# Appendices to the TCARE Replication Manual

# Improving Options for Persons with Alzheimer's Disease and Their Caregivers in the State of Georgia

**T**ailored **C**aregiver **A**ssessment and **Re**ferral®
Project
July 1, 2007 – March 31, 2010

Prepared By:
Rhonda J.V. Montgomery, PhD
Jung Kwak, MSW, PhD
Jeannine M. Rowe, MSW
Jessica Jacobs, MSW
Josh Lang, MA
Katharine O'Connell Valuch, MA
Maggie Wallendal, MSW

University of Wisconsin-Milwaukee
Helen Bader School of Social Welfare
Office of Applied Gerontology
May 31, 2010

# TABLE OF CONTENTS

# LIST OF TABLES

# LIST OF FIGURES

# EXECUTIVE SUMMARY

## INTRODUCTION

This report covers the project activities and findings related to the Georgia Alzheimer's Disease Supportive Services Program, a demonstration project funded by two grants from the Administration on Aging. The report covers grant periods from July 1, 2007 to December 31, 2008 and January 1, 2009 to March 31, 2010. Initial funds were awarded by the AOA to implement and evaluate the impact of the Tailored Caregiver Assessment and Referral® (TCARE®) protocol. In January 2009, the scope of the project was expanded to integrate the Tailored Caregiver Assessment and Referral® (TCARE®) protocol into the State of Georgia's Nursing Home Diversion project and improve the state's long-term care options for persons with Alzheimer's disease and their caregivers.

## GOALS

The major objectives of the project were to:

1. Extend the length the initial TCARE® demonstration project to obtain longitudinal data regarding the impact of TCARE® on caregiver and care manager outcomes.
2. Link the TCARE® protocol service taxonomy with the State of Georgia's Enhanced Service Program (ESP), an electronic resource database used by care managers.
3. Test the web-based version of the TCARE® protocol, TCARE®*e*.
4. Expand the number of care managers trained to use TCARE® in the State of Georgia.

## BACKGROUND

### *TCARE® Protocol Description*

The Tailored Caregiver Assessment and Referral® protocol is a manualized protocol designed to enable care managers to more effectively support family caregivers by efficiently targeting services to their needs and strengths (see Figure 1, the six-step TCARE process on page 49). The protocol is built upon knowledge and insights gained from past research focused on caregivers and caregiver interventions and is grounded in the *Caregiver Identity Theory* articulated by Rhonda J.V. Montgomery and Karl Kosloski[1] (R.J.V. Montgomery, Rowe, & Kosloski, 2007).

The TCARE® protocol guides care managers through an assessment and care planning process that helps them examine the care context and identify the sources and types of stress that a caregiver is experiencing. Because the protocol is designed to assist with targeting appropriate

---

[1] Montgomery, R. J. V., Rowe, J. M., & Kosloski, K. (2007). Family caregiving. In J. A. Blackburn & C. N. Dulmus (Eds.), Handbook of gerontology: Evidence-based approaches to theory, practice, and policy (pp. 426-454): John Wiley & Sons.

services, it is believed that the services recommended for use by caregivers will be more appropriately tailored to their needs and strengths and that caregivers served will be more apt to use these services. Consequently, the TCARE® protocol is expected to translate into positive outcomes for caregivers, and likely more effective use of resources.

## STUDY DESIGN

A longitudinal randomized trial was conducted to assess the impact of TCARE® on caregiver identity discrepancy, burden, depression, upliftsservice use, and the caregivers' intention to the place the care receiver in an alternate care setting. The evaluation also assessed care managers' satisfaction with their jobs and job burnout. The study was conducted in regions served by the following three agencies: (1) Atlanta Regional Commission (ARC) AAA; (2) Coastal Georgia AAA; (3) and Southeast Georgia AAA. Services were provided by these agencies and their contractors.

Study participants included 12 care managers employed by the three participating agencies and 97 caregivers served by the agencies. Care managers assigned to the TCARE® group participated in an intensive training process to learn and practice the TCARE® protocol. A process evaluation was conducted to document and maintain the fidelity of implementation of the TCARE® process by care managers. Care managers in the control group continued to use normal or customary practices.

A uniform screening process was used to identify caregivers eligible for participation. Caregivers scoring medium or high on one or more measures of caregiver stress or depression were invited to participate and randomly assigned to the TCARE® or control group. Data for each caregiver were collected at the time of enrollment and at three month-intervals for up to a one-year period.

Descriptive analyses were conducted to provide profiles of characteristics of caregivers and care managers. The effects of the TCARE® protocol were tested by using random effects regression growth curve analysis and random intercept regression analysis using the SAS Proc Mixed procedure.

## STUDY RESULTS

### *Characteristics of Caregivers Contacting AAAs for Support Services*

The majority of caregivers who contact the participating agencies were highly stressed while they were strongly committed to their caregiving roles. Over 80 percent of caregivers expressed a desire to keep their relatives out of an institution or long-term care setting while the majority of these caregivers exhibited high levels of caregiving related stress and depressive symptoms.

### *Fidelity of Implementation of TCARE® Protocol*

Findings from the process evaluation provided evidence that the TCARE® training process adequately prepared care managers to consistently and accurately implement the TCARE® protocol and maintain fidelity with the protocol over time.

### *Differences Between Groups in Care Plans Developed by Care Managers*

More than 80% of the care plans for caregivers in both the TCARE® group and the control group included some type of in-home service and almost 90% of caregivers for whom these services were recommended used the service.

In contrast, there were significant differences between the groups' care plans with regard to the inclusion of support services that address the emotional strains, stress, and depression associated with caregiving. Care plans for caregivers in the TCARE® group included a wider range of service types and were more apt to include services that would address the psychosocial and physical needs of the caregiver.

The four categories of services that were most frequently included on these care plans for the TCARE® group were medical and/or behavioral health services, support groups, counseling or socio-psychological education, and caregiver education focused on skills and/or information. Two of the service categories, medical and/or behavioral health services, and support groups, were included *only* on care plans for caregivers in the TCARE® group.

### *Service Use by Caregivers*

Only seven types of services were used by more than five caregivers across the groups regardless of recommendation by care managers. In order of frequency of use, these types of services included in-home services, medical/behavioral health services, counseling or social psychological education, support groups, caregiver education focused on skills and/or information, adult day services, and assistive technologies. With the exception of in-home services, a larger portion of the caregivers in the TCARE® group reported using each of these services.

The importance of inclusion of these services on care plans and the care consultation process is illustrated by fact that, in the absence of any recommendation for medical/behavioral health services or support groups, *no one* in the control group used medical or behavioral health services and *only three* individuals attended a support group.

### *Outcomes for Caregivers*

Findings from the evaluation provide solid evidence that using the TCARE® protocol to serve family caregivers leads to *lower levels of identity discrepancy, stress burden,* and *depression.* Results from the data analysis affirmed statistically significant differences between the two groups for measures of all three of these outcomes. The data also revealed similar trends for intention to place and uplifts, although not statistically significant. Caregivers in the TCARE® group were experiencing a decrease in their desire to place the care receivers in an institutional setting and increase in uplifts over time while caregivers in the control group experienced the opposite. The differences in these scores, however, only approached statistical significance in part due to the small sample size. It is noteworthy that differences between the groups in intention to place and relationship burden were statistically significant (i.e., caregivers in the TCARE® group had significantly lower scores than those in the control group) in a parallel multisite study that included a sample of 266 caregivers.

### *Care Manager Satisfaction*

Although the small sample size did not allow for statistical analyses of the data pertaining to job satisfaction of care managers, the descriptive findings indicate higher levels of *overall job satisfaction, more satisfaction with job demands, lower levels of burnout, and higher levels of satisfaction with administrative challenges* for care managers using the TCARE® protocol. These findings echo the general positive view of the protocol that has been expressed anecdotally by care managers.

## TRAINING AND DEVELOPMENT ACTIVITIES

A second major thrust of the demonstration project was to develop and enhance an infrastructure to support and expand adoption and implementation of TCARE® throughout the state. Activities directed toward this goal included augmenting, testing, and refining an electronic version of the TCARE® process and training Master TCARE® Trainers.

### *Enhancing and Testing of TCARE®e*

TCARE®*e* was created to assist care managers with using the TCARE® process to serve family caregivers. The TCARE®*e* web-based system was designed to enable users to easily transition between the TCARE®*e* system and state wide electronic resource databases. The TCARE® team collaborated with staff from the Georgia Department of Aging Services and the Atlanta Regional Commission to create a prototype using Georgia's Enhanced Services Program (ESP) resource database. In November 2008, the results of this effort were incorporated into the TCARE®*e* system with guidance from web administrators.

Two training sessions were held in January 2009 to introduce TCARE®*e* to certified TCARE® care managers which were attended by 24 care managers and administrators. All certified care managers in Georgia received a username and password to access the TCARE®*e* site along with a TCARE®*e* Quick Start Guide to help navigate through the system. In February 2010, questionnaires were sent to 48 certified care managers requesting feedback about their use or non-use of TCARE®*e*. Feedback from the questionnaire has provided guidance for making changes and embellishments to the TCARE®*e* system.

### *Training of TCARE® Master Trainers*

In September 2009, the UWM team trained seven individuals to become TCARE® Master Trainers. Three of the individuals were from the Atlanta area and four were from the Savannah/Brunswick area. All seven trainees were certified as TCARE® Master Trainers after conducting a TCARE® training for 12 care managers who were mentored by UWM trainers.

## SUMMARY

Overall, the findings provide strong support for the merits and benefits of the TCARE® protocol as an effective mechanism for helping family caregivers. Data from the process evaluation affirmed the feasibility of training care managers from a wide range of organizations to consistently and accurately implement the TCARE® protocol.

Findings from the outcome evaluation documented the influence of the protocol on the practices of care managers and on the well-being of family caregivers. As predicted, care managers trained to use the TCARE® protocol included a larger number and wider variety of services on care plans.  Most of these services which addressed the emotional aspects of the caregiving role and focused on stress and depression of caregivers. Similarly, caregivers experienced significant improvement in stress and depression as a result of TCARE® protocol over time.

Measures taken to refine and augment the electronic version of TCARE® to include Georgia’s electronic resource data base enhanced its utility for use in Georgia. These efforts, in combination with the training and certification of seven Master TCARE® Trainers, have laid a valuable foundation for replicating the protocol throughout the state.

# I. INTRODUCTION

The State of Georgia Division of Aging Services (DAS) is committed to supporting older adults and their family caregivers. To achieve this goal, the DAS engages in innovative research that aims to improve the quality of life for family caregivers.

As part of their research efforts, the DAS has collaborated with researchers in the Office of Applied Gerontology at the University of Wisconsin-Milwaukee (UWM) to implement, evaluate, and expand a care management protocol designed to support family caregivers. The research activities were made possible by two grants from the Administration on Aging's (AOA) Alzheimer's Disease Supportive Services Program (ADSSP).

Initial funding awarded in July 2007 (through December 31, 2009) by the AOA provided the means to implement and evaluate the impact of the Tailored Caregiver Assessment and Referral® (TCARE®) protocol. Findings from the initial project can be found in the report submitted to the DAS (R. J. V. Montgomery, Rowe, & Kwak, 2009). Subsequent funding, awarded through the ADSSP program, provided the means to extend the TCARE® evaluation and enhance the TCARE® program.

## A. GOALS

The goal of the successive grant was to expand the scope of the Tailored Caregiver Assessment and Referral® (TCARE®) demonstration project and integrate it with Georgia's Nursing Home Diversion project to improve the state's long care options for persons with Alzheimer's disease and their caregivers. The major objectives of the project were to:

1. Extend the length the initial TCARE® demonstration project to obtain longitudinal data regarding the impact of TCARE® on caregiver outcomes.
2. Link the TCARE® protocol service taxonomy with the State of Georgia's Enhanced Service Program (ESP), an electronic resource database used by care managers.
3. Test the web-based version of the TCARE® protocol, TCARE®*e*.
4. Expand the number of care managers trained to use TCARE® in the State of Georgia.

Process and outcome evaluations were conducted to assess the outcomes of the TCARE® protocol for caregivers and care managers. The purpose of the process evaluation was to document the fidelity of the process. The outcome evaluation was designed to assess the impact of TCARE® on caregiver identity discrepancy, burden, depression, uplifts, service use, and the caregivers' intention to the place the care receiver in an alternate care setting. The outcome evaluation also assessed care managers' satisfaction with their jobs and levels of job burnout.

This report covers the project activities and findings related to each of the four objectives. The report covers two AOA grant periods: July 1, 2007-December 31, 2008 and January 1, 2009 to March 31, 2010.

## II. BACKGROUND

Family caregivers are the backbone of the long-term care system in the United States. They provide over 80% of the care to frail and older adults and save society over $375 billion dollars per year (Houser & Gibson, 2008). This provision of care does not come without costs. An extensive body of literature documents the link between caregiving and a variety of negative mental and physical health outcomes (Schulz & Sherwood, 2008).

Over the past two decades, considerable effort has been made by researchers and providers toward creating and assessing the benefits of caregiver interventions. Evidence documenting the relative benefits of the various types of services, however, remains uneven. Equally problematic, both the practice and the research communities have consistently reported under-utilization of services by caregivers when they are made available (Schulz et al., 2002; Sorensen, Pinquart, & Duberstein, 2002).

The most encouraging findings from investigations are those from recent studies that employed rigorous designs to demonstrate the value of support services (Schulz et al., 2002). However, the effect sizes observed in the intervention studies have been clinically insignificant or modest at best, and the reported outcomes have varied across different types of caregivers (Sorensen et al., 2002). Nevertheless, two sets of findings from recent studies provide valuable clues about implementing caregiver support programs in a manner that is both effective and efficient. First, evidence from studies that have assessed the impact of single component interventions such as family counseling (Mittelman, 2000), behavioral therapy (Teri, Logsdon, Uomoto, & McCurry, 1997), and care management (Gitlin, Reever, Dennis, Mathieu, & Hauck, 2006) indicate that such programs are most effective for reducing caregiver burden when the services are provided in sufficient quantities and targeted to specific needs. Second, the most promising findings regarding the positive impact of support services on caregivers have emerged from studies that include a relatively comprehensive set of multiple support services (Bourgeois, Schulz, & Burgio, 1996; Burgio, Solano, Fischer, Stevens, & Gallagher-Thompson, 2003). The success of these multi-component programs becomes quite understandable when one considers the longitudinal nature of the caregiving experience and the great diversity that exists among caregivers. Multi-component interventions have a higher probability of meeting the caregiver’s immediate needs because there is a chance that at least one of the support services available in the package is appropriate for a caregiver at any given time. It is also the case that multi-component interventions will have a higher probability of meeting caregivers’ needs as they change over time.

While informative, the findings from these studies do not easily translate to practice because they do not provide critical information for effective targeting of services to the diverse population of caregivers. Specifically, previous research findings have not provided clear guidelines for assessing caregivers’ needs nor for linking caregivers with a set of services that is specifically targeted to meet the individual needs of caregivers. Consequently, service providers tend to use a “shotgun” approach to deliver services. That is to say, caregivers are offered the services that are available in their communities with little knowledge about which services are most needed and most likely to benefit the caregiver at that point in time. Unfortunately, this practice creates the circumstance that many caregiver services go unused, and/or they are provided at a point in time that is too late to fully benefit the caregiver or the care receiver. In short, the failure to assess caregivers' needs and strategically target services can be a very inefficient and wasteful strategy to support caregivers. The Tailored Caregiver Assessment and Referral® protocol was developed to address this need.

## III. TCARE® PROTOCOL DESCRIPTION

The Tailored Caregiver Assessment and Referral® protocol is a manualized protocol designed to enable care managers to more effectively support family caregivers by efficiently targeting services to their needs and strengths. The protocol is built upon knowledge and insights gained from past research focused on caregivers and caregiver interventions and is grounded in the *Caregiver Identity Theory* articulated by Rhonda J.V. Montgomery and Karl Kosloski (R.J.V. Montgomery et al., 2007). The Caregiver Identity Theory describes caregiving as a systematic process of identity change. This identity change is understood to be a significant factor influencing the type and level of caregivers' stress or burden and serves as a model for effective targeting of services.

The TCARE® protocol guides care managers through an assessment and care planning process that helps them examine the care context and identify the sources and types of stress that a caregiver is experiencing. The protocol is designed to assist with targeting appropriate services, and thus, it is believed that the services recommended for use by caregivers will be more appropriately tailored to their needs and strengths and that caregivers served will be more apt to use these services. Consequently, the TCARE ® protocol is expected to translate into positive outcomes for caregivers, and likely more effective use of resources.

The TCARE® manual includes a set of six tools and instructions to guide care managers through a six step caregiver assessment and referral process that leads to an individualized care plan (see TCARE process in Figure 1) . Using this protocol, care managers (1) assess caregivers' needs with the *Assessment* form; (2) interpret the scores on key measures to determine the types and level of need using the *Assessment Summary Sheet*; (3) identify appropriate goals and support strategies using the *Decision Maps*, and develop a list of service options that are available in the local community and consistent with identified goals and support strategies using the *Guide for Selecting Support Services*; (4) consult with the caregiver to create a care plan that is both appropriate and acceptable to the caregiver using the *Care Plan Consultation Worksheet*; and (5) create the mutually agreed upon care plan using the *Caregiver Care Plan*. The manual also includes instructions regarding how to conduct follow-up assessments with caregivers at 3-month intervals.

Figure 1
Six-Step TCARE® Process

**Step 1: Conduct 40-minute Assessment**

| Tool | Description |
|---|---|
| • 32- item *TCARE® Assessment Form* | • Assess caregiver: demographics, length & phase of caregiving, obligations, physical & emotional health<br>• Assess care receiver: demographics, ADLs/ IADLS, behaviors, diagnoses |

**Step 2: Transfer Key Information to Assessment Summary**

| Tool | Description |
|---|---|
| • *Assessment Summary Sheet* | • Calculate scores for key measures<br>• Transfer scores and information for each domain to summary sheet<br>• Interpret scores as low, medium or high using ranges included on tool<br>• Note other useful information. |

**Step 3: Create Care Consultation Worksheet**

| Tools | Description |
|---|---|
| • *Assessment Summary Sheet*<br>• *Decision Maps* (algorithm)<br>• *Guide to Selecting Support Services*<br>• Local directory or data base of services/resources | • Use burden scores to identify correct decision map<br>• Use decision algorithm to identify intervention goal, strategies and initial list of recommended services/resources<br>• Tailor recommendations to caregiver's needs, preferences, & availability<br>• Identify local resources |

**Step 4: Consult with Caregiver**

| Tools | Description |
|---|---|
| • *Assessment Summary Sheet*<br>• *Care Consultation Worksheet* | • Share & interpret information from *Assessment Summary Sheet*<br>• Discuss recommended goal(s) & strategies<br>• Review list of recommended services and discuss benefits<br>• Jointly make decisions regarding services/resources to include on care plan |

**Step 5: Create Care Plan**

| Tools | Description |
|---|---|
| • *Care Consultation Worksheet*<br>• *Caregiver Care Plan* | • Record decisions made during care consultation including: interventions goal(s), strategies, services with specific information to access service/resource<br>• Responsibilities of caregiver<br>• Responsibilities of care manager<br>• Triggers for follow-up |

**Step 6: Follow-up**

| Tools | Description |
|---|---|
| • *Follow-up TCARE® Assessment Form*<br>• *Assessment Summary Sheet*<br>• *Decision Maps* (algorithms)<br>• *Guide to Selecting Support Services*<br>• Local directory or data base of services/resources<br>• *Care Consultation Worksheet*<br>• *Caregiver Care Plan* | • Conduct follow-up assessment at 3-month intervals by telephone or in-person<br>• Complete steps 2- 4 of TCARE® process<br>• Adjust care plan as appropriate |

# IV. TCARE® EVALUATION

## A. STUDY OVERVIEW

### *1. Goals*

The goals of the evaluation were to (1) assess the fidelity of the implementation of TCARE® by care managers and (2) evaluate the impact of TCARE® on caregiver outcomes.

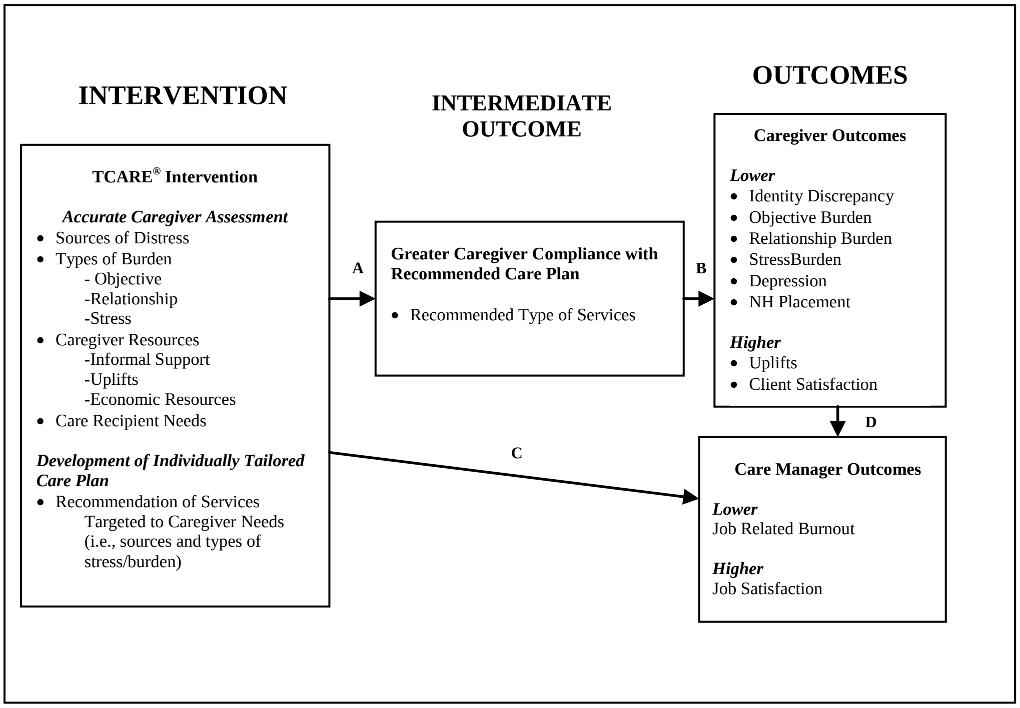
### *2. Study Design*

A longitudinal randomized trial was conducted in regions served by the following three agencies: (1) Atlanta Regional Commission (ARC) AAA; (2) Coastal Georgia AAA; (3) and Southeast Georgia AAA. Services were provided by these agencies and their contractors. The study included 12 care managers employed by these three participating agencies and their contractors, and 97 caregivers served by these agencies. Care managers in the TCARE® group were trained to use the TCARE® protocol. Care managers in the control group continued to use normal or customary practices. Caregivers were identified for participation using a uniform screening process implemented by Gateway staff. Data for caregivers were collected at the time of enrollment (baseline) and at three month-intervals for a period of one year. Data for the process evaluation pertaining to the accuracy and consistency of the care managers' implementation of the TCARE® protocol were collected throughout the study. Care managers also completed a questionnaire pertaining to job satisfaction. Descriptive analyses were conducted to provide profiles of caregivers' and care managers' characteristics. The effects of the intervention (i.e., TCARE® protocol) were tested using random effects regression growth curve analysis and random intercept regression analysis using the SAS Proc Mixed procedure.

