

## OPEN MEETING MINUTES

Name of Governmental Body: Family Caregiving Workgroup Governor's Task Force on Caregiving		Attending: : Task Force Members: Lisa Pugh, Todd Costello, Denise Richter, Jane Mahoney, Susan Rosa, Helen Marks Dicks	
Date: 1/14/2020	Time Started: 9:00 pm	Time Ended: 12:00 pm	Phone Participants: Carol Bogda, Irma Perez State Staff: Faith Russell, DHS, Lynn Gall, DHS, Daniel DeValve, DHS; Allie Boldt, DHS; Andrew Evenson, DWD
Location: Community Living Alliance, 1414 Mac Arthur Rd, Madison, WI 53714			Presiding Officer: Lisa Pugh and Todd Costello

### Minutes

Goal of the day is to refine workgroup recommendations and reach a consensus on priorities to recommend to the full Task Force.

Correction to previous notes – There is no hyphen in the name Helen Marks Dicks.

### Caregiver Clearinghouse

Recommendation:

Step 1: First year of biennium: State conducts or contracts out to do a statewide assessment and evaluation of existing system and resources. Assessment could be done by entities other than state government, like the school of nursing, etc. Geographically map resources. Set up a system for increasing awareness of current resources with ADRCs, counties and tribes.

Step 2: Second year of the biennium: Fund staff to support a toll-free number and share data collected. ID what's missing, what's working well, and needs to be expanded into other areas of the state. ID how to expand programs and implement best practice models. Begin to staff and build the clearinghouse, including resources the clearinghouse needs, decide if they should be providing training to groups, creating resources, hiring more staff.

Comments:

The goal of a clearinghouse is to reach caregivers at medium levels of stress in order to enable them to continue in their roles longer. It is a diversion from the need to enroll in Medicaid programs, saving both state and federal funds. ADRCs and tribes would be able to use the clearinghouse system.

A caregiver clearinghouse would be a team or office of individuals within DHS who would serve the following functions:

- Collect information on current programs that are available by county so could be accessed by counties and ADRCs.
- Make innovation grants available.
- Be the point of coordination for services and explanations of services Collect caregiver data for the State of Wisconsin

Some clearinghouse resources could be web-based, but there also needs to be a human being readily available. This could be done through the creation of a State Office on Caregiving or other configuration that would serve as a clearinghouse.

Wisconsin currently lacks complete caregiving statistics. This clearinghouse would also be charged with data collection. Middle income people are the big unknown when it comes to caregiving data related to needs and numbers. Data is only available for people enrolled in one of the Medicaid programs, plus a segment of the non-Medicaid caregivers accessing the AFCSP and NFCSP. It was stressed that the medical arena needs to help educate people about resources. They should be involved with creating and maintaining the accuracy of current resources at a clearinghouse, as well as primary partners in helping spread the word that caregiver supports are available.

Remaining questions:

- T-Care has a resource mapping exercise: Could that be used build a better clearinghouse?
- Should this be a state government function or an RFP to an organization to build a clearinghouse? It was mentioned that the nonprofits that could possibly do it may be perceived as having a slant. What about the ADRCs? Being able to be a trusted resource in the eyes of the public is critical. Is it best to be in state system to avoid conflict of interest? It was also noted that creating a clearinghouse using an RFP process will have less stability among staff compared to housing it in a state agency.
- How would we elevate the status of a caregiver clearinghouse? Does it deserve its own office?. How can we build a clearinghouse that serves those completing the assessment in a real place with real people who are helpful and can respond to people's needs any hour of the day?

## Legislative package

Recommendation to Support a legislative package that includes:

- Wisconsin Care Act
- Wisconsin Credit for Caregiving
  - Current version of S.B. 126 introduced, assigned to Committee
  - A substitute amendment has narrowed the credit:
    - Lowered credit to \$500 (from \$1,000)
    - Eliminated coverage in certain circumstances including nursing homes, Family Care, IRIS
    - Added a sunset date
  - Supports original/broader bill without substitute amendment
  - Supports Wisconsin Medical Leave Act expansion. Wis. Stat. 103.10.
  - Updates language to expand when leave can be used, e.g.:
    - Ensures "Serious health condition" includes chronic conditions
    - Ensures caregiving is covered (with a definition of "caregiving")

Comments:

- These are not low income programs.
- It is a package aimed to support the middle class.
- Re: tax credit—when presenting to full Task Force, emphasize the different contexts affected by the substitute amendment by Sen. Testin: includes not just nursing homes but also Family Care & IRIS

Documents made available:

- Wisconsin 2019 SB 516 [Care Act]
- The Caregiver Advice Record Enable (CARE) Act [map showing states that have/have not enacted]
- Voters Support the Care Act
- Family Caregiving in Wisconsin: Overwhelming Support for Care Act
- Wisconsin 2019 SB 126 [Credit for Caregiving Act]
- Wisconsin Senate Substitute Amendment 1 to 2019 SB 126 [Senator Testin]
- Fiscal Estimate (2019 Session), Introduction No. SSA-SB126
- Family Caregiving in Wisconsin: Overwhelming Support for Caregiver Tax Credit
- Support Family Caregivers: Support for the WI Credit for Caregiving Act
- FAQ: WI Credit for Caring as Amended 9/19
- Valuing the Invaluable: Putting a Dollar Value to Family Caregiving
- Report Spotlights Financial Toll of Family Caregiving

#### Remaining questions:

- Clarify who is currently eligible to take leave
- Review Governor Evers's proposed expansion of medical leave during last budget - did this include, e.g., modernization of who can take leave? Identify specific reasons why it did not pass.
- Review state toolkit for dealing with Alzheimer's/Dementia

### **TCare Caregiver Assessment**

#### Recommendation:

Pilot the adoption of the TCare caregiver assessment as a competitive RFP in 3-5 consortia that include Medicaid and non-Medicaid partners, ADRCs, MCOs, IRIS consultant agencies, tribes, health care providers. Request funding for five years, including hiring a project manager. Required evaluation component to evaluate cost savings related to utilization and Medicaid diversion. And health status of participating caregivers. Measure financial and other benefits to family caregivers.

