GEORGIA DIVISION OF AGING SERVICES
ALZHEIMER'S DISEASE AND SUPPORT SERVICES PROGRAM

Manual on Integrating the TCARE® Protocols into the
Nursing Home Diversion Initiative
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I   Project Background

Georgia received two Alzheimer's Disease Supportive Services Program (ADSSP) grants, covering July 1, 2007 to December 31, 2008 and January 1, 2009 to March 31, 2010. Initial funds were awarded by the Administration on Aging 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. With AoA's award of the second ADSSP TCARE grant, the Georgia TCARE project became a longitudinal study.

Purpose of this Manual

One of the project deliverables for the second grant was to *provide a manual for integrating the TCARE protocol into the Nursing Home Diversion initiatives to enhance the state's capacity to prevent or delay nursing home placement.* Since the initial goals for the project were developed, there have been a number of additional opportunities to implement TCARE into the state's long term care system, including the Medicaid waivered program and the developmentally disabled population. Those opportunities will also be described in this manual.

Contact Information about this Manual

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Additional Information about TCARE

The University of Wisconsin has a website, which will provide detailed information about TCARE. The website can be accessed at www.tcare@uwm.edu.

Why Consider Caregiver Assessment?

Family caregivers provide the majority of long-term care for persons with Alzheimer's Disease. Although caregivers often report positive aspects of their experience, a large body of literature documents significant negative social, psychological and physical health

consequences[1]. For example, a recent national study conducted by Evercare and the National Alliance for Caregiving found that 91% of the caregivers surveyed suffered from depression; 53% report that their overall health has gotten a lot worse because of providing care. The most common aspects of their health that have worsened as a result of their caregiving include energy, sleep, stress, panic attacks, pain, headaches, and weight gain or loss[2]. Although assessment of persons with chronic or disabling conditions is a core element of practice in medical, health, and social service settings, assessment of the family caregivers' situations lags far behind, as health practitioners and social service providers still do not routinely assess the health risks and well-being of family caregivers[3].

Both the practice and research communities have consistently reported under-utilization of services by caregivers[4]. This is often due to the fact that services are provided to caregivers with little knowledge or understanding of their specific needs. In truth the majority of care managers simply offer caregivers services that are available in the community with little knowledge or insight about which services are most needed and likely to be used by a caregiver at any given time. Equally problematic is the fact that services are made available to caregivers based on assessment of a care receiver's needs (e.g., functional status) rather than their own needs. As a consequence, caregivers do not use services because they do not perceive them to be needed or useful[5]. The end result is that caregivers frequently place loved ones in a nursing home at times when it is unnecessary or premature.

Despite the fact that caregiver assessment has been in the forefront of long term care discussion since the inception of the National Family Caregiver Support Program in 2000, little progress has been made to incorporate caregiver assessment into long term care systems. To

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[1] Schulz R, U Martire, L. M. Family Caregiving of Persons with Dementia: Prevalence, Health Effects, and Support Strategies. *American Journal of Geriatric Psychiatry*. 2003: 12 (3):10

[2] *Evercare Study of Caregivers in Decline: Findings from a National Study*. In collaboration with the National Alliance for Caregiving. September 2006: 5.

[3] *Ahead of the Curve: Emerging Trends and Practices in Family Caregiver Support*. Feinberg, LF, K. Wolkwitz, and C. Goldstein. AARP Public Policy Institute and the National Center on Caregiving/Family Caregiver Alliance. March 2006: 8

[4] Montgomery, RJV, and Kosloski K. Family Caregiving: Change, Continuity, and Diversity, in: Rubinstein R., Lawton M, ed. Alzheimer's Disease and Related Dementias: Strategies in Care and Research. New York: Springer Publications; 2000: 143-171

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

date, no longitudinal control design studies (i.e, randomized studies comparing caregivers/care receivers assessed through usual practices with caregivers assessed through a caregiver assessment protocol) have been conducted to examine the benefits of caregiver assessment. Given the demonstrated link between the availability of a family caregiver and nursing home placement, a demonstration project that can definitively document the economic and human benefits of assessing and assisting caregivers is extremely timely. Certainly empirical evidence demonstrating that caregivers whose needs are assessed and met are able to keep loved ones at home for longer periods of time than are family caregivers who are served solely or primarily on the basis of the functional level and needs of the caregivers will help sway policy and practice and lead to important systems change.