### *3. Guiding Model and Hypothesis*

The premise for the demonstration project was that use of the TCARE® protocol by care managers will (1) assure consistent and accurate assessment of caregivers' needs and (2) help care managers develop individually tailored care plans that include support services that are appropriately targeted to caregivers' needs and that are acceptable to caregivers. The model shown in Figure 1 identifies the central hypotheses tested. Specifically, it is hypothesized (*Path A, Figure 1*) that the development of individually tailored care plans that are designed to address the sources of stress will foster greater compliance of caregivers with the care plan (i.e., caregivers will use types of services recommended). In turn, it is hypothesized (*Path B, Figure 1*) that timely and appropriate use of support services will lead to positive outcomes for caregivers (i.e., lower identity discrepancy, burden and depression; higher uplifts and satisfaction with care management services; lowered intention to place the care receiver in alternate setting). When caregivers experience positive outcomes, care managers are more likely to be satisfied with their jobs (*Path C, Figure 1*). Consequently, by providing a structured and transparent process for working with families, the protocol will directly lead to greater job satisfaction and lower staff burnout (*Path D, Figure 1*).

Figure 2. *Guiding Model for TCARE® Intervention Study*



Outcomes examined for caregivers included caregiver identity discrepancy, caregiving burden, depression, uplifts, intention to place, use of services, compliance with recommended care plans, and satisfaction with care management services. Outcomes examined for care managers were job satisfaction and burnout.

The outcome evaluation addressed seven hypotheses on caregiver outcomes. Compared with caregivers in the control group, caregivers in the TCARE® group will:

1. Use a wider variety of support services.
2. Demonstrate greater compliance with the care plan.
3. Experience lower levels of identity discrepancy.
4. Experience lower levels of caregiver burden and higher level uplifts.
5. Experience lower levels of depression.
6. Experience lower level of intention to place a care receiver in alternative setting.
7. Experience higher level of satisfaction with care management services received.

The outcome evaluation also addressed two hypotheses on care manager outcomes. Compared with care managers in the control group, care managers using TCARE® protocol will:

1. Experience a higher level of job satisfaction.
2. Experience a lower level of job related burnout.

### *4. Human Subjects Approval*

This research project was approved by the University of Wisconsin-Milwaukee's Institutional Review Board (IRB) on September 27, 2007 (IRB # 08.064) and the Georgia Division of Human Resources' IRB on December 2, 2007 (IRB # 071201).

## B. IMPLEMENTATION AND MONITORING OF TCARE® PROTOCOL

### *1. TCARE® Training Process*

A total of seven care managers were trained to use TCARE®. Five were from the Visiting Nurse Health System, one was from the Alzheimer's Association-Georgia Chapter, and one was from the Chatham County Board of Health. Additionally, five supervisors and three persons from the DAS attended the training sessions. The training process included (1) a two-day intensive training conducted in July 2007; (2) a one-day practicum training held in September 2007; (3) a web-based application training conducted in January 2008; and (4) on-going technical assistance.

The two-day intensive training covered information about the diversity of family caregivers and the caregiving experience, the *Caregiver Identity Theory*, instruction for implementing the five step TCARE® process, and using the TCARE® tools. The training format included lectures, large group discussions, and small group sessions during which care managers used case studies to apply the process.

The one-day practicum training was conducted two months later, after the care managers had the opportunity use the process with a client family. During this follow-up session, key concepts were reviewed and care managers had an opportunity to share their experiences using the process in small groups. The session also included a lecture and discussion about mechanisms for identifying and cataloguing services, resources, and educational opportunities for family caregivers in their local communities.

Upon completion of the second training session, care managers were instructed to try the process with a second client family. Their experiences with the second application were reviewed and discussed during the final training session which was conducted as a webinar. On-going technical assistance was made available to all participants throughout the study.

### *2. Assessment and Monitoring Fidelity of Implementation*

Consistent and accurate implementation of the TCARE® process is necessary to obtain maximum benefits of the protocol and to enable a valid assessment of its feasibility. To monitor and facilitate accurate implementation of the TCARE® process by care managers, all TCARE® forms completed for each caregiver were reviewed by staff at the time of the baseline assessment, the 6-month follow-up assessment, and the 12-month follow-up assessment. Each case was reviewed using a 27-item checklist and assigned scores for two measures of fidelity.

The *mechanics* score is a measure of the extent to which the care manager correctly recorded information on the TCARE® forms (i.e., the Assessment Form, the Assessment Summary Sheet, the Care Plan Consultation Worksheet, and the Care Plan) and selected the correct decision map. The score for mechanics was created by using an 18-item check list. The scores for each case reflect the percentage of items from the inventory that were correctly completed (i.e., items correct/18). A composite score was then created for each care manager at each data collection point by averaging the scores for all of the cases submitted by the care manager.

The *process implementation* score is a measure of the extent to which the care manager created a viable care plan that accurately reflected the TCARE® protocol. The process implementation score was created by reviewing the Care Plan Consultation Worksheet with the Care Plan using a 9-item inventory checklist. The score for each care plan reflected the percentage of items from a 9-item check list that were correctly completed (i.e., items correct/9). A composite score was created for each care manager at each data collection point by averaging the scores for each of the cases reviewed.

Two members of the study team who hold MSW degrees and have extensive practice experience independently reviewed and scored all forms. When reviewers disagreed, they met to gain consensus. To ensure accurate and consistent compliance of the protocol throughout the project period, care managers whose average score for completed cases was less than 70% on either dimension of fidelity were contacted by one of the two reviewers and offered technical assistance.

### *3. Findings from Process Evaluation*

Composite scores were calculated for each care manager at each time point. Fifty-three caregiver cases submitted by six care managers were reviewed at baseline.The average number of baseline cases submitted by these six care managers was nine (SD = 10.0, range = 1-26). Twenty-eight cases were reviewed at 6-months that were submitted by five care managers. The average number of cases submitted by these five care managers at the second review point was six (SD = 4.5, range = 2-11). Finally, 16 cases were reviewed at 12-months that were submitted by four care managers. The average number of cases submitted by these four care managers at the third review point was four (SD = 2.9, range = 1-7). Compliance scores for each dimension and time point are shown in Table 1.

Table 1. *Care Manager Compliance Scores on Two Dimensions at Three Time Points*

| | Baseline Review | 6-Month Review | 12-Month Review |
|---|---|---|---|
| Care Managers and Cases | | | |
| # Care Managers | 6 | 5 | 4 |
| # Cases Reviewed | 53 | 28 | 16 |
| Mechanics Dimension | | | |
| Mean Score (SD) | 68 (18.0) | 71 (13.3) | 71 (12.5) |
| Range | 37-85 | 56-83 | 55-83 |
| Process Implementation Dimension | | | |
| Mean Score (SD) | 85 (16.7) | 89 (9.9) | 92 (5.7) |
| Range | 61-100 | 72-96 | 87-100 |

Care managers demonstrated greater compliance on both dimensions of implementation over time. At baseline, the average care manager compliance score was 68% for mechanics and 85%

for process implementation. At 6-months, similar scores were observed. The average score was 71% for mechanics and 89% for process implementation. At 12-months, the average care manager compliance score was 71% for mechanics and 92% for process implementation.

*Accuracy at Time 1.* The mean score of 68% on mechanics at baseline indicated that overall care managers did a fair job completing the forms and selecting the correct decision map. A review of individual care manager scores revealed three care managers had an overall score of 50 or less, or 1 standard deviation below the mean. A review of the scoring forms for the 53 cases revealed that the two errors mostly commonly made were failure to complete all questions on the TCARE® Caregiver Assessment Form and incorrect addition of the scores for scales. The third most common error was failure to write the care plan in a language that could be easily understood by the caregiver. Most often this entailed the use of abbreviations and shorthand to identify service providers or the recommended quantity of a service. Fortunately the majority of these errors did not impact the ability of the care managers to accurately identify goals, strategies, or service recommendations. After reviewing the TCARE® forms, a member of the training team contacted care managers who demonstrated difficulty with completing the forms and provided technical assistance.

The mean score of 85% for process implementation at baseline indicates that care managers were generally able to create viable care plans that accurately reflected the TCARE® process. The range of the scores, however, indicated some variation in competency among the care managers. A review of individual scores revealed that three of the six care managers had an overall score of less than 68% or 1 standard deviation below the mean. The most common error for process implementation was failure to record on the care plan the desired outcomes for the selected strategies and triggers for follow-up. Although these items are important for the development of viable care plans, the errors did not interfere with the actual selection or recommendation of services.

*Accuracy over Time.* As shown in Table 1, the scores for the two measures of fidelity increased slightly over time with the process implementation score rising to 92% for the 12-month follow-up. The data provide evidence that care managers were generally consistent and accurate in their implementation of the TCARE® process.

## C. STUDY METHODS

### 1. Sampling Procedure and Sample Description

### Selection & Enrollment of Caregivers

The study sample included 97 family caregivers who contacted one of the participating Gateway agencies seeking information or services for themselves or for their care receivers. Caregivers who contacted a Gateway agency were screened for eligibility for the demonstration with the TCARE® Caregiver Screen. The screen included a question regarding memory loss and intention to place, and measures of identity discrepancy, objective burden, relationship burden, stress burden, depression, and uplifts. To be considered eligible for the demonstration, caregivers had to (1) report that their care receivers had a memory problem and (2) score high on at least one of the three types of burden measures, the identity discrepancy measure, or the depression measure, or indicate that they “probably would” or “definitely would” place their care recipients in a nursing home.

***Characteristics of Caregivers Screened***

As of March 31, 2010, 177 caregivers were screened for the study. Of these, 156 caregivers were determined to be eligible for the study and randomly assigned to the TCARE® group or the control group. One hundred four caregivers agreed to participate in the study; however, only 97 of the total of 104 caregivers were enrolled into the study by completing the baseline interview. Table 2 summarizes caregiver screening, assignment, and enrollment.

Table 2: *Caregivers Screened and Enrolled into the Study between September 1, 2007 to March 31, 2010 (n=177)*[1]

| | **Number (%)** |
|---|---|
| **Number of Caregivers Screened** | **177** |
| Number of Caregivers with Positive Screen (i.e., eligible for the study) | 156 (88.1) |
| Number of Caregivers with Negative Screen (i.e., not eligible for the study) | 21 (11.9) |
| **Eligible Caregiver Group Assignment** | **(n=156)** |
| Number of caregivers referred to intervention (TCARE®) | 78 (50.0) |
| Number of caregivers referred to control | 78 (50.0) |
| **Number of Caregivers Enrolled into the Study** | **(n=97)** |
| TCARE® | 53 (54.6) |
| Control | 44 (45.4) |

[1] A total of 272 screens were completed as part of the Georgia Demonstration. Ninety-five of the screens are not included in the data reported because the individuals were either placed on a waiting list or were not immediately eligible for the study. Many of those caregivers were re-screened at a later time.

Of the 177 caregivers screened, data were available for 170 caregivers. As shown in Table 3, the majority of caregivers were caring for a parent (52.5%) and a relative with a memory problem (99%).

Table 3. *Characteristics of Caregivers Screened (n=170)*[1]

| | **Number (%)** |
|---|---|
| **Relationship to the care recipient (n=170)** | |
| Spouse/Partner | 53 (31.18) |
| Parent | 95 (55.88) |
| Other | 22 (12.94) |
| **Care recipient memory loss (n=169)** | |
| No memory problem | 1 (0.59) |
| Memory or cognitive problem suspected | 23 (13.61) |
| Probable Alzheimer's, not medically diagnosed | 17 (10.06) |
| Yes, Alzheimer's was medically diagnosed | 128 (75.74) |

[1] The total (170) includes the 21 screens of caregivers who were not eligible for the study due to a) low scores, b) no intention to place, or c) no memory problem.

Table 4 includes mean scores for caregivers on measures included in the TCARE$^{®}$ Screen. As shown, the majority of persons screened for eligibility scored in the medium and high ranges on the three measures of burden and the depression measure. Scores on identity discrepancy, however, were more equally distributed across screening score ranges. With regard to intention to place, 15.88% indicated that they “probably would” or “definitely would” place their care receivers in a nursing home.

Table 4. *Caregiver Scores on Key Outcome Measures in TCARE$^{®}$ Screen (n=170)*

| | **Previously Determined Ranges of Scores for Eligibility Criteria** | | | | | | **Average Caregiver Scores on Screen** |
|---|---|---|---|---|---|---|---|
| | **High** | | **Medium** | | **Low** | | |
| | **Range** | **%** | **Range** | **%** | **Range** | **%** | **Mean (SD)** |
| Relationship Burden | *11-25* | 47.65 | *6-10* | 34.12 | *5-5* | 18.24 | 11.24 (5.47) |
| Objective Burden | *19-30* | 75.88 | *11-18* | 20.59 | *6-10* | 3.53 | 23.28 (6.31) |
| Stress Burden | *14-25* | 66.67 | *9-13* | 21.43 | *5-8* | 11.90 | 15.65 (5.54) |
| Depression-CESD[1] | *12-30* | 64.71 | *6-11* | 22.94 | *0-5* | 12.35 | 14.32 (7.30) |
| ID Discrepancy | *19-36* | 37.88 | *12-18* | 37.88 | *6-11* | 25.44 | 16.86 (7.18) |
| Uplifts | | | | N/A | | | 19.16 (6.08) |
| Intention to Place | | **Yes** | | | **No** | | N/A |
| | | 15.88 | | | 84.12 | | |

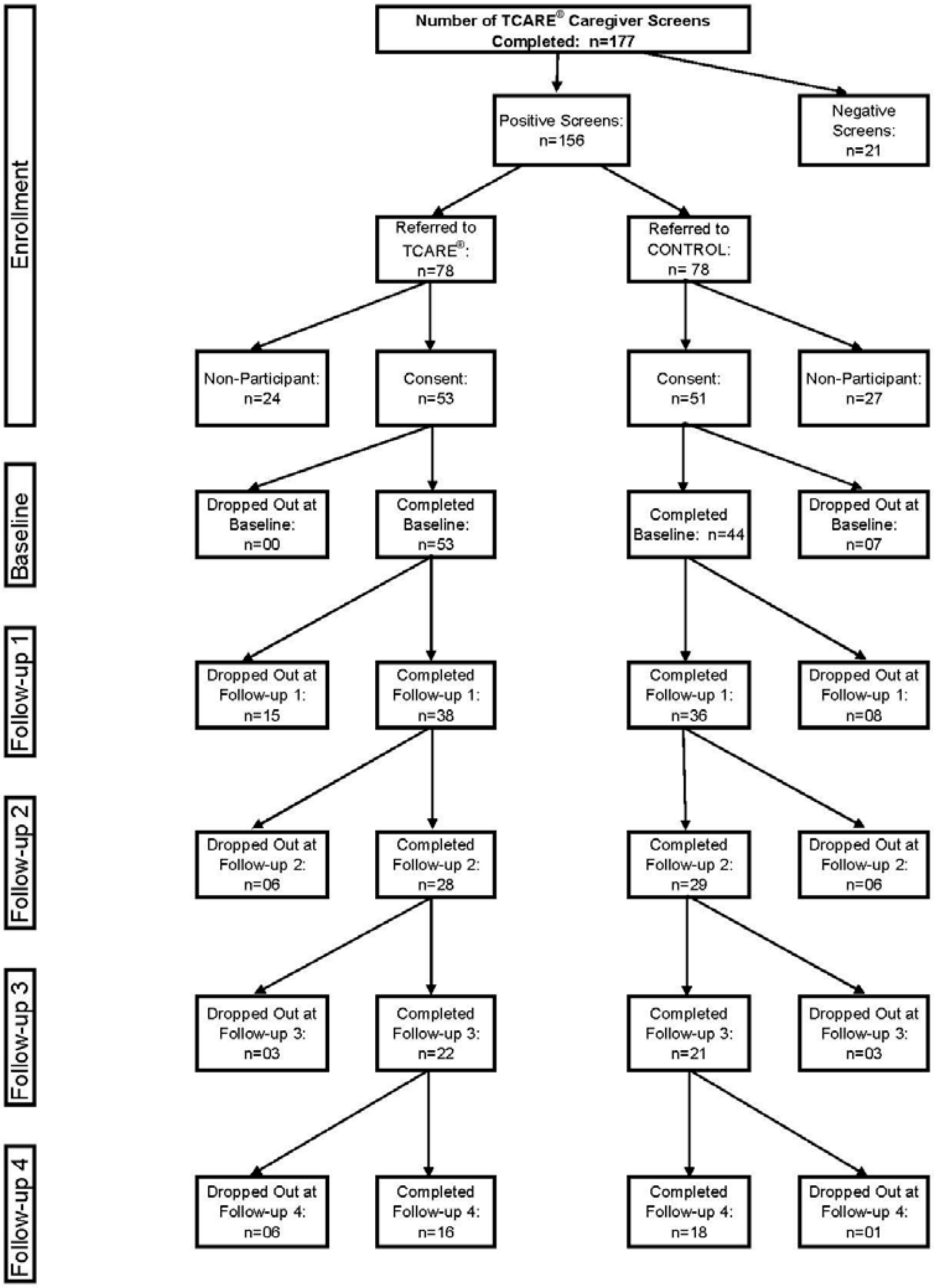
[1] The screen ranges for Depression-CESD reported here are different from the eligibility criteria used by the screening staff when completing the screen. The ranges reported here were converted to a scale of 0-3 per item from the 1-4 per item range that was used by the screening staff. These changes were made to reflect the ranges that are often used when determining depression from a clinical stance.

These scores on the key measures indicate that the majority of caregivers who contact the participating agencies were highly stressed yet strongly committed to their caregiving roles. The vast majority of caregivers expressed a desire to keep their relatives out of an institution or long-term care setting (over 80 percent). Over 70 percent of caregivers fell under the ‘high’ range (19-30) of the pre-established screening criteria for objective burden. This suggests caregivers spend a substantial amount of time and effort related to their caregiving role. Lastly, it is important to note that over 60 percent of caregivers scored 10 or higher on the depression measure. This suggests that caregivers exhibited high levels of depressive symptoms. In practice, a score of 10 or higher is used as a clinical cut-off score to determine whether there is a need for a mental health evaluation (Andersen, Malmgren, & Cater, 1994).

### *Attrition of Caregiver Sample*

Of the 104 caregivers who initially agreed to participate in the study, 97 completed the baseline interview and were enrolled into the study. Of the initially enrolled 97 caregivers, 74 completed first follow-up interviews, 57 caregivers completed second follow-up interviews, 43 caregivers completed third follow-up interviews, and 34 caregivers completed fourth follow-up interviews (final interviews). Figure 2 provides an overview of the enrollment and data collection process as well as attrition of caregivers at specific time points.

Figure 3. *Caregiver Enrollment and Attrition through March 31, 2010*



Tables 5 and 6 include the number and percentage of caregivers who completed the first four interviews or assessments. As shown in Table 5, a total of 43 caregivers completed the first three follow-up interviews. Of the TCARE® group, 22 caregivers (41.5%) completed three follow-up interviews, while 21 (47.7 %) caregivers in the control group completed three follow-up interviews.

Table 5. *Caregiver Interviews Completed by Time and Group*

| | **TCARE®** | **Control** | **Total** |
|---|---|---|---|
| | | **Number (%)** | |
| Baseline | 53 (100) | 44 (100) | 97 (100) |
| Follow-up 1 | 38 (71.7) | 36 (81.8) | 74 (76.3) |
| Follow-up 2 | 28 (52.8) | 29 (65.9) | 57 (58.8) |
| Follow-up 3 | 22 (41.5) | 21 (47.7) | 43 (44.3) |

Of the 43 caregivers who completed three follow-up interviews, 15 (44.1%) were spouses and 25 (48.1%) were adult children (see Table 6).

Table 6. *Caregiver Interviews Completed by Time and Relationship*

| | **Spouse** | **Parent** | **Other** | **Total** |
|---|---|---|---|---|
| | | **Number (%)** | | |
| Baseline | 34 (100) | 52 (100) | 11 (100) | 97 (100) |
| Follow-up 1 | 27 (79.4) | 40 (76.9) | 7 (63.6) | 74 (76.3) |
| Follow-up 2 | 20 (58.8) | 33 (63.5) | 4 (36.4) | 57 (58.8) |
| Follow-up 3 | 15 (44.1) | 25 (48.1) | 3 (27.3) | 43 (44.3) |

We compared baseline characteristics of the 43 participants who completed the third follow-up interview (i.e., nine months from baseline) with those of the 54 participants whose third follow-up outcome data were not available. There were no significant differences on any of baseline characteristics between the two groups of caregivers.

The primary reasons for attrition were death of the care recipient (51%), verbal refusal (17%), or the caregiver was discharged from the care management program(10%). As shown in Table 7, caregivers in the TCARE® group were more likely than caregivers in the control group to drop out because their care receivers died, had been placed in a nursing home, or they had been discharged from care management services. Caregivers in the control group were more likely than caregivers in the TCARE® group to drop out of the study because they did not want to complete the interviews over the phone with the UWM research team. There was no significant difference between the two groups in the number of caregivers who dropped out from the study.

Table 7. *Caregiver Dropout Reasons*

| | TCARE® | Control | Total |
|---|---|---|---|
| | | Number (%) | |
| CR death or NH placement | 16 (51.2) | 5 (29.4) | 21 (51.2) |
| Verbal Refusal | 0 (0.0) | 7 (41.2) | 7 (17.1) |
| CG discharged from CM | 4 (16.7) | 0 (0.0) | 4 (9.8) |
| Other reason | 4 (16.7) | 5 (29.4) | 9 (21.95) |
| *Total* | 24 (100) | 17 (100) | 41 (100) |

### *Background Characteristics of Caregivers at Baseline*

Table 8 includes background and demographic information on the 97 caregivers who were enrolled into the study and completed baseline interviews. The majority of caregivers enrolled in the study were female (84.5%), adult children (53.6%), and married (64.2%). At the baseline interview, on average, caregivers were 63 years old. About 25 percent of the caregivers reported that they worked full time, while 38 percent reported that they were fully retired. Fifty-four percent of caregivers were White and 42 percent were Black or African American. About 47 percent of the caregivers reported that they were in fair, poor, or very poor health. On average, caregivers provided about 53 hours of care for their care receivers per week. Specifically, caregivers spent almost 19 hours assisting their care receivers with eating, bathing, dressing, or toileting; about 22 hours preparing meals, doing laundry, and light housework; providing about 7 hours of transportation, and about 4 hours helping with legal matters, banking, and money matters per week. There were no significant differences in all baseline characteristics between caregivers in TCARE® group and control group, except for the self-reported number of caregiving hours. Caregivers in the TCARE® group reported a significantly higher number of hours spent on helping with instrumental activities of daily living such as meal preparation or providing transportation than caregivers in the control group.

