T-CARE: Tailored Caregiver Assessment and Referral Process
An Evidence-Based Protocol to Enhance Family Caregiver Supports and Services

**A Position Paper for the Michigan Long Term Care Supports and Services Commission
Prevention and Caregiver Support Workgroup**

I. Background

Dr. Rhonda Montgomery and colleagues are creating evidence-based practices that will enhance the ways in which care managers currently assess and support family caregivers of elders and adults with disabilities. The term 'care manager' as used here encompasses a broad group of service providers which include supports coordinators, options counselors, case coordinators, care consultants, care coaches and family specialists.

T-CARE is an evidence-based care management protocol that refers to **Tailored Caregiver Assessment and Referral.** It is based upon Dr. Montgomery's extensive research of twenty-plus years on family caregiving and intervention programs. T-CARE is grounded in a conceptual framework called the Caregiver Identity Model that was developed by Dr. Montgomery and her colleague, Dr. Karl Kosloski. The model helps family caregivers and those who work with them to understand that caregiving involves a systematic process of identity change as people assume new activities, roles and responsibilities in a primary relationship. Changes in identity can have a strong impact on caregivers' stress levels and their need for support and assistance.

II. Goal

The major goal of the T-CARE process is to enhance the skills of practitioners to effectively and efficiently target services to benefit family caregivers by providing a manualized protocol and training for the care management process. Use of the T-CARE process enables care managers to:
- Identify the types and extent of caregiver distress being experienced
- Identify appropriate caregiver support strategies and offer options for assistive services
- Meld the extensive knowledge of researchers about caregiving with the experiences of family caregivers and practice knowledge of service providers to create a more effective process of family caregiver support.

III. Development

The T-CARE protocol is the result of an iterative development process that involved repeated consultation with and feedback from a large number of service organizations and care managers. Pilot tests in four states have improved the protocol, training process and provided anecdotal evidence that care managers can implement it. Care managers that participated in the pilots have indicated the process has improved the services they currently offer.

Core measures within the T-CARE screening and assessment tools have been fine-tuned with extensive help of families enrolled the **League of Experienced Family Caregivers.** The League is a growing web-based, national registry of family caregivers who continue to share their unique insights and caregiving experiences through a series of questionnaire surveys. The registry serves as an important vehicle for testing measures of caregiver strengths, needs and resources. These

measures provide the building blocks for further development and refining of clinical assessment tools. Over 1000 caregivers have enrolled to date. See www.familycaregivers.uwm.edu.

IV. Vision

Wide use of the T-CARE protocol will (1) maximize the impact of family caregiver services, (2) help more consumers and (3) provide better supports while reducing costs.

 T-CARE will increase the effectiveness and efficiency of efforts to support family caregivers by helping care managers to *target services effectively. C*aregivers and care managers will work together to determine needs through an assessment and consultation process that will match suitable community resources with identified needs. Care managers will learn how to:
- Identify caregivers' needs
- Understand goals for intervention
- Recommend services that match identified goals and support strategies
- Introduce supports and services at the optimal time, when caregivers can and will use them
- Increase caregivers' commitment and follow-through with care plans which they develop in consultation with a care manager.
- Efficiently use scarce resources to effectively support services.

This approach for supporting family caregivers is consistent with good care management practice which includes:
1. An assessment of needs and strengths
2. Establishing an intervention or treatment goal (*address specific symptoms of distress*)
3. Identification of appropriate supports in the sufficient quantity
4. Provision of services in a timely manner
5. Consultation with clients to assure their understanding of options and enable them to make informed choices.

V. Key Premises of T-CARE

A. Use of the T-CARE Protocol

1. Matching services with needs leads to:
   - The right services at the right time
   - Greater follow through with care plan
   - Greater potential for positive impact
2. Consumer choice and transparency are critical to achieving successful outcomes.
3. The process requires care managers to obtain insights about the caregiving context:
   - Strengths and challenges
   - Types and sources of stress/burden
   - Appropriate goals
   - Optimal support strategies (not services)
   - Awareness of options not previously identified

4. A wide array of services is useful and available to support caregivers.
5. Not all communities have all types of caregiver services

B. T-CARE Training Process
1. Training takes time and practice.
2. Care managers are taught how to assess caregiver 'needs' rather than 'eligibility.'
3. Reasons caregiver assessment is necessary: (a) care managers do not know what caregivers need and (b) caregivers often have trouble assessing their own needs.
4. The process gives care managers an opportunity to help caregivers identify their own needs and educate them about support strategies and service options.

C. T-CARE Training Principles
1. Information gained through this process puts caregivers in the driver's seat and helps them make informed decisions.
2. Caregiver assessment is not enough. Consultation and education are equally important.
3. Caregivers' choices must be valued and respected.
4. 'Good care management skills' remain important. T-CARE is an aid to care managers, not a substitute for honed skills.
5. The goal of assessment is to promote caregiver control and self-management by:
   - Assessing strengths and needs
   - Linking identified strengths and needs with support strategies and services.
6. The ultimate goal is *prevention*. The more time care managers spend up front with consumer families leads to less service delivery time overall.