For these reasons, the Georgia Division of Aging Services was convinced that the identification and implementation of a caregiver assessment process would lead to improved caregiver health and well-being, and would translate into longer lengths of stay for care receivers in their own homes.

II   THE GEORGIA TCARE PROJECT

What is TCARE?

The Tailored Caregiver Assessment and Referral® protocol is a 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[6] . The TCARE® protocol, developed at the University of Wisconsin at Madison, 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 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

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[6] Montgomery, R.J.V., & Dosloski, 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.

TCARE® protocol is expected to translate into positive outcomes for caregivers, and likely more effective use of resources.

Goals of the Georgia ADSSP Project

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.

Study Design

A longitudinal randomized trial was conducted 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 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 care giving. 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 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[7], stress burden[8],* 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[9] and uplifts[10], 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 multi-site 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*

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[7] 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 discrepancy which 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.
[8] Stress burden-stress due to aspects of life, measured by tension, nervousness, and anxiety.
[9] 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 care placement?
[10] Uplifts-positive psychological outcomes associated with caregiving.

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 (*see UWM Final Report on the Georgia project in the Appendices*).

III	Creating a Paradigm Shift: Assessing Caregivers

Care managers have traditionally assessed needs of care receivers, not caregivers. Though there is an increasing amount of literature on the need to assess caregivers, unless there is an increase in funding for additional staff to assess care receivers, organizations are likely to encounter some types of resistance to implementing caregiver assessment. There are several ways to accomplish this shift.

Voluntary Participation

The Georgia Division of Aging Services (DAS) decided to begin its work with TCARE® with voluntary participation from the state's twelve Area Agencies on Aging. Over a period of several years, the Georgia Division of Aging Services invited the AAAs to a number of forums to talk about the needs of caregivers, including but not limited to AAA meeting presentations, webinars, and meetings lasting one or two days. The purpose of these meetings was to convince first the administration of organizations that caregiver assessment was in their best interest. A cornerstone of this strategy was to share with Georgia's aging network some data, gathered over a 30 year period from Dr. Rhonda Montgomery through her role of evaluator of Alzheimer's Disease demonstration grants funded by the U. S. Administration on Aging. The data showed that when offered free or low-cost respite:

- 1/3 never used it
- 1/3 used it for less than 2 months
- 1/3 used it from 9 months to 2 years

This suggests that respite is not always the most appropriate service; further, the literature suggests it is over-prescribed.

Further data shared with the network included a slide which shows that care receiver's needs do not predict a care giver's intention to place a care receiver in an institutional setting:

CARE RECEIVER'S NEEDS TO NOT PREDICT INTENTION TO PLACE	
Measures of Need	Intention to Place
ADL/IADL	-.14
Problem Behaviors	-.07
Copyright Rhonda JV Montgomery & Associates 2009. Total data from TCARE and League of Experienced Family Caregiver Studies. 4-14-09. N= 568	

This type of information is quite surprising to a wide variety of health care professionals who presume that assistance with ADLs, IADLs, or problem behaviors are predictors of intention to place. Equally surprising is the data from the slide below, which shows that care giving activities themselves are not good predictors of intention to place, either:

CAREGIVING ACTIVITIES DO NOT PREDICT INTENTION TO PLACE	
Personal Care	.03
Housework	.08*
Transportation	.08
Banking/Legal Matters	.01
Copyright Rhonda JV Montgomery & Associates 2009. Total data from TCARE and League of Experienced Family Caregiver Studies. 4-14-09. N= 568	

The purpose of education is to begin to shift thinking and for the network to realize that basing services solely on the basis of care receiver needs ignores the health, well-being, and continued ability of the caregiver to continue in the care giving role.

The next step in this approach is to begin some pilot projects in TCARE®. In Georgia, DAS   accomplished this by applying for ADSSP Grants. DAS selects its grant partners by submitting a Request for Collaboration to Area Agencies on Aging (AAAs. Grant partners are selected based on criteria outlined in the Request. Over the next several years, the ADSSP Project Coordinator and participating AAAs made periodic presentations at AAA meetings and at the annual Georgia Gerontology Society conference.

At the conclusion of the two ADSSP TCARE® grants, AAAs were requested to voluntarily begin a TCARE® project in the following fiscal year. Six of Georgia's twelve AAAs agreed to begin a TCARE® project.