Table 8. *Characteristics of Caregivers Enrolled into Study (n=97)*

| | All | TCARE® (n=53) | Control (n=44) |
|---|---|---|---|
| | | Mean (SD) | |
| **Age in years** | 63.09 (12.37) | 62.81 (13.35) | 63.43 (11.21) |
| | | Percentage | |
| **Gender** | | | |
| Male | 15.5 | 9.4 | 22.7 |
| Female | 84.5 | 90.6 | 77.3 |
| **Race** | | | |
| White | 54.6 | 47.2 | 63.6 |
| Black or African American | 42.3 | 50.9 | 31.8 |
| Other | 1.0 | 0.0 | 2.3 |
| 2 or more | 2.1 | 1.9 | 2.3 |
| **Marital status** | | | |
| Single | 17.9 | 15.7 | 20.5 |
| Married/Domestic partner | 64.2 | 66.7 | 61.4 |
| Widowed | 5.3 | 5.9 | 4.5 |

Table 8. *Characteristics of Caregivers Enrolled into Study (n=97)*

| | **All** | **TCARE® (n=53)** | **Control (n=44)** |
|---|---|---|---|
| Other | 12.6 | 11.8 | 13.6 |
| **Education** | | | |
| 8th grade or less | 2.1 | 1.9 | 2.3 |
| Attended high school, did not graduate | 12.4 | 13.2 | 11.4 |
| High school graduate (Diploma or GED) | 24.7 | 26.4 | 22.7 |
| Some college/post high school training | 41.2 | 35.8 | 47.7 |
| Bachelor's degree | 8.2 | 7.5 | 9.1 |
| Graduate degree | 11.3 | 15.1 | 6.8 |
| **Relationship to the care recipient** | | | |
| Spouse/Partner | 35.1 | 35.8 | 34.1 |
| Parent | 53.6 | 50.9 | 56.8 |
| Other | 11.3 | 13.2 | 9.1 |
| **Self reported health** | | | |
| Very Poor | 1.0 | 1.9 | 0.0 |
| Poor | 7.3 | 9.6 | 4.5 |
| Fair | 38.5 | 34.6 | 43.2 |
| Good | 44.8 | 48.1 | 40.9 |
| Very good | 8.3 | 5.8 | 11.4 |
| **Employment Status** | | | |
| Work full time | 24.7 | 22.6 | 27.3 |
| Work part time | 2.1 | 1.9 | 2.3 |
| Retired | 38.1 | 35.8 | 40.9 |
| Homemaker | 9.3 | 13.2 | 4.5 |
| Unemployed | 14.4 | 13.2 | 15.9 |
| Other | 11.3 | 13.2 | 9.1 |
| **Caregiver annual income** | | | |
| Under $10,000 | 3.2 | 1.9 | 4.7 |
| $10,000-$14,999 | 12.6 | 11.5 | 14.0 |
| $15,000-$34,999 | 46.32 | 44.23 | 48.84 |
| $35,000-$49,999 | 12.6 | 15.4 | 9.3 |
| $50,000-$74,999 | 15.8 | 19.2 | 11.6 |
| Over $75,000 | 9.5 | 7.7 | 11.6 |
| **Nursing Home Diversion Program** | 5.2 | 3.8 | 6.8 |

| | | **Mean (SD)** | |
|---|---|---|---|
| **Caregiver assistance (hours per week)** | **All** | **TCARE® (n=53)** | **Control (n=44)** |
| Eating, bathing, dressing or toilet functions | 19.47 (16.94) | 19.77 (15.10) | 19.05 (19.37) |
| Meal preparation, laundry or light housework* | 21.88 (15.70) | 24.36 (16.58) | 18.60 (14.00) |
| Provide transportation to/from appointments** | 7.37 (6.99) | 8.74 (6.99) | 5.55 (6.57) |
| Legal matters, banking, money matters* | 4.24 (5.45) | 5.21 (6.29) | 2.92 (3.74) |
| *Total hours** | *53.21(29.53)* | *58.08 (25.08)* | *46.59 (33.89)* |

* $p$ <.05; ** $p$ <.001

### *Background Characteristics of Care Recipients at Baseline*

Almost all of the caregivers reported that their care receivers had some type of cognitive or memory problem (98%) and the care receivers lived with them (83%). Almost half of the caregivers (47.42%) reported that the person they cared for was unable to perform at least one activity of daily living (ADL) at all and 95.9 percent reported that their care receivers were unable to do at least one instrumental activity of daily living (IADL). About 40 percent of care receivers had an annual income of less than $15,000. With regard to behavioral problems of the care receivers, caregivers were asked to respond to how often they observed 15 specific behaviors of their care receivers during the past week using a 4-point response scale (0 = no days to 3 = 5 or more days). The average score for behavioral problems was 15.93 (SD=8.79). Table 9 includes care receiver demographic, cognitive, and functional characteristics.

Table 9. *Characteristics of Care Receivers Cared for by Caregivers Enrolled in Study (n=97)*

| | **All** | **TCARE® (n=53)** | **Control (n=44)** |
|---|---|---|---|
| | | **Percentage** | |
| **Care Recipient annual income** | | | |
| Under $10,000 | 12.6 | 9.4 | 16.7 |
| $10,000-$14,999 | 27.4 | 18.9 | 38.1 |
| $15,000-$34,999 | 40.00 | 43.40 | 35.71 |
| $35,000-$49,999 | 8.4 | 9.4 | 7.1 |
| $50,000-$74,999 | 8.4 | 13.2 | 2.4 |
| Over $75,000 | 3.2 | 5.7 | 0.0 |
| **Care recipient living arrangement** | | | |
| Lives alone in own home | 10.4 | 3.8 | 18.2 |
| Lives in household with the caregiver | 83.3 | 90.4 | 75.0 |
| Lives with a relative other than the caregiver | 5.2 | 5.8 | 4.5 |
| Lives in a group environment | 1.0 | 0.0 | 2.3 |
| **Care recipient memory loss** | | | |
| No memory problem | 2.1 | 0.0 | 4.5 |
| Memory or cognitive problem suspected | 11.6 | 13.7 | 9.1 |
| Probable Alzheimer's, not medically diagnosed | 15.8 | 9.8 | 22.7 |
| Yes, Alzheimer's, medically diagnosed | 70.5 | 76.5 | 63.6 |
| **ADLs** People who cannot do at least 1 ADL at all | 47.42 | 45.28 | 50.00 |
| **IADL** People who cannot do at least 1 IADL at all | 95.88 | 98.11 | 93.18 |
| | | **Mean (SD)** | |
| **Problem Behavior** (0-45) | 15.93 (8.79) | 16.60 (9.25) | 15.05 (8.2) |

### *Characteristics of Care Managers*

The twelve care managers who participated in the study were individuals employed by participating agencies or their contractors. Half of the care managers were trained to use TCARE® and the other half used their agencies' "usual" practices (i.e., control) to serve family caregivers. These 12 care managers were selected by administrators of the participating organizations to participate. Each agency was asked to identify an equal number of care managers for assignment to the TCARE® and control groups. Administrators of the agencies providing care management services for the AAA identified one or two staff members able and willing to attend the TCARE® training session and use the TCARE® process to work with caregivers assigned to the TCARE® group. Care managers selected for the control condition served clients assigned to the control group using their *usual practice*.

Eleven of the 12 care managers who participated in the demonstration project were female. Seven (58%) of the care managers were white and five (42%) were African American. On average, the care managers were 46 years old. The majority of the care managers were married (58%), and one quarter of the sample were single. Ninety-two percent of the care managers in the study had a bachelor's degree or higher level of education.

All of the care managers have been working in the social services industry for at least five years, with the majority working in social services for ten years or more. The length of time that these care managers have been working at their particular agencies ranged from one to twelve years. However, the care managers trained to use TCARE® were more apt to have been long term employees. Four of the six care managers in the control group were employed by their agencies for less than four years. In contrast, one of the care managers in the TCARE® group was employed by his/her agency for three years, and the remaining care managers in the TCARE® group worked at their agencies for more than five years.

### *2. Data Collection*

Data pertaining to caregiver outcomes were collected for caregivers in the TCARE® group by care managers as part of the TCARE® protocol at the time of enrollment and subsequent 3-month intervals up to one year. Data for caregivers in the control group were collected by trained interviewers at UWM using items contained within the TCARE® Caregiver Assessment. Interviews were conducted shortly after the caregiver was enrolled and at three-month intervals. Service use data were collected by care managers using client record information, case notes, and agency tracking systems. Interviews were also conducted by trained interviewers at UWM with caregivers regarding satisfaction with care management services after they had been enrolled in the study for twelve months, approximately two months after their care receivers had passed away, or at the end of the continuing evaluation period (March 2010).

A one-time mailed survey was completed by care managers in both the TCARE® and control groups about job satisfaction and job-related burnout.

### *3. Variables and Measurement*

#### *Caregiver Outcomes*

The key outcomes examined for caregivers included several domains: (1) use of support services; (2) compliance with care plan; (3) caregiver identity discrepancy, (4) caregiver burden and uplifts, (5) depression; (6) intention to place; and (7) satisfaction with care management services.

*Caregiver use of support services* was defined as the extent to which a caregiver used an array of services offered by care managers. Use of a variety of support services was measured using monthly service use information provided by care managers for individual caregivers.

*Caregiver compliance with care plans* was defined as the extent to which a caregiver actually used the services recommended in the care plan. Caregiver compliance for both the first and second care plans was measured by comparing care plans to the first three months of service use reported for each client by care managers that immediately followed the date of the care plan.

*Caregiver Identity Discrepancy* was defined as the affective psychological state that accrues when there is a disparity between the care activities in which a caregiver is engaging and his/her identity standard. Identity discrepancy was measured using a six point, 6-item scale included in the TCARE® Caregiver Assessment Tool. Scores ranged from 6-36 (α=.796).

*Stress burden* was defined as a generalized form of negative affect that results from caregiving. Stress burden was measured using a five point, 5-item scale included in the TCARE® Caregiver Assessment Tool. Scores ranged from 5-25 (α=.870).

*Relationship burden* was defined as demands for care and attention over and above the level that the caregiver perceives is warranted by the care receiver's condition. Relationship burden was measured using a five point, 5-item scale included in the TCARE® Caregiver Assessment Tool. Scores ranged from 5-25 (α=.842).

*Objective burden* was defined as a negative psychological state that results from the perception that caregiving activities and responsibilities are infringing on other aspects of the caregiver's life, including time and energy to address other family obligations, leisure activities, and personal needs. Objective burden was measured using a five point, 6-item scale included in the TCARE® Caregiver Assessment Tool. Scores ranged from 6-30 (α=.862).

*Depression* was measured using a four point, 10-item short version of the Center for Epidemiological Studies-Depression (CES-D) scale. The clinical cut off score using this scale is 10 points or above. The scale captured four underlying dimensions of depressive symptoms to include dysphoria, somatic complaints, positive affect, and interpersonal distress. Scores ranged from 0 to 30 (α=.799).

*Uplifts* was defined as the positive psychological outcome associated with caregiving. Caregiver uplifts were measured with a five point, 6-item scale included in the TCARE® Caregiver Assessment Tool. Scores ranged from 6-30 (α=.880).

*Intention to place* was defined as the caregiver's plan to place the care receiver in an alternate care setting and abdicate the role of primary caregiver. Two items were used to assess intention to place. The first item asked caregivers whether they would place their care receivers in a nursing home or other long term care facility, given their relatives' current condition. The second item asked about the caregivers' intention to place their care receivers if their care receivers' condition became worse. Responses for these two items are coded on a 4-point scale. These two items were combined to create a composite score representing the intention to place in current health and future health status (if worsened) among caregivers. Scores ranged from 2 to 8, with a higher score indicating higher level of intention to place.

*Satisfaction with services* was defined as the extent to which a caregiver was satisfied with various components of care management services that she/he received from the care manager. Caregivers were asked a total of 17 items using 6-point Likert-type scale, with possible scores ranging from 17-85 (α= 0.951). Four items were taken from a study examining community based respite programs (R.J.V Montgomery, 2002). The other 13 items were modified questions from the AoA Performance Outcomes Measures Project (POMP) (AOA, 2004).

### *Care Manager Outcomes*

*Job satisfaction for care managers* was defined as the extent to which a care manager was satisfied with various components of his/her job. Job satisfaction was measured using a series of questions that tap six dimensions of job satisfaction: overall job satisfaction, satisfaction with job demands, satisfaction with job-related challenges, satisfaction with administrative support, satisfaction with co-worker relations, and sense of accomplishment at work. Thirty-eight questions were used, and response options ranged from 1 (strongly disagree) to 4 (strongly agree). The following are the scores ranges for each sub-scale: 26 to 36 for overall job satisfaction, 14 to 24 for satisfaction with job demands, 14 to 20 for satisfaction with job-related challenges, 12 to 23 for satisfaction with administrative support, 15 to 20 for satisfaction with co-worker relations, and 19 to 24 for sense of accomplishment at work.

*Burnout* for care managers was measured using a series of questions adapted from the Maslach Burnout Inventory (Maslach, 1981). Five questions were used and response options ranged from 1 (strongly disagree) to 4 (strongly agree). Scores ranged from 11 to 20.

## *5. Data Analyses*

Data pertaining to outcome measures for *caregivers* were analyzed using descriptive statistics, chi-square tests, and independent samples t-tests, as well as random effects regression growth curve analysis, and random intercept regression analysis using the SAS Proc Mixed procedure. Data pertaining to outcome measures for *care managers* were examined using descriptive statistics.

### *Caregiver Outcome Analyses*

For all outcome variables, descriptive analyses were conducted including simple frequency distributions, cross-tabulations, means, standard deviations, and percentages. Review of skewness and kurtosis of key dependent variables revealed the presence of mild skewness or kurtosis (both index values were less than 1 or larger than -1 for all dependent variables). Thus, only the results based on raw scores for key outcome variables are reported.

*Service Use and Compliance with Care Plans*. To assess these two hypotheses, we conducted a series of analyses to examine the number and types of services recommended on care plans as well as patterns of caregivers' service use. The analyses were completed by linking information drawn from care plans with data provided by care managers about caregivers' service use.

*Longitudinal Analyses for Caregiver Identity Discrepancy, Burden, Uplifts, Depression and Intention to Place.* We conducted random effects regression growth curve analysis and random intercept regression analysis to test the main hypothesis that caregivers in the TCARE® group will have improved scores on all key outcome variables compared to caregivers in the control group.

For stress burden and depression as outcomes, we report the results based on the random effects growth curve analysis which estimated the longitudinal trajectories for individual participants at one level, with the intercepts and slopes of these person-specific longitudinal trajectories analyzed as the effects of between-subjects predictors at a higher order second level (Singer & Willett, 2003). For all other outcomes, random intercept regression model analysis was used. This technique estimates the intercept (i.e., mean score) on the basis of the between-subjects predictors at a higher order second level (Singer & Willett, 2003).

Our original intent was to  conduct three-level multilevel modeling (MLM) to take into account the nested structure of the data (i.e., repeated measurement on caregiver outcomes nested within caregivers who were also nested within care managers). According to Muthen and Satorra (Muthen & Satorra, 1995), the  minimum size for the design effect required for multilevel analysis is 2. The average design effect sizes for outcome variables over four time points ranged from 1.0805 (uplifts) to 1.7963 (depression) for our sample. These results suggested that there was not a significant cluster effect (i.e., the effect of care manager level) on caregiver outcomes to require multilevel analysis. Thus, instead of MLM analysis, we conducted random effects regression growth curve analysis and random intercept regression models which fit the data best while accounting for the unbalanced structure of the data. We conducted all analyses using restricted maximum likelihood estimation as provided by the SAS Proc Mixed procedure (Littell, Milliken, Stroup, & Wolfinger, 1996).

The analyses included data from the 53 participants in  the TCARE® group and 44 participants in the control group who completed the baseline interview. Caregivers whose care recipients were institutionalized were also included in the analysis, because caregivers were still involved in caregiving for their care receivers. The models included one predictor for time that measured the amount of time that elapsed since the date of the baseline interview. The metric for time was originally calculated in days and converted to months. The baseline month was coded as 0 and only the observations measured during a 9-month observation period were included. A total of 243 observations were included in final statistical analysis. Predictor variables included in the analysis were group (TCARE® vs. control), time, and a group by time interaction term.

### *Care Manager Outcome Analysis*

Data pertaining to outcome measures for *care managers* were  examined using descriptive statistics due to small sample size (n=12).

## D. RESULTS

### *1. Caregiver Outcomes*

The primary goal of the demonstration project was to effectively support family caregivers by tailoring care plans for caregivers to their specific needs and circumstances. It was hypothesized that the TCARE® process would facilitate better outcomes for caregivers, by encouraging care managers to recommend a wider range of services and by fostering greater compliance of caregivers with the recommendations included on the care plan. It was anticipated that this pattern of service use, in turn, would promote higher levels of uplifts and lower levels of identity discrepancy, the three types of caregiver burden (i.e., objective burden, relationship burden, and stress burden), and depression for caregivers in the TCARE® group when compared to the control group. The seven main hypotheses of the study are:

Compared with caregivers in the control group, caregivers in the TCARE® group will:

1. Use a wider variety of support services.
2. Demonstrate greater compliance with the care plan.
3. Experience lower levels of identity discrepancy.
4. Experience lower levels of caregiver burden and higher level uplifts.
5. Experience lower levels of depression.
6. Experience lower level of intention to place a care receiver in alternative setting.
7. Experience higher level of satisfaction with care management services received.

As shown in Tables 10-18, the results of the data analyses provide evidence to support six of the seven hypotheses.

### *Service Use*

To assess the two hypotheses related to service use, we conducted a series of analyses to examine the number and types of services recommended on care plans, as well as patterns of caregivers' service use. The analyses were completed by linking information drawn from care plans with data provided by care managers about caregivers' service use.

Complete data for the initial care plan and data pertaining to service use for three months were available for 94 of the 97 caregivers for whom the baseline assessments were completed. Three caregivers were excluded from this analysis due to missing service use data for two caregivers and the absence of a care plan for one individual. Fifty-one (54%) of the 94 caregivers were in the TCARE® group and 43 (46%) were in the Control group. Due to the staggered enrollment process and attrition, the number of care plans available for review decreased substantially for later observation periods. Only 45 caregivers had updated care plans at the time of first follow-up, 34 caregivers had care plans updated at the second follow-up point, and 27 caregivers at third follow-up point.

***Variation in the Types of Services Recommended by Care Managers***

One feature of the TCARE® process is that it encourages care managers to focus on strategies for helping families meet an established goal rather than on obtaining specific services. This process is intended to prompt care managers to identify and recommend a wider range of service types to assist caregivers. Findings from a review of initial and first follow-up care plans for both groups indicate that, indeed, the care plans for the TCARE® group differed in important ways from those developed for members of the control group. Overall, a greater number and variety of services were recommended for caregivers in the TCARE® group than the control group.

Table 10 summarizes the mean differences in the number of services recommended out of the total of 22 possible services for the initial and first follow-up care plan by group. As shown, the average number of services included in the initial care plan for caregivers in the TCARE® group was 3.6 services, which was significantly higher than that of the control group (1.5 services)..

Table 10. *Number of Services Recommended by Care Managers*

| | **TCARE (n=51) Mean (SD)** | **Control (n=43) Mean (SD)** | **Difference** | ***p*** |
|---|---|---|---|---|
| **Care Plan** | | | | |
| Initial Care plan | 3.6 (1.2) | 1.5 (0.1) | 2.1 | <0.001 |
| First Follow-up Care plan | 3.5 (1.2) | 1.5 (0.72) | 2.0 | <0.001 |

The differences between the care plans for the two groups are more clearly illustrated in Table 11. The table provides a detailed listing for the types of services that were recommended in the care plans along with the number of persons for whom the serivces were recommended.

Of the total of 22 possible types of services, 17 were included on at least one of the initial care plans developed by TCARE® care managers, but only 13 different types of services were included in at least one of the care plans created by control care managers. The tendency for TCARE® trained care managers to include a greater variety of services is more strongly demonstrated in the follow-up care plans. A total of 19 different types of services were included on care plans developed by care managers in TCARE® group, while only 8 different types of services were included on any of the care plans developed for the control group.

The care plans for the two groups not only differed in terms of the number and variety of services that were included, but also in terms of the types of services that were most frequently recommended. The only service that was recommended for almost all caregivers in both groups was some type of in-home service. Although there was variation among the care plans in the specific type of in-home services recommended, almost all of the initial care plans (TCARE® group = 42; Control group = 37) and first follow-up care plans (TCARE® group = 34; Control group = 14) included some type of in-home support services.

Table 11. *Types of Services Recommended by Group and Care Plan*

| | **Initial Care Plan** | | | **First Follow-up Care Plan** | | |
|---|---|---|---|---|---|---|
| | **TCARE® (n=51)** | **Control (n=43)** | **$\chi^2$=(1,94)** | **TCARE® (n=36)** | **Control (n=17)** | **$\chi^2$=(1,53)** |
| **Services Recommended** | | | | | | |
| Adult Day Services | 10 | 4 | 1.266 | 8 | 2 | 0.283 |
| Assistive Technologies | 4 | 6 | 0.386 | 3 | 8 | 8.306** |
| Behavioral Health Services | 26 | 0 | 27.809*** | 17 | 0 | 9.751** |
| Case management | 0 | 1 | .007 | 1 | 0 | 0 |
| Counseling for caregiver | 8 | 11 | 1.416 | 8 | 1 | 1.181 |
| Education | | | | | | |
| Information Education | 22 | 1 | 18.875*** | 17 | 0 | 9.751** |
| Socio-psychological education | 22 | 0 | 21.870*** | 12 | 0 | 5.546* |
| Skills education | 3 | 0 | 1.056 | 2 | 0 | 0.048 |
| Education – Care Receiver | 0 | 0 | NA | 0 | 0 | NA |
| *Any Education*[1] | *40* | *1* | *51.896**** | *25* | *0* | *19.646**** |
| Informal help network | 1 | 0 | 0 | 1 | 0 | 0 |
| Info/Referral | 1 | 0 | 0 | 1 | 0 | 0 |
| In-Home services | | | | | | |
| Companion | 9 | 10 | 0.455 | 6 | 5 | 1.14 |
| Home health care | 3 | 7 | 1.672 | 2 | 1 | 0 |
| Personal care | 16 | 16 | 0.354 | 8 | 5 | 0.322 |
| Other[2] | 24 | 11 | 4.605* | 18 | 8 | 0.04 |
| *Any In-Home Service*[3] | *42* | *37* | *.237* | *34* | *14* | *0* |
| Living environment | 0 | 1 | .007 | 1 | 0 | 0 |
| Medical Health Services | 18 | 1 | 13.746*** | 10 | 1 | 2.166 |
| Overnight respite | 3 | 1 | .114 | 1 | 0 | 0 |
| Palliative /hospice | 2 | 0 | .354 | 3 | 0 | 0.347 |
| Rehabilitation | 0 | 1 | .007 | 0 | 0 | NA |
| Support Groups | 31 | 0 | 36.297*** | 19 | 0 | 11.785*** |
| Transportation | 0 | 0 | NA | 0 | 0 | NA |

* $p < 0.05$;  ** $p < .01$;  *** $p < .001$

[1] Number of people for whom any of the four educational services were recommended

[2] Includes respite and home delivered meals

[3] Number of people for whom any of the four in-home services were recommended

Apart from this one exception, the pattern of service recommendations and service use differed considerably between the two groups. Most notably, five types of services were recommended more frequently for the TCARE® group than for the control group. The chi-square tests for differences were statistically significant for all five types of services which reflected the fact that each of these services were recommended for none or only one of the caregivers in the control group. These services included (1) behavioral health services, (2) information education, (3) socio-psychological education, (4) medical health services, and (5) support groups. In contrast, for the TCARE® group behavioral health services were recommended for 26 caregivers. Socio-psychological education programs and information education were recommended for 22 caregivers. Medical health services were recommended for 18 caregivers, and support groups and were recommended for 31 caregivers. This same pattern of differences was observed in the follow-up care plans.