#### Comments:

- The goal is to find a caregiver needs assessment that provides a "trigger" for identifying at-risk families in need of more intense case management, including those who don't have a strong system of informal support and caregivers who are more affected by stress and/or depression.
- TCare focuses on the early identification of at-risk caregivers; allows programs to target and provide resources to who need them most. One key question asked is "How close are you to nursing home placement?" TCare is ACL accredited and evidence-based.
- Require an evaluation component to evaluate cost savings related to TCare utilization and Medicaid diversion and improvement in the health status of participating caregivers.
- Clearly define and report all financial and other benefits.
- Make sure current caregiver support programs have sufficient funds to provide services and supports identified by the TCare assessment.

TCare was created almost 15 years ago by Rhonda Montgomery at UW-Milwaukee and has undergone changes since its earlier, more cumbersome versions. TCare does offer caregiver assessments for caregivers of different populations; military, older adults, dementia, IDD – and assessments are available in several different languages.

There is a one-time \$10,000 infrastructure development fee and a \$2,000 annual fee per user for trained assessors. Other states have rolled-out TCare as a pilot program, but TCare developers recommended implementing it statewide at one time.

Key benefit: Diverting some people from having to enter Medicaid programs. For existing Medicaid populations the benefit is recognizing the role of the person who is providing natural supports and making sure they can continue doing that at the same level. Agencies would see this as an enormous value. A caregiver's intention to place in a nursing home or other institutional setting is a HUGE part of evaluating the stress and situation of the person.

Other states have done this. Needs to be embedded in home and community based waiver programs. Needs to be a trigger process that allows for a voluntary participation in an assessment. Some states require an assessment when a certain number of hours of caregiving are provided. The TCare triage tool triggers based on other things, too – more related to a caregiver's stress identify level. TCare includes a continuous engagement model for friendly texting engagement that rates caregiver stress on a continuous basis, which identifies when caregivers are stressing out and need more help.

We should expect to hear that current Medicaid rates do not cover the cost of providing caregiver supports. There may be a need to include a request for additional funds to cover rate increases or provide a pay-for-performance bonus when agencies using TCare show cost savings or benefits to caregivers' health status

Remaining questions:

- Can Wisconsin use 1115 or other waivers to tap federal funding to draw down Medicaid match to do this? May not have to rely totally in state GPR.
- Does the assessment ask if a caregiver feels comfortable performing tasks required of them? (medical, etc.) Do you feel trained?
- Is the assessment tool culturally appropriate for all ethnicities and cultures?
- What happens to the findings of an assessment?
- What if the supports and services needed don't exist where a caregiver lives?
- Some MCOs have contracts with agencies to provide caregiver training on safe transfer, etc. Do we need more of those types of agreements?

## Public Awareness Campaign

Recommendation:

- Design a comprehensive, long-term campaign
- Main message: WI supports caregivers
  - Caregivers need support
  - Elevate a culture of caring
  - Drive people to clearinghouse website and toll-free number
  - Educate public on magnitude of the need
- RFP to marketing firm to develop and run campaign
- Stakeholder input
- Research/evaluation before, during, and after
- Outcomes of campaign:

- Increased use of traffic to/use of clearinghouse resources
  - Toll-free# and website
- Increased public awareness and positive attitude toward caregiving
- Increased public support of caregiving

#### Remaining questions:

- Estimated cost and proposed timeline of public outreach campaign (at least for initial investment)
    - Any data or evidence re: length, resources required for effective campaign?
    - What are examples of state awareness campaigns– and how much did they cost, how long were they, any evidence of effectiveness? (Dementia and ADRC campaigns should be reviewed for comparison.)
  - Consider emphasizing need for significant investment to develop new resources for caregivers. Task Force recommendations will drive more people to look for resources, so the state needs to invest more money into caregiver supports to respond to people when more people make contact.
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#### Quorum discussion

- Reviewed “Quorum Summary” handout. Contact Allie Boldt with any questions.
- Quorum being proposed by co-chairs for full Task Force: super-majority
  - Means super-majority to take a vote, and super-majority for a vote to pass.
- Quorum being proposed by co-chairs for workgroups: Simple majority (5 members)
  - Expectation is that most decisions in workgroups will be made by consensus in most instances.
  - Members may have discussions between meetings, e.g., to coordinate on assignment, but caution against any discussions involving 5 or more people
  - Best practice: Content of external discussions that do take place must be reported to full workgroups and full Task Force in an open meeting.

#### Public comments

Request to create a system or a Task Force policy for providing handouts at public meetings. It was noted that DHS can make copies of handouts if sent well in advance.

#### Next Steps

On January 30, sub-groups should come prepared to explain priorities on their slides and have researched questions that still remain.