

## **PROGRAM DESCRIPTION**

Tailored Caregiver Assessment and Referral (TCARE) is a care management protocol designed to support family members who are providing care to adults, of any age, with chronic or acute health conditions. TCARE is grounded in the Caregiver Identity Theory, which conceptualizes caregiving as a series of transitions that result from changes in the caregiving context and in personal norms that are grounded in familial roles and culture. A major tenet of the theory is that identity discrepancy, defined as a disparity between a caregiver's behavior and his or her identity standards, or personal norms, is a major source of caregiver stress. Identity discrepancy can be manifested in three domains of burden (objective burden, relationship burden, and stress burden) and in depression.

TCARE is a triaging mechanism for identifying strategies and services to minimize identity discrepancy. The comprehensive system includes software, assessment tools, decision algorithms, and a training and technical assistance program. TCARE is implemented by the care manager (usually a social worker, nurse, or other human service professional) after he or she has completed training and become certified as a TCARE "assessor." The protocol, using Web-based software that enables care managers to integrate extensive information, begins with a 40- to 60-minute assessment, in which the care manager meets with the caregiver, either over the phone or in person, and assesses caregiver demographics, length and phase of caregiving, obligations, and physical and emotional health. The care manager also obtains information regarding the care receiver, such as demographics, activities of daily living (e.g., walking, bathing, dressing), and instrumental activities of daily living (e.g., cooking, shopping, managing medication). Key information is transferred to an assessment summary sheet, and scores are calculated for each of the key measures. Using these scores and other algorithms, the care manager identifies intervention goals, strategies, and an initial list of recommended services and resources (e.g., respite services, psychoeducational skills training, cognitive behavioral therapy, family counseling) from a catalog of 90 types of services. These recommendations, including the type of services and the amount of services, are tailored to the caregiver's needs, preferences, and availability. The care manager consults with the caregiver to discuss the findings and provides the caregiver with information to make an informed choice on whether to use the recommended services and how the services will help with his or her caregiving needs. The process is repeated at 3-month intervals so that the care plan can be adjusted as appropriate. The full assessment and referral process requires 2½ to 3 hours of staff time to complete, and this time includes two 1-hour meetings (over the phone or in person) with the caregiver.

In the studies reviewed for this summary, the follow-up periods included both the TCARE triage process and the receipt of any tailored services by participants.

## **Descriptive Information**

**Areas of Interest** 

- Caregiver support
- Long-term services and supports



Outcomes	<ul> <li>Review Date: June 2014</li> <li>Caregiver identity discrepancy</li> <li>Intention for nursing home placement</li> <li>Depressive symptoms</li> <li>Relationship burden</li> <li>Stress burden</li> </ul>			
Ages	<ul> <li>18-25 (Young adult)</li> <li>26-49 (Adult)</li> <li>50-60 (Older adult)</li> <li>61-74 (Older adult)</li> <li>75-84 (Older adult)</li> <li>85+ (Older adult)</li> </ul>			
Genders	<ul><li>Female</li><li>Male</li></ul>			
Races/Ethnicities	<ul> <li>Black or African American</li> <li>White</li> <li>Race/ethnicity unspecified</li> </ul>			
Settings	<ul><li>Home</li><li>Other community settings</li></ul>			
Geographic Locations	<ul> <li>Urban</li> <li>Suburban</li> <li>Rural and/or frontier</li> </ul>			
Funding	Partially/fully funded by Administration on Aging			
Adverse Effects	No adverse effects, concerns, or unintended consequences were identified by the developer.			
Implementation History	TCARE was first implemented in 2008. It was tested with the aging population between 2008 and 2012 in two randomized controlled studies in Georgia, Michigan, Minnesota, and Washington. In 2012, a military version of TCARE was evaluated at 10 Soldier and Family Assistance Centers at Fort Bliss (Texas), Fort Bragg (North Carolina), Fort Campbell (Kentucky), Fort Gordon (Georgia), Fort Hood (Texas), Fort Knox (Kentucky), Fort Riley (Kansas), Fort Stewart (Georgia), Joint Base Lewis- McChord (Washington), and Schofield Barracks (Hawaii). Since 2008, TCARE has been implemented in over 250 organizations in 17 States, serving approximately 20,000 nonprofessional family caregivers.			
Adaptations	The TCARE protocol was adapted for use with U.S. military personnel, as part of a program to support wounded troops. The TCARE assessment form has been adapted for use with those caring for individuals with developmental disabilities. Cultural adaptations have been made to the TCARE protocol for use with minority caregivers and those whose first language is not English. The assessment tool has been translated into Chinese, Korean, and Spanish. The Tailored Care Enterprises team is working with the University of Hawaii Center on Aging and the Hawaii Executive Office on Aging to conduct a feasibility study to culturally adapt the protocol to support caregivers in Hawaii's multicultural population and to create a blended training curriculum to include Web-based and in-person training.			



