Alzheimer’s Disease Supportive Services Program
Evidence-Based Translation Report

The Skills2Care Intervention the New Jersey Aging Services Network
Introduction

This report serves as a guide to the translation of Skills2Care intervention, lessons learned and the plan for its implementation into the New Jersey aging services network. The intervention is based upon rigorously conducted research (in randomized controlled trials) with its results published in peer-reviewed journals. This evidence-based program has been developed and tested by Dr. Laura N. Gitlin and her colleagues over the past 20 years through funding from the National Institute on Aging, National Institute on Nursing Research, the National Institute of Mental Health, and the Pennsylvania Department of Health, Tobacco Grant Funds.

Using randomized clinical trial methodologies, these series of studies have shown that a 6-visit home-based intervention designed to enhance caregiver skills to manage daily care challenges results in important benefits for both caregivers and persons with dementia at the mild to severe stages of dementia. With regard to family caregivers, Skills2Care results in less upset with troublesome behaviors, less need for assistance from others, improved mood, and enhanced mastery and self-confidence (Gitlin et al., 2003), with these improvements enduring for 12 months (Gitlin et al., 2005). For dementia patients, Skills2Care reduces the frequency of occurrence of problem behaviors (Gitlin et al., 2001, 2005), and slows the rate of functional decline (Gitlin et al., 2001).

As aging networks in NJ and other states move forward with implementation of the intervention, it is imperative to maintain fidelity to the original Skills2Care intervention when designing the program. There are 4 components (listed in Section I - Translation of Skills2Care) of the intervention that may not be changed.

I. Background

New Jersey is committed to providing home and community-based services (HCBS) to people with ADRD as evidenced by the nearly 20-year old, state-funded Alzheimer’s Adult Day Services Program (AADSP) for people with ADRD and the recent development of the AoA Demonstration Grant: Environmental Interventions for Dementia Care. Both programs are designed to provide supportive services to caregivers that will enable them to maintain the person with (in the home for as long as possible, by providing caregivers with respite services and skills to make the home environment safer and more suitable for persons with ADRD, respectively.
The rapidly growing aging population in NJ, combined with the increasing numbers of people diagnosed with ADRD and the escalating cost of care for these individuals, creates an urgency to implement effective programs that assist in maintaining a home environment supportive of caregivers and persons with ADRD.

This presents the problem for NJ of caring for the growing number of people with ADRD and determining how best to support and provide effective services to the ADRD caregiver and at the same time make the best use of the limited federal and state dollars available. Providing better supports for family caregivers is consistent with NJ’s goals of rebalancing its long-term care system in favor of care in the community, avoiding premature or unnecessary institutionalization, and giving consumers greater control of how and where they receive long-term care services.

The challenge for New Jersey’s aging services network is to provide cost-effective supports and services that caregivers of people with ADRD find useful in solving problems associated with behavioral changes, managing caregiver stress, caring for oneself to maintain physical and emotional health, and creating a home environment that supports the ADRD caregiver-care receiver dyad.

New Jersey chose the Skills2Care program because it is one of the few evidence-based home interventions that addresses behavioral challenges and associated caregiver distress by providing caregivers with specific knowledge, skills and strategies to manage daily care.

The goals of Skills2Care are: 1) demonstration of the benefits of a home-based program for ADRD caregivers in managing challenging behaviors and creating a safe home environment supportive of persons with ADRD; 2) reduction of the stress and physical burden of caregivers, decreasing the likelihood of burnout and premature institutionalization of persons with ADRD; 3) improvements for the caregiver (less upset with troublesome behaviors, less need for assistance from others, improved mood, and enhanced mastery and self-confidence) and the care receiver (reduced frequency of occurrence of problem behaviors and slowed rate of functional decline).

Skills2Care is theory-based, it is portable and replicable such that its protocols are standardized and all intervention materials including training of occupational therapists, assessment forms and caregiver materials can be disseminated for use. The condition of reproducibility is essential if the intervention is to be transferable into real-world practice and have national adoption potential. This is a unique intervention that is not offered in traditional home care, or through the services offered by the Alzheimer’s Association or family caregiver programs funded under the National Family Caregiver Act. Also, currently, patients with dementia are only treated for acute medical conditions and have limited to no access to interventions designed to improve their life quality, and have little to no caregiver skill training involvement beyond that related to the presenting acute concern.

a. Original Intervention:
Skills2Care involves an active and maintenance phase over a 12-month period as shown in Table 1 (see Appendix A). The active phase involves up to six 90-minute home visits spaced over the first 6 months such that caregivers have opportunities to practice strategies that are introduced first with a health professional and then independently. The maintenance phase involves three 15-20 minute check-in calls to reinforce skills introduced in the active phase and provide on-going validation and support.

The occupational therapist (OT) initiates Skills2Care by introducing the goals of the program and conducting an assessment of the home environment for safety, support of daily function and ease of navigation, caregiver concerns and management style, and caregiver-care receiver interactions. During this visit, the OT introduces basic education about dementia, potential triggers of behaviors, the potential role of the environment, and the importance of taking care of self as a caregiver. The OT and caregiver prioritize care problems and the OT instructs caregivers in a basic stress reduction technique (deep breathing). Following the initial OT assessments, the OT continues working with the family caregiver at home. Over a series of visits and for each caregiver-identified problem area, the OT provides: 1) education about the role of the environment, 2) skill-building in identifying antecedents to or triggers for the target behavior or contributing factors to the problem area using a structured problem-solving approach, 3) specific strategies reflecting modifications to the physical (home safety, adaptive equipment, decluttering, signage) and social environment (task simplification strategies, communication strategies) to manage the problem area, and 4) stress reduction techniques to reduce caregiver distress and promote a calm environment.

