OPEN MEETING MINUTES

Name of Governmental Body: Family Caregiving Workgroup Governor's Task Force on Caregiving			Attending: : Task Force Members: Lisa Pugh, Todd Costello, Jane Mahoney, Susan Rosa, Helen Marks Dicks, Sen. Kathy Bernier, Rep. Deb Kolste, Irma Perez, Delores Sallis State Staff: Faith Russell, DHS, Lynn Gall, DHS, Daniel DeValve, DHS; Allie Boldt, DHS; Andrew Evenson, DWD
Date: 2/6/2020	Time Started: 1:00 pm	Time Ended: 4:00 pm	
Location: Community Living Alliance, 1414 Mac Arthur Rd, Madison, WI 53714			Presiding Officer: Lisa Pugh and Todd Costello

Minutes

GOVERNOR'S TASK FORCE ON CAREGIVING
Family Caregiving Workgroup
February 6, 2020

I. THE MEETING WAS CALLED TO ORDER AT 1:00 p.m.

II. APPROVAL OF MINUTES FROM 1/14/20

Sue Rosa motioned to approve. Jane Mahoney seconded.
Approved unanimously

III. WELCOME AND OVERVIEW

Co-chairs provided welcome remarks and an overview of meeting structure:
The workgroup will be reviewing the comments and questions that Task Force members submitted on each policy idea. The group will work through ideas in order of preliminary rankings received. The goal of this discussion is to work through a template designed to help track remaining questions and next steps. [See attachment for the group notes on these questions recorded on the template.]

Questions include:

- Will the workgroup want to reframe the proposed policy idea in any way to address member concerns?
- Is additional data needed?
- What are the next steps, and who will be responsible?
- Who else might be involved?
- How will additional information be shared?

IV. DISCUSSION OF POLICY IDEAS

a. ***Statewide caregiver assessment: Collect additional caregiver data for the state of Wisconsin.*** This idea was moved to later in the meeting, to discuss along with "Statewide caregiver assessment: pilot adoption of the T-Care assessment."

b. ***Caregiver Clearinghouse: Assess and evaluate the existing ways different types of caregivers currently access supports, and provide single entry point for caregiver support services and resources.*** Identify and map caregiver resources geographically and develop a strategy for increasing awareness of current resources within ADRCs, counties and tribes. This recommendation will require funds to staff the Clearinghouse.

- Discussion today reflected a need to further develop this idea before making a recommendation. Specifically, questions were asked about how a caregiver clearinghouse would serve and interact with ADRCs. Clarity is also needed about the focus and cost of a proposed public awareness campaign and operation/staffing of a toll-free phone line.
- Was there a rationale behind not building off the ADRC infrastructure?
- Response from group and discussion: This idea would not replace the ADRCs caregiver support function. Rather, a clearinghouse would be to advertise and promote a single toll-free number for resources/referrals to ADRCs and other organizations that provide caregiver support services. Concern is that now, caregivers do not always get routed to the right place. This is especially true for caregivers with language barriers. The goal is for clearinghouse staff to connect individuals to their ADRC or other resources in their communities.
- ADRCs are already intended to be a 'one stop shop.' However, it was pointed out that ADRCs do not necessarily serve all populations that hire or have a caregiver, and many other people are not aware what services ADRCs provide.
- It was agreed that there is a need for clearer identification of existing gaps, and deeper research into whether a clearinghouse' or similar service could help fill such gaps.
- Another recommendations could include a "face-lift" for ADRCs.
- Proposed reframing: rather than suggesting a 'clearinghouse,' could propose to enhance caregiver access to information and services.

Remaining questions:

- A primary goal of establishing a clearinghouse is to compile a high-quality and current list of existing services and resources for caregivers. Who would be the 'keeper' of this list? Could there be overlap in compiling such a list with the development of a caregiver assessment pilot?
- What gaps exist with respect to ADRC services for caregivers of children?

Proposed next steps

- Compile more information about ADRCs, requirements for operation, and how they are funded. Invite Carrie Molke, Bureau of Aging and Disability Resources Director, to present and have a discussion at the Feb. 20, 2020 workgroup meeting. Discussion questions could include:
    1. What populations are not served by ADRCs, and how are these populations connected to caregiver supports?
    2. Could these gaps be filled by additional training for ADRC staff?

3. What would it take to expand current charge of ADRCs to ensure broader populations of caregivers can receive services/referrals… e.g., caregivers of children (including grandparents and other relatives)?
4. Are there ADRCs in other states that serve youth?
5. How do ADRCs ensure access to families that speak languages other than English?
6. How are ADRCs funded?

c. *Legislative Change: Support the Wisconsin CARE Act.*

This proposed legislation would ensure that one or more family caregiver/friend is on file and notified when a person is admitted to a hospital or other facility, or discharged home. The CARE Act also requires hospitals to educate and demonstrate how to perform medical/ nursing-related tasks that caregivers will be expected to perform on their own.