# **QUALITY OF RESEARCH**

#### Review Date: June 2014

#### **Documents Reviewed**

The documents below were reviewed for Quality of Research. The research point of contact can provide information regarding the studies reviewed and the availability of additional materials, including those from more recent studies that may have been conducted.

#### Study 1

Kwak, J., Montgomery, R., O'Connell Valuch, K., & Kosloski, K. (2013, November). *Results of a randomized trial of an innovative care management protocol for family caregivers.* Poster presented at the annual meeting of the Gerontological Society of America, New Orleans, LA.

Montgomery, R. J. V., Kwak, J., Kosloski, K., & O'Connell Valuch, K. (2011). Effects of the TCARE intervention on caregiver burden and depressive symptoms: Preliminary findings from a randomized controlled study. *Journals of Gerontology, Series B: Psychological Sciences and Social Sciences, 66*(5), 640–647. PubMed abstract available at http://www.ncbi.nlm.nih.gov/pubmed/21840840

#### Study 2

Kwak, J., Montgomery, R. J. V., Kosloski, K., & Lang, J. (2011). The impact of TCARE on service recommendation, use, and caregiver well-being. *Gerontologist*, *51*(5), 704–713. PubMed abstract available at http://www.ncbi.nlm.nih.gov/pubmed/21593010

#### **Supplementary Materials**

Montgomery, R., & Kwak, J. (2008). TCARE: Tailored Caregiver Assessment and Referral. *American Journal of Nursing, 108*(9, Suppl.), 54–57. PubMed abstract available at http://www.ncbi.nlm.nih.gov/pubmed/18797229

Montgomery, R. J. V., & Kosloski, K. (2009). Caregiving as a process of changing identity: Implications for caregiver support. *Generations*, *33*(1), 47–52.

Montgomery, R. J. V., & Kosloski, K. D. (2012). Pathways to a caregiver identity and implications for support services. In R. C. Talley & R. J. V. Montgomery (Eds.), *Caregiving across the lifespan: Research, practice, policy*. New York, NY: Springer.

O'Connell Valuch, K., Kwak, J., Brondino, M., Kosloski, K., & Montgomery, R. J. V. (2010, November). *Caregiver Identity Discrepancy Scale: Reliability, construct validity and unidimensionality*. Poster session presented at the annual meeting of the Gerontological Society of America, New Orleans, LA.

Savundranayagam, M. Y., & Montgomery, R. J. V. (2010). Impact of role discrepancy on caregiver burden among spouses. *Research on Aging*, *32*(2), 175–199.



Savundranayagam, M. Y., Montgomery, R. J. V., & Kosloski, K. (2011). A dimensional analysis of caregiver burden among spouses and adult children. *Gerontologist*, *51*(3), 321–331. PubMed abstract available at http://www.ncbi.nlm.nih.gov/pubmed/21135026