The OT provides the caregiver a tailored action plan (one to three pages) for each problem area which states the target problem area (e.g. repetitive questioning, caregiver needs respite), the target agreed upon treatment goals (e.g. reduce frequency of occurrence of repetitive questioning in the morning and caregiver anger when behavior occurs; or caregiver takes an exercise class three times a week), potential triggers that may contribute to the behavior (e.g. feelings of despair and loss of control in person with dementia; unclear caregiver communication, difficulty way-finding in a cluttered environment; highly stressed caregiver), and directions for implementing customized strategies (e.g. specific communication approaches, statements to avoid, use of tone and touch to provide reassurance, use of activities to engage person).

As part of the treatment plan, caregivers may be referred to AAA programs for the provision of adaptive devices, referred to their physician if they score depressed on an assessment, referred for physical therapy if there is a fear of falling or back/neck strain or injury due to caregiving. Caregivers build performance skills by practicing problem solving and strategy identification with the OT and then practicing strategies independently between scheduled sessions. The maintenance phase occurs between months 6 and 12 and involves three telephone contacts in which the OT reinforces strategy use, validates caregiver actions, and helps caregiver apply learned skills to newly emerging care problems.
b. Translation of Skills2Care:

There are 4 primary features of Skills2Care, which cannot be modified, in this translation effort. These include the following elements: 1) Client-driven and collaborative. In Skills2Care, the OT provides strategies for areas of concern that are identified by caregivers. The strategies recommended by the occupational therapist are tailored to the caregiver’s unique situation and reflect the goals of the caregiver and care preferences. In this way, Skills2Care is culturally responsive and effective for diverse caregivers. 2) Active involvement of caregiver in each aspect of the intervention process. Caregivers are engaged in problem identification and problem solving. Therapists use active therapeutic techniques including role play, simulation and/or demonstration, provide written materials including simple-to-read instructions for using strategies, and provide practice opportunities to learn new communication techniques and other skills. Research shows that active involvement of caregivers results in greater use of strategies and better outcomes. 3) Focus on dyad. The strategies introduced in Skills2Care are designed to improve life quality of both the person with dementia and the caregiver. Thus, the interventionist must focus on the dyad. 4) Home-based. Instruction takes place in the context in which care occurs to maximize tailoring of strategies to fit the particulars of the care situation and the ability of caregivers to learn new approaches.

c. Partners:

The Division of Aging and Community Services (DACS), in the New Jersey Department of Health and Senior Services (DHSS), administered the grant. DACS is designated as the State Unit on Aging and has administrative authority for the state’s 21 AAAs (and their network of 500 provider agencies), as well for the caregiver state-funded programs, Statewide Respite Care Program (SRCP) and AADSP, and the HCBS waiver programs.

DHSS contracted with Dr. Laura N. Gitlin, Director, Center for Applied Research on Aging and Health (CARAH), Thomas Jefferson University, Philadelphia, PA. As principal investigator for the evidence-based practice on which the NJ proposal was founded, Dr. Gitlin was uniquely qualified to act as consultant on all grant activities and assure fidelity to the original research.

The Mercer County Area Agency on Aging (AAA) was chosen as the translation site for Skills2Care, in part, because it has a diverse population. Minorities, limited English-speaking, and economically disadvantaged Mercer County residents will be targeted for participation. The Mercer AAA is uniquely qualified to identify and target this population through its established outreach efforts and aging services network, which includes, but is not limited to; AAA outreach workers, care managers and intake and assistance staff; the Alzheimer’s Association’s local support groups; Trenton Behavioral Health; Interfaith Caregivers of New Jersey; Safe Homes and Transportation Program, and others. Additionally, the state-funded caregiver programs and the in Mercer will be a source for identifying potential participants from diverse cultures and economic backgrounds.

This project was evaluated by the Rutgers School of Social Work (SSW). SSW has the expertise to effectively evaluate the Skills2Care Program assess quality and integrity of such
programs and develop, implement and monitor quality improvement measures for caregiver programs to improve family dementia care.

The evaluation has two primary objectives: 1) Document specific use in all service encounters of key features of the Skills@Care as well as deviations from or enhancements to the program during this project; and 2) Assess the effects of the intervention on the primary caregiver and the person with ADRD using methods consistent with the Philadelphia REACH study (Gitlin et al, 2003).

II. Reach
Target Audience

The target audience for the intervention is the primary caregivers of persons experiencing memory loss, dementia or Alzheimer’s disease. Caregivers are usually family members or friends and do not include paid caregivers such as home health aides.

Selection Process

Selection criteria for participation in the intervention were simple and straightforward.
1) Caregivers needed to reside in Mercer County or actively participate in the delivery of caregiving in Mercer County. 2) Caregivers expressed that the person they were caring for had symptoms of or diagnosis of memory loss, dementia, or Alzheimer’s disease. 3) Caregivers could not participate if they were actively seeking placement in a long term care setting in the next 6 months.

Recruitment strategies

• Creation and distribution of flyers
  o County website/county press release
  o Issued to all Mercer County Aging Network providers
  o Flyer distributed at all public speaking engagements (summarized below)
  o Flyer displayed at County satellite facility
  o Direct mail

• Public speaking engagements
  o All Alzheimer’s Association affiliated caregiver support groups
  o All non-affiliated Alzheimer’s Association caregiver support groups
  o Specially designated ESP presentations, i.e. Senior Care Adult Day Program
  o Church-based senior or social ministry groups; Interfaith Caregivers Greater Mercer County
  o Senior advisory councils
  o Assisted Living Conference
  o Presentation and flyer distribution at Mercer County Network Connections (provider networking group)
  o Mercer County quarterly grantee meetings
  o Women’s Caregiving Symposium

• Webinar specifically geared to Aging Network Providers given by ESP workgroup
Articles in statewide NJ Foundation for Aging publication entitled *Renaissance*

**Enrollment Process**

- Interested parties called the Office on Aging and were directed to Eileen Doremus, who did the initial information collection and recorded on the Profile sheet.
- Profile sheet referred to enrollees by special code; this was the only means whereby communication was shared about the caregiver (CG) and care receiver (CR). Confidentiality was conscientiously upheld through process.
- Profile sheet was emailed to Amy Tiedemann at Rutgers who in turn called the CG to do an initial interview to gather baseline information.
- Profile sheet was emailed to Tracey Vause-Earland, Jefferson Elder Care who managed the Occupational Therapists (OT) who delivered the intervention.
- Tracey Vause-Earland assigned OT to CG.
- OT made initial call to CG to schedule first encounter.