### *Service Recommendations and Compliance*

The data presented in Table 12 and Table 13 provide a more complete description of the differences between the two groups in the pattern of services recommended and the use of services by caregivers. The tables summarize information for each group and differences between the groups in the following areas: (1) the number and percentage of caregivers for whom each service category was recommended on the care plan; (2) the number and percent of caregivers who complied with the recommendation by using the service; and (3) the total number and percent of caregivers in each group who used each service type regardless of whether or not the service was included on the caregivers' care plan. Table 12 summarizes information for the initial care plan period while Table 13 focuses on the first follow-up period.

It is important to point out several aspects about the information in Tables 12 and 13. First, the categories for service types have been consolidated to improve the accuracy of the findings. During data analysis it was discovered that there was variation in the way different care managers recorded the same type of service use. This was particularly the case for the sub-categories of *in-home services*, where there was a lack of uniformity in the definitions of home health carecare' and 'personal care'. To address this issue of variation in reporting, a number of categories were combined into a single categories including (1) medical health services and behavioral health services; (2) counseling and socio-psychological education; (3) information education, caregiver skills education, and information and referral services; and (4) companion, home health care, personal care, and other in-home services such as in-home respite. The new categories are listed in Tables 12 and 13 along with footnotes indicating the original categories. If a recommendation was made for more than one of the services included in the broader category, only one recommendation was counted.

Second, for clarity and better understanding of the data, the service categories are listed by frequency of recommendations made by care managers. The seven services that were most frequently included on care plans are listed first.

Third, it should be noted that in some instances a caregiver's ability to use a recommended service may have been restricted by an access barrier such as being placed on a waiting list or due to a lack of available funds. While the number of caregivers who were affected by barrier issue was small, the presence of an access barrier was factored into the calculation of compliance scores so that caregivers who were not able to comply with a recommended service were not considered to be non-compliant.

Lastly, statistical tests for differences were conducted only for service types that were recommended for five or more caregivers.

As shown in Table 12, during three months of the intial care plan period, only 7 of the 14 service types listed were recommended on care plans for more than 8% of the sample. The caregivers' compliance rates for these seven services ranged from 25% to 88% for TCARE® group and from 0% to 100% for control group.

Several patterns can be discerned from the data shown in Table 12. First, in-home services was the category that was most frequently recommended and most frequently used by caregivers. Approximately 85% of the sample used some type of in-home service (84% of the TCARE® group and 86% of the control group). Care plans created at both assessment times included some type of in-home service for more than 80% of the caregivers in both groups. For the initial care plan the rate of compliance was 88% for the TCARE® group and  89% for the control group. Although in-home services was the most frequently recommended and useduse, the use of services was not statistically significant between the two groups.

Second, the largest difference between the groups in *recommended services on the care plans* and  caregivers' *compliance with recommendations* were observed for the four types of services most frequently included on the care plans of caregivers in the TCARE® group in addition to in-home services.

Two types of services most commonly recommended and used by caregivers in the TCARE® group were either  not included on the initial care plans for anyone in the control group (support groups), or recommended for only one person in the control group (medical/behavioral health). Support groups were recommended for 31 (61%) of caregivers in the TCARE® group and used by 10 (32%) of those caregivers during the initial care plan period. During the first follow-up period (see Table 13), support groups were recommended for 19 (53%) of the caregivers and 5 (26%) used the services.  During the initial care plan period, medical/behavioral health services were recommend for 38 (75%) of the individuals in the TCARE® group and were used by ten (26%) of the individuals for whom it was recommended. During the first follow-up period (see Table 13), medical/behavior health services were recommended for 23 (64%) of caregivers in the TCARE® group and used by 4 (17%) of those individuals.

Similar patterns were observed for recommendations for counseling and education programs. Care plans for 23 (45%) of the caregivers in the TCARE® group included a recommendation for caregiver education focused on skills or information about diseases or services and 6 (26%) of the caregivers used the service. In contrast, a recommendation for this type of caregiver education appeared on only one care plan for a caregiver in the control group and this individual did attend the program. These patterns were repeated for follow-up care plans.

Counseling or socio-psychological education programs were recommended for 27 (53%) of the caregivers in the TCARE® group and were used by 16 (59%) of these individuals during the initial care plan period. In comparison, this type of service was recommended for only 11 (26%) caregivers in the control group and used by only 4 of these individuals (36%).

The data pertaining to compliance with recommendations for adult day services and assistive technologies as well as other remaining service categories are less informative because the number of caregivers for whom these services were recommended is quite small. Consequently the patterns are more subject to idiosyncrasies of individuals and less interpretable. For example, at both observation times, recommendations were made for adult day care services for more caregivers in the TCARE® group than for those in the control group (10 vs. 4 at initial; 8 vs. 2 at first follow-up). Similarly, more caregivers in the TCARE® group followed the recommendation and used adult day care services (4 vs. 2 at initial; 3 vs. 2 at first follow-up). However, due to the small numbers, the actual compliance rates were greater for the control group.

The only service that was more frequently recommended for caregivers in the control group and more frequently used by them was assistive technologies. This service was recommended for 6 individuals in the control group during the initial care plan period and 5 of those individuals used the service. In contrast, assistive technologies were included on the care plans of only 4 caregivers in the TCARE® group and only one person actually used the service. A similar pattern was observed during the first follow-up care plan period.

The last set of observations to be made about the data shown in Table 12 concern the total number of caregivers who used each service, regardless of whether the service was included on their care plans. Overall, with two exceptions (informal help network and education for care receivers) a larger portion of the caregivers in the TCARE® group reported using each of the service types. Although there is great variability in the rate of usage across the different types of services, caregivers in the TCARE® group used a wider variety of services compared with caregivers in the control group. This pattern is parallel to that observed for recommendations included in care plans.

Finally, it is important to comment on the use of educational programs by 27 (53%) of the TCARE® group and 18 (42%) of the control group. While a relatively large portion of each groups attended some type of educational program, this service was not included on the care plans for the majority of the persons who attended them. Educational programs were recommended for 23 (45%) of the caregivers in the TCARE® group but were used by only 6 (26%) of these individuals. Notably, 21 of the caregivers from the TCARE® group attended an educational program although it had not been recommended by the care manager. A similar pattern was observed for the control group. While 18 (42%) of the caregivers in the control group attended an education program, this service was only recommended to one caregiver in the control group. It appears as if the decision to attend a caregiver educational program is made independent of recommendations from care managers.

As shown in Table 13, the pattern of service use observed for the first follow-up care plan was similar to that reported at the time of the initial care plan (i.e., greater variety in use of services among the TCARE® group). For both groups the rate of service use again ranged between 0% and 88%. As was true for the initial care plan, the two services that were used by caregivers in both groups were in-home services and education for caregivers. For the TCARE® group, three additional services - assistive technologies, education for caregivers, and support groups - were used by more than a quarter of caregivers. For the control group, an assistive technology was used by over 35% of caregivers. As with the initial care plan, the rate of service use across all of the different types was higher for the TCARE® group. The one exception was use of adult day services, which was used by only 4 caregivers (11%) in the TCARE® group and 3 caregivers (18%) in the control group.

Table 12. *Service Recommendation, Compliance, and Use by Group for Initial Care Plan Period*

| | Care plans that recommended the service | | | | | Caregivers who complied with the care plan | | | | | Caregivers who used the service[1] | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **TCARE® (n=51)** | | **Control (n=43)** | | **$\chi^2$ (1,94)** | **TCARE® (n=51)** | | **Control (n=43)** | | **$\chi^2$ (1, 79)[2]** | **TCARE® (n=51)** | | **Control (n=43)** | | **$\chi^2$ (1,94)** |
| | **N** | **%** | **N** | **%** | | **N** | **%** | **N** | **%** | | **N** | **%** | **N** | **%** | |
| **Service Category[3]** | | | | | | | | | | | | | | | |
| In-Home Services[4] | 42 | 82% | 37 | 86% | 0.237 | 37 | 88% | 33 | 89% | 0 | 43 | 84% | 37 | 86% | 0.055 |
| Medical/Behavioral Health[5] | 38 | 75% | 1 | 2% | 47.146*** | 10 | 26% | 0 | 0% | 0 | 11 | 22% | 0 | 0% | 8.520*** |
| Counseling *and* Socio-Psych Education[6] | 27 | 53% | 11 | 26% | 7.251** | 16 | 59% | 4 | 36% | 1.089 | 19 | 37% | 16 | 37% | 0 |
| Support Group | 31 | 61% | 0 | 0% | 36.297* | 10 | 32% | 0 | NA | NA | 17 | 33% | 3 | 7% | 8.166** |
| Education for Caregiver[7] | 23 | 45% | 1 | 2% | 20.255*** | 6 | 26% | 1 | 100% | 0.219 | 27 | 53% | 18 | 42% | 1.148 |
| Adult Day Services | 10 | 20% | 4 | 9% | 1.226 | 4 | 40% | 2 | 50% | 0 | 7 | 14% | 3 | 7% | 0.521 |
| Assistive Technologies | 4 | 8% | 6 | 14% | NA | 1 | 25% | 5 | 83% | NA | 8 | 16% | 6 | 14% | NA |
| Overnight Respite | 3 | 6% | 1 | 2% | NA | 2 | 67% | 0 | 0% | NA | 3 | 6% | 0 | 0% | NA |
| Palliative or Hospice Care | 2 | 4% | 0 | 0% | NA | 0 | 0% | 0 | NA | NA | 3 | 6% | 1 | 2% | NA |
| Rehabilitation Services | 0 | 0% | 1 | 2% | NA | 0 | NA | 0 | 0% | NA | 4 | 8% | 1 | 2% | NA |
| Informal Help Network | 1 | 2% | 0 | 0% | NA | 0 | 0% | 0 | NA | NA | 1 | 2% | 4 | 9% | NA |
| Living Environments | 0 | 0% | 1 | 2% | NA | 0 | NA | 0 | 0% | NA | 1 | 2% | 0 | 0% | NA |
| Education for Care Receiver | 0 | 0% | 0 | 0% | NA | 0 | NA | 0 | NA | NA | 0 | 0% | 4 | 9% | NA |
| Transportation | 0 | 0% | 0 | 0% | NA | 0 | NA | 0 | NA | NA | 3 | 6% | 0 | 0% | NA |

* $p < 0.05$; ** $p < .01$; *** $p < .001$

[1] Regardless of whether service was recommended

[2] Only the largest sample size is reported. The total sample size for each category varies depending on the how many care plans included a recommendation for the given service.

[3] Service category is listed in the order of the most frequently recommended service to the least frequently recommended service among all caregivers regardless of the group

[4] In-Home Services (Companion, Home health care, Personal care, and other)

[5] Medical Health Services and Behavioral Health Services

[6] Counseling for Caregiver and Socio-psychological education

[7] Information Education, Skills Education, and Info/Referral

Table 13. *Service Recommendation, Compliance, and Use by Group for First Follow-Up Care Plan Period*

| | **Care plans that recommended the service** | | | | | **Caregivers who complied with the care plan** | | | | | **Caregivers who used the service**[1] | | | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | **TCARE® (n=36) N** | **(%)** | **Control (n=17) N** | **(%)** | **$\chi^2(1,53)$** | **TCARE® (n=36) N** | **(%)** | **Control (n=17) N** | **(%)** | **$\chi^2(1,53)$[2]** | **TCARE® (n=36) N** | **(%)** | **Control (n=17) N** | **(%)** | **$\chi^2(1,53)$** |
| **Service Category**[3] | | | | | | | | | | | | | | | |
| In-Home Services[4] | 31 | 82% | 14 | 82% | 0 | 27 | 87% | 12 | 86% | 0 | 29 | 81% | 15 | 88% | 0.092 |
| Medical/Behavioral Health[5] | 23 | 64% | 1 | 6% | 13.427*** | 4 | 17% | 0 | 0% | 0 | 6 | 17% | 0 | 0% | 1.751 |
| Counseling *and* Socio-Psych Education[6] | 17 | 47% | 1 | 6% | 7.052** | 5 | 29% | 0 | 0% | 0 | 9 | 25% | 9 | 53% | 4.02* |
| Support Group | 19 | 53% | 0 | 0% | 11.785*** | 5 | 26% | 0 | NA | NA | 10 | 28% | 1 | 6% | 2.166 |
| Education for Caregiver[7] | 18 | 50% | 0 | 0% | 10.739*** | 6 | 33% | 0 | NA | NA | 11 | 31% | 11 | 65% | 5.547* |
| Adult Day Services | 8 | 22% | 2 | 12% | 0.283 | 3 | 38% | 2 | 100% | 0.625 | 4 | 11% | 3 | 18% | 0.049 |
| Assistive Technologies | 3 | 8% | 8 | 47% | NA | 1 | 33% | 6 | 75% | NA | 14 | 39% | 6 | 35% | NA |
| Overnight Respite | 1 | 3% | 0 | 0% | NA | 0 | 0% | 0 | NA | NA | 0 | 0% | 0 | 0% | NA |
| Palliative or Hospice Care | 3 | 8% | 0 | 0% | NA | 1 | 33% | 0 | NA | NA | 3 | 8% | 0 | 0% | NA |
| Rehabilitation Services | 0 | 0% | 0 | 0% | NA | 0 | NA | 0 | NA | NA | 3 | 8% | 1 | 6% | NA |
| Informal Help Network | 1 | 3% | 0 | 0% | NA | 0 | 0% | 0 | NA | NA | 0 | 0% | 0 | 0% | NA |
| Living Environments | 1 | 3% | 0 | 0% | NA | 0 | NA | 0 | NA | NA | 1 | 3% | 0 | 0% | NA |
| Education for Care Receiver | 0 | 0% | 0 | 0% | NA | 0 | NA | 0 | NA | NA | 1 | 3% | 0 | 0% | NA |
| Transportation | 0 | 0% | 0 | 0% | NA | 0 | NA | 0 | NA | NA | 5 | 14% | 0 | 0% | NA |

* *p* <0.05; ** *p*<.01; *** *p*<.001

[1] Regardless of whether service was recommended

[2] Only the largest sample size is reported. The total sample size for each category varies depending on the how many care plans included a recommendation for the given service

[3] Service category is listed in the order of the most frequently recommended service to the least frequently recommended service among all caregivers regardless of the group

[4] In Home Services (Companion, Home health care, Personal care, and other)

[5] Medical Health Services and Behavioral Health Services

[6] Counseling for Caregiver and Socio-psychological education

[7] Information Education, Skills Education, and Info/Referral

### *Key Caregiver Outcome Scores at Baseline*

Baseline scores for the seven caregiver outcome measures are shown in Table 14 for the total sample and separately for the TCARE® and control group. At baseline, mean scores for measures of the seven characteristics for the total sample of caregivers were: 18.9 (SD=7.2) for *identity discrepancy;* 24 (SD=5) for *objective burden;* 10 (SD=4.9) for *relationship burden;* 14 (SD=4.9) for *stress burden;* 12 (SD=6.0) for *depression;* 17 (SD=6.0) on *uplifts;* and 4.27 for *intention to place* (SD=1.75). There were no statistically significant differences between the two groups on any of the outcome measures at baseline.

Table 14. *Caregiver Scores on Outcome Measures at Baseline*

| | **All (N=97) Mean(SD)** | **TCARE® (n=53) Mean(SD)** | **Control (n=44) Mean(SD)** |
|---|---|---|---|
| Identity Discrepancy | 18.9 (7.2) | 18.11 (6.84) | 18.16 (6.86) |
| Objective Burden | 24 (5.0) | 24.04 (6.39) | 24.48 (5.16) |
| Relationship burden | 10 (4.9) | 10.17 (5.17) | 11.88 (5.10) |
| Stress burden | 14 (4.9) | 14.47 (5.33) | 14.74 (5.33) |
| Uplifts | 17 (6.0) | 16.94 (6.41) | 17.31 (6.39) |
| Depression | 12 (6.0) | 13.13 (6.27) | 13.91 (6.29) |
| Intention to Place | 4.27 (1.75) | 4.38 (1.67) | 4.14 (1.86) |

### *Changes in Outcome Scores by Group over Nine Months*

Table 15 provides the scores for the seven measures of caregiver outcomes for the two groups at each follow-up time. Table 16 presents the statistical results from random intercept regression models for caregiver *identity discrepancy, objective burden, relationship burden, uplifts and intention to place.* Table 17 presents the statistical results of random effects regression models for *stress burden* and *depression*. **We found significant *group by time* interaction effects for caregiver *identity discrepancy* [*F*(1, 143)=4.75, *p*=0.0309], *stress burden* [*F*(1, 144)=5.07, p=0.0258), and *depression* [*F*(1, 143)=4.89, *p*=0.0286].** These results indicate that over time scores on these three measures for caregivers assigned to the TCARE® group decreased while scores for caregivers in the control group increased.

Although differences were observed between the trajectories of scores for the two groups for *uplifts* and *intention to place*, they were not statistically significant. The effect of the interaction of *group by time*, however, approached statistical significance for *uplifts* [*F*(1, 139)=2.92, p=0.0896) and *intention to place* [*F*(1, 143)=3.22, p=0.0746). There was no significant *group by time* interaction effects for *objective burden* (*F*(1, 144)=0.02, *p*=0.8912) or *relationship burden* (*F*(1, 143)=0.60, *p*=.4407).

The trajectories of change in the five key outcome measures for which differences were observed are shown inFigures 3-7. By the nineth month, caregivers in the TCARE® group experienced a significant decrease in *identity discrepancy*, *stress burden*, and *depression* scores from baseline while the scores for these outcome measures for caregivers in the control group increased (Figure 3, Figure 4, and Figure 5). A similar trend occurred for *intention to place* although there was limited variation for both groups. At baseline caregivers in the TCARE® group had a slightly higher level of intention to place. Yet, over time, their scores decreased while those of the control group increased. As predicted, a reverse pattern was observed for *uplifts* although the difference in the trajectory was not statistically significant.

No statistically significant differences were found between the groups over time for scores on *relationship burden* or *objective burden*. However, the pattern of changes in the scores for *relationship burden* was similar to that found for *identity discrepancy, stress burden,* and *depression*. The model predicted mean score for *relationship burden* for the TCARE® group decreased slightly from 10.26 at baseline to 9.81 while the score for the control group remained unchanged (from 11.55 to 11.73). Unlike the other measures of caregiver burden, the levels of objective burden did not change substantially across observation periods for either group.

Table 15. *Caregiver Scores on Outcome Measures at Three Follow-up Time Points*

| | **First Follow-up** | | **Second Follow-up** | | **Third Follow-up** | |
|---|---|---|---|---|---|---|
| | **TCARE$^{®}$ (n=38) Mean(SD)** | **Control (n=35) Mean(SD)** | **TCARE$^{®}$ (n=28) Mean(SD)** | **Control (n=29) Mean(SD)** | **TCARE$^{®}$ (n=22) Mean(SD)** | **Control (n=21) Mean(SD)** |
| Identity Discrepancy | 17.32 (6.87) | 19.14 (7.55) | 17.21 (6.22) | 19.90 (7.30) | 16.68 (7.63) | 20.24 (7.65) |
| Objective Burden | 24.97 (4.16) | 22.86 (5.68) | 23.86 (4.15) | 23.34 (5.51) | 23.09 (4.25) | 24.38 (6.26) |
| Relationship burden | 10.76 (5.38) | 11.43 (5.97) | 10.04 (5.41) | 12.03 (5.62) | 10.95 (5.86) | 12.19 (5.82) |
| Stress burden | 14.26 (4.88) | 14.94 (5.53) | 12.64 (4.26) | 14.79 (6.44) | 12.77 (5.06) | 15.71 (5.20) |
| Uplifts | 15.92 (6.08) | 16.65 (6.09) | 18.14 (6.07) | 15.86 (5.84) | 17.82 (5.81) | 15.80 (5.74) |
| Depression | 12.03 (6.55) | 14.29 (6.79) | 11.96 (6.14) | 14.72 (6.69) | 12.05 (6.53) | 15.00 (6.36) |
| Intention to Place | 4.13 (1.53) | 4.2 (1.84) | 4.39 (1.42) | 4.17 (1.92) | 4.32 (1.46) | 4.14 (1.62) |

Table 16. *Random Intercept Regression Models of Caregiver Identity Discrepancy, Objective Burden, Relationship Burden, and Uplifts*

| | **Caregiver Identity Discrepancy** | | | **Objective Burden** | | | **Relationship Burden** | | | **Uplifts** | | | **Intention To Place** | | |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| | Est. | *SE* | p | Est. | *SE* | p | Est. | *SE* | P | Est. | *SE* | p | Est. | *SE* | *p* |
| Intercept | 18.47 | 1.02 | <.0001 | 23.97 | 0.79 | <.0001 | 11.55 | 0.75 | <.0001 | 17.18 | 0.94 | <.0001 | 4.13 | 0.26 | <.0001 |
| Group (0=control, 1=TCARE®) | -0.34 | 1.38 | 0.8045 | 0.15 | 1.07 | 0.8910 | -1.29 | 1.06 | 0.2248 | -0.56 | 1.27 | 0.6571 | 0.25 | 0.35 | 0.4754 |
| Time | 0.13 | 0.10 | 0.1821 | -0.05 | 0.07 | 0.4404 | 0.02 | 0.06 | 0.7959 | -0.13 | 0.08 | 0.0981 | 0.04 | 0.03 | 0.1572 |
| Group X Time | -0.30 | 0.14 | 0.0309 | 0.01 | 0.09 | 0.8912 | -0.07 | 0.09 | 0.4407 | 0.18 | 0.11 | 0.0896 | -0.07 | 0.04 | 0.0746 |

Table 17. *Random Effects Regression Growth Curve Models for Stress Burden and Depression*

| | **Stress Burden** | | | **CES-D** | | |
|---|---|---|---|---|---|---|
| | Est. | *SE* | p | Est. | *SE* | *p* |
| Intercept | 14.75 | 13.86 | 13.86 | 13.86 | 0.95 | <.0001 |
| Group (0=control, 1= TCARE®) | -0.19 | -0.90 | -0.90 | -0.90 | 1.29 | 0.4851 |
| Time | 0.06 | 0.08 | 0.08 | 0.08 | 0.10 | 0.428 |
| Group X Time | -0.24 | -0.32 | 0.03 | -0.32 | 0.15 | 0.0286 |