#### Outcomes

	Outcome 1: Caregiver Identity Discrepancy		
Description of Measures	Caregiver identity discrepancy is defined as the affective psychological state that accrues when there is a disparity between the care activities in which a caregiver is engaging and those activities that would be otherwise consistent with his or her identity standard. Using a scale ranging from 1 (strongly disagree) to 6 (strongly agree), respondents indicated the extent to which they agreed with each of 6 statements (e.g., "The things I am responsible for do not fit very well with what I want to do," "It is difficult for me to accept all the responsibility for my [care recipient]"). Scores range from 6 to 36, with higher scores indicating greater caregiver identity discrepancy.		
Key Findings	TCARE was evaluated in two randomized controlled trials (RCTs) that compared TCARE and treatment as usual. Care managers assigned to the treatment as usual group served caregivers following the normal customary practices of their organization. In one study, family caregivers were served by care managers from social service organizations in Georgia, Michigan, Minnesota, and Washington. In the other study, family caregivers were served by care managers from three area agencies on aging in Georgia. Assessments for both studies were conducted at baseline and at 3-, 6-, and 9-month follow-ups. Over time, caregivers in the intervention group had a decrease in caregiver identity discrepancy, whereas caregivers in the treatment as usual group had an increase ( $p = .012$ , Study 1; $p = .0309$ , Study 2).		
Studies Measuring Outcome	Studies 1 and 2		
Study Designs	Experimental		
Quality of Research Rating (0.0–4.0 scale)	3.7		

Outcome 2: Intention for Nursing Home Placement			
Description of Measures	The caregiver's current and future intention to place the care receiver in a nursing home was assessed with 2 items. Using a 4-point scale ranging from "definitely not" to "definitely would," respondents indicated whether they intended to place the care receiver in a nursing home or other long-term care facility, given the care receiver's current condition, as well as the care receiver's future condition if it became worse. Scores range from 2 to 8, with higher scores indicating the caregiver's greater intention to place the care receiver in a nursing home or other facility.		

Key Findings	TCARE was evaluated in an RCT that compared TCARE and treatment as usual. Care managers assigned to the treatment as usual group served caregivers following the normal customary practices of their organization. Family caregivers were served by care managers from social service organizations in Georgia, Michigan, Minnesota, and Washington. Assessments were conducted at baseline and at 3-, 6-, and 9-month follow-ups. Over time, caregivers in the intervention group had a decrease in intention to place the care receiver in a nursing home, whereas caregivers in the treatment as usual group had an increase ( $p = .002$ ).	
Studies Measuring Outcome	Study 1	
Study Designs	Experimental	
Quality of Research Rating (0.0–4.0 scale)	3.5	

Outcome 3: Depressive Symptoms			
Description of Measures	Depressive symptoms were assessed with the 10-item version of the Center for Epidemiological Studies–Depression scale. Using a 4-point scale ranging from "rarely or none of the time (less than 1 day)" to "all of the time (5-7 days)," respondents indicated the frequency of various depressive symptoms experienced during the past week (e.g., "I was bothered by things that usually don't bother me," "I felt depressed," "My sleep was restless"). Scores range from 0 to 30, with higher scores indicating more frequent depressive symptoms.		
Key Findings	TCARE was evaluated in two RCTs that compared TCARE and treatment as usual. Care managers assigned to the treatment as usual group served caregivers following the normal customary practices of their organization. In one study, family caregivers were served by care managers from social service organizations in Georgia, Michigan, Minnesota, and Washington. In the other study, family caregivers were served by care managers from three area agencies on aging in Georgia. Assessments for both studies were conducted at baseline and at 3-, 6-, and 9-month follow-ups. Over time, caregivers in the intervention group had a decrease in the frequency of depressive symptoms, whereas caregivers in the treatment as usual group had an increase ( $p = .0051$ , Study 1; $p = .0286$ , Study 2).		
Studies Measuring Outcome	Studies 1 and 2		
Study Designs	Experimental		
Quality of Research Rating (0.0–4.0 scale)	3.8		