**Challenges and Resolutions**

- **Challenge:** During extended delays in securing fully executed contracts, Mercer County experienced a lay-off of key staff that would be instrumental in the implementation of ESP.
- **Resolution:** Since Executive Director is a trained and certified social worker, she was able to assume all County related responsibilities for ESP.

- **Challenge:** Lower numbers of caregivers recruited than we had anticipated.
- **Resolution:** Besides the aforementioned Recruitment Strategies:
  - Increase direct mailing outreach
  - Increase personal meetings with Geriatricians/physicians serving seniors
  - Do more features in local media
  - Invite selves on local cable shows

- **Resolution:** Eliminating the in-between call with Rutgers may have increased the enrollment.

**Discuss any innovations that would be valuable for the aging network.**

- The most important connection is that OT and CG can now rely on yet another support system, the Offices on Aging, for additional caregiver support of a multitude of services.
- The ability to add ESP to the array of caregiver services will be extremely beneficial. Since most of the support that caregivers of those with dementia need are at times we are not in our offices, ESP offers tools that caregivers can be reminded of and use at any time.

**III. Adoption**
Skills2Care is a proven home program that improves well-being and skills of family caregivers, slows decline in daily functioning of persons with dementia, and reduces challenging behaviors that can trigger nursing home placement. Skills2Care, formally known as Environmental Skill-building Program (ESP), was tested by the National Institutes of Health Resources to Enhance Alzheimer’s Caregivers Health (REACH I) demonstrating evidence in reducing caregiver burden and enhancing management skills.

Occupational therapists come to practice with varied educational experiences on dementia management. While therapists provide basic caregiver education as standard care, a systematic approach to identify and focus on caregiver concerns is not consistently used. Skills2Care builds on the basic knowledge and skills of occupational therapists; however, it is unconventional compared to traditional OT practice and requires training in its assessments, protocols, client-centered care models, and treatment principles. Occupational therapists are certified in Skills2Care to provide hands-on-education to families to enhance their abilities to manage day-to-day. Skills2Care requires a high level of clinical reasoning, face-to-face practice time and follow-up coaching opportunities during the training and certification process.

Certification requirements for occupational therapists include the following essential components:

- Eight hours of assigned readings
- Eight hours of Web-based asynchronous training (lectures and active learning exercises)
- Two days of on-site training
- One case presentation to demonstrate application of core treatment principles and integration of key components of intervention
- Up to five (5) coaching sessions via teleconference
- Up to five completed cases (minimum of three sessions per case) within 6 months

Training topics center on dementia and understanding challenging behaviors; the nature of caregiving and cultural considerations; core treatment principles (client-centered, cultural competency, tailoring/customizing, active learning techniques, problem-solving oriented); and program components and delivery procedures.

Four occupational therapists were identified and interviewed through recruitment efforts conducted by the executive director of Mercer county Office on aging and the clinical coordinator of the Skills2Care program. All four occupational therapist met the following criteria: licensed occupational therapists, a minimum of two years of geriatric experience, and history of home-based therapy experience. One of the therapists worked for a home health agency (Visiting Nurse Association of Mercer County) and the other three therapists worked for Jefferson Elder Care, a clinical service and training program at Thomas Jefferson University. The occupational therapists were provided with User ID and passwords to complete assigned readings and participate on the web-based, training modules to prepare for the future face-to-face training workshop. The clinical coordinator of the Skills2Care program conducted a 2-day workshop and provided therapists with manual of procedures, guiding scripts, treatment documentation forms, and comprehensive training through active learning. The workshop took place in an ample sized conference room located in Mercer County’s outreach center conveniently located for all participants. Therapists practiced assessment, intervention delivery, and documentation completion. Administration procedures such as the referral process, team
One of the benefits of instituting a web-based training site is the opportunity to regularly review learning modules thus enhancing skill development. The Skills2Care web-site provides trainees with all the assessment and treatment documentation forms, guiding scripts, case scenarios, videos, updated bibliography, and web-links to additional resources.

Following the training workshop, the occupational therapists participated in 5 group coaching sessions with the clinical coordinator (via teleconference) to discuss challenging cases, share strategies and resources, and reinforce fidelity to core treatment principles (discussed further in Implementation section). The coaching sessions included input from the project director and the executive director of Mercer County Office on Aging, resulting in a diverse repertoire of ideas and suggestions supporting caregiver intervention.

Previous Skills2Care studies have shown that immediate access to caregivers after training enhances therapist adoption capacity (Gitlin, Jacobs, & Earland, 2010). One of the challenges that occurred in the Mercer County project was a time lapse between Skills2Care training and program delivery due to delayed IRB approval. To address this problem, a booster training session was supplemented to review, reinforce, and practice intervention protocols and documentation with the therapists prior to working with their first caregiver.