Mandatory Participation

Having reviewed the data and final report from the Georgia project as prepared by the University of Wisconsin, DAS senior leadership made a decision to require the statewide implementation of TCARE® through its 12 AAAs. In its explanation to the aging network, the following factors were cited:

- Momentum at the federal level for implementing evidence-based programs
- Great interest at the state level for a triage system to divert individuals from going into a nursing home and focusing heavily on caregivers
- The next four year state plan (beginning in SFY 2012) would have a focus in the area of evidence-based caregiver support

IV   Implementation

Contract with UWM

To receive training, certification, and use of the TCARE® protocols, it is necessary to enter into a contractual agreement with the University of Wisconsin at Milwaukee. The Georgia Division of Aging Services, as well as the aging program in Washington state, have entered into agreements with the UWM in order to use TCARE®. For more information, contact the UWM at 414-229-1122, or visit their website at www.tcare@uwm.edu.

Policy Review

After the decision has been made to implement TCARE®, it is necessary to review and revise all state policies to see what changes are needed in order to implement TCARE® throughout the aging network. In the instance of Georgia, the following policies had to be revised:

- Client Assessment
- Case Management
- In-Home Respite
- Out-of-home respite

- Access to Information and Services/ Aging Disability and Resource Centers (ADRCs

Suggested revisions were then sent to Georgia AAAs with a three week window in which AAAs could review and comment on the proposed changes.

A major change that affected most of the policies was to specify TCARE® as the assessment instrument to be used to assess caregivers

Area Plan Goals

Since the Division had announced to the AAAs that implementation of TCARE® was now a required service in all Area Plans beginning in SFY 2012, it was necessary to provide some sample goals for AAAs to consider as they developed their goals for the program.

DAS required AAAs to complete two different goals for the four year Area Plan cycle. The first set of goals (usually one goal per year of the four year cycle) relates to the information and assistance/ADRC component. All AAAs are to integrate TCARE® into their central intake unit (called Gateway/ADRC in Georgia) by the end of the four year planning cycle. One way to begin this would be to complete the TCARE® screen on a percentage of caregivers in specified counties. During the four year planning cycle, the AAAs will increase both the percentage of screens and the number of counties, depending on their staff's increasing proficiency and increased funding (*see sample Gateway area plan goal in appendix*).

The second set of goals pertains to in-home respite. DAS selected in-home respite, since all AAAs have an in-home respite program. Further, in-home respite is a service funded under Title IIIE, the National Family Caregiver Support Program, which means that the caregiver is the client. For any in-home respite paid for with Title IIIE funds, AAAs are required to document the caregiver as the client, and to verify eligibility for IIIE, must additionally list the care receiver information.

A sample in-home respite goal would be to complete TCARE® screens on 50% of their in-home respite caregivers within the first year of the new Area Plan cycle, increasing the percentage each year during the cycle (*see sample in-home respite area plan goal in the appendix*).

Train-the-Trainer component

States that desire to implement TCARE® on a broad scale will desire to train their own TCARE® Master Trainers (MTs). The other option is to continue to pay the University of Wisconsin (UWM) to come to their state any time they wish to train care managers in TCARE®.

Georgia decided it was much more cost effective to have our own MTs than to have UWM to send staff to Georgia for this purpose.

UWM will send staff to one's state for a period of 2-3 days to train the master trainers. The training will include segments where the trainees will each be responsible for teaching specified components of TCARE®, so that both UWM staff and peers can provide feedback. Georgia has the following recommendations regarding Master Trainers:

- since MTs are required by UWM to teach in pairs (and in the case of Georgia, we use teams of three Master Trainers), recruit MTs who live in the same geographic area. This will make it easier to schedule trainings, and will also reduce the cost of the costs of the training

- recruit teams of MTs in different parts of the state, which will greatly enhance your ability to be able to offer trainings more readily to your network

- states should consider paying honorariums to the organizations which provide the MTs, since the training cycle to train care managers the equivalent of five to six work days during the course of several months (*see TCARE® Training Activities & Checklist in the Appendices*). Georgia, for example, reimburses each organization $800 per MT to complete the training for a new group of care managers

- states should consider including three persons in a MT team instead of the two that UWM requires for the training. DAS makes this recommendation because:
  - most Master Trainers already have full-time jobs. The less material they have to prepare, the easier it will be for them to schedule additional trainings into the course of a year
  - if a Master Trainer, for whatever reason, is unable to make the scheduled training, the training event will not have to be canceled
  - there are homework assignments to be reviewed during the training, and with three instead of two MTs, it lessens the additional time needed to teach others and makes it more easier to get a commitment

Once Master Trainers complete the initial 2-3 day face-to-face training, they teach one class of care managers with a UWM staff member in observance. The UWM staff member then provides feedback to each MT. Upon completion of the first class with feedback completed by the UWM staff member, the Master Trainer is considered certified.