Outcome 4: Relationship Burden				
Description of Measures	Relationship burden was assessed with the Relationship domain of the Montgomery Borgatta Caregiver Burden Scale (modified version), which contains 5 items regarding the demands for care and attention over and above the level that the caregiver perceives is warranted by the care receiver's condition (i.e., the extent to which the care recipient's behavior is perceived by the caregiver to be manipulative or overly demanding). Using a scale ranging from 1 (not at all) to 5 (a great deal) to indicate the extent to which their caregiving responsibilities changed each aspect of their life, respondents rated each item (e.g., "Have your caregiving responsibilities caused conflicts with your care recipient?" and "Have your caregiving responsibilities made you feel you were being taken advantage of by your relative?"). Scores range from 5 to 25, with higher scores indicating a greater relationship burden.			
Key Findings	TCARE was evaluated in two RCTs that compared TCARE and treatment as usual. Care managers assigned to the treatment as usual group served caregivers following the normal customary practices of their organization. In one study, family caregivers were served by care managers from social service organizations in Georgia, Michigan, Minnesota, and Washington. In the other study, family caregivers were served by care managers from three area agencies on aging in Georgia. Assessments for both studies were conducted at baseline and at 3-, 6-, and 9-month follow-ups.			
Studies Measuring Outcome	Studies 1 and 2			
Study Designs	Experimental			
Quality of Research Rating (0.0–4.0 scale)	3.7			

Outcome 5: Stress Burden				
Description of Measures	Stress burden was assessed with the Stress domain of the Montgomery Borgatta Caregiver Burden Scale (modified version), which contains 5 items regarding the perceived effects of caregiving on affect. Using a scale ranging from 1 (not at all) to 5 (a great deal) to indicate the extent to which their caregiving responsibilities changed each aspect of their life, respondents rated each item (e.g., "Have your care responsibilities made you nervous?"). Scores range from 5 to 25, with higher scores indicating greater stress burden.			
Key Findings	TCARE was evaluated in two RCTs that compared TCARE and treatment as usual. Care managers assigned to the treatment as usual group served caregivers following the normal customary practices of their organization. In one study, family caregivers were served by care managers from social service organizations in Georgia, Michigan, Minnesota, and Washington. In the other study, family caregivers were served by care			

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	managers from three area agencies on aging in Georgia. Assessments for both studies were conducted at baseline and at 3-, 6-, and 9-month follow-ups. Over time, caregivers in the intervention group had a decrease in stress burden, whereas caregivers in the treatment as usual group had an increase ( $p < .0001$ , Study 1; $p = .0258$ , Study 2).
Studies Measuring Outcome	Studies 1 and 2
Study Designs	Experimental
Quality of Research Rating (0.0–4.0 scale)	3.7

### **Study Populations**

The following populations were identified in the studies reviewed for Quality of Research.

Study	Age	Gender	Race/Ethnicity	
Study 1	<ul> <li>18-25 (Young adult)</li> <li>26-49 (Adult)</li> <li>50-60 (Older adult)</li> <li>61-74 (Older adult)</li> <li>75-84 (Older adult)</li> <li>85+ (Older adult)</li> </ul>	<ul> <li>79.7% Female</li> <li>20.3% Male</li> </ul>	<ul> <li>75.7% White</li> <li>19.4% Black or African American</li> <li>7.9% Race/ethnicity unspecified</li> </ul>	
Study 2	<ul> <li>26-49 (Adult)</li> <li>50-60 (Older adult)</li> <li>61-74 (Older adult)</li> <li>75-84 (Older adult)</li> <li>85+ (Older adult)</li> </ul>	<ul> <li>84.5% Female</li> <li>15.5% Male</li> </ul>	<ul> <li>54.6% White</li> <li>42.3% Black or African American</li> <li>3.1% Race/ethnicity unspecified</li> </ul>	

# Quality of Research Ratings by Criteria (0.0-4.0 scale)

	Ratings				
Criterion	Outcome 1	Outcome 2	Outcome 3	Outcome 4	Outcome 5
Reliability of Measures	3.9	3.3	4.0	4.0	4.0
Validity of Measures	3.3	3.0	3.8	3.5	3.5
Intervention Fidelity	3.9	3.9	3.9	3.9	3.9



	Ratings				
Criterion	Outcome 1	Outcome 2	Outcome 3	Outcome 4	Outcome 5
Missing Data and Attrition	3.6	3.3	3.6	3.6	3.6
Potential Confounding Variables	3.5	3.5	3.5	3.5	3.5
Appropriateness of Analysis	4.0	4.0	4.0	4.0	4.0
Overall Rating	3.7	3.5	3.8	3.7	3.7