In addition to the group coaching sessions, therapists readily used e-mail and individual phone contacts to communicate with clinical coordinator on questions regarding assessment, protocols, intervention strategies or other challenging dilemmas encountered with dyads. During the early phase of the program, the clinical coordinator received approximately 3-5 inquiries per month which were successfully resolved or referred to the executive director of Mercer County Office of Aging. Therapists were encouraged to reach out directly to the Office of Aging as needed. Moreover, therapists supported each other outside of formal coaching sessions as they shared ideas and resources resulting in a collaborative work relationship.

IV. Implementation

Skills2Care is a systematic, evidence-based intervention designed to identify and address caregiver concerns and reduce their stress while caring for individuals with dementia-related conditions. Previous studies have shown that 6-visit home-based intervention designed to enhance caregiver skills to manage daily care challenges results in important benefits for both caregivers and persons with dementia. Skills2Care is grounded in five immutable treatment principles: client centered (caregiver identified target areas); problem solving (caregivers practice the skill of identifying challenging behaviors and strategies); tailoring (dose, intensity, and strategies are customized to person-environment configurations); action-oriented (practice, role-play, skill building); and cultural relevance (the occupational therapist identifies values guiding care decisions to assure appropriateness of tailored strategies).

Therefore, it is imperative to deliver this program as intended and ensure intervention fidelity. There were a number of procedures implemented to ensure that the intervention was
delivered properly and successfully. First, a comprehensive training certification program was conducted. ESP Certification requirements included three criteria: 1) Therapists must demonstrate competency in providing each component of the program; 2) Therapists must apply core treatment principles in the delivery of the program; and 3) Therapists must interpret program effectiveness and modify approaches based on unique situations. Throughout the training process, occupational therapists monitored each required training activity by documenting the date of completion followed by their initials on the ESP Certification Checklist (ESP Manual of Procedures for Occupational Therapists, 2010). During the face-to-face and booster workshops, therapists role-played/practiced all of the assessment tools and various intervention protocols demonstrating proficiency as evaluated by certified ESP trainer (clinical coordinator).

To enhance fidelity, therapists participated in 5 group coaching sessions over the initial months to reinforce fidelity to core treatment principles and adherence to intervention session by session protocols. During one of the teleconference coaching sessions, each therapist was responsible for preparing and presenting a written case report following the Case Report Guidelines outlined in the ESP Manual of Procedures for Occupational Therapists (2010). The case report should reflect the five core treatment principles mentioned above. The report addressed four competency areas: Introduction of the caregiver (relationship to person with dementia, years in caregiving, description of caregiver as a person); Delivery of the program (how the program was introduced to the caregiver, process and results of assessments, session by session content); Closure (review caregiver’s upset and confidence scores and level of change); and Program Outcomes (what worked & what didn’t work, in-depth impression of observed change in caregiver).

The clinical coordinator completed a Case Report and Presentation Assessment Worksheet (ESP Training Protocol) to evaluate therapist’s competency in stated categories. Throughout the coaching session/presentation, all participants asked probing questions to better understand presenter’s clinical reasoning and decision-making process. Soon after the case report presentation, individualized feedback to presenter was provided by the clinical coordinator.

In addition to appraising the therapists’ case presentations and written documentation for intervention fidelity, the OTs were required to regularly update clinical coordinator, via e-mail, on scheduled and completed intervention sessions. The Clinical coordinator monitored each case per therapist maintaining the following information: case ID number, Date of baseline interview, date of session contacts, and projected date of 12 month follow-up interview. One of the communication challenges was timeliness in providing this data to clinical coordinator. Occasionally the clinical coordinator needed to reach out to therapists requesting session updates. It was important to know when the active phase of ESP concluded so Rutgers could conduct the 6-month interview prior to initiating the maintenance phase of ESP. One of the therapists had greater challenges in scheduling intervention sessions due to limited flexibility within the home health agency system.

The dosage and duration of the Skill2Care intervention is not typical to the traditional ‘homecare’ provision of services (e.g. treatment provided 2-3x/week). The agency therapist had a difficult time interweaving periodic ESP sessions within her often busy, tightly scheduled patient caseload. To address this quandary, the clinical coordinator collaborated with the
occupational therapist and the agency’s rehabilitation supervisor to develop time management strategies and additional supports needed to monitor intervention fidelity. To successfully embed ESP within the traditional homecare therapist’s schedule, a close working partnership between key stakeholders (occupational therapist, dedicated agency-based supervisor and ESP clinical coordinator) is required. The agency-based supervisor must allocate time within the therapists’ schedule to deliver ESP as per protocol. Support and commitment from agency administration is critical to ensuring full implementation.

V. EFFECTIVENESS SECTION

This project was evaluated by the Rutgers School of Social Work (SSW). The primary objective of the evaluation was to assess the effects of the ESP intervention on the primary caregiver and the person with ADRD using methods consistent with the Philadelphia REACH study (Gitlin et al, 2003). The evaluation also documented the experiences of the trained Occupational Therapists implementing the intervention.

Intended outcomes

SSW evaluated whether the ESP intervention had the intended outcomes for caregivers and care receivers, that is, it resulted in less upset with troublesome behaviors, less need for assistance from others, improved mood, and enhanced mastery and self-confidence for the caregiver and reduced the frequency of problem behaviors and slowed the rate of functional decline for the person with ADRD. The expected outcomes for the occupational therapists, assessed with qualitative data only, were that each felt adequately prepared to provide ESP and were able to implement the program successfully.

Data collection

Caregivers To assess the effects of ESP on primary caregivers and individuals with ADRD, SSW adopted a battery of measures from the Philadelphia REACH study into a detailed questionnaire administered by phone to caregivers at baseline (immediately after enrollment into the program), and at six months after the intervention began (immediately after the active phase was complete).