Training Care Managers

Once either Master Trainers are in place, or the decision has been made to bring UWM staff to your state to train, states need to develop a training plan. The training plan provide to the aging network should include:

- a document with general information about TCARE®, including what it is, how the process works, what costs are involved for the training, and who needs to attend (*see attached document, TCARE® Information and SFY 2011 Activities, in Appendix*)

- a calendar of events for the fiscal year, so that AAAs can see when training will be available in their region, and plan accordingly (*see attached document, TCARE® Calendar of Events SFY 2011).*

- a training brochure, which explains the training process. AAAs and other organizations need to know that there are four steps involved in care managers becoming trained and certified in TCARE® (*see attached TCARE® training brochure*):

  o a face-to-face 2 ½ training, with a homework assignment to bring to the training

  o one month after the initial training, a 2 hour webinar where trainees complete submit a case study in advance and complete steps 1-3 of the TCARE® process

  o one month after the first webinar, a 2 hour webinar where trainees complete a case study in advance, complete steps 1-5 of the TCARE® process, and review key concepts of TCARE®

  o care managers go on-line and take an exam, which assesses their proficiency with using the TCARE® process.

Georgia has the following recommendations regarding training care managers:

- define the term "care manager" for the AAAs who will be selecting those to send to the training. DAS uses the term broadly to cover individuals who are arranging for services for caregiver/clients. These care managers may or may not have had formal training in social work, counseling, or a related field.

- limit training of care managers to 16 at a time, which is the number of recommended by UWM. This will ensure that care managers are able to receive individual attention from instructors, and will also ensure that participants are able to ask more questions and interact more when breaking into small groups during the training

- be clear in your instructions to AAAs that the training is for care managers who will use the full TCARE® assessment. Training for information and assistance (intake/ADRC) staff is a different kind of training.

Georgia currently has two teams (each team consisting of three) Master Trainers. In SFY2011, each team will conduct two trainings, enabling 64 additional care managers (16 per training) to be trained during the fiscal year.

TCARE® Screening at Gateway

Based on recommendations of care managers from around the country, UWM developed a TCARE® screening instrument to identify which caregivers are in need of a full assessment and who may benefit from the TCARE ®process.

Once the staff member becomes 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.

Training/Coordination with Intake/ADRC Staff

ADRC/Gateway staff who desire to use the TCARE® screen must take a webinar hosted by UWM staff. The webinar takes approximately one hour. Once ADRC/Gateway staff members complete a webinar, they are authorized to receive and use the TCARE® screen.

Georgia recommends at least two webinars for intake staff be held in the same year as care manager training. It should also be made clear that only those persons who are going to administer the TCARE® screen need this webinar, and that those persons who are to administer the TCARE® assessment and protocols must take a different training with certification.

The TCARE® State Coordinator coordinates closely with the ADRC State Coordinator in all facets of TCARE® planning and implementation activities. Both coordinators include each other as presenters when they conduct their respective meetings within the aging network.

TCARE® Process for Care Managers

Once a TCARE® Screen is completed at the Gateway level, and it is determined from scores on the screen that a caregiver could benefit from a full TCARE® assessment, there are six steps involved:

- Conduct a 40 minute assessment, using the 32 item TCARE® Assessment instrument

- Transfer key information to the Assessment Summary Sheet

- Create a Care Consultation Worksheet

- Consult with the Caregiver

- Create a Care Plan

- Follow Up, usually conducted at three month intervals

The illustration on the following page illustrates the six step TCARE® process.

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 • 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 • Transfer scores and information for each domain to summary sheet • Interpret scores as low, medium or high using ranges included on tool • Note other useful information.