#### **Study Strengths**

Internal consistency reliability was adequate to high for all outcome measures. The items used to assess intention for nursing home placement have face validity, and the other outcome measures have evidence of construct validity. Intervention fidelity efforts included TCARE care managers receiving 2 days of intensive training, a 1-day follow-up practicum session, and a Web-based application training, and all intervention group cases were reviewed by the research team at baseline and the 6-month follow-up for adherence to the intervention protocol. One study reported the results of analyses of scores from a 27-item fidelity checklist. The mean scores for mechanics (accuracy of the information recorded) and implementation (consistency of the care plan with the TCARE protocol) improved from baseline (68% and 71%, respectively) to the 6-month follow-up (85% and 89%, respectively). Although attrition was high at the 9-month follow-up, there were almost no missing data for program completers, and restricted maximum likelihood estimation was effectively used to address missing data and attrition. Caregivers were randomly assigned to intervention or treatment as usual groups. There were no significant differences between caregivers in the intervention and treatment as usual groups at baseline on demographic or outcome measures. Repeated measures random effects regression analysis was used.

#### Study Weaknesses

The items used to assess intention for nursing home placement are not established in the field. Evidence of the validity of the measures for the diversity of the study samples was unclear. In one study, there was no discussion of the characteristics of those who dropped out relative to those who remained, nor was there a discussion of how attrition might have affected the outcomes. Care managers were not randomly assigned to the intervention or treatment as usual group.

## **READINESS FOR DISSEMINATION**

Review Date: June 2014



#### **Materials Reviewed**

The materials below were reviewed for Readiness for Dissemination. The implementation point of contact can provide information regarding implementation of the program and the availability of additional, updated, or new materials.

Kwak, J., Montgomery, R., O'Connell Valuch, K., & Kosloski, K. (2013, November). *Results of a randomized trial of an innovative care management protocol for family caregivers.* Poster presented at the annual meeting of the Gerontological Society of America, New Orleans, LA.

Montgomery, R. J. V., & colleagues. (2010). *TCARE military family member assessment*. Milwaukee: University of Wisconsin–Milwaukee.

Montgomery, R. J. V., & colleagues. (2010). *TCARE military family member assessment: Follow-up form.* Milwaukee: University of Wisconsin–Milwaukee.

Montgomery, R. J. V., Rowe, J. M., Jacobs, J., & associates. (2010). *Guide for selecting support services: Military.* Milwaukee: University of Wisconsin–Milwaukee Research Foundation.

Montgomery, R. J. V., Rowe, J. M., Jacobs, J., & associates. (2010). *Tailored CARE: Tailored Caregiver Assessment and Referral user manual* (Version 3.0). Milwaukee: University of Wisconsin–Milwaukee Research Foundation.

Program Web site, http://www.tailoredcare.com

Tailored Care Enterprises, LLC. (2014). TCARE training manual. Mequon, WI: Author.

TCARE training presentation materials:

- 1. Tailored CARE: Improving Care for Caregivers [PowerPoint slides]
- 2. Exploring the Caregiver Experience [PowerPoint slides]
- 3. Caregiver Identity Change Theory [PowerPoint slides]
- 4. Rethinking Support Services [PowerPoint slides]
- 5. TCARE Screening [Video]
- 6. Assessment & Overview of Steps [PowerPoint slides]
- 7. TCARE Decision Maps [PowerPoint slides]
- 8. Introduction to the Guide for Selecting Support Services [PowerPoint slides]
- 9. The "Ity Lens" Helps Make Decisions [PowerPoint slides]
- 10. Creation of the Care Plan Consultation Worksheet & Care Plan [PowerPoint slides]
- 11. Follow-Up [PowerPoint slides]
- 12. Wrap-Up [PowerPoint slides]

Other materials and forms:

- Educational Resource Form
- Local Resources—Organization Resource Profile



- Sample TCARE Certificate of Certification
- Six-Step TCARE Process
- TCARE Assessment Questions
- TCARE Brochure
- TCARE Certification Exam (with sample narrative and assessment form)
- TCARE Process Video
- TCARE Related Bibliography

#### Readiness for Dissemination Ratings by Criteria (0.0-4.0 scale)

Criterion	Rating
Implementation Materials	3.9
Training and Support	3.5
Quality Assurance	4.0
Overall Rating	3.8