<table>
<thead>
<tr>
<th>Domain</th>
<th>Measures</th>
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<tbody>
<tr>
<td>Characteristics of primary caregiver</td>
<td>ADSSP* Template</td>
</tr>
<tr>
<td>Characteristics of person with ADRD</td>
<td>ADSSP Template</td>
</tr>
<tr>
<td>Outcomes related to Care Receivers</td>
<td>Revised Memory and Behavior Problem Checklist (disruptive and memory-related behaviors); Functional Independence Measure (mobility domain); Index of IADL Dependence</td>
</tr>
<tr>
<td>Outcomes for Caregivers—measures of stress reduction</td>
<td>a) Objective burden (vigilance, total hours of IADL help, help received from others for ADLs); b) Subjective burden (upset with memory-related behaviors, upset with disruptive behaviors, upset with ADL assistance, upset with IADL assistance</td>
</tr>
<tr>
<td>Outcomes for Caregivers—measures of skills enhancement</td>
<td>Dementia Management Strategies Scale – self-appraisal of ability to provide care; Task Management Strategy Index – use of positive caregiving strategies; Perceived Change Index – caregiver well-being</td>
</tr>
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An online survey was created by entering all questions into survey design software (Snap Survey Software). The project director trained two Master’s level graduate students currently attending Rutgers University in the administration of the questionnaire. Approval for human subjects research was obtained from Rutgers University as well as the New Jersey DHSS’ Institutional Review Board (IRB) before caregivers were contacted for participation in an interview.

Immediately after registering for the program, the Mercer AAA sent a profile sheet for each caregiver containing contact information and details on the caregiving situation to SSW via email over a secure network. The interviewers then contacted the caregivers by phone. Informed consent was obtained from the caregivers and each was advised that participation in the research interview was voluntary and confidential. The interviews lasted from 30 to 45 minutes each and the interviewer entered the caregivers’ responses concurrently into the online survey template, which created a database of responses for analysis. As soon as an interview was complete, SSW contacted Thomas Jefferson University to initiate the OT visits with the caregivers. Likewise, SSW was informed by Thomas Jefferson University when each caregiver had completed the active phase of the intervention and the interviewers then called the caregivers again and administered the same questionnaire.

**Sample** The Office on Aging sent 36 caregiver profiles to SSW over the course of the project. Of these, five caregivers were never reached, one withdrew from the program due to personal circumstances, and one care receiver passed away before the caregiver was interviewed. Twenty-nine caregivers were reached and completed the baseline interview. Between November of 2011 and March of 2012, nine caregivers had completed the active phase of the intervention and were interviewed a second time.

**Challenges** The greatest challenge in the data collection phase was reaching caregivers and conducting interviews soon after registration for ESP. Due to the demanding nature of their lives, it was difficult for some caregivers to find a convenient time to participate in the interview and they occasionally needed to cancel scheduled interview calls. In some cases, it took a month or more to interview a caregiver, delaying their start in ESP and resulting in so few caregivers completing the active program phase and completing a second interview before the end of the funded project.

There was also some confusion among caregivers about the purpose of the call and SSW’s role in the project. Because the call from SSW was the first they received, caregivers often thought the interviewers were the OTs or the information being gathered was the initial step in program participation. Extra explanation of the purpose of the research component and the use of the data was often required. Both of the above challenges will be removed as the program is maintained because the external evaluation is completed and caregivers will begin ESP immediately after registration.
Occupational Therapists  To assess the impact of the program on the trained Occupational Therapists, SSW held a focus group with the OTs after each had completed the active phase of the intervention with at least one caregiver. The session was held in the evening at a convenient meeting room in the Trenton, NJ area and was attended by all four OTs implementing the program. Amy Tiedemann, Ph.D., project director at SSW, facilitated the focus group and asked the OTs a set of prepared questions concerning ESP training, preparation, implementation, challenges, professional development, and lessons-learned (see Appendix for question guide). Informed consent was also received from the participants for this research activity and the focus group lasted approximately 90 minutes. The session was audio recorded and a verbatim transcript was created by a professional transcription service provider.

Analysis and Findings

Caregiver Questionnaire  As mentioned earlier, the collection of data followed a pre-post survey design (i.e., baseline and 6-month follow-up surveys). 29 caregivers responded at baseline and nine responded to the follow-up survey. Of the baseline respondents, 48.3% were under 60 years old, 79.3% female, 37.9% had been caregiving for two or less years, and 44.8% where daughter/daughter-in-law to the person with dementia. The care receivers of these caregivers at baseline were 69.0% 85+ years of age, 72.4% female, and 69.0% white non-Hispanic. Of the follow-up respondents, 33.3% were under 60 years old, 66.7% female, 55.6% had been caregiving for 2 or less years, and 44.4% where daughter/daughter-in-law to the person with dementia. The care receivers for the follow-up group were 66.7% 85+ years of age, 66.7% female, and 55.6% white non-Hispanic.

Baseline and follow-up surveys collected caregiver information on basic activates of daily living (ADLs; Gitlin et al. 2003) and instrumental activities of daily living of the care receiver (IADLs; Gitlin et al. 2003), whether the caregiver helped with those activities, and level of subjective burden related to helping with these activities. For example, caregivers were asked if they help the care receiver with bathing, dressing, and toileting as well as provide help with food preparation, housekeeping, or transportation. Table 1 contains both baseline and 6-month follow-up information for the average number of items indicated by respondent (i.e., care receiver needs help in that area), average number of respondents per item, and average level of subjective burden (upset/bother) felt by caregiver for helping. Because the number of respondents is very small, the lack of statistical power prevents the use of traditional statistical methods to conduct group comparisons. Therefore, percentages and averages offer a non-statistical method for comparing responses at pre and post survey times.

In table 1, the baseline and follow-up values of 86.60% vs. 97.37% indicates that members in the follow-up group are helping more with identified IADL items than the baseline group and are identifying more items on average (i.e. 4.22 vs. 3.34 respectively). For ADL items, baseline and follow-up groups are similar in number of indicated items, but showed a decrease in the level of subjective burden from helping (i.e. 2.32 vs. 1.19 respectively).