Step 3: Create Care Consultation Worksheet	
Tools	**Description**
• *Assessment Summary Sheet* • *Decision Maps* (algorithm) • *Guide to Selecting Support Services* • Local directory or data base of services/resources	• Use burden scores to identify correct decision map • Use decision algorithm to identify intervention goal, strategies and initial list of recommended services/resources • Tailor recommendations to caregiver's needs, preferences, & availability • Identify local resources

Step 4: Consult with Caregiver	
Tools	**Description**
• *Assessment Summary Sheet* • *Care Consultation Worksheet*	• Share & interpret information from *Assessment Summary Sheet* • Discuss recommended goal(s) & strategies • Review list of recommended services and discuss benefits • Jointly make decisions regarding services/resources to include on care plan

Step 5: Create Care Plan	
Tools	**Description**
• *Care Consultation Worksheet* • *Caregiver Care Plan*	• Record decisions made during care consultation including: interventions goal(s), strategies, services with specific information to access service/resource • Responsibilities of caregiver • Responsibilities of care manager • Triggers for follow-up

Step 6: Follow-up	
Tools	**Description**
• *Follow-up TCARE® Assessment Form* • *Assessment Summary Sheet* • *Decision Maps* (algorithms) • *Guide to Selecting Support Services* • Local directory or data base of services/resources • *Care Consultation Worksheet* • *Caregiver Care Plan*	• Conduct follow-up assessment at 3-month intervals by telephone or in-person • Complete steps 2- 4 of TCARE® process • Adjust care plan as appropriate

The TCARE® screen and TCARE® Assessment tools are completed on pencil and paper (though in Georgia we are building both of these into our AIMS system which will be discussed in the next section of this Manual, under IT Development).   The remaining steps in the TCARE® process, beginning with the Assessment Summary Sheet, are completed by accessing them on the TCARE® website at the University of Wisconsin.   Certified TCARE® care managers are able to go onto the UWM website to access the remaining tools listed above in the TCARE ®process, beginning with the Assessment Summary Sheet. The TCARE® protocols are owned by the University of Wisconsin and the University Foundation. States contract with UWM for training, and access to the TCARE® screen, assessment tool, and access to their TCARE® website, referred to as TCAREe®.

V	Building Your Infrastructure

IT Development

AIMS is the accountability and payment system developed and maintained by DHS Division of Aging Services and DHS Office of Information Technology with assistance from our partners - the Area Agencies on Aging and aging network providers. AIMS, which stands for the Aging Information and Management System, was designed specifically for aging services contracted with DHS, Division of Aging Services to include planning and contracting, authorizing providers and services, tracking client data, as well as financial and payment for the Area Agencies on Aging and providers. AIMS has a number of features which includes the following:

- AIMS is the centralized database for documenting services provided by the aging network
- AIMS is a web based system and easy to access by all users
- AIMS facilitates accurate, complete, and timely data collection and data entry
- AIMS provides for planning and analyzing the effectiveness of aging programs
- AIMS provides consistent data for contracting, accountability and management of aging services efficiently

- AIMS saves historical data used to measure impact of services provided to clients

over time

During SFY 2011, DAS will build both the TCARE® screen and the TCARE® assessment tool into AIMS. Testing will be completed during SFY 2011as well, and the AAAs will begin using both the TCARE® screen and assessment tool in AIMS in SFY 2012, which begins July 1, 2011.

As previously discussed, once a TCARE® screen assessment is completed, it is necessary to go to a UWM website in order to complete the TCARE® protocol process. Another option open to states implementing TCARE® is to build all of the TCARE® protocols, starting with the TCARE® screen and assessment, as well as the protocols accessed through the UWM TCARE® website into your own data and management information systems. Washington state, for example, has built the entire TCARE® protocol into its IT system.

Crosswalk to ESP Data Base

States that have a data base, whether electronic or otherwise, will need to develop a crosswalk between services available in their state and the TCARE® Guide for Selecting Support Services. To understand why this is necessary, it is important to understand the steps involved in using the TCARE® process.

As previously discussed at the beginning of Section II of this manual, care managers follow a seven step process in the TCARE® protocols. Once a care manager completes an Assessment Summary Sheet which contains the particular scores of a caregiver related to different types of stress, and/or depression, the next step is to refer to the Service Selection Maps in the TCARE® process. Decision algorithms built into the Service Selection Maps cross-references the TCARE® Guide for Selecting Support Services and identifies the most appropriate goals, and accordingly, the most appropriate services which would most likely the caregiver's types of stress, and/or reduce the caregiver's depression.