#### **Dissemination Strengths**

The user manual includes all of the tools and information needed to implement the program. Participant criteria and implementer qualifications are described, and assessment forms, decision maps, and service planning forms are very clear and easy to use. Video presentations provide excellent introductions to the program and demonstrations of how the screening is implemented. The TCARE software allows users to integrate local, regional, and statewide resources as needed with support from the Tailored Care Enterprises team. Training materials and support resources are extensive and audience appropriate, tailored to individual organizational types. As a part of the licensing fee, ongoing consultation and support are available through Tailored Care Enterprises, who address issues at all levels of implementation (i.e., policy, administration, intake, and program delivery) through in-person meetings, phone calls, and Webinars. The TCARE software guides the screening process, monitors outcomes, and directs planning and decisionmaking on the basis of responses to screening questions—all of which promote fidelity and quality of implementation. Care managers (i.e., assessors) must be trained and certified annually.

#### **Dissemination Weaknesses**

Little guidance is provided on incorporating TCARE into existing services or recruiting participants. It is unclear how frequent training opportunities are available; training options are not clearly presented in a central, public location (such as on the program Web site).

## Costs

The cost information below was provided by the developer. Although this cost information may have been updated by the developer since the time of review, it may not reflect the current costs or availability of items (including newly developed or discontinued items). The implementation point of contact can provide current information and discuss implementation requirements.



## Implementation Materials

Item Description	Cost	Required by Developer	
TCARE Overview Webinar	Free	No	
Annual licensing fee (includes ongoing consultation and technical support)	<ul> <li>Medicaid organizations:         <ul> <li>For 1–50 assessors, \$350 per assessor</li> <li>For 51–100 assessors, \$300 per assessor</li> <li>For 101 or more assessors, \$250 per assessor</li> </ul> </li> <li>For-profit organizations:         <ul> <li>For 1–100 assessors, \$600 per assessor</li> <li>For 101–200 assessors, \$480 per assessor</li> <li>For 201 or more assessors, \$360 per assessor</li> </ul> </li> </ul>	Yes	
2-day, on-site TCARE Assessor Training (includes TCARE Training Manual and TCARE User Manual)	<ul> <li>Medicaid organizations: \$19,000 for up to 12 assessors, plus travel expenses for 2 trainers</li> <li>For-profit organizations: \$23,000 for up to 12 assessors, plus travel expenses for 2 trainers</li> </ul>	Yes, one training option is required	
2-day, off-site TCARE Assessor Training	\$1,700 per assessor	Yes, one training option is required	
2-hour TCARE Screen Training Webinar	\$250 for up to 30 assessors	No	
Replacement TCARE Training Manual	\$100 each	No	
Replacement TCARE User Manual	\$110 each	No	
Incorporation of regional/statewide resource database into TCARE software	\$6,400 per site	No	
Program evaluation support	Varies depending on site needs	No	
Creation of State/organizational data reports	Varies depending on site needs	No	



Item Description	Cost	Required by Developer	
Tailored Care Enterprises review fee (includes review and approval of any changes made to licensed materials)	\$60 per hour	Yes	
2-hour Assessor Recertification Webinar	\$50 per assessor	Yes, if assessor did not complete 5 TCARE cases during licensing year	

# **OTHER CITATIONS**

Hauptman, H., & Korte, I. (2013, January). *Family Caregiver Support Program: A report on the FY 2012 expansion.* Olympia: Washington State Department of Social and Health Services, Aging and Disability Services Administration. Available at

http://www.altsa.dshs.wa.gov/stakeholders/TCARE/documents/FCSP%20Expansion%20Report%20-%20January%207%202013.pdf

Miller, M. (2012, November). *Did expanding eligibility for the Family Caregiver Support Program pay for itself by reducing the use of Medicaid-paid long-term care*? (Document No. 12-11-3901). Olympia: Washington State Institute for Public Policy. Available at http://www.wsipp.wa.gov/ReportFile/1110/Wsipp\_Did-Expanding-Eligibility-for-the-Family-Caregiver-Support-Program-Pay-for-Itself-by-Reducing-the-Use-of-Medicaid-Paid-Long-Term-Care\_Full-Report.pdf

Montgomery, R. J. V. (2011). *Final narrative report: Assessing a care management protocol to strategically support family caregivers* (Report submitted to the Jacob & Valeria Langeloth Foundation).