Figure 4. *Changes in Identity Discrepancy Scores by Group*

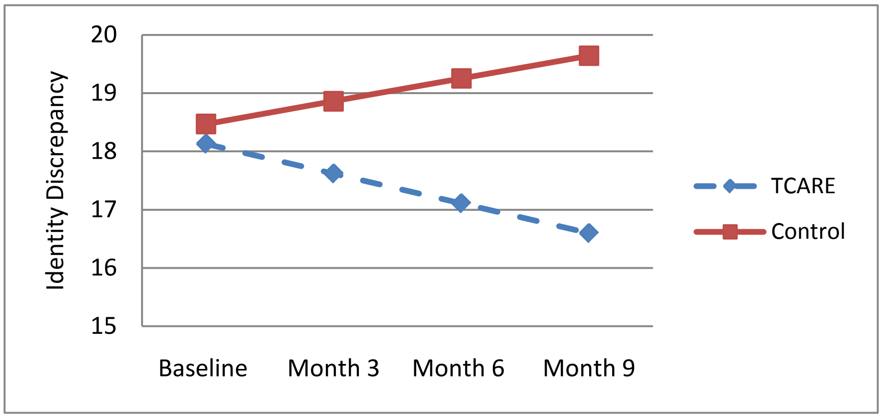


Figure 5. *Changes in Stress Burden Scores by Group*

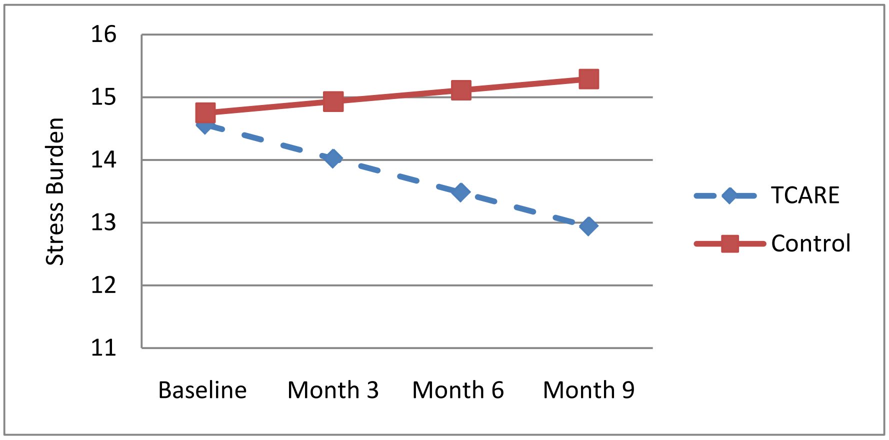


Figure 6. *Changes in Depression Scores by Group*

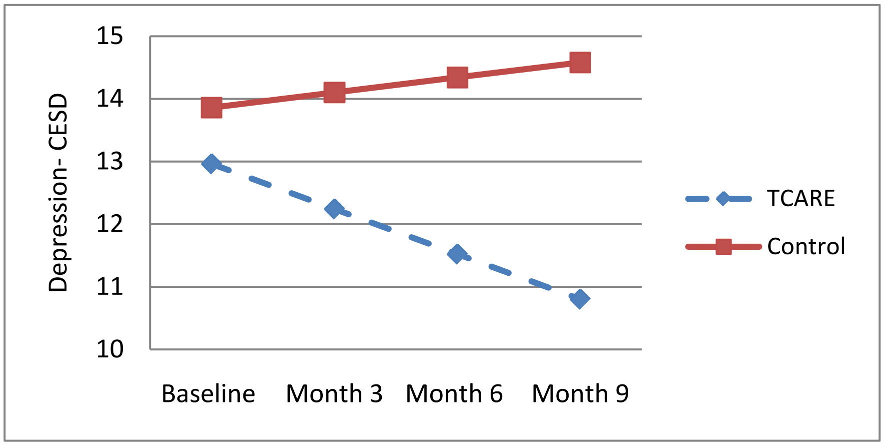


Figure 7. *Changes in Uplifts by Scores Group*

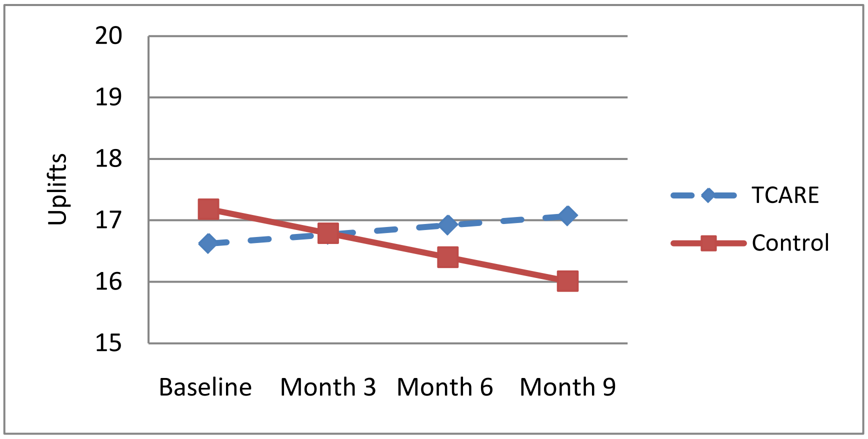
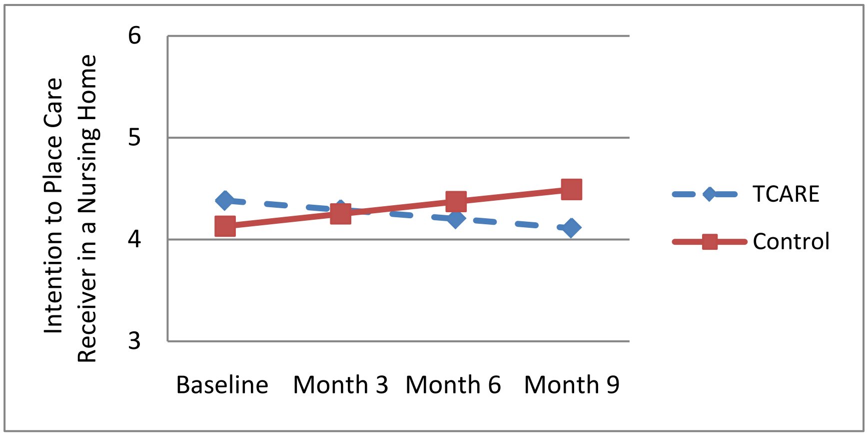


Figure 8. *Changes in Intention to Place Scores by Group*



### *Caregiver Satisfaction with Care Management Services*

Sixty-five caregivers completed a brief interview that included a series of questions about their satisfaction with care management services. On average, both caregivers in the TCARE® and control groups were highly satisfied with the care management services that they received. There was no significant difference between the scores for the two groups. The average score for caregiver satisfaction was 80.53 (SD=10.01), with the minimum possible score being 17, and the maximum possible score being 85.

## *3. Care Manager Outcomes*

### *Care Managers Job Satisfaction*

Twelve care managers (6 in each group) completed the job satisfaction questionnaire that included a series of questions about six dimensions of job satisfaction and a set of questions about job related burnout. The mean scores for job satisfaction and burnout are shown in Table 18 with higher scores indicating higher levels of job satisfaction or burnout. An examination of the mean scores for the two groups reveal slightly higher scores for TCARE® care managers on all of the dimensions of job satisfaction except for the dimension of *sense of accomplishment* and *coworker relations.* For burnout, care managers in TCARE® group reported a slightly lower level of burnout than care managers in control group. Although the observed differences are encouraging with regard to the merits of the TCARE® protocol, the small sample of care managers (n=12) precludes analyses that would be necessary to affirm the statistical significance of the differences.

Table 18. *Care Manager Job Satisfaction and Burnout Scores (N=12)*

| | **TOTAL** | **TCARE® (n=6)** | **Control (n=6)** |
|---|---|---|---|
| | | **Mean (SD)** | |
| Overall Satisfaction (9-36) | 32.7 (3.26) | 33.6 (4.33) | 32.0 (2.19) |
| Job Demands (6-24) | 19.7 (3.10) | 20.4 (3.78) | 19.2 (2.64) |
| Burnout (5-20) | 16.3 (2.74) | 15.5 (3.45) | 17.2 (1.72) |
| Administrative Challenges (6-24) | 20.3 (3.60) | 21.3 (2.25) | 19.3 (4.60) |
| Coworker Relations (5-20) | 17.6 (1.66) | 17.3(1.36) | 18.2 (1.94) |
| Job Challenges (5-20) | 17.0 (2.00) | 17.4 (1.67) | 16.7 (2.34) |
| Sense of Accomplishment (6-24) | 21.7 (1.61) | 21.3 (1.86) | 22.0 (1.41) |

# DISCUSSION

Overall, the findings from the evaluation provide strong support for the merits and benefits of the TCARE® protocol as an effective mechanism for helping family caregivers. As suggested by the title of the protocol, the Tailored Caregiver Assessment and Referral® process is designed to help care managers tailor a care plan to the unique needs and circumstances of caregivers and encourage caregivers to use the recommended services. It is believed that this targeting process will maximize the benefits that caregivers gain from the use of support services.

### *Feasibility for Wide Implementation*

Findings from the process evaluation confirmed that the training program for care managers successfully prepared care managers to implement the TCARE® process in a manner that was consistent with the manualized protocol and that they were able to maintain fidelity with the protocol throughout the demonstration project. Moreover, both survey data and anecdotal reports indicated that care managers were pleased with the process and found it useful for working with family caregivers. During the project period several care managers reported that their initial skepticism about caregivers' willingness to participate in the assessment process was not valid and that both care managers and caregivers appreciated the opportunity to explore the needs of the caregivers in a more structured manner. Although the small sample size did not allow statistical analyses of the data, the descriptive findings showing higher levels of overall job satisfaction, more satisfaction with job demands, lower levels of burnout, and higher levels of satisfaction with administrative challenges echoed the general positive view of the protocol by care managers.

### *Inclusion of a Wider Variety of Support Services on Care Plans*

The hypothesized impact of the TCARE® protocol on the design of care plans and caregivers' use of services was affirmed by findings from analyses of the number and types of services included on care plans and the patterns of service use by caregivers. Care plans prepared for caregivers served by care managers using the TCARE® protocol differed from those prepared by care managers using usual practices in two important ways. First, care plans for caregivers in the TCARE® group generally included more service recommendations and multiple types of services that were selected to address different types of needs. Second, although there was some variation, a large portion of the care plans for caregivers in the TCARE® group included one or more services that addressed physical and/or mental health needs of the caregiver. The four categories of services that were most frequently included on these care plans were medical and/or behavioral health services, support groups, counseling or socio-psychological education, and other caregiver education. All of these services have the potential to address emotional strain, caregiver stress, and/or depression. Two of the service categories,i.e. medical and/or behavioral health services and support groups, were included only on care plans for caregivers in the TCARE® group.

The differences observed in types of services recommended is consistent with the fact that the TCARE® Assessment Tool includes a screen for depression and health issues and prompts care managers to make recommendations to caregivers to seek behavioral or medical health services when caregivers' scores indicate high levels of depression or poor health. Similarly, the number of recommendations for attendance of support groups reflects the decision algorithms that are built into TCARE® protocol, which ultimately identify support groups and a variety of educational topics as services that could potentially benefit caregivers experiencing high levels of stress or depression.

### ***Caregivers' Use of Services***

Unless caregivers embrace and follow the recommendations included in their plan, the mere inclusion of services on care plans would be unlikely to promote the well-being of caregivers. A critical step in the TCARE® process is the caregiver consultation meeting that occurs after the care manager has examined and interpreted the caregiver's answers to the questions on the assessment tool. During this meeting the care manager shares and interprets the caregiver's scores on key outcome measures including identity discrepancyand caregiver burden, then discusses the care plan consultation worksheet with the caregiver. The purpose of this consultation meeting is to fully inform caregivers about their options for support services and foster their compliance with the recommendations on the care plan by engaging them in the selection process and creating a viable care plan.

The importance of inclusion of services on care plans and the care consultation process is illustrated by the fact that in the absence of any recommendation for medical/behavioral health services or support groups, no caregiver in the control group used medical or behavioral health services and *only three* individuals attended a support group. During the first observation period the compliance rates for the two services for caregivers in the TCARE® group were 59% and 32% respectively. Although these rates are lower than would be desired, they do point to the value of the TCARE® protocol for encouraging caregivers to seek and use services other than direct in-home care services.

In addition to highlighting differences between the care plans for the two groups and the wider variety of services used by those in the TCARE® group, the data also revealed similarities between the groups that are of interest. Perhaps most important for understanding the outcomes of the demonstration is the high prevalence for both groups of recommendations for some types of in-home services and the high rates of caregiver compliance and usage of these services.

This pattern likely reflects two trends. First, it is well known that caregivers are most apt to seek help for the care receiver rather than for their own stress or mental health needs and they tend to seek help late in the caregiving process when the care receiver has high levels of impairment. Consequently, it is not surprising that the majority of caregivers enrolled in the project were in need of assistance with care tasks. Second, the high rates of use of in-home services also likely reflect long standing policies and practices regarding support services for family caregivers. Most caregiver support programs have primarily focused on temporarily relieving caregivers of direct care tasks by introducing various forms of in-home support services, but generally have not attended to the emotional strains of the caregiving role. These practices and policies are reflected in the eligibility criteria that are most often used for allocating in-home and respite services and in the disproportionate allocation of available caregiver funds by area agencies on aging to direct care services. Consequently, the usual practice for all of the care managers was to recommend in-home services for the caregivers they work with because they tend to be individuals caring for persons in need of extensive assistance with ADLs and IADLs and these services are most widely available. The general focus on relieving caregivers from direct care tasks may also account for the similarities in the portion of the two samples that used adult day and assistive technologies. It should be noted that these types of services most directly addressed objective burden as opposed to stress burden, relationship burden, or depression.

### *Insights Regarding the Impact of TCARE® on Caregivers*

As a result of receiving a systematic, targeted process of assessment and care planning, it was expected that caregivers would experience long-term benefits such as improvement in their mental health as well as an increased sense of satisfaction in caregiving. In our study, we found that TCARE® was effective in lowering identity discrepancy experienced by caregivers. Caregivers in the TCARE® group had identity discrepancy scores that were, on average, 3 points lower than the scores of caregivers in the control group by the ninth month. In addition, caregivers in the TCARE® group also reported lower levels of stress burden by the ninth month. TCARE® caregivers also experienced substantially lower levels of depressive symptoms compared with caregivers in the control group over the 9-month period. Of particular note is that by the ninth month, the depression score for the TCARE® group decreased to 10.8, which was just above the cut-off score of 10, while caregivers in the control group had an average score of 14.58.

Together with the findings regarding the greater number and variety of services included on care plans and the higher usage of services by caregivers in the TCARE® group, the statistically significant differences between the two groups for measures of *identity discrepancy, stress burden, and depression* clearly support the notion that the TCARE® process helps care managers tailor care plans and fosters the use of services that promote the well-being of the caregiver. This conclusion is further supported by the differences that were observed for the two groups in uplifts and intention to place. The observed differences between the two groups in both measures were approaching significance. It is very likely that such results are due to a relatively small sample size for this current study. It is informative to note that we observed significant differences between the groups in intention to place and relationship burden in a sample of 266 caregivers who participated in a larger study that used a randomized control group study design.

To fully explore the link between the TCARE® process and nursing home placement, it would be necessary to conduct survival analyses. However, we could not conduct survival analysis with our sample because only a small number of caregivers placed a relative in a nursing home (n=5) during the duration of the study, and information on the exact time of nursing home placement was not available. Of the five caregivers with relatives placed in a nursing home, one caregiver already had a relative in a nursing home at baseline, three caregivers dropped out of the study before the first follow-up interview because the caregiver was placed in a nursing home, and one caregiver placed a relative in a nursing home before the third follow-up interview. Furthermore, there was no information available on the exact time from the baseline interview when the care receiver was placed in a nursing home.

Unlike the other measures of caregiver burden, the levels of objective burden did not change substantially across observation periods for either group. While any explanation for this lack of change is somewhat speculative, there may be at least two possible explanations. First, a large segment of caregivers participating in the study were caring for care receivers with high impairment and have been doing so for extended periods of time (e.g., 47 percent of care receivers could not perform at least one or more ADLs at all and on average, caregivers spent 53 hours per week caring for care receiver). At baseline, the average score on objective burden was 24 (SD= 5) and over 70 percent of caregivers fell under the ‘high’ range (19-30) of the pre-established screening criteria. Caregivers who continue to provide such high levels of care are generally very committed to the role whether or not their caregiving responsibilities interfere with their lives. Given the continued need by many care receivers for intense care, it is perhaps understandable that caregivers’ level of objective burden was not lowered. Simply put, caregivers in this situation “do what needs to be done” regardless of the consequences.

Second, care managers from both groups recommended or offered caregivers types of services that generally help caregivers attend to tasks related to ADLs or IADLs for care receivers such as in-home services (e.g., companion, home health care, and personal care services) as discussed in more detail in the ***Service Recommendations and Compliance*** section. While a wider variety of services that address the mental and physical health of the caregiver were recommended for and used by caregivers in the TCARE® group, in-home services and adult day care were used by almost an equal proportion of caregivers in each group. As noted above, these services offer relief for caregivers from specific caregiving tasks and are most apt to alleviate objective burden. Consequently, given the comparable patterns of  use of direct care support services by the two groups of caregivers, it is not surprising that we did not observe differences between the two groups in objective burden..

# V. REFINING AND TESTING TCARE®*e*

The second and third goals of the Georgia demonstration project were focused on augmenting, testing and refining an electronic version the TCARE® process. TCARE®*e* was created to assist care managers with using the TCARE® process to serve family caregivers.

The TCARE®*e* software automates the TCARE® process by using data entered into the TCARE® Assessment Summary Sheet to implement the decision algorithm, identify appropriate goal(s), strategies and support services, create the Care Plan Consultation Worksheet, and a Caregiver Care Plan. As the program leads care managers through the TCARE® process, it creates an Assessment Summary Sheet, a Care Plan Consultation Worksheet, and a Caregiver Care Plan. The program allows care managers to print completed forms so that they may be shared with caregivers. TCARE®*e* is a secure website and is HIPAA compliant. Client information entered using the site **may not** be accessed by anyone other than the assigned TCARE® care manager. To ensure security, every TCARE® certified care manager is given a unique user name and password. It is expected that the TCARE®*e* software will cut the time in half that was spent completing the paper and pencil version. Funds allocated for this project supported training of care managers who were previously TCARE® certified to use TCARE®*e* and explore its merits and limitations.

### *B. Linking TCARE® to the Enhanced Service Program (ESP) Resource Database*

The second goal of the extendedGeorgia demonstration project was to link TCARE®*e* with the Enhanced Service Program (ESP) resource database used by Area Agencies on Aging throughout Georgia. The TCARE®*e* web based system was designed to enable users to easily transition between the TCARE®*e* system and state wide electronic resource databases. The TCARE® team in collaboration with the Georgia Department of Aging Services and the Atlanta Regional Commission created a prototype using Georgia's Enhanced Services Program (ESP) resource database. First, members of the TCARE® team collaborated with staff from the Atlanta Regional Commission (ARC) to create a crosswalk between the Guide for Selecting Support Services and resources applicable to the aging population found in Georgia's state wide resource database, ESP. In November 2008, the results of this effort were incorporated into the TCARE®*e* system with guidance from web administrators. Support staff created a database of the search terms used by ESP for each of the 73 service categories listed in the Guide for Selecting Support Services, which was then incorporated into the TCARE®*e* system. In December 2008 web administrators received the URL for the ESP database from Sheila Melton from ARC and programmed it into the TCARE®*e* system. In October 2009 the TCARE® team received a written memorandum giving staff permission to access the ESP system for training and demonstration purposes only.

### *C. TCARE®e Training & Technical Assistance*

The third goal of the project was to test and refine TCARE®*e*. Two training sessions were held in January 2009 to introduce TCARE®*e* to Certified TCARE® care managers. On

January 20, 2009, a TCARE®*e* Training was conducted in Atlanta, Georgia. Eleven care managers and four administrators were trained to implement TCARE®*e*. On January 22, 2009, a second TCARE®*e* training was conducted in Brunswick, GA with 9 care managers participating. In addition to the two training sessions, one-on-one technical support has been provided to those care managers having difficulties navigating around the site.

On July 23, 2009, all certified care managers in Georgia received an email containing a username and password to access the TCARE®*e* site along with a TCARE®*e* Quick Start Guide to help navigate through the system. Throughout the next 12 months a series of TCARE®*e* Refresher Webinars and Webinar trainings were conducted for care managers. Two TCARE®*e* Refresher Webinars were held on August 3 and 4, 2009 for eleven care managers and one administrator who wanted a second walk through of the program.

Seven one-hour TCARE®*e* Trainings were conducted by the TCARE® project team for care managers trained by Master Trainers in the state of Georgia. These trainings sessions were conducted using ***GoTo****Meeting*® technology. Webinars were conducted December 1 and 3, 2009, March 3, 8, and 30, 2010 and April 1 and 5, 2010. After each training session care managers were emailed their username and password along with a TCARE®*e* Quick Start Guide that contained useful information on how to navigate through the program.

### *C. Refinement of TCARE®e*

Throughout the project care managers were encouraged to contact our team with questions, suggestions, or concerns about navigating through the program. To facilitate technical assistance an icon was built into the system that can be used by administrators to generate an email request addressed to the TCARE® team. Care managers may use this function at anytime while navigating through the program.

On February 4, 2010, the TCARE® team emailed a questionnaire to the 48 certified care managers requesting feedback about their use or non-use of TCARE®*e*. For those who did not respond, a follow-up email was sent on February 16, 2010. Care managers were asked about the elements or aspects of TCARE®*e* that they liked or disliked and changes and additions they would like to be made to the program. Feedback from the questionnaire has provided guidance for making changes and embellishments to the TCARE®*e* system

# VI. TCARE® TRAINING & EXPANSION

The fourth goal of the demonstration project was to facilitate wider adoption and use of TCARE® throughout the state. To accomplish this goal, the UWM team trained and certified seven individuals as TCARE® Master Trainers. The seven trainees included three care managers, two supervisors, and two intake staff who had previously been certified to use TCARE®. Three of the individuals were from the Atlanta area and the other four were from the Savannah/Brunswick area.

The training protocol for TCARE® Master Trainers included an initial two-day intensive session and a mentored apprentice TCARE® training. The initial training took place in September 2009. During the two-day session participants reviewed and practiced teaching the core elements of the TCARE® process using training materials made available on the TCARE® website.

In October 2009, the seven trainees were mentored by UWM trainers as they conducted a TCARE® training for 12 care managers. The mentored apprentice training included a one day pre-training session which was used to review individual assignments and powerpoints, and conduct mock group activities. UWM trainers oversaw all segments of the TCARE® training during the 2-day initial session, the 1-day follow-up training and the two webinar refresher sessions.

All seven certified master trainees successfully completed the master training program. Completion of the program enables certified master trainers to conduct future trainings throughout the state. Materials needed to conduct TCARE® trainings can be downloaded by certified trainers from the TCARE® website. Arrangements have already been made by DAS to host a TCARE® training in the fall of 2010 that will be conducted by the some of the newly certified Master Trainers.

# VII. SUMMARY

This report provided a detailed description of a three-year demonstration project conducted by the State of Georgia Division of Aging Services (DAS) in collaboration with researchers in the Office of Applied Gerontology at the University of Wisconsin-Milwaukee (UWM). The project was funded by two awards from the AoA and involved implementing and evaluating the impact of the Tailored Caregiver Assessment and Referral® (TCARE®) protocol.