 Georgia uses an electronic data base, called the Enhanced Services Program (ESP) to identify over 23,000 services for older adults, persons with disabilities, and caregivers. ESP was developed by the Atlanta Regional Commission, and is used by Georgia's aging network, Aging and Disability Resource Centers (ADRCs), the Alzheimer's Association and many other

organizations to identify programs and services appropriate to meet the needs of caregivers and care receivers.

In the case of Georgia, the following steps occurred to complete the crosswalk:

- using the TCARE® Guide for Selecting Services, the UWM Research Team classified general categories and service elements within the ESP taxonomy that could address specific caregiver needs

- ARC reviewed the initial service taxonomy crosswalk to confirm whether ESP resources were assigned to be the most appropriate categories within the TCARE® framework

- conference calls were scheduled after each review of the crosswalk to ensure that UWM understood and incorporated ARC's suggestions

- the UWM Research Team completed modifications to the Crosswalk and sent it to ARC for final review (*see a sample page of the TCARE® & ESP Crosswalk and Taxonomy in the Appendices*).

Integration into Nursing Home Diversion Initiatives

Georgia has been awarded three Nursing Home Diversion (NHD) Modernization and/or Community Living grants since January 2008 (in subsequent funding cycles, the program named changed from Nursing Home Diversion to Community Living grants). The purpose of these grants is to invite 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. This concept is most frequently referred to as self-determination, or self-directed care. When Georgia applied for a second demonstration grant on TCARE®, its goal was to enhance TCARE® by integrating it into the nursing home diversion project to improve the state's long-term care options for caregivers.

States that wish to replicate this should undertake the following action steps:

- determine your state's current eligibility requirements for NHD. This will include both Medicaid financial eligibility and your state's mechanism and threshold for meeting the

frailty level for nursing home placement. In Georgia, the DON-R is used as a needs assessment to determine where there are deficits in functioning, as wells as to document the needs for assistance across a range of impairments including Activities of Daily Living, Instrumental Activities of Daily Living, and unmet need for care. Persons must have scores of 15 or higher and have one unmet need for care on the Determination of Need (DON-R) to be eligible for the Medicaid-waivered services, called the Community Care Services Program (CCSP) {*See the DON-R in the Appendices}.*

For more detailed information about the DON-R:

- o *go to www.odis.dhr.state.ga.us*

- o *Go to Index*

- o Select Aging Services

- o Select Policy Manual 5300, Home and Community Based Services

- o Select 114-Guidelines & Requirements for Client Assessment

- o View 114.7 and 114A-1.1

- determine eligibility for TCARE®. Eligibility is determined by the following scores on the TCARE® screen:

  - o caregivers rating moderate or high in stress, relationship, or objective burden

  - o and/or who have a moderate or high identity discrepancy

  - o and/or who are depressed

  - o and/or who have intention to place (*note: see page 18 of the Final UWM Report, in Appendices 1 for definitions of the three types of burden identity discrepancy*)

  - develop instruments to be used in the screening, such as:

o   a Financial Worksheet to determine Medicaid financial eligibility (*see Financial Worksheet in the Appendices*).

- conduct an orientation regarding use of NHD program and targeting criteria for those persons conducting TCARE® screens on caregivers. Georgia did this via webinar, and provided a Powerpoint for those being trained to follow (*see a copy of the Powerpoint in the Appendices*)

The end result was that a number of families had care receivers enrolled in the NHD/CL projects and their caregivers enrolled in TCARE®, thus ensuring that they were receiving comprehensive interventions maximizing independence and the ability to prolong length of stay in the community.

Integration into Medicaid Waivered Programs

Georgia began its implementation of TCARE® with its non-Medicaid Home and Community Based Services (HCBS) program. Representatives of the Medicaid-waivered program, the Community Care Services Program, were invited to all meetings where TCARE® was introduced to Georgia's aging network. Simultaneously, CCSP Program administrators were involved in a dialogue with field staff regarding the needs of caregivers. Consequently, CCSP program administers decided to require the use of TCARE® with caregivers of CCSP clients for the following reasons:

o   feedback from the aging network field, indicating that needs of caregivers were not being adequately addressed

o   results of the Georgia study indicating that caregivers receiving TCARE® were less likely to place family members in institutional care

o   data indicating that caregivers enrolled in TCARE® experienced lower levels of identity discrepancy, stress burden, and depression

Similar to the non-Medicaid implementation, the CCSP TCARE® implementation will be a phased in over a number of years beginning in SFY2012.

