaining fidelity to the protocol to achieve the expected positive outcomes. We will address both of these areas in this chapter.

MAINTAINING AND SUSTAINING FIDELITY

The importance of fidelity to the original protocols of the intervention has been stressed throughout this manual. With time, counselors and supervisors may be replaced and the protocols can be easily altered as they are “handed down” to new staff. Avoiding drift becomes even more important, requiring dedication to the training and manuals provided at the onset of the project and conscientious adherence to the supervisory plan.

New counselors and supervisors should be encouraged to go through the training before reviewing the work of their predecessor so that the “right way” will be upper most in their minds.

Continuing the activities necessary for ongoing evaluation will also ensure ongoing fidelity.

Specifically these activities include:

- Weekly or bi-weekly team meetings (with or without clinical supervision).
- Supervisory reviews of fidelity check lists and documentation in randomly selected client files.
- Periodic observation of sessions, in person or by audio tapes.

MAINTAINING AND SUSTAINING FINANCIAL SUPPORTS

Planning for ongoing funding of the intervention should begin in the planning phase. Where and how the program is embedded within your agency can be very important in determining ongoing sustainability. Your agency's decision to provide the services with in-house staff or contract with outside provider agencies will impact how sustainable it may be. For instance, if you embed the services in your existing staff who will continue with their current work while providing these new services?

Of the implementation sites authoring this manual, the ability to sustain post grant funding has been mixed. In Georgia one implementation site will be continuing to provide this service to a reduced number of clients through a contracted counselor. The Wisconsin and Minnesota implementation sites are looking to prove Medicaid long term care waiver savings to sustain state-level funding as well as considering cost sharing and private pay options.

Recently funds available through the Older American's Act have been identified as supports to family caregivers. Title IIID can be used for "Gerontology Counseling" services.

Title III-E, the National Family Caregiver Support Program and the Older Americans Act, as amended, address the need to acknowledge and encourage the role caregivers play in the country's home and community-based services system.

The following are services available under Title III - E: Counseling Support Groups, Respite, Supplemental Services (home modifications, assistive technologies, emergency response systems, and incontinence supplies), and Family Care Assistance and Family Care Information. Much of the work of this intervention could fall within these funded activities.