VI. Expected Benefits

A. Uniform Assessment
- The protocol guarantees caregivers equal opportunity to obtain help
- Caregivers are not dependent on the knowledge of an individual care manager

B. The protocol informs intervention and care plans. Its focus is:
- Prevention, not crisis
- Strategies, not services

C. The protocol provides guidance for organizational planning
- It helps identify service gaps
- It helps identify new resources
- It guides allocation of resources

VII. Expected Outcomes

A. For Caregivers:
- Consistent and quality care management
- Equal access to information and resources
- Enough information to make informed decisions

B. For Care Managers:
- Everyone has access to the same information and knowledge about community resources
- Greater ability for co-worker support and collaboration
- Saves time by drawing upon a uniform resource base

C. For Organizations:
- Better use of scarce resources
- Greater potential for current funding
- Provide leadership in meeting needs of family caregivers of clientele served
- Greater satisfaction of consumer families and care management staff

VIII. Congruency with Michigan Medicaid Long-Term Care Task Force Recommendation

The T-CARE process is consistent with Recommendation 5 of *Modernizing Michigan Medicaid Long-Term Care: Final Report of the Michigan Medicaid Long-Term Care Task Force.* **Support, implement and sustain prevention activities through (1) community health principles; (2) caregiver support; and (3) injury control, chronic care management and palliative care programs that enhance the quality of life, provide person-centered outcomes and delay or prevent entry into the long-term care system.**

Following are excerpts of the ***October 2004 Report of Workgroup F: Chronic Care*** which describe underlying elements of the recommendation:

(1) Community health principles
- *Secondary prevention* aims to promote effective healing and recovery at the onset of disease or disability via triage, ongoing effective treatment and follow-up. *Tertiary prevention* aims to maximize quality of life and eliminate or reduce complications via management of residual disability, chronic disease and age-related decline.
- Strong prevention and caregiver support programs will lessen the need for entry into long-term care programs
- Efforts to ease the work of family or volunteer caregivers can indirectly improve the health and well-being of other family members.
- A community-based approach mandates greater interaction across service 'silos' and governmental branches.

(2) Caregiver Support
- Family caregivers provide direct services themselves, supervise formal services and assist care recipients in acquiring health services.
- Care for elderly does not come without costs or risks to the caregiver (*i.e., psychological strain, depression, increased mortality, reduced work hours or leaving the workforce*)
- Family caregivers often neglect to take care of themselves, since they may view the well-being of the care recipient as the priority and have little time or energy left over for their own health care.

- Supporting caregivers means helping the care recipient since the first and foremost concern of most caregivers is quality care for the care recipient.
- Workgroup F proposed development and implementation of wraparound protocols that address both the consumer and the caregiver support needs, to prevent harm to both the consumer and the caregiver.

(3) Programs that enhance the quality of life, provide person-centered outcomes and delay or prevent entry in the long-term care system

- Older adults and people with disabilities have unique aspects of care that differ from able-bodied adults. They are often treated inappropriately due to the lack of specialized training in geriatrics or disabilities.
- Medication management is a frequent need of both populations. Medication management for elderly (persons) is very different due to the risk of side effects and toxicity from polypharmacy.
- Assistive devices and technology to reduce dependence among the disabled are grossly under-utilized, due in part to costs or lack of awareness.

VIX. Controlled Design Studies to Examine Impact of T-CARE Protocol

Dr. Rhonda Montgomery is the Principal Investigator of three controlled design studies currently underway to examine the impact of the T-CARE protocol on care management practices. The first is a 24-month study being conducted on a small scale in Wisconsin with funding from the Healthier Wisconsin Partnership Program and the Helen Bader Foundation. The UWM research team is conducting process and outcome evaluations with chapters of the Alzheimer's Association to examine the extent to which implementation of the T-CARE protocol will:

- Prompt family caregivers to seek support services earlier in the care process
- Lead to greater follow through by family members with care plans
- Lead to lower levels of caregiver stress and burden
- Prompt timely reassessment and updating of care plans
- Enhance the ability of families to continue caring for persons with dementia

The second study is being conducted in Georgia with funding from the Administration on Aging's Alzheimer's Disease Demonstration Program (ADDGS) to implement and assess the impact of T-CARE protocol on a larger scale within four Area Agencies on Aging. Objectives:

- Train care managers to use the T-CARE assessment tools and implement a care management process
- Expand the array of caregiver resources appropriate for caregiver needs
- Increase care managers' knowledge of and access to enhanced caregiver services
- Increase the number of families of persons with dementia using caregiver support services study
- Evaluate caregiver burden, depression and satisfaction with services.

A third larger study is getting underway in Georgia, Michigan and Washington with grant funding from the National Alzheimer's Association and in-kind support from the Helen Bader Foundation. This 30-month study will assess the impact of the T-CARE protocol on the health and well-being of family caregivers of individuals with dementia, in addition to the impact on service organizations in relation to the use and costs of caregiver support services. The study will include 400 families and 80 care managers from the three states. The protocol will be implemented and tested in Michigan among three Single Point of Entry (SPE) Demonstration sites and selected service organizations within the planning and service areas of each region.

It is anticipated that each controlled study will contribute to a growing body of knowledge about effective caregiver interventions. In addition, care managers will be better able to tailor service recommendations to the unique circumstances, beliefs and needs of individual family caregivers which are linked to specific support strategies.

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