Table 1. Comparison of Baseline and 6-Month Follow-up IADL and ADL information
IADL

<table>
<thead>
<tr>
<th>Metric</th>
<th>Baseline (N=29)</th>
<th>6-Month Follow-up (N=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average number of respondents per IADL items</td>
<td>12.125</td>
<td>4.75</td>
</tr>
<tr>
<td>% number of respondents per IADL item by N</td>
<td>41.81%</td>
<td>52.78%</td>
</tr>
<tr>
<td>Average number of IADL items per respondent</td>
<td>3.34</td>
<td>4.22</td>
</tr>
<tr>
<td>Average number of respondents with IADL item who helped</td>
<td>10.5</td>
<td>4.625</td>
</tr>
<tr>
<td>% of respondents per IADL item by # who help</td>
<td>86.60%</td>
<td>97.37%</td>
</tr>
<tr>
<td>Average level of upset/bothered for caregiver by helping</td>
<td>1.64</td>
<td>1.10</td>
</tr>
</tbody>
</table>

ADL

<table>
<thead>
<tr>
<th>Metric</th>
<th>Baseline (N=29)</th>
<th>6-Month Follow-up (N=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average number of respondents per ADL items</td>
<td>9.43</td>
<td>3.00</td>
</tr>
<tr>
<td>% number of respondents per ADL item by N</td>
<td>32.52%</td>
<td>33.33%</td>
</tr>
<tr>
<td>Average number of ADL items per respondent</td>
<td>2.28</td>
<td>2.33</td>
</tr>
<tr>
<td>Average number of respondents with ADL item who helped</td>
<td>7.83</td>
<td>2.67</td>
</tr>
<tr>
<td>% # of respondents per ADL item by # who help</td>
<td>83.03%</td>
<td>89.00%</td>
</tr>
<tr>
<td>Average level of upset/bothered for caregiver by helping</td>
<td>2.32</td>
<td>1.19</td>
</tr>
</tbody>
</table>

The Task Management Strategy Index (TMSI), Dementia Management Strategies Scale Short Version (DMSSs), and the Perceived Change Index (PCI) were included in this study (Gitlin et al. 2003). These measures identify current strategies caregivers use when caring for the person with dementia as well as change in the level of burden in caregivers’ lives. Table 2 contains the information from the caregivers who participated in both the baseline and follow-up surveys and the difference level in responses. Because the number of caregivers who responded to both surveys is small, no obvious difference is recognized for the TMSI or the DMSSs. However, there does seem to be a recognized improvement (i.e. positive gain) for the PCI.

Table 2. Baseline and 6-Month Follow-up Index and Scale Information (N=8)

<table>
<thead>
<tr>
<th></th>
<th>TMSI (a)</th>
<th>DMSSs (a)</th>
<th>PCI (b)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Baseline</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall item response average</td>
<td>2.79</td>
<td>3.68</td>
<td>2.54</td>
</tr>
<tr>
<td>Min. item response average</td>
<td>1.50</td>
<td>2.50</td>
<td>2.00</td>
</tr>
<tr>
<td>Max item response average</td>
<td>3.81</td>
<td>4.25</td>
<td>3.00</td>
</tr>
<tr>
<td><strong>6-Month Follow-up</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall item response average</td>
<td>3.22</td>
<td>3.85</td>
<td>3.59</td>
</tr>
<tr>
<td>Min. item response average</td>
<td>1.13</td>
<td>1.63</td>
<td>2.88</td>
</tr>
<tr>
<td>Max item response average</td>
<td>4.50</td>
<td>4.88</td>
<td>4.38</td>
</tr>
<tr>
<td><strong>Gain Levels</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Overall average reported gain</td>
<td>0.42</td>
<td>0.21</td>
<td>1.05</td>
</tr>
<tr>
<td>Min. average reported gain</td>
<td>-0.50</td>
<td>-1.38</td>
<td>0.25</td>
</tr>
<tr>
<td>Max average reported gain</td>
<td>1.38</td>
<td>1.38</td>
<td>2.00</td>
</tr>
</tbody>
</table>
Likert-type scale: 1-Never, 2-Rarely, 3-Sometimes, 4-Often, 5-Always

Likert-type scale: 1-Gotten Much Worse, 2-Gotten Somewhat Worse, 3-Stayed the Same, 4-Improved Somewhat, 5-Improved a Lot

The Revised Memory and Behavior Problem Checklist (RMBP) asked caregivers whether the care receiver engaged in various difficult behaviors (yes, no) and how bothered or upset caregivers were about these behaviors. Table 3 shows that caregivers at the follow-up interview reported more problems than at baseline but reported experiencing less subjective burden related to these behaviors.

Table 3. Comparison of Baseline and 6-Month Follow-up: RMBP count and Level of Upset/Bothered

<table>
<thead>
<tr>
<th></th>
<th>Baseline (N=29)</th>
<th>6-Month Follow-up (N=9)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of Reported Problems</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average number of respondents per problem</td>
<td>17.12</td>
<td>6.62</td>
</tr>
<tr>
<td>% number of respondents per problem by N</td>
<td>59.03%</td>
<td>73.53%</td>
</tr>
<tr>
<td>Average number reported problems per respondent</td>
<td>20.07</td>
<td>25</td>
</tr>
<tr>
<td>Level of Upset/Bothered (a)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Average level of bother/upset per problem</td>
<td>3.13</td>
<td>1.83</td>
</tr>
<tr>
<td>Minimum average level reported</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Maximum average level reported</td>
<td>4</td>
<td>2.5</td>
</tr>
</tbody>
</table>

(a) Likert-type scale: 1-Not at all, 2-A Little, 3-Moderately, 4-Very Much, 5-Extremely

These same 34 RMBP items ask caregivers to rate their level of confidence in dealing with the issues and problems. 14 of these items contained enough response information to examine potential changes in reported confidence levels from pre to post survey times. 13 items showed improvement in caregiver confidence and one reported no change. The average confidence level reported in the baseline survey was 2.79, while the average level for the follow-up was 4.51. The resulting average confidence increase (in a 5-point likert-type scale from 1 - “Not At all Confident” to 5 - “Very Confident”) was 1.16.