A randomized control group study design was used to assess outcomes for caregivers and care managers. Overall, the findings provide strong support for the merits and benefits of the TCARE® protocol as an effective mechanism for helping family caregivers. Data from the process evaluation affirmed the feasibility of training care managers from a wide range of organizations to consistently and accurately implement the protocol.

The outcome evaluation documented the influence of the protocol on the practices of care managers and on the well-being of family caregivers. As predicted, care managers trained to use the TCARE® protocol included a larger number and wider variety of services on care plans. Most of the additional services that were included addressed the emotional aspect of the caregiving role and focused on stress and depression of caregivers.

The study findings document differences between the TCARE® and control groups on key outcome measures. Over time caregivers in the TCARE® group experienced a decline in identity discrepancy, stress burden, depression, and intention to place and an increase in uplifts.

No difference was observed between the groups in objective burden over time. This lack of difference is consistent with the finding that almost 85% of the caregiver in both groups used support services that were intended to relieve them of direct care tasks that tend to be linked most directly with objective burden.

In addition to affirming the merits of the TCARE® protocol, the project included efforts to refine and augment the electronic version of TCARE® and link it with Georgia's electronic resource data base. These efforts, in combination with the training and certification of seven Master TCARE® Trainers, have laid a valuable foundation for replicating the protocol throughout the state.

# REFERENCES

Andersen, E. M., Malmgren, J. A., & Cater, W. B. (1994). Screening for depression in well older adults: Evaluation of a short form of the CES-D (Center for Epidemiologic Studies Depression Scale). *American Journal of Preventive Medicine, 10*(2), 77-84.

AOA. (2004). *Performance outcomes measures project V (POMP): Case management survey module*. Retrieved January 2009. from https://www.gpra.net/default.asp.

Bourgeois, M. S., Schulz, R., & Burgio, L. (1996). Intervention for caregivers of patients with Alzheimer's disease: A review and analysis of content, process, and outcomes. *International Journal of Human Development,, 43,* 35–92.

Burgio, L. D., Solano, N., Fischer, S. E., Stevens, A., & Gallagher-Thompson, D. (2003). Skill building: Psychoeducational strategies. In C. D.W. & D. Gallagher-Thompson (Eds.), *Innovative interventions to reduce dementia caregiver distress: A clinical guide* (pp. 119-138). New York: Springer.

Gitlin, L. N., Reever, K., Dennis, M. P., Mathieu, E., & Hauck, W. W. (2006). Enhancing quality of life of families who use adult day services: Short- and long-term effects of the adult day services plus program (Vol. 46, pp. 630-639).

Houser, A., & Gibson, J. (2008). *Valuing the invaluable: The economic value of family caregiving, 2008 update*. Washington, DC: AARP.

Littell, R. C., Milliken, G. A., Stroup, W. W., & Wolfinger, R. D. (1996). *SAS system for mixed models*. Cary, NC: SAS Institute.

Maslach, C. J., S. E. . (1981). The measurement of experienced burnout. *Journal of Occupational Behavior*, *2*, 99-113.

Mittelman, M. S. (2000). Effect of support and counseling on caregivers of patients with Alzheimer's disease. *International Psychogeriatrics*, *12*(1), 341-346.

Montgomery, R. J. V. (2002). *A new look at community-based respite programs: Utilization, satisfaction, and development*. New York: Haworth Press.

Montgomery, R. J. V., Rowe, J. M., & Kosloski, K. (2007). Family caregiving. In J. A. Blackburn & C. N. Dulmus (Eds.), *Handbook of gerontology: Evidence-based approaches to theory, practice, and policy* (pp. 426-454): John Wiley & Sons.

Montgomery, R. J. V., Rowe, J. M., & Kwak, J. (2009). *Final Report to the State of Georgia Division of Aging Services: The Tailored Caregiver Assessment and Referral® Protocol Project: July 1, 2007 – December 31, 2008*. Milwaukee, WI: University of Wisconsin-Milwaukee.

Muthen, B., & Satorra, A. (1995). Complex sample data in structural equation modeling. In P. Marsden (Ed.), *Sociological Methodology* (Vol. 25, pp. 267-316). Cambridge, MA: Blackwell.

Schulz, R., O'Brien, A., Czaja, S., Ory, M., Norris, R., Martire, L. M., et al. (2002). Dementia caregiver intervention research: In search of clinical significance. *Gerontologist, 42*(5), 589-602.

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving (Vol. 108, pp. 23-27 ).

Singer, J. D., & Willett, J. B. (2003). *Applied Longitudinal Data Analysis: Modeling change and event occurrence*. Oxford, New York: Oxford University Press.

Sorensen, S., Pinquart, M., & Duberstein, P. (2002). How effective are interventions with caregivers? An updated meta-analysis. *The Gerontologist, 42*(3), 356-372.

Teri, L., Logsdon, R. G., Uomoto, J., & McCurry, S. M. (1997). Behavioral treatment of depression in dementia patients: A controlled clinical trial (Vol. 52, pp. P159-166).

| Goal 1 - Objective #2 | Annual Performance Measure | Action Steps | Annual Update on Objective |
|---|---|---|---|
| The objective should state what will be accomplished; when it will happen and why the outcome is needed. | Describe quantifiable annual performance measure that assures stated objective/outcome will be achieved. If this is the first year for measuring this objective, then state how baseline is calculated. | Describe realistic and specific action steps needed and state date to be completed and person responsible to accomplish this task (When and Who). | Brief update on the progress toward meeting this objective. Was it met or not met? What was the measurable outcome at the end of fiscal year? (Reported in next Area Plan) |
| **Goal 1 - Objective #2 SFY 2012** | **SFY 2012** | **SFY 2012** | **SFY 2012** |
| **Implement TCARE at ADRC/Gateway for caregiver referrals in all counties of the AAA by 2015**<br>**T-Care helps identify: 1) presence of depression; 2) types and levels of stress; 3) appropriate goals for supporting caregivers; 4) strategies to meet goals, and 5) an array of services consistent with goals and strategies.** | **1) Complete TCARE screens on caregivers (includes determination of depression and stress, and intention to place in a nursing home ) for 25% of the region's counties for openings in caregiver programs by June 2012** | **1) Train new Gateway staff on use of TCARE screen**<br>**2) Gateway/ADRC staff screen callers for 25% of the region's counties for openings in caregiver programs**<br>**3) Gateway/ADRC staff refers caregivers who meet TCARE criteria for case management** | **Example of Annual Update: (Completed in SFY 2013 Area Plan)**<br>**1 training session was held**<br>**27% of caregivers were screened for TCARE in 33% (3 out of 9) of counties served**<br>**35% met criteria were referred to case management for full T-Care assessment and care plan to reduce level of stress.** |

|  |  |  |  |
|---|---|---|---|
| **Goal 1 - Objective #2 SFY 2013** | **SFY 2013** | **SFY 2013** | **SFY 2013** |
| **Implement TCARE at ADRC/Gateway for caregiver referrals in all counties of the AAA by 2015**<br>**T-Care helps identify: 1) presence of depression; 2) types and levels of stress; 3) appropriate goals for supporting caregivers; 4) strategies to meet goals, and 5) an array of services consistent with goals and strategies.** | **1) Complete TCARE screens on caregivers (includes determination of depression and stress, and intention to place in a nursing home) for 50% of the region's counties for openings in caregiver programs by June 2013** | **1) Train new Gateway staff on use of TCARE screen.**<br>**2) Gateway/ADRC staff screen callers for 50% of the region's counties for openings in caregiver programs**<br>**3) Gateway/ADRC staff refer caregivers who meet TCARE criteria for case management** | **Example of Annual Update: (Completed in SFY 2014 Area Plan)**<br>**2 training sessions were held**<br>**30% were screened for TCARE in 55% (5 out of 9) of counties served**<br>**45% met criteria were referred to case management for full T-Care assessment and care plan to reduce level of stress.** |
| **Goal 1 - Objective #2 SFY 2014** | **SFY 2014** | **SFY 2014** | **SFY 2014** |
| **Implement TCARE at ADRC/Gateway for caregiver referrals in all counties of the AAA by 2015.**<br>**T-Care helps identify: 1) presence of depression; 2) types and levels of stress; 3) appropriate goals for supporting** | **1) Complete TCARE screens on caregivers (includes determination of depression and stress, and intention to place in a nursing home) for 75% of the region's counties for openings in caregiver programs by June 2014.** | **1) Train new Gateway staff on use of TCARE screen.**<br>**2) Gateway/ADRC staff screen callers for 75% of the region's counties for openings in caregiver programs.**<br>**3) Gateway/ADRC staff refer caregivers who meet TCARE criteria to service providers for openings in caregiver programs** | **Example of Annual Update: (Completed in SFY 2015 Area Plan)**<br>**1 training session was held**<br>**40% were screened for TCARE in 77% (7 out of 9) of counties served** |

|  |  |  |  |
|---|---|---|---|
| caregivers; 4) strategies to meet goals, and 5) an array of services consistent with goals and strategies. |  | in those counties. | 50%% met criteria were referred to case management for full T-Care assessment and care plan to reduce level of stress. |
| **Goal 1 - Objective #2 SFY 2015** | **SFY 2015** | **SFY 2015** | **SFY 2015** |
| Implement TCARE at ADRC/Gateway for caregiver referrals in all counties of the AAA by 2015.<br>T-Care helps identify: 1) presence of depression; 2) types and levels of stress; 3) appropriate goals for supporting caregivers; 4) strategies to meet goals, and 5) an array of services consistent with goals and strategies. | 1) Complete TCARE screens on caregivers (includes determination of depression and stress, and intention to place in a nursing home) for 100% of the region's counties by June 2015. | 1) Gateway/ADRC staff complete TCARE screens for 100% of the region's counties for openings in caregiver programs<br>2) Gateway/ADRC staff refer caregivers who meet criteria to care managers<br>3) Care managers complete TCARE assessments and care plans for 100% of caregivers who meet criteria and who will participate | Example of Annual Update:<br>(Completed in SFY 2016 Area Plan)<br>1 training<br>50% were screened for TCARE in 100% (9 out of 9) of counties served<br>45% met criteria were referred to case management for full T-Care assessment and care plan to reduce level of stress.<br>60% of caregivers who were referred for full assessment received caregiver services and care plan to reduce level of stress. |

| Goal 2 - Objective #2 | Annual Performance Measure | Action Steps | Annual Update on Objective |
|---|---|---|---|
| The objective should state what will be accomplished; when it will happen and why the outcome is needed. | Describe quantifiable annual performance measure that assures stated objective/outcome will be achieved. If this is the first year for measuring this objective, then state how baseline is calculated. | Describe realistic and specific action steps needed and state date to be completed and person responsible to accomplish this task (When and Who). | Brief update on the progress toward meeting this objective. Was it met or not met? What was the measurable outcome at the end of fiscal year? (Reported in next Area Plan) |
| **Goal 2 - Objective #2 SFY 2012** | **SFY 2012** | **SFY 2012** | **SFY 2012** |
| **Implement TCARE with caregivers for In-Home Respite Program by 2015** | **Establish a baseline for # of caregivers receiving T Care full assessment and then referred for in-home respite.** | **Care managers will complete the T-Care full assessment at time of reassessment for clients receiving In-Home Respite during SFY 2012** | **Example of Annual Update: (Completed in SFY 2013 Area Plan)**<br>**27% of caregivers received T care full assessment and referred for in-home respite in SFY 2012** |
| **Goal 2 - Objective #2 SFY 2013** | **SFY 2013** | **SFY 2013** | **SFY 2013** |
| **Implement TCARE with caregivers for In-Home Respite Program by 2015** | **Complete TCARE screens on 50% of in-home respite caregivers by June 2013.** | **Care managers will complete the T-Care full assessment at time of reassessment for clients receiving In-Home Respite during SFY 2013** | **Example of Annual Update: (Completed in SFY 2013 Area Plan)**<br>**52 % of in-home respite caregivers have received T Care full assessment in 2013** |
| **Goal 2 - Objective #2** | **SFY 2014** | **SFY 2014** | **SFY 2014** |

| SFY 2014 | | | |
|---|---|---|---|
| Implement TCARE with caregivers for In-Home Respite Program by 2015 | Complete TCARE screens on 75% of in-home respite caregivers by June 2014. | Care managers will complete the T-Care full assessment at time of reassessment for clients receiving In-Home Respite during SFY 2014 | Example of Annual Update: (Completed in SFY 2013 Area Plan)<br>80% of in-home respite caregivers have received T Care full assessment in SFY 2014 |
| **SFY 2015** | **SFY 2015** | **SFY 2015** | **SFY 2015** |
| Implement TCARE with caregivers for In-Home Respite Program by 2015 | Complete TCARE full assessment on 100 % in-home respite caregivers by June 2015. | Care managers will complete the T-Care full assessment at time of reassessment for clients receiving In-Home Respite during SFY 2015 | Example of Annual Update: (Completed in SFY 2013 Area Plan)<br>98% of in-home respite caregivers have received T Care full assessment in SFY 2015 |

Purpose: This form is to assist TCARE® Master Trainers with identifying and tracking all activities needed to conduct TCARE® training.

State: Cohort: Training Date:

Key Contact: Trainers:

| Master Trainer Tasks | When | Complete? | Date | Notes |
|---|---|---|---|---|
| 1. Set up Time 1 and Time 2 training | As scheduled | ☐ | | Work with key contact to determine dates and locations, and identify training needs. |
| 2. Send Time 1 Welcome/Homework Letter | One month prior to training | ☐ | | Send letter to key contact. Key contact to disseminate to cohort. |
| 3. Conduct Time 1 Training | As scheduled | ☐ | | Per outlined curriculum. |
| 4. Send Time 2 Homework Letter | Within 5 business days of completed Time 1 training | ☐ | | Send letter to key contact. Key contact to disseminate to cohort. |
| 5. Identify tentative webinar (Time 3) dates | 2 weeks prior to Time 2 training | ☐ | | Work with key contact to identify possible dates. One webinar session needed for every 8 trainees. |
| 6. Conduct Time 2 training | As scheduled | ☐ | | Per outlined curriculum. |
| 7. Send out Time 3 Homework/Proposed Webinar Dates Letter | Within 5 business days of completed Time 2 training | ☐ | | Send letter to key contact. Key contact to disseminate to cohort. |
| 8. Manage receipt of case summary homework (Time 3 assignment) | As submitted | ☐ | | Create hard folder and log receipt. File in mutually agreed upon location. |

| | | | | |
|---|---|---|---|---|
| 9. Communicate with key contact regarding receipt of case summaries received from cohort | By due date already established | ☐ | | Communicate with key contact about cases received and missing. |
| 10. Case summaries to reviewer | On cohort due date | ☐ | | Provide review with all copies of case summaries. |
| 11. Set up Time 3 webinars | As scheduled | ☐ | | Schedule using the GoToMeeting Software. |
| 12. Send out Time 3 Log-in Information Letter | Within 5 business days of webinar | ☐ | | Send letter to key contact. Key contact to disseminate to cohort. |
| 13. Identified trainer, review case summaries | Within 3 business days of scheduled webinar | ☐ | | Review cases to evaluate understanding of the process. Tailor webinar presentation or discussion to meet the needs of cohort. |
| 14. Conduct Time 3 webinar(s) | As scheduled | ☐ | | Conduct training using GoToMeeting Software. |
| 15. Track Time 3 webinar attendees | At webinar | ☐ | | May use software to print a hard copy of checklist. |
| 16. Instruct attendees to complete certification exam within 2 weeks | At completion of webinar | ☐ | | Within webinar presentation, the last slide should be information on where to take the exam. |
| 17. Complete Trainee Face Sheet and Submit to UWM TCARE® Training Team | Within 3 business days of Time 3 webinar | ☐ | | A face sheet will be completed for each trainee who a Master Trainer wishes to certify. |
| **UWM TCARE® Training Team Tasks** | **When** | **Complete?** | **Date** | **Notes** |
| **OVERSEE THE EXAM AND CERTIFICATION PROCESS** | | | | |
| 1. Communicate status of exam process for each trainee. | Upon each individual trainee's completion of exam | ☐ | | UWM Team will communicate with Master Trainer or Key contact the status of exams completion for each trainee. |

| | | | | |
|---|---|---|---|---|
| 2. Contact trainees who fail exam to discuss and offer a second exam. | Within 2 business days of failure | ☐ | | Work with trainee to offer alternate exam. |
| 3. Complete Trainee Face Sheet for each trainee & return copy to Master trainer or key contract. | Within 7 business days of completion | ☐ | | Will complete bottom portion of Trainee Face sheet – indicate certification and provide Master Trainer or key contact with copy. |
| 4. Provide TCARE® Certification Certificate. | With 7 business days of successful completion. | ☐ | | Provide each trainee who successfully completes the training and certification with TCARE® Certification Certificate. |

## Georgia Aging Network TCARE Caregiver Assessment Project
## Information regarding Implementation and SFY 2011 Activities

In a letter sent to AAAs on June 15th, 2010, Dr. Jay Bulot, Director of DAS, indicated that there is a lot of momentum at the federal level for implementing evidence based programs. Further, there is a lot of emphasis at the state level for a triage process to divert individuals from going into a nursing home and focusing heavily on caregivers. Therefore, Dr. Bulot stated, the next four year Area Plan will have a focus in the area of evidence-based caregiver support. Based upon the work in Georgia over the past few years, DAS is moving toward implementing TCARE statewide.

### What is TCARE?

TCARE, or Tailored Caregiver Assessment and Referral protocol is an evidence-based process that guides care managers in 1) understanding caregivers needs 2) strategically selecting and recommending services, 3) consulting with caregivers to give them the opportunity for informed choice, and 4) creating a care plan that caregivers will embrace and follow. TCARE was developed by Dr. Rhonda Montgomery and colleagues at the University of Wisconsin (UWM0.

TCARE helps identify: 1) presence of depression 2) types and levels of stress
3) appropriate goals for supporting caregivers 4) strategies to meet goals, and 5) an array of services consistent with goals and strategies.

### Background of TCARE Projects in Georgia

Georgia has participated in two demonstration projects regarding TCARE, funded by the U.S. Administration on Aging. The first grant was for 15 months, concluding September 30, 2008. DAS then requested and was approved for a second grant to turn the TCARE project into a longitudinal study, with enhancements. The data collection of the second grant concluded June 30, 2010. Participating organizations in this grant were the Atlanta Regional Commission AAA, Coastal Georgia AAA, Southern Georgia AAA, and the Alzheimer’s Association. Both grants in this study were randomized trials.

A second TCARE project was a four state study, funded by the National Alzheimer’s Association, which included Georgia, Washington, Minnesota, and Michigan. This study concluded June 30, 2010.

**Findings from the Georgia Study**

Findings from the evaluation provide solid evidence that using the TCARE® protocol to serve family caregivers leads to *lower levels of identity discrepancy*[2], *stress burden*[3], and *depression.* Results from the data analysis affirmed statistically significant differences between the two groups for measures of all three of these outcomes. The data also revealed similar trends for intention to place[4] and uplifts[5], although not statistically significant. Caregivers in the TCARE® group were experiencing a decrease in their desire to place the care receivers in an institutional setting and increase in uplifts over time while caregivers in the control group experienced the opposite. The differences in these scores, however, only approached statistical significance in part due to the small sample size.

**It is noteworthy that differences between the groups in intention to place and relationship burden[6] were statistically significant (i.e., caregivers in the TCARE group had significantly lower scores than those in the control group) in a parallel multisite study that included a sample of 266 caregivers** (*Note: The parallel study Dr. Montgomery is referring to is the four state study*).

Additional findings and information about TCARE may be found in the Final Report from UWM which is attached. Findings from the four-state study are not officially available yet, though Dr. Montgomery has included one finding related to intention to place in the paragraph above. Findings from both the Georgia and four state studies will be submitted for peer review to *The Gerontologist* later this calendar year.

---

[2] Identity Discrepancy-psychological state that accrues when there is a disparity between the care activities in which a caregiver is engaging and his/her identity standard. An example of identity discrepancywhich demonstrates that it is not the task, but how you feel about the task that is causing the discrepancy would be a son providing personal care for his mother.

[3] Stress Burden-stress due to aspects of life, measured by tension, nervousness, and anxiety.

[4] Intention to place-A question on the TCARE screen asks "given your relative's (spouse/partner/parent) CURRENT CONDITION, would you consider placing him/her in a different type of care setting, such as a nursing home or another care facility for long-term placement? Choices are definitely not, probably not, probably would, definitely would, does not apply-relative is in care facility

[5] Uplift-positive psychological outcome associated with caregiving.

[6] Relationship Burden-demands for care and attention over and above the level that the caregiver perceives are warranted by the care receiver's condition.

## TCARE Screening at Gateway

Based on recommendations of care managers, a screening instrument was developed to identify which caregivers are in need of a full assessment and may benefit from the TCARE process. ADRC/Gateway staff must take a webinar hosted by UWM staff; the webinar is specifically designed for those who administer a TCARE screen. The webinar takes approximately one hour. In collaboration with UWM, DAS will schedule two webinars this fiscal year for Gateway staff. The dates of the webinars will be listed later in these instructions.

Once ADRC/Gateway staff members complete a webinar, they are authorized to use the TCARE screen. Once the screener is familiar with the screen, it takes an average of 12-15 minutes to complete. Screeners then add the scores on the screening tool. For the purposes of the Georgia and four state studies, those caregivers rating moderate or high on any of three types of burden, **and/or** who have a moderate or high identity discrepancy, **and/or** who are depressed, **and/or** who have intention to place relatives into a nursing home or other long term care setting are referred on to a care manager for a full TCARE assessment. Thus, use of the TCARE screen becomes a triage process to identify those caregivers in crisis.

## TCARE Process for Care Managers

Care managers must complete a training program and be certified to use the TCARE protocols. The training consists of: 1) attendance and completion of a 2 1/2 day initial training, with homework assignments prior to the training 2) approximately three weeks after the initial training, completion of a homework assignment and participation in a two hour application training webinar 3) approximately three weeks after the Application training, participation in a Review Training webinar, and 4) taking of a web-based Certification exam, administered by UWM. Once a care manager passes the exam, they are eligible to use TCARE (*note: there are proprietary fees for the exam and access to the TCARE protocols that will be discussed later in this document*).

During the training, care managers learn about the seven step TCARE process, which includes the following tools:

- Caregiver Screen (discussed above)
- Caregiver Assessment Form (the Care Manager conducts this assessment face-to-face with the caregiver)
- Assessment Summary Sheet
- Service Selection Maps (decision algorithms)
- Guides for Selecting Support Services
- Care Plan Consultation Worksheet
- Care Plan

Once a care manager completes the assessment, they:

- go to the UWM website and access TCARE e, to complete the remaining steps in the TCARE process. They enter some of the data, (such as scores on burdens, identity discrepancy, depression, and intention to place) from the Assessment Form into the Assessment Summary Sheet.
- Service Selection Maps (decision algorithms) have been built into TCARE e, which automatically choose the best strategies/interventions to address the needs identified.
- The care manager goes to the Guide for Selecting Support Services is a detailed listing of the types of services which are most likely to address the needs for the caregiver. The Guide uses a hyper-link to get to the ESP Data Base, which cross-walks the services listed in the TCARE Guide with those services available in the ESP Data base for the area in which the care manager is searching for (for your reference, a copy of the cross walk is attached, though the use of the hyperlink itself is all done electronically).
- The Care Manager then prints a Care Consultation Worksheet and either mails it to the Caregiver or conducts another home visit. The Care Manager explains the services recommended to the Caregiver, and why they are recommended, based on the particular scores, to increase compliance with the care plan (we know from research that caregivers will not use services when they do not perceive them to be needed or useful[7]).
- Once the Care Manager and caregiver agree on the services, the Care Manager creates a Care Plan, and mails a copy to the Caregiver,
- Follow-up is recommended at regularly scheduled intervals; Georgia's aging network will decide how often to schedule them through participation in a TCARE Work Team, which will be described below.