Montgomery, R. J. V. (2011). *Final scientific progress report: Accessing a protocol to strategically support family caregivers* (Report submitted to the Alzheimer's Association; Grant No. IIRG-07-60123).

Montgomery, R. J. V., Kwak, J., Rowe, J. M., Jacobs, J., Lang, J., O'Connell Valuch, K., & Wallendal, M. (2010). Improving options for persons with Alzheimer's Disease and their caregivers in the State of Georgia: Tailored Caregiver Assessment and Referral project final report—July 1, 2007–March 31, 2010 (Report submitted to the Georgia Division of Aging Services).

Montgomery, R. J. V., Rowe, J. M., & Kwak, J. (2009). *Final report: Georgia Division of Aging Services regarding Tailored Caregiver Assessment and Referral (TCARE) protocol project July 1, 2007–December 31, 2008* (Report submitted to the Georgia Division of Aging Services).

# **TRANSLATIONAL WORK**

TCARE has been implemented in over 250 organizations in 17 states. The most successful translation of the TCARE protocol into practice has been accomplished by the State of Washington. The Family Caregiver Support Program (FCSP) was established by the Washington State Department of Social and Health Services, Aging and



Disability Services Administration (ADSA), to provide a more comprehensive array of information, resources, and services for unpaid family caregivers caring for adults with functional disabilities. In 2007 TCARE was integrated into the FCSP and implemented through the State's 13 area agencies on aging (AAAs).

The TCARE protocol is designed to tailor services to the unique needs of each caregiver, thereby reducing depression and burdens (i.e., objective, relationship, and stress burdens) associated with caregiving. TCARE provides a consistent, objective, and reliable screening and assessment process that identifies at-risk caregivers and allows care managers to target resources to those most in need and determine whether support and services are making a measurable difference to caregivers. TCARE also helps inform policy through the collection of statewide data. Washington is the first State to automate the full TCARE process through integrating the assessment tools and decision algorithms into the State's client data system, using custom-built software.

Eligible caregivers are those who provide uncompensated care for a parent, spouse, or another adult with medical issues, mobility limitations, or decreased cognitive functioning. As a result of a significant increase in funding in Fiscal Year (FY) 2012, 1,518 new caregivers received information and limited services (up to a value of \$250 once annually). A total of 859 new caregivers received the TCARE screening and services without going further in the TCARE process, and 2,273 new caregivers received a TCARE assessment and/or a care plan and tailored services. To date, the State of Washington has served over 11,000 caregivers using TCARE, and more than 8,000 of these caregivers have completed the full TCARE process at least once.

When TCARE was first launched in Washington, ADSA and its AAA partners formed a policy oversight committee to develop comprehensive policies for implementation and establish restrictive criteria for assessments and costlier services in response to budget constraints. From July 2009 to January 2010, significant staffing resources were dedicated to training, implementation, and policy development related to TCARE. At that time, a portion of the TCARE protocol, the TCARE screen, was offered to all interested family caregivers to identify those who should receive a full assessment. The full TCARE protocol, which includes a caregiver assessment, consultation, and care planning, along with a more comprehensive set of services, was available only to those family caregivers at the highest levels of burden.

Recognizing the need to better serve family caregivers before they are close to placing their loved ones in a longterm care facility, the 2011 Washington Legislature expanded the FCSP to serve more caregivers by increasing its funding by \$3.45 million for FY 2012. This increase allowed the FCSP to serve up to 1,500 new family caregivers who were experiencing depression and/or burdens but were not yet eligible to receive a full TCARE assessment and care plan, as well as related services, under the previous criteria. Most of this funding was used to pay for higher tier services offered to more families as a result of lowering eligibility thresholds. The increased funding in FY 2012 assumed that savings would be achieved by diverting care receivers from more costly Medicaid longterm care services. To serve the increased number of caregivers, the AAAs or other community service partners hired new staff, and many staff had to be certified to administer TCARE. The TCARE certification process, managed by Tailored Care Enterprises, LLC, includes an intensive, on-site, 2-day training plus assessment practice and online testing; it can take up to 6 weeks for staff to become certified, but most staff are certified in 4 weeks.