Finally, at the conclusion of the follow-up interview, caregivers were asked for their opinion of the ESP program and working with an OT. Caregivers make overwhelmingly positive comments about the importance and helpfulness of the program for them, for example, saying that “ESP has made a huge difference for our family” and “I would recommend this program to anyone” and “Now I accept the way things are and use strategies to cope.” Caregivers also praised the OTs with comments like, “my OT was very objective AND cared very much” and “My OT gave us strategies for dealing with so many things – she taught us so much!”

Focus Group Analysis and Findings  The project director at SSW analyzed the focus group transcript by question and identified themes in the responses. In particular, the analysis focused on similarities and differences in the OTs’ answers. Key quotes representing major themes are included in this report.
Recruitment and Training  Three of the Occupational Therapists became trained in ESP at the request of their home-care agency employers, while one became aware of the opportunity through Mercer AAA promotion activities (a presentation by Executive Director) and independently pursued certification. All the OTs had recognized the need for caregiver specific services in their practice already. For example the OTs stated:

There is a gaping need here, however, under the payment system, that (working with caregivers), isn’t an opportunity.

In my experience, you did help the caregiver but it wasn’t caregiver specific.

The OTs had a positive assessment of the ESP training and overall felt prepared to begin the intervention. One problematic issue was a lag after training before the OTs could be assigned to caregivers and start in the field (due to delayed IRB approval for the evaluation and the interview process):

I did feel prepared but I think what was really difficult was the time between ending the training and then actually getting in. So by the time I had to go into the field and do it, I definitely felt rusty. But then we had the refresher (training) and that was good.

Implementation  Once in the field, the ESP intervention required OTs to use a different process than they were accustomed to and to re-frame the purpose of their work:

It’s a different focus for most of us or all of us (OTs), really, than what we’re used to.

It’s not the physical hands-on. You try to role play a few things if you can, but you’re not moving around and treating the person in that physical way.

This difference was positive, however:

And for the first time in a long time, this has been a cognitive process, where I’m studying and reviewing before I go out there. I like that aspect of it, though, because I’ve been doing the same thing for so long. For me it was a whole stimulating thing again that I could add and learn and build upon.

The OTs identified several challenges with implementation, for example, as with the evaluation, scheduling with caregivers was often difficult and flexibility in accommodating caregivers was required. Furthermore, this made completing the intervention steps in the exact order of the protocol challenging:

Some (caregivers) I’ve met out at other places so that impacts whether you can do the environmental assessment or even the depression screen at the right time. Certain things just don’t always flow in the order.

Impact  All the OTs felt they could see the positive impact of the program on caregivers:
I think that when you get back there and you come back that second month, the mood, at least in my clients, changes, it’s different.

When I see that anxiety lift...there’s one woman that stands out. When she came in the second session, I said, “My God, she looks so different.” You could just see the brightness in her.

But at about session 4 or 5, I start to see they get calmer. They have gotten calmer; they are better.

These observations affected the OTs belief in the effectiveness of the program:

I think that sometimes this is the best thing because they can’t do it themselves. The need someone to support them. There are one or two caregivers I can think of that when I finished them all up, I thought, “I don’t think I did that much for them, cause they were really actually doing pretty well.” But they felt like they gained so much. So if they learned one thing or they felt more confident or more supported in their role, then that’s the benefit.

The OTs identified several factors that influenced how effective the program was for caregivers, for example, economic situation, mental health, family support/conflict, previous relationship between the caregiver and care receiver, and the willingness to receive help.

The involvement in ESP also impacted the OTs themselves both professionally and personally:

I feel more empowered in caregiving. I think we get stuck by what we get paid to do versus what is our domain of concern and what’s our scope of practice and how can we help people? And I think this blew that door open a little bit and gave us the ability to say, “No, no, no, this is our role and we can do this.”

I think professionally it has definitely impacted me in how I practice. I’m much more patient with working with people with dementia and with their caregivers than I was before ESP. Because I finally feel I have some additional tools to bring to the table. I’m seeing more and more people with dementia in my daily practice and it’s going to continue to grow. So I think it has helped me also just in my community and in people I know and in friends who have dementia, family members. I know that it helps me to bring more to the conversation: socially, personally, as well as professionally.

Program Assessment  Overall, the OTs felt that ESP was well run and identified several important strengths, for example, the support provided by the larger program team, the availability of information on resources for caregivers and those with ADRD, and the connection to the Mercer AAA.

The OTs also made concrete suggestions for changes in the administrative aspects of the intervention, for example making addition copies available of specific materials used during
sessions. These suggestions have been shared with the Mercer AAA for making program improvements in the future.

Comparison to Previous Findings

The SSW evaluation team compared the findings of this evaluation to those on caregiver/care receiver behavioral and stress outcomes from the published work on ESP research and translation in other environments. The suggested findings show strong support for previous published work with regards to less subjective burden, increases in confidence levels, and positive perceived change among caregivers (Gitlin et al., 2003). The most significant difference was that the reported years of caregiving is recognizably fewer in this evaluation than the respondents are in the previous published work. Likewise, these findings parallel published work showing positive assessment and implementation of the program by Occupational Therapists (Gitlin, et al. 2010). Even though the sample size was far too small to conduct statistical analyses, the descriptive information is compelling and show very positive outcomes for caregivers.