During SFY 2011, which DAS is using as a training year, the CCSP program has identified six of Georgia's 12 AAAs to begin training CCSP staff in TCARE®.   DAS non-Medicaid Home and Community Based Services (HCBS) staff are collaborating with CCSP staff to ensure that both non-Medicaid Home and Community-Based (HCBS) and Medicaid Community Care Services Program (CCSP) care managers receive TCARE® care manager training.

Integration with Developmental Disability (DD) Community

The Division of Aging Services and the Department of Behavioral Health and Developmental Disabilities have a successful working relationship, as evidenced by Georgia's network where every Area Agency on Aging has implemented a fully functioning Aging Disability and Resource Center. Through ADRC Coalition meetings, information on TCARE® was presented, and as a result, a number of DD organizations expressed interest in exploring the feasibility of adapting TCARE® for use with the DD population. During 2009, one orientation and two work group meetings were held with representatives of organizations working with the DD population (*see TCARE® DD Workgroup Participants list in the Appendices*).

Consensus from all three meetings was that the TCARE® protocol had great potential for enhancing support services for family members caring for persons with developmental disabilities.(*see TCARE® DD Report 2009 in the Appendices*). DD participating organizations developed an abstract, outlining the rationale for adapting TCARE® to use with DD families, and its potential benefit for the families who support and care for persons with DD *(see Appendices for the TCARE® DD Abstract)*.

In 2010, key staff members from the Department of Behavioral Health and Developmental Disabilities (DBHDD) were involved in a series of four webinars and meetings to make further refinements to the TCARE® DD protocols. At the time this manual went to press, DBHDD is considering conducting a pilot project with TCARE® and DD in the state.

Since all states are working to more effectively integrate aging and disabilities resources into a seamless system through ADRCs, Georgia encourages states that are going to implement TCARE® to:

- include the state's ADRC Coordinator involved in on-going communication as TCARE® is implemented with the aging population

- implement the TCARE® protocols with aging clients first

- identify whether the state's TCARE® Master Trainers will also be the ones to learn the TCARE® DD protocols, or if different persons should be trained for TCARE® DD

VI   Discussion and Recommendations

Little progress has been made to incorporate caregiver assessment into long term care systems. However, due to several research articles and evidence-based studies which are expected to go to press during 2011, the use of TCARE® for caregiver assessment will provide strong support for the merits and benefits of the TCARE® protocol as an effective mechanism for helping family caregivers. The first of those articles, published in *The Gerontologist* in December, 2010, provides solid evidence of the multi-dimensionality of the different kinds of caregiver burden and the need to address them as such when providing interventions for caregivers[11] *(see a complete copy of this article in the Appendices).*

States that are interested in further developing, refining, and integrating their long term care systems for both non-Medicaid and Medicaid populations should consider implementing TCARE®, as the Georgia study documents differences between 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[12].

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[11] A Dimensional Analysis of Caregiver Burden Among Spouses and Adult Children. M. Savundranayagam, Rhonda J.V. Montgomery, and Karl Kosloski. The Gerontologist Advance Acess. December 6, 2010.

[12] Improving Options for Persons with Alzheimer's Disease and Their Caregivers in the State of Georgia. University of Wisconsin-Milwaukee. May 31, 2010. The entire report is included in the Appendix of this manual as Appendices 1.

VI I	APPENDICES

Appendix One   TCARE® UWM Final Report on Georgia ADSSP Project

Appendix Two   TCARE® Sample Gateway Area Plan Goal

Appendix Three   Sample Gateway In-Home Respite Plan Goal

Appendix Four   TCARE® Training Activities & Checklist

Appendix Five   TCARE® Information and SFY 2011 Activities

Appendix Six   TCARE® Calendar of Events

Appendix Seven   TCARE® Training Brochure

Appendix Eight   Sample TCARE® & ESP Crosswalk and Taxonomy

Appendix Nine   DON-R

Appendix Ten   Nursing Home Diversion Financial Worksheet

Appendix Eleven   Nursing Home Diversion Power Point

Appendix Twelve   TCARE® DD Workgroup Participants

Appendix Thirteen   TCARE® DD Report

Appendix Fourteen   TCARE® DD Abstract

Appendix Fifteen   Article on Caregiver Burden, *The Gerontologist*