## TCARE Activities for SFY 2011

SFY 2011 will afford the opportunity for all AAAs to train Gateway and some care managers in TCARE. Six AAAs had voluntarily planned to implement a TCARE project during the fiscal year. For the six remaining AAAs, this will be the time to get some of your staff trained and to get started. Once **AAAs have care managers certified in TCARE, they need to be prepared to begin using it upon completion of training—experience has shown that this is crucial so that they can practice what they have learned.**

---

[7] Kosloski, K., and Montgomery, RJV, Youngbauer J. Utilization of Respite Services: A Comparison of Users, Seekers, and Nonseekers. The Journal of Applied Gerontology. 2001: 20 (1): 111-132.

### *Care Manager Training Dates in SFY 2011*

Training for care managers is a four step process. As outlined on the attached brochure, it involves: 1) a 2 ½ day face-to-face training 2) approximately 3 weeks later, participation in a webinar, with homework submitted in advance 3) about 3 weeks later, participate in a second webinar, with homework submitted in advance 4) care managers then go on-line and take a 2 hour web-based certification exam.

DAS will provide four trainings for Care Managers during the fiscal year:

| | |
|---|---|
| August 17-19, 2010 | In Brunswick at the Coastal Georgia AAA offices<br>(note: this class is full) |
| October, 2010 | In Atlanta at the Alzheimer's Association |
| March 15-17, 2011 | In Brunswick at the Coastal Georgia AAA offices |
| April 2011 | In Atlanta at the Alzheimer's Association |

Every AAA will be offered a number of slots to get care managers trained this fiscal year. We will send notices to you in advance of each to register your staff. Class size for each training is limited to 16 persons to optimize one-on-one interaction between instructors and participants.

Future trainings for care managers and Gateway staff will be offered in subsequent years so that additional staff members can be trained as your TCARE projects evolve during the four year Area Plan cycle.

### *Who Will Conduct the Care Manager Training*

Georgia has two teams of TCARE Master Trainers. Team Atlanta is composed of staff from the Visiting Nurse Health Systems, and the Alzheimer's Association, Georgia Chapter. Team Brunswick is composed of staff from the Coastal Georgia AAA and the Chatham County Board of Health.

### *Travel Costs for Care Manager Training*

*DAS will pay for training materials, fees for Master Trainers, web-based certification exams for care managers, and access to TCARE e for certified care managers.*

**AAAs will need to cover the travel expenses for each care manager certified in TCARE, which will include three nights in a hotel, mileage, and meals.** To assist AAAs in estimating the cost of the travel, the locations for the training are as follows**:**

ARC, Legacy Link, Middle Georgia, Northeast, Northwest, & Three Rivers care manager training events will be held in Atlanta at the Alzheimer's Association.

CSRA, Coastal, Heart, River Valley, Southern Georgia, and SOWEGA care managers training events will be held in Brunswick at the Coastal Georgia AAA offices.

### *Gateway Webinar Dates in SFY2011*

In collaboration with UWM, DAS will provide two webinars for Gateway staff during SFY2011 to demonstrate how to use the TCARE screen. **If your TCARE goals do not include the involvement of Gateway staff this fiscal year you probably should wait to train your Gateway staff in use of the TCARE screen until the fiscal year in which you want them involved in TCARE.** Several Gateway webinars will be offered each year for several years, so as your TCARE phase-in continues, have your Gateway staff trained during the year in which they will be involved in TCARE in your region. Dates of the webinars for this fiscal year are:

- October 7, 2010 1-2 PM
- March 30, 2011 1-2 PM

Registration will be sent at later dates; as phone lines for each call are limited to 14, AAAs are encouraged to have several staff sit at one computer monitor and listen in to the calls.

### Development of a TCARE Work Team and Meeting Dates/Times in SFY 2011

A number of issues related to the implementation of TCARE will be decided by the TCARE Work Team. These issues include but are not limited to: 1) deciding the criteria for referral to care management for a full TCARE assessment, 3) how often to re-assess, and 3) fidelity of the TCARE process, that is, ensuring that our training and execution of TCARE is done correctly so that we can achieve the same results as the two TCARE studies.

Two face-to-face meetings are planned for SFY2011 in Macon. One will be held on February 17, 2012, from 10:00 AM-3:30 PM and the other will be on May 19th, 2012 from 10:00 AM-3:30 PM. Both meetings will be held at the Middle Georgia AAA offices. *For those who wish to participate but are unable to travel, the meeting will also be available via telephone.* While AAAs are not required to participate, it is DAS's hope that all will since the decisions made will affect everyone and will become policy.

### AIMS Development

During the year, DAS ITS Team is having the TCARE Screen and Assessment Tools built into AIMS. The build is estimated to be completed by early in calendar year 2011. Until then, AAAs can use the paper and pencil versions of the Screen and Assessment, which will be provided to you. (As previously stated, once the assessment is complete, certified TCARE care managers can go to the web to complete the TCARE assessment process).

## Statewide TCARE Contract

DAS is in the process of negotiating a contract with the University of Wisconsin (UWM). The contract is necessary to provide services including but not limited to web-based certification examinations for care managers, access to Georgia care managers to TCARE e, Training Manuals for care managers, User Manuals for care managers, webinars for Gateway staff, and additional technical assistance or training needs.

In addition to the cost of the training itself, DAS will pay for the on-line exams necessary for care managers to become certified in TCARE, and will pay for access to TCARE e for certified care managers.

## TCARE Calendar of Events

For your convenience and planning purposes, a separate handout is attached which details all of the TCARE dates and locations for SFY 2011.

## Instructions for Area Plan

In the Area Plan for 2012-2015, AAAs should include TCARE goals in two sections: 1) in Gateway/ADRC, and 2) Under HCBS Caregiver and TCARE. Examples of objectives in each of these sections will be included in the Area Plan instructions.

Depending on available funding, AAAs may specify a particular county or counties and/or target special populations i.e. Alzheimer’s caregivers where TCARE will be utilized.

Area Plan instructions will be provided to AAAs in the near future.

# TCARE CALENDAR OF EVENTS FOR SFY 2011
## Revised 8/9/10

**Registration for all events required. Registration information will be sent out well in advance of each event.**

**Care Manager Training: Generally, limited to 3 Care Managers/training. Exceptions will apply and will be conveyed to individual AAAs. Training is for 2 ½ days, beginning early on Day 1 and adjourning on day three in time to drive home.**

**Atlanta trainings (Oct 2010, April 2011) for ARC, LL, Middle Ga, NE, NW, and Three Rivers.**

**Brunswick March 2012 training is for CSRA, Coastal, Heart, River Valley, So. Georgia, and SOWEGA (August 2010 is for AAAs that participated in Georgia demo or four-state study, to train their care managers who were control (not treatment group).**

**Gateway Webinars: Open to all AAAs. Limit one phone line/AAA, so multiple Gateway staff in each AAA will need to share a phone line and computer screen to watch the webinar.**

**TCARE Work Team: Open to all AAAs, and participation is optional. Face-to-face meetings in Macon, with telephone conferencing available for those who want to participate but who are unable to travel.**

| Date | Event | Notes |
|---|---|---|
| August 17-19, 2010 | Care Manager Training Brunswick | For CSRA, Coastal, Heart, So. Ga, Alz. Assoc. |
| October 7, 2010<br>1:00-2:00 PM | Gateway Webinar | For any AAA registration required |
| October 26-28, 2010 | Care Manager Training Atlanta | For ARC, LL, Middle, NE, NW, & Three Rivers |
| February 17, 2012<br>10:00 AM-3:30 PM | Work Team Macon | For all AAAs (phone participation also avail). |
| March 22-24, 2012 | Care Manager Training Brunswick | For CSRA, Coastal, Heart, River Valley, So. Georgia, and SOWEGA |
| March 30, 2012<br>1:00-2:00 PM | Gateway Webinar | For any AAA Registration required |
| April 5-7, 2011 | Care Manager Training Atlanta | For ARC, LL, Middle, NE, NW, & Three Rivers |
| May 19, 2012<br>10:00 AM-3:30 PM | Work Team Macon | For all AAAs (phone participation also avail). |

# TCARE® TRAINING

## SPONSORED BY:

**What is TCARE®?** Tailored Caregiver Assessment and Referral (TCARE®) is a caregiver assessment and referral process that is designed to assist care managers or family specialists who work with family caregivers. The TCARE® process provides care managers with tools for accurately accessing caregivers' needs. It also provides care managers with a process for using information to target appropriate services and create highly individualized tailored care plans. The TCARE® process was developed by Rhonda J.V. Montgomery and colleagues at the University of Wisconsin-Milwaukee (UWM)[1].

**Who can use TCARE®?** Care managers or family specialists who want to use TCARE® in their work with family caregivers must be trained and certified to use the process.

**What does the training and certification involve?** The training consists of three segments: (1) two and a half day intensive training, (2) web-based application training, and (3) web-based review training. Certification consists of participation in the training activities and successful completion of an on-line exam.

| | **In-Person Training (2 ½ Days)** | **Application Training Web-based (2 hours)** | **Review Training Web-based (2 hours)** | **Certification Exam Web-based (2 hours)** |
|---|---|---|---|---|
| What? | A two and a half day (20 hours) in-person training conducted by TCARE® trainers. | A web based (2-hour) training conducted by TCARE® trainers. | A web based (2-hour) training conducted by TCARE® trainers. | A two hour web-based exam. |
| When? | As scheduled. | Three weeks after in-person training; as scheduled. | Three weeks after application training; as scheduled. | Following review training; as scheduled. |
| Why? | Provides an overview of the TCARE® process and guiding theory. Also includes group work where participants utilize case studies to apply the process. | Provides an opportunity to review cases submitted in advance of web-based training. Strong emphasis on applying the TCARE® process. | Provides an opportunity to review cases submitted in advance of web-based training. Strong emphasis key concepts of the TCARE® process. | The exam is used to assess care manager's proficiency with using the TCARE® process. |
| What's required? | Participant writes a short one-page narrative summary about an existing client family and brings it to training. | Participant completes steps 1-3 of the TCARE® process with an existing client family in advance of training. | Participant completes steps 1-5 of the TCARE® process with a different existing client family in advance of training. | Computer with internet access, and username and password to access exam on TCARE® website[1] (provided by UWM staff post review training). |

**If you are interested in attending an upcoming TCARE® Training, please contact:**

Contact Person Name:

Contact Person Phone:

Contact Person Email:

# CROSSWALK OF TCARE AND ENHANCED SERVICES PROGRAM (ESP) TAXONOMIES

**Color Key:**

- 🟦 **= TCARE Category**
- 🟩 **= TCARE Descriptor of Service Element**
- 🟨 **= ESP Category**
- 🟧 **= Other Examples for Possible Inclusion**
- 🟪 **= Grandparenting (caregivers of adults who also provide child care)**

| T Code | TCARE Category Descriptor | ESP Category | ESP Descriptor | Other Possible TCARE Categories |
|---|---|---|---|---|
| **1.** | **ADULT DAY SERVICES (Experience time away from care responsibilities)** | | | |
| **1a** | **Health model** | | | |
| | | Adult Day Care | Adult Day Care | (1b. Adult Day Services) |
| | | Adult Day Care | Adult Day Health | |
| | | BI/SCI | BI/SCI Respite Out-of-Home | (1b. Adult Day Service; 10a. Overnight Respite Services) |
| | | DD | Adult Day Programs-Develop.Disabilities | |
| | | DD | DD- Adult Day Program | |
| **1b** | **Social model** | | 2 | |
| | | Adult Day Care | Adult Day Care | (1a. Adult Day Services) |
| | | BI/SCI | BI/SCI Respite Out-of-Home | (1a. Adult Day Services;  10a. Overnight Respite Services) |
| | **Other Examples** | **DD** | **Specialized Clubs/DD** | (7.Informal Help Network:other examples) |
| | | **BI/SCI** | **Specialized Clubs/Brain Injury-SCI** | (7.Informal Help Network:other examples) |
| | | **BI/SCI** | **BI/SCI Recreation Programs** | (7.Informal Help Network:other examples) |
| **2.** | **ASSISTIVE TECHNOLOGIES (Promote safety and functional abilities of care receiver)** | | | |
| **2a** | **Emergency Response Systems (e.g. medical alert, in-home monitoring)** | | | |
| | | Emergency Response Systems | Emergency Response Systems | |
| | | Emergency Response Systems | Personal Emergency Notification Systems | |
| **2b** | **Home Modifications (ramps, walk-in shower, grab-bars)** | | | |
| | | Housing Services | Energy Conservation/Weatherization | |
| | | Housing Services | Home Modifications | |
| | | Housing Services | Maintenance and Repair | |
| **2c** | **Home safety features (e.g, lighting, locks, exit door alarm)** | | | |
| **2d** | **Assistive devices and care supplies (e.g. low beds, mobility devices, commodes, protective garments)** | | | |
| | | Animal Services | Canine Assistance Program | |
| | | Animal Services | Pet Supportive Service | |
| | | Animal Services | Vetinarian Service | |
| | | Caregiver Services | Caregiver Support Program | (g; p y ; g<br>and Protection: financial) |
| | | Caregiver Services | Caregiver Voucher Programs | (1a,b. Adult Day Services; 8. In-Home Supports/Services; 6b. Financial and Legal Services) |

| | | |
|---|---|---|
| Health Support Services | Assistive Technology Devices | (4.3a. Education:build CG skills) |
| Health Support Services | Daily Living Aids | (4.3a. Education:build CG skills) |
| Health Support Services | Durable Medical Equipment | (4.3a. Education:build CG skills) |
| Health Support Services | Specialized Clothing | (4.3a. Education:build CG skills) |

# Appendix 114-A

## Core Assessment Instruments for Non-Medicaid Home and Community Based Services

### 114-A-1.1 About the DON-R

The Determination of Need-Revised (DON-R) assessment instrument was developed during 1987 through 1989 by a team of researchers at the Gerontology Center of the University of Illinois at Chicago for use by the Illinois Department on Aging's statewide network in determining eligibility for home and community based services, including its Medicaid waiver program. The DON not only provides the basis for determining program eligibility, but also provides sufficient information for case managers to evaluate care needs and develop plans of care.

The DON is used as a basic individual needs assessment to determine where there are deficits in functioning and where there are remaining strengths, including the presence or absence of a support system. The DON provides documentation of the need for assistance across a range of impairments and is a true ordinal scale. An ordinal scale provides clearly defined meanings for each level of impairment, each level of unmet need for care and each functional activity. Thus changes in score represent actual changes in capacity and/or need for assistance and the scoring can be used to track changes over time.

When originally field tested, the DON was normed to a nursing home population on the impairment scale. People in the community with impairment level scores of 15 or higher are similar in their degree of impairment to the upper two-thirds of a nursing home population. However, it is the unmet need for care which has more bearing on the actual potential for placement outside the home. The availability of a continuous range of scores means that staff responsible for planning or assisting others with planning for care are able to develop plans to order only the actual amount of service needed and can provide the basis for controlling costs. The DON can assist in developing a plan of care which promotes independence in the community, or if assessing the strengths of someone already in a nursing home, to help the resident remain as independent as possible in that setting.

## 114-A-1.2 Summary of the Determination of Need-Revised (DON-R) Assessment of Functional Impairment and Unmet Need for Care

| | Column A | Column B | |
|---|---|---|---|
| Function | Level of Impairment | Unmet Need for Care | Comments |
| 1. Eating | 0 1 2 3 | 0 1 2 3 | |
| 2. Bathing | 0 1 2 3 | 0 1 2 3 | |
| 3. Grooming | 0 1 2 3 | 0 1 2 3 | |
| 4. Dressing | 0 1 2 3 | 0 1 2 3 | |
| 5. Transferring | 0 1 2 3 | 0 1 2 3 | |
| 6. Continence | 0 1 2 3 | 0 1 2 3 | |
| 7. Managing Money | 0 1 2 3 | 0 1 2 3 | |
| 8. Telephoning | 0 1 2 3 | 0 1 2 3 | |
| 9. Preparing Meals | 0 1 2 3 | 0 1 2 3 | |
| 10. Laundry | 0 1 2 3 | 0 1 2 3 | |
| 11. Housework | 0 1 2 3 | 0 1 2 3 | |
| 12. Outside Home | 0 1 2 3 | 0 1 2 3 | |
| 13. Routine Health | 0 1 2 3 | 0 1 2 3 | |
| 14. Special Health | 0 1 2 3 | 0 1 2 3 | |
| 15. Being Alone | 0 1 2 3 | 0 1 2 3 | |
| Box A: Subtotal Col. A, Items 1-6 | **Box A** | **Box B** | Box B: Subtotal Col. B, Items 1-6 |
| Box C: Subtotal Col. A, Items 7 - 15 | **Box C** | **Box D** | Box D: Subtotal Col. B, Items 7- 15 |
| Box E: Subtotal Box A and Box C | **Box E** | **Box F** | Box F: Subtotal Box B and Box D |
| | | **Box G** | Box G: Subtotal Box E and Box F |

| **Score:** | **Interpretation:** |
|---|---|
| 0 | No Impairment or no unmet need for care |
| Greater than 1 and less than or equal to 1.5 | Mild impairment or mild unmet need for care |
| Greater than 1.5 and less than or equal to 2 | Mild to Moderate impairment or mild to moderate unmet need for care |

| | |
|---|---|
| Greater than 2 and less than or equal to 2.5 | Moderate impairment or moderate unmet need for care |
| Greater than 2.5 | Severe impairment or unmet need for care |

### 114-A-1.3 Overview of Scoring the Impairment Level

**Table 1**

| **Impairment Level Score** | **And If …** |
|---|---|
| Score “0” if the client performs or can perform all essential components of the activity, with or without assistance… | - no significant impairment level remains;<br>- the activity is not required by the client (refers to these IADLs only: medication management, routine health and special health); and/or<br>- the client may benefit from but does not require verbal or physical assistance |
| Score “1” if the client performs or can perform all essential components of the activity, with or without assistance, but some impairment of function remains which requires verbal or physical assistance in some or all components of the activity … | - client experiences *minor, intermittent fatigue* in performing the activity;<br>- client *takes longer* than would be required for an unimpaired person to complete the activity;<br>- client must perform the activity *more often* than an unimpaired person; and/or<br>- client requires *some* verbal prompting to be able to complete the task. |
| Score “2” if the client cannot perform most of the essential components of the activity, with or without assistance, but some impairment of function remains which requires verbal or physical assistance in some or all components of the activity … | - client experiences *frequent or rapid fatigue or minor exertion* in performing the activity;<br>- client takes an *excessive amount of time* to perform the activity;<br>- client must perform the activity *much more frequently* than an unimpaired person; or<br>- client requires *frequent* verbal prompting to complete the task. |

| | |
|---|---|
| Score “3” if the client cannot perform the activity and requires someone else to perform the task, although s/he may be able to assist in small ways; or requires constant verbal or physical assistance. | |

Note: A score of “0” in functional impairment will automatically yield a score of “0” for unmet need.

## 114-A-1.4 Overview of Scoring Unmet Need for Care

**Table 2**

| **Unmet Need for Care Score** | **And If …** |
|---|---|
| Score "0" , regardless of the impairment level if the client's need for assistance is met to the extent that the client is at no risk to health or personal safety… | - client has no need for assistance; and/or<br>- additional assistance would not benefit the client. |
| Score "1" if the client's need for assistance is met most of the time… | - there is minimal risk to health or personal safety if additional assistance is not provided. |
| Score "2" if the client's need for assistance is *not* met most of the time…. | - there is moderate risk to health or personal safety if additional assistance is not provided |
| Score "3" if the client's need for assistance is seldom or never met or there is severe risk to health and safety…. | - the client would require acute medical intervention if additional assistance is not provided. |

In-depth training is available upon request to the Division.

# Financial Worksheet

| | | |
|---|---|---|
| **Consumer Name:** | **Representative Name:** | |
| **Income** | **Consumer** | **Spouse** |
| Wages or Salary (Earned Income) | | |
| Net Wages from Self-Employment | | |
| Social Security Pensions, Survivor Benefits and Disability Payments | | |
| Public Assistance (Includes AFDC, SSI, General Assistance) | | |
| Dividends, Interest, Royalties | | |
| Private Pensions or Annuities | | |
| Unemployment Compensation | | |
| Workers Compensation | | |
| Alimony | | |
| Child Support | | |
| Veteran's Pensions | | |
| Military Allotments | | |
| **Total Gross Income:** | $ 0.00 | 0 |
| **(Cost of Out-of-Pocket Healthcare, Rx, OTC Meds)** | | |
| **Total Net Income:** | $0.00 | $0.00 |
| **Grand Total Net:** | $0.00 | |
| **Resources** | **Consumer** | **Spouse** |
| Life Insurance, Cash Value | | |
| Burial Policy, Cash Value | | |
| Burial Plot | | |
| Savings Accounts | | |
| Checking Accounts | | |
| Trust Funds | | |
| Stocks and Bonds | | |
| IRA's and Annuities | | |
| Second Property/Land | | |
| Second Automobile | | |
| CD's | | |
| Other | | |
| **Total:** | $0.00 | $0.00 |
| **Grand Total:** | $0.00 | |
| Recent transfer of resources or home/property? If yes, enter amount and date of transfer. | | |

I understand that it is my responsibility to disclose correct and complete information. I hereby attest that the information that I have supplied is complete and accurate to the best of my knowledge. I realize that any changes must be reported as soon as possible.

| | |
|---|---|
| Signature: | Date: |

# Support Options

Your Home, Your Community, Your Choice

Atlanta Regional Commission

---

## Background

- Federal Initiative – A0A
- DHR/DAS awarded Nursing Home Diversion Modernization Grant (NHDM) - January 2008
- ARC, AAA – Demonstration Site

---

## Key Elements

- Modernization
  - OAA funds and other state revenues are used in a more flexible manner to provide more service options.
- Consumer-Directed Care Model
  - Empowers consumers to direct their service dollars.
- Nursing Home Diversion
  - Delays or prevents nursing home placement.

---

## What is Support Options?

- A demonstration program that invites consumers who are at-risk of nursing home placement and Medicaid spend-down to actively participate in managing their own services within an established budget.