The additional funding provided by the Washington State Legislature in FY 2012 also was used to conduct a review of the FCSP by the Washington State Institute for Public Policy (WSIPP). The review confirmed that



caregivers screened after the expansion were more likely to receive a full assessment and a broader range of support services than those screened in prior years. Family caregivers who participated in the full TCARE assessment and continued to be served through the FCSP 6 months later demonstrated positive changes. Despite an increase in assistance needed by their care receivers (e.g., daily living activities) over the 6-month period, caregivers demonstrated lower objective burden, stress burden, identity discrepancy, and depression. Although the focus of the FCSP has always been on improving outcomes for caregivers, the expansion and the WSIPP study led to the measurement of outcomes for care receivers as well. Care receivers whose caregivers were screened after expansion were approximately 20% less likely to enroll in Medicaid long-term care services in the 12 months following screening compared with prior years, despite the fact that more postexpansion care receivers were already enrolled in Medicaid medical coverage at the time of screening. Care receivers whose caregivers were screened after expansion were slower to transition to Medicaid long-term care, after controlling for differences in baseline characteristics.

Next steps in maintaining the TCARE protocol in the State of Washington include the following: (1) sustain funding for the FCSP at the current expansion levels; (2) consider a longer term study of the impact related to Medicaid long-term care diversion and savings, as well as the impact of caregiving on employment, family caregivers' health outcomes, and health care costs; (3) continue to target higher levels of services to those caregivers and care receivers at highest risk, including caregivers whose care receiver is enrolled in Medicaid medical coverage at the time of the screen, caregivers whose care receiver has been diagnosed with dementia, caregivers whose screen responses indicate a greater number of high burdens; (4) implement a standardized satisfaction feedback survey with caregivers using the program; and (5) implement a new system of tracking services and expenditures provided to each individual caregiver, which would help to address questions regarding whether specific services may have affected the use of Medicaid long-term care.

Site With	Articles Describing Site's Translational Work, by Category					
Translational Work	Planning/ Partners	Adoption	Reach/ Recruitment	Implementation	Effectiveness	Maintenance
Washington State	Articles 1–3	Articles 1 and 3	Articles 1–3	Articles 1–3	Articles 1–3	Articles 1 and 3
Article Number	Article Reference					
1	Hauptman, H., & Korte, I. (2013, January). <i>Family Caregiver Support Program</i> : A report on the FY 2012 expansion. Olympia: Washington State Department of Social and Health Services, Aging and Disability Services Administration. Available at http://www.altsa.dshs.wa.gov/stakeholders/TCARE/documents/FCSP%20Expansion%20Report%20- %20January%207%202013.pdf					

Article Number	Article Reference
2	Lavelle, B., Mancuso, D., Huber, A., & Felver, B. E. M. (2014, April). Expanding eligibility for the Family Caregiver Support Program in SFY 2012: Updated findings (RDA Report 8.31). Olympia: Washington State Department of Social and Health Services, Research and Data Analysis Division. Available at http://publications.rda.dshs.wa.gov/1502/470/
3	Miller, M. (2012, November). Did expanding eligibility for the Family Caregiver Support Program pay for itself by reducing the use of Medicaid-paid long-term care? (Document No. 12-11-3901). Olympia: Washington State Institute for Public Policy. Available at http://www.wsipp.wa.gov/ReportFile/1110/Wsipp_Did-Expanding-Eligibility-for-the-Family- Caregiver-Support-Program-Pay-for-Itself-by-Reducing-the-Use-of-Medicaid-Paid-Long-Term- Care_Full-Report.pdf

## CONTACTS

To learn more about implementation or research, contact:

Rhonda J. V. Montgomery, Ph.D. Tailored Care Enterprises, LLC (262) 236-6944 rhonda@tailoredcare.com

#### Additional program information can be obtained through the following Web site:

http://www.tailoredcare.com