VI. Maintenance

Funded proposals were required to provide Alzheimer’s Disease and Supportive Services Program statutorily defined direct services which are limited to home health care, personal care, day care, companion services, short term care in health facilities and other respite care to individuals with Alzheimer’s disease and related dementias who are living in single family homes or congregate settings. NJ and the AoA project officer, in consultation, determined that Skills2Care was respite care service, for the purposes of the funded project.

In planning for the sustainability of Skills2Care, NJ examined the Older Americans Act (OAA) service definitions and NJ service taxonomies which define and standardize OAA approved services. The Skills2Care intervention and service delivery components are in line with the Professional In-Home Education and Support service taxonomy. This service is eligible for funding under National Family Caregiver Support Program, Title IIIE. Professional In-Home Education and Support is reported to NAPIS as a Group I Registered Service.

The Mercer County AAA is taking the steps necessary to embed Skills2Care into its service delivery system, 2013 Area Plan Contract (APC). Mercer is following the governmental contracting procedures to secure a qualified approved provider to deliver the Skills2Care intervention. As an Aging and Disability Resource Center, Mercer County AAA has modified its intake and data collection in Harmony for Aging and Adult Services SAMS Case Management.

Harmony for Aging and Adult Services SAMS Case Management is a comprehensive integrated case management system that enables agencies to share and manage all consumers in a single, secure database across the state, including local agencies and providers. Collecting data in SAMS will allow the AAA to run reports on service usage, completers and non completers.

VII. Budget and Cost Analysis
VIII. Conclusion

a. Lessons learned:

1. Attrition

   I. Attrition in this target population is to be expected. Rates of attrition vary and may be impacted by the stage of dementia, perceived burden and stress of the caregiver. It is important to deliver the service as soon as possible after the caregiver has enrolled in the intervention. The AAA must provide strong orientation to providers to encourage caregiver referrals to the AAA as needed for ongoing support in addition to the intervention.

   II. The AoA funded project provided for the caregiver’s first contact, after enrollment, to be with the Rutgers evaluation staff to collect baseline data. A number of caregivers had difficulty understanding this step in the process and withdrew from the program, even with additional support from the AAA. The NJ Skills2Care project team discussed this issue. With feedback from caregivers, the AAA determined that this will not be a concern going forward as the evaluation step is not an integral component of the intervention.

2. Limited Flexibility in Home Health Systems

   Although the home health agency volunteered a staff member to become a trained certified interventionist, her schedule did not allow for the integration of the intervention activities into the routine work day, and the project’s clinical coordinator had to intervene with the agency’s administration. Providers of the intervention must have the freedom to incorporate the non-traditional intervention activities into their traditional OT work effort.

3. Home Health Systems Lack of Understanding of the Skills2Care Intervention

   Mercer AAA hoped to build a strong core group of trained certified providers to support the delivery of the Skills2Care Intervention in Mercer and surrounding counties. While the initial interest in the program was strong, the agencies had difficulty understanding this service and the support for the intervention was lacking. One solution suggested by Dr. Gitlin was to offer training on Medicare B reimbursement of the Skills2Care Intervention as part of their participation in the project.

   This solution did not have the intended outcome. One for profit agency of OTs, Independent Domain, completed the training and certification and has expressed interest in continuing with the sustained intervention.

   One visiting nurse association has a trained and certified OT, but the agency does not support the intervention efforts in their traditional system.
b. Additional Challenge and Solutions:

Dr. Gitlin has accepted a position at Johns Hopkins University and left Thomas Jefferson University (TJU) at the end of 2010.

As TJU holds the license for ESP and continued as a direct partner in the project. Tracey Vause-Earland, who was the clinical coordinator on the project and assistant professor at TJU remained with project. Dr. Gitlin has expressed a desire to remain with the project through to its conclusion. Dr. Gitlin indicated that Johns Hopkins is agreeable to her continued participation in the project. To facilitate this change, TJU negotiated a contract with Johns Hopkins University for Dr. Gitlin’s services.

Closing Thoughts

Eileen Doremus, Executive Director, Mercer County AAA, shares some insights about the value of the Skills2Care intervention.

Jim* was four years into his dementia when his wife Mary* learned about Mercer County’s Skills2Care Program. She struggled not only with Jim’s changing behaviors but also with now having to handle household finances, home maintenance and the increased demands of assisting Jim with his activities of daily living.

Caregivers like Mary rarely receive the support needed to handle the unexpected behaviors associated with the disease’s progression. Skills2Care afforded Mary immediate acknowledgement of the challenges she is facing with Jim’s dementia, offered coping skills and connected her to the Mercer County Office on Aging to assist with other services to support her living in her community. She was able to learn about adult medical day care for Jim, financial services for herself and how to receive temporary relief from her caregiving duties via respite services. Mary eventually went away for a weekend to enjoy a family function she previously would not have been able to attend.

Mercer County’s older adult population includes grandparents, parents, siblings, spouses and partners with dementia. Logically, grandchildren, adult children, siblings, spouses and partners are assuming the role of caregiver. Most of the care provided those with dementia comes from family caregivers and is informal in nature; meaning that it is not supported by an agency or an organization. Education, training and support usually comes at the expense of the caregiver having to leave the confines of their home, search on the internet or comb through printed materials that are fortunately readily available. Caregivers are offered support group listings, dementia specific trainings and invitations to tour and be come acquainted with surrounding residential care settings for eventual placement purposes.
What is missing is the intimacy of dealing with “my” situation; the immediacy of access to information that has been learned and practiced and the acknowledgment that it is okay to put myself first once in awhile. This is the intrinsic value of Skills2Care.

*Names have been changed.

IX. References