---

## Who is eligible for Support Options?

- **Eligible consumers must:**
  - **Be age 60 or older**
  - **Meet frailty level for nursing home placement**
  - **Have a total individual income not to exceed $2,022 per month**

---

## Eligibility Continued

- Have resources:
  - 12,000-$39,000 for a single individual
  - $116,400-$143,400 for a couple
  - Pay a cost share based on HCBS-Non Medicaid sliding scale for cost share

## What Counts as Income?

- Wages or Salary
- SS Pensions, Survivor Benefits, Disability Payments
- Public Assistance (Includes SSI)
- Dividends, Interest, Royalties
- Private Pensions or Annuities
- Unemployment Compensation

## Income Continued…

- Worker's Compensation
- Veteran's Pensions
- Military Allotments

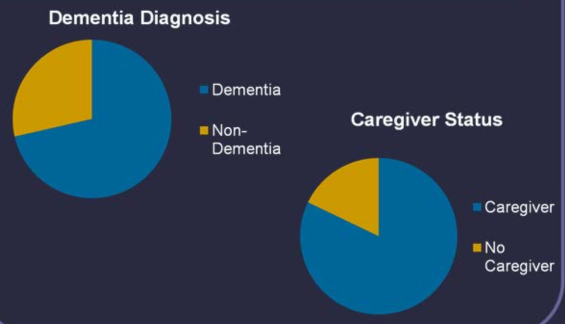
## What Counts as Resources?

- Cash value of life insurance and burial policies
- Burial plot
- Savings and checking accounts
- Trust funds
- Stocks, bonds, IRA's, CD's, and annuities
- 2nd home, property, automobile

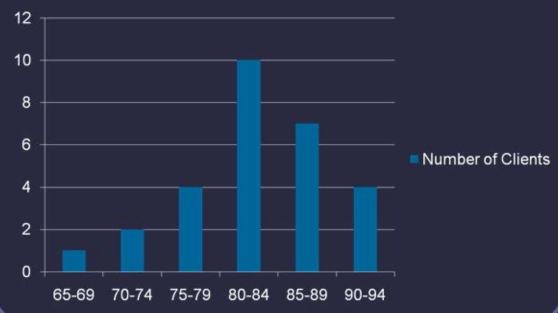
## More on Income & Resources

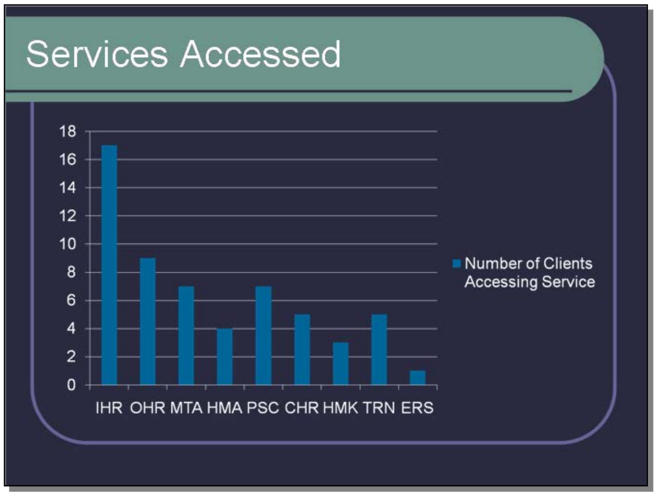
- Cost share is based on the consumer's net income, not gross income
- The consumer's home or 1st automobile are not counted as resources
- Although we don't verify resources, we do ask that all consumer's/family representatives sign our Financial Agreement

## Consumer Profiles

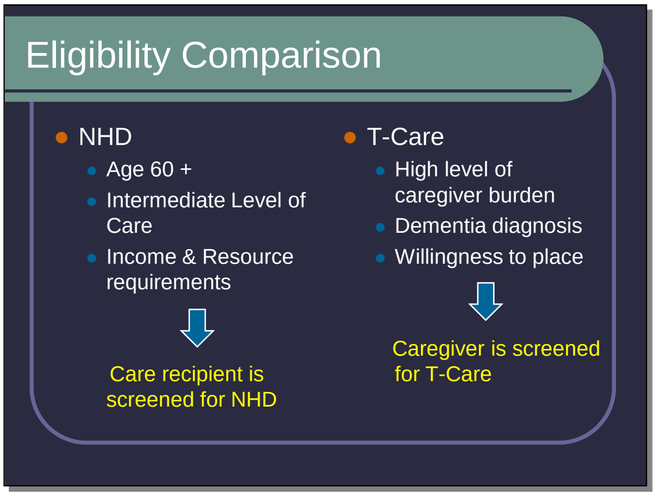


## Age Distribution





## Services Accessed



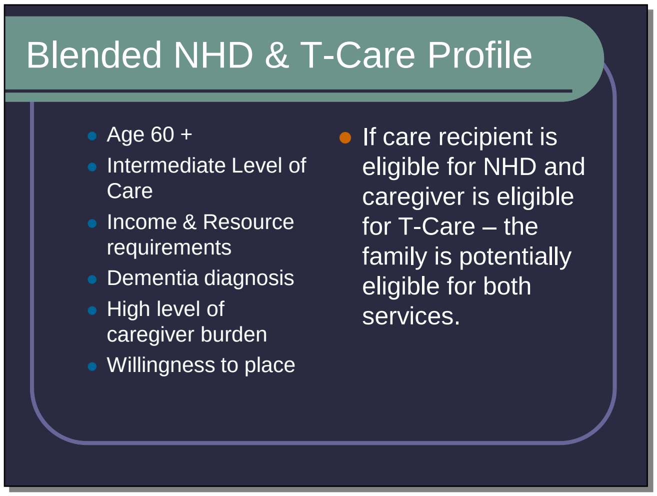
## Eligibility Comparison

- NHD
  - Age 60 +
  - Intermediate Level of Care
  - Income & Resource requirements

Care recipient is screened for NHD

- T-Care
  - High level of caregiver burden
  - Dementia diagnosis
  - Willingness to place

Caregiver is screened for T-Care



## Blended NHD & T-Care Profile

- Age 60 +
- Intermediate Level of Care
- Income & Resource requirements
- Dementia diagnosis
- High level of caregiver burden
- Willingness to place

- If care recipient is eligible for NHD and caregiver is eligible for T-Care – the family is potentially eligible for both services.

## Support Options Contact Info

- Cara Pellino, Support Options Counselor
- Atlanta Regional Commission
- 404-463-3158
- cpellino@atlantaregional.com

# Appendix C

## TCARE®/DD Work Group Participants

## State of Georgia - 2 9

| Name | Organization | Work Group 1 January | Work Group 2 August | Work Group 3 October |
|---|---|---|---|---|
| Alan Goldman | DAS |  | X |  |
| Barbara Dale | VNHS | X | X | X |
| Beth English | Easter Seals |  | X |  |
| Cheryl Harris | ADRC | X |  |  |
| Cliff Burt | State of Georgia, Division of Aging Services, Administration | X | X | X |
| Debora Cook | DBHDD |  | X | X |
| Dorothy Davis | VNHS |  |  |  |
| Dottie Adams | Governors’ Council on Handicapped |  |  |  |
| Felicia Anderson | Dekalb Developmentally Disabled Council |  |  |  |
| Ginny Helms | Atlanta Alzheimer’s Association | X |  |  |
| Jamie Cramer | Georgia Division of Aging Services |  |  |  |
| Janet Deal | Believe There Care Managers |  | X |  |
| Janice Nodvin | Project Grand – Georgia | X |  |  |
| Jeni Coyne | State of Georgia, Division of Aging Services, Access to Services | X | X |  |
| Jennifer Reed | DBHDD – Region 1 | X |  |  |
| Kathy George | VNHS | X |  |  |
| Kim Grier | Georgia Division of Aging Services |  | X |  |
| Lana Hardy | Atlanta Alliance for Developmental Disability | X | X |  |
| Lesa Hope | Atlanta Alliance for Developmental Disability | X |  |  |
| Leslie Sessley | State of Georgia, Division of Aging Services, Administration | X |  |  |
| Maria Greene | Division Director |  | X |  |
| Maria Lee | DBHDD– Region 1 | X | X | X |
| Mary Lou Vegara | Atlanta Regional Commission | X | X | X |
| Michelle Schwartz | The Columbus Creative |  |  |  |
| Norma Lundy | Atlanta Regional Commission – DD | X |  |  |
| Patricia Griffiths | Emory & Veterans Administration |  | X |  |

# Appendix C

## TCARE®/DD Work Group Participants

## State of Georgia - 2 9

| Name | Organization | Work Group 1 January | Work Group 2 August | Work Group 3 October |
|---|---|---|---|---|
| Renee Simenaux | Believe There Care Managers | | X | X |
| Riki Bolster | Atlanta Alliance on Developmental Disabilities | | X | X |
| Robyn Berger | Dekalb County Disability Council | X | | |
| Scott Bonk | DBHDD – Region 1 | | | X |
| Sheryl Arno | Dekalb DD Council | | X | |
| Cathie Berger | Atlanta Regional Commission | X | | |
| Sue Burgess | Atlanta Regional Commission – DD | | | X |
| Whitney Fuchs | GA Community | | X | X |

# Adapting and Expanding the Use of TCARE® in Georgia

## Implementing TCARE® for use with the Developmental Disabled Population

**Rhonda Montgomery & Jessica Jacobs**

**University of Wisconsin-Milwaukee**

**November 2009**

---

## Overview of TCARE®

The Tailored Caregiver Assessment Process (TCARE®) is an evidence based care management process that was designed to assist care managers and family specialists who work with older adults and family caregivers. What sets the TCARE® process apart from other care management processes is that the primary focus of TCARE® is on the caregiver. The TCARE® protocol was created in 2007 and is currently being evaluated in a three year, multi-site randomized trial with 20 organizations located in Georgia, Michigan, Minnesota and Washington. Early findings from a small demonstration study completed in Georgia show statistically significant differences between the control and treatment groups in the level of caregivers' burdens, uplifts and depression. With these findings, in addition to the overwhelming positive response from care managers and organizations implementing the TCARE® process, UWM was approached by the Georgia Division of Aging Services to assess the potential benefits and viability of using or adapting the TCARE® protocol for use with families caring for an individual with a developmental disability. This document provides a summary of the process that was used to explore the feasibility of adapting TCARE® for use by organizations serving the DD population and a work plan for steps that would be necessary to conduct a pilot project.

## Project Activities

To explore the feasibility of adapting TCARE®, three meetings were held with members of the University of Wisconsin-Milwaukee TCARE® team and key informants with expertise and experience working with older adults and person with developmental disabilities (See Appendix C). An orientation meeting was held on January 21, 2009 in Atlanta, Georgia, and two workgroups were conducted on August 6, 2009 in Decatur, Georgia and on October 16, 2009 in Atlanta, Georgia.

### Initial Orientation Meeting, January 2009

The purpose of the orientation meeting was to enable the UWM team to become more familiar with programs serving the DD population, share information about the TCARE® process and the Identity Change Theory, and determine whether there was interest from service providers to explore implementation of the TCARE® process by their organizations. The discussion during this initial meeting enabled the UWM team to gain a better understanding of the ways in which service providers worked with the DD population and their family members. The meeting also provided the team with feedback regarding the applicability of the Caregiver Identity Change Theory for this population and the potential merits of using the TCARE® process. During this initial meeting participants were asked to identify issues and barriers that would need to be addressed to successfully adapt TCARE® within organizations serving the DD population. The outcome of the initial meeting was that there was a general consensus that the Caregiver Identity Change Theory resonated with participants and that the TCARE® process could potentially benefit the DD population and their family members. Plans were made to conduct a meeting that would include care managers and directors who worked directly with the target population and explore the types of changes or adaptations that might be necessarily to adapt

TCARE® for use by providers serving the DD population.

## Workgroup Meeting, August 2009

The first workgroup session , held on August 6, included 18 individuals from a variety of state and community based service organizations that serve persons with developmental disabilities and their families. The purpose of this session was to explore questions and barriers that would need to be addressed to successfully adapt TCARE® within organizations serving the DD population. This group agreed that the Caregiver Identity Change Theory could potentially inform providers working with family caregivers, but identified aspects of the theory that might not be fully applicable to the DD population. The group also agreed that some questions on the Screen and Assessment tools would need to be revised or modified to make it more applicable to the DD population. Additionally, suggestions were made regarding changes that might be necessary in the Guide for Selecting Support Service.

## Workgroup Meeting, October 2009

The second workgroup included 11 individuals who participated in the initial workgroup. During this more intense one-day working session, the group examined and discussed key elements of the Caregiver Identity Change Theory and its implications for serving the DD population. The group also discussed in-depth, the Screening tool, the Assessment tool, and the Guide for Selecting Support Service and identified more specific changes and additions that would be necessary. At the close of the meeting, the discussion focused on the next steps to be taken to move forward an initiative to test and implement the TCARE® process within service organizations serving those with a developmental disability.

## General Findings from Planning Project

The following is a short summary of information gathered during the work group sessions followed by a suggested work plan to implement the TCARE® process with the DD population in the State of Georgia.

### Is the TCARE® process applicable to the DD population?

After being fully informed about the Caregiver Identity Change Theory and the content and process for implementing the TCARE® protocol, participants in the workgroups consistently concluded that the Caregiver Identity Change Theory, the foundation of the TCARE® process, was relevant to those caring for an individual with a developmental disability. There was also consensus that the TCARE® protocol had a great potential for enhancing support services for family members caring for persons with a developmental disability.

### Identified Target Population

After substantial discussion regarding the segments of the DD population that could benefit from the use of the TCARE® protocol, there was general consensus among participants in the two workgroups that the TCARE® process would be most appropriate for parents and relatives (siblings, grandparents, other family members, foster parents) providing care to an individual 12 years of age or older. It was generally agreed upon that children start entering puberty around age 12 and it is at that time when parents become more aware that their child’s social, emotional, and physical functioning levels are different then other children the same age. This acknowledgement can create a significant shift in the care context. There was also a few participants who believed the age limit could be lowered to age 10 with the two notions that some children enter puberty earlier than others and that the earlier resources are put in place, the likelihood of a crisis occurring diminishes.

## Screening Process

Consensus was also reached affirming the viability and potential benefits of using the TCARE® Screening tool to identify caregivers who might benefit from a more in-depth assessment and care management process. Currently many service provider organizations work with families in a reactive rather than proactive manner. Many participants felt that an introduction of a more formal and consistent screening process would greatly enhance service delivery and likely help families, especially those on waiting lists. The TCARE® process could be used to help families locate and use other community services that would support their efforts to care for their family members. Although there was a general positive response to the utility of using a Screening tool, there was also some concerns and questions raised. For example; Who would administer the Screen? To whom would the Screen be administered to? Would there be a need for additional staff hours? Who would pay the additional cost necessary to implement a screening process within each organization? Overall, the main concern raised was that implementing the TCARE® protocol would create a significant system shift where the family as unit is the main focus rather than just the care receiver.

## TCARE® Assessment Form

The eight page TCARE® Assessment tool includes questions focused on both the caregiver and care receiver that are intended to capture the key information about the caregiving context. The tool includes questions about the caregiver’s physical, emotional and financial resources and their problems and concerns. The form also includes questions about the functional abilities and

impairments of the care receiver. The measures included in the assessment have been developed specifically for the TCARE® Assessment tool and tested through cognitive interviews and questionnaires completed by approximately 1000 family caregivers caring for older adults. The family members participating in this testing and norming process are members of the League of Experienced Family Caregivers (LEFC), a caregiver registry created for this purpose.

Although there was a general consensus among participants in the workgroups that most of the questions included in the TCARE® Assessment tool are appropriate and useful for assessing the needs of caregivers of persons with a developmental disability, the group made several suggestions for changes and additions that would enhance its utility for this client population (See Appendix A). There was a general agreement that any effort to adapt the TCARE® tool would come from the insights and contributions of key members of the two work groups who volunteered to help the UWM team identify new measures and adapt existing measures.

## TCARE® Guide for Selecting Support Services

The Guide for Selecting Support Services is a generic catalogue of services that could be used to support family caregivers. It is organized into 15 major categories and currently includes a total of 73 sub-categories of services. The Guide not only provides a list of services, but is organized in a matrix that links each service with one or more strategies for supporting families that are identified through the TCARE® process. Currently the Guide provides a list of services that would be appropriate for a family member providing care for an adult relative. After reviewing the Guide, workgroup participants indicated that many of the service categories were deemed appropriate for the DD population, but there were several recommendations for additions and changes (See Appendix B). In order for the Guide to be a viable resource for those caring for a

relative with a developmental disability, the Guide must be revised to incorporate services that would be appropriate for that said population, but also services that are appropriate for both older and younger populations. It would also be important to facilitate the inclusion of these additional service categories into the Enhanced Services Program (ESP), Georgia’s statewide database of resources.

## Proposed Work Plan

The discussions, consensus and suggestions that emerged from the three meetings with key informants have been used to devise the following work plan as a suggested avenue for advancing an initiative to extend the use of the TCARE® process into organizations serving persons with a developmental disability.

1. Establish a planning group comprised of representatives of organizations that are willing to devote staff time or other resources to an initiative aimed at adapting TCARE® for use with caregivers of persons with a developmental disability and conducting a pilot project to assess the merits of the protocol for the DD population.
2. Devise a plan to engage the state in this effort.
3. Seek funding from public and or private sources to implement a pilot project.
4. Augment and revise TCARE® tools.
    a. Revise questions and measures included in the TCARE® Screening tool and the TCARE® Assessment tool. This effort would require:
        i. Establishing a work group comprised of care managers and key informants to collaborate with UWM to modify questions based on the feedback received from the workgroups conducted. (See Appendix A)

    ii. Creation of a questionnaire with new and revised measures by the UWM team using advice from the workgroup.
    iii. Testing of new and revised questions and measures with caregivers of persons with a developmental disability. This would require collaboration with key organizations to recruit a minimum of 200 caregivers of persons with a developmental disability to the LEFC registry to test these measures.
    iv. Based on data gathered, the UWM team will create a TCARE®/DD Assessment tool appropriate for assessing a family unit with a developmentally disabled individual.

b. Augment the TCARE® Guide for Selecting Support Services. This effort would require:
    i. Establishing a work group comprised of care managers/family specialists and resource specialists (e.g. persons familiar with resources available to the DD population) to collaborate with UWM to adapt the TCARE® Guide for Selecting Support Services to enhance its utility for working with families caring for persons with a developmental disability. This task would require a structured process to identify specific additions to the Guide.
    ii. Collaboration between ARC and UWM to link and build upon an existing crosswalk that links the categories in the TCARE® Guide to the resource taxonomy used in the ESP Resource Database.

5. Implement an 18 month pilot project to test the feasibility and benefits of using TCARE® to support caregivers of persons with a developmental disability. Specific tasks would include:
    a. Identification of two or more partner organizations willing to test the TCARE® protocol.
    b. Establishing a research design and protocol that organizations are able to comply with.
    c. Training staff to use the TCARE® protocol.
    d. A 15 month implementation and observation period.

## What is TCARE?

**Tailored Caregiver and Assessment, referred to as TCARE®, is an evidence-based care management process that was designed to target services for those who are providing support. The TCARE protocol is used to assess the needs of those family members providing support, guiding professionals in 1) understanding those particular family member's needs 2) strategically selecting and recommending services 3) consulting with those family members to help them choose appropriate services, and 4) creating a care plan that family members will embrace and follow.**

**The TCARE protocol is currently being evaluated in a three year, multi-site randomized trial with 20 organizations in Georgia, Michigan, Minnesota, and Washington.**

## How is TCARE relevant to persons who have developmental disabilities and the families who support them?

**Professionals working in long term care across several states have raised questions regarding whether TCARE can be adapted for use with those in the developmentally disabled community. The University of Wisconsin at Milwaukee, (UWM), has responded by facilitating three meetings in Georgia to explore the possibility.**

**Georgia has the distinction of being the first state in the nation to explore the possibility of adapting TCARE for the benefit of the DD community. Work from the three Georgia sessions with DD professionals this year has resulted in suggestions for changes and additions that would enhance TCARE's utility for the DD population. After discussion regarding the segments of the DD population that could benefit from the use of the TCARE protocol, there was general consensus that TCARE would be most appropriate for parents and relatives providing support/care to an individual 12 years of age or older.**

## Why look at a protocol to work with the families providing supports? We have always had the person with the disability as our focus.

**The developmental disability community, like the aging community, has traditionally focused its services on the person with DD, or in the case of aging, on the older person. Research, however, suggests that those persons providing support are under great physical, emotional, and financial strain, which in turn affects their ability to promote and help their loved ones sustain independence:**

- **A shortage of well-qualified, reliable, and affordable health care workers has a direct impact on the health and safety of persons with chronic conditions or disabilities. It also has a direct impact on the health and well-being of family members who must pick up the extra workload, much of which requires training and support they do not have, and which adds to their caregiving burden[8].**

- **Family support providers who provide care 36 or more hours weekly are more likely than non-caregivers to experience symptoms of depression or anxiety. For spouses the rate is six times higher[9].**

- **Caregivers use prescription drugs for depression, anxiety, and insomnia two to three times as often as the rest of the population[10]**

- **Family members put their own health and well being at risk in the service of their loved ones as they simultaneously save the health care system significant amounts of money[11].**

---

[8] Donelan, K., et al. (2002). Challenged To Care: Informal Caregivers in a Changing Health Care System. *Health Affairs*, July/August 2002, 222-231.

[9] Cannuscio, C.C., C Jones, D., Kawachi, I., Colditz, G.A., Berkman, L., & Rimm, E. (2002). Reverberation of Family Illness: A longitudinal Assessment of Informal Caregiver and Mental Health status in the Nurses' Health Study. American Journal of Public Health, 92, 305-311.

[10] George, LkK., & Gwyther, L.P. (1986). Caregiver Well-Being: A multidimensional Examination of Family Cargivers of Demented Adults. *The Gerontologist*, 26 (2), 253-260. As cited by Scharlach, A.E., Lowe, F.F., and Schneider, E.L, (1991). *Elder Care and the Work Force: Blueprint for Action*. Ontario, Canada: Lexington Books.

[11] Schulz R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: the caregiver health effects study. *JAMA*, 282, 2215-2219.

- **Forty-two percent of parents of children with special needs lack basic workplace supports, such as paid sick leave and vacation time[12]**

## How can TCARE help those providing care? How, in turn, will this promote the independence of the person receiving supports?

**It is believed that the TCARE protocol will assure consistent and accurate assessment of the needs of family members providing support; help care managers develop individually tailored care plans that include services that are appropriately targeted to meet the needs of the family members providing support, thereby reducing their stress/burden and depression. Georgia data from the first year shows lower levels of stress burden and depression at the three month and six month follow-up assessment which were statistically significant. Two other measures showed similar patterns, though not statistically significant.**

## Where do we go from here?

**In collaboration with interested representatives from organizations who work with individuals with developmental disabilities, the Division of Aging Services is requesting that the Department of Behavioral Health and Developmentally Disabled (DBHDD) allow this group to develop a Work Plan that would adapt TCARE for use with persons providing support and conduct a pilot project to assess the merits of the TCARE protocol for the DD Population.**

## If the DBHDD needs additional information regarding this request, who should they contact?

**There are two resources. The first is the website for the University of Wisconsin, which can be found at:**

**http://www4.uwm.edu/tcare/**

**This website contains information on TCARE, including training and research projects in process. Also, please contact Cliff Burt, Aging Services Coordinator, at 404-657-5336, or by Email, at gcburt@dhr.state.ga.us, regarding the Georgia projects, including the work sessions with the DD community.**

---

[12] Heyman,J. (2000). *The Widening Gap*, New York: Basic Books.