- Following the Task Force meeting on January 30, Task Force members submitted questions about HIPPA compliance, what is being done in other states, and questions related to concerns raised previously by stakeholders that are opposed to the legislation.
- It was noted that the Wisconsin Hospital Association (WHA) has presented data showing that hospitals are already doing what the CARE Act would require. Questions were asked about the source of this data. Helen Marks Dicks believes the data is from CMS via a survey that asked whether patients received written instructions upon being discharged. It was noted that an AARP survey of caregivers completed within the past 12 months found that in many cases, instructions were only provided on a piece of paper.
- The WHA has voiced a concern that hospitals are already highly regulated and do not need to be subjected to additional regulation.

Remaining questions:

- Can DHS or someone else provide the workgroup with data that shows if there was a reduction in readmission rates in the 40 states that have implemented the CARE Act?
- How have other states addressed concerns around liability (if instructions are not properly communicated)? Concerns about HIPPA? (*Note: Generally, HIPPA concerns are addressed in hospital because the patient designates a caregiver and consents to share information with that person.)*
- Is there a projection or way to estimate how many people could be impacted if the CARE Act is adopted in Wisconsin? Numbers or a percentage of individuals would both be helpful to know.

Proposed next steps:

- Helen Marks Dicks volunteered to gather information to respond to the questions above, including compiling variations of the CARE Act that were adopted in other states (including any modifications made to address hospital concerns).

- Sen. Bernier offered to arrange a meeting between the workgroup and the Wisconsin Hospital Association (aiming for 3/19/20). The topic of the meeting can be broader than the CARE Act, such as other ways hospitals, caregivers, providers and state government can to work together in service of charges named in the Governor's Executive Order, or improving ways to prepare caregivers who will be providing post-discharge care. *Note: WHA members employ CNAs and others.*

d. ***Public awareness campaign: Launch a comprehensive, long-term campaign to support Wisconsin caregivers. Elevate culture of caregiving, drive people to clearinghouse with information, and educate public on the magnitude of need.***
    - How would we measure success?
    - What will the connection be between the campaign, the proposed 'clearinghouse' and ADRCs?
    - How much does an effective professional public service campaign cost?
    - Who will be the proposed audience? The other workgroup is also proposing an outreach campaign, so it may make sense to combine the two goals on separate tracks.
    - Ad campaign example to review - Wilder Campaign; Aging Minnesota
    - Support for this policy idea might hinge on where things land with the clearinghouse and centralized toll-free number. A public awareness campaign would need to have a clear 'ask' for audience members. Without the toll-free number, what would this campaign be driving people to do?
    - A primary goal of the proposed awareness campaign is educating the public regarding the magnitude of need and a growing problem, including how much it is costing. How much it will cost in the future to do nothing.
    - A public awareness campaign on family caregiving issues and a campaign on the direct care workforce shortage might look very different (e.g., directing people to apply for jobs or training). It could be that there is already more awareness of the paid direct care worker shortage.
    - A public awareness campaign could it backfire if it drives too many people to reach out for help, and there are not sufficient personal care workers or financial investments/ resources to address the level of need? *Response: A lot of times, what caregivers need is not a worker, but a referral to a program or service.*

Remaining questions:

- What would the campaign be asking people to do?
- Could the campaign direct people to the ADRCs, building off the infrastructure that already exists?

Proposed next steps:

- Propose meeting with Carrie Molke to discuss who ADRCs reach (and do not reach) and how ADRC caregiving resources are compiled and shared. This discussion may result in a reframing of this policy idea.
- Ensure that the two Task Force workgroups are coordinating on any proposed public awareness campaigns.
- The last budget included an awareness campaign relating to dementia caregiving, with the aim of driving people to resources including the ADRCs and e.g., the Alzheimer's Association. Review this proposal and any information about outcomes of this campaign.
- Sen. Bernier offered to speak to Chippewa County caregiver referrals at her ADRC.

e. ***Legislative Change: Caregiver Tax Credit. Support a Wisconsin Credit for Caregivers (2019 Wisconsin Senate Bill 126, as introduced).***
   - The original bill would provide a $1,000 non-refundable tax credit to cover out-of-pocket costs for caregiving individuals earning up to $75,000 per year.
   - This a non-refundable credit is for family members as defined by the Probate Code. Covered items including home modification, diapers, payments for supplemental insurance, and other goods/services designed to keep people in their home. Non-refundable means there will only be a benefit for those with tax liability.
   - Rep. Deb Kolste read a list of groups that have come out in support of this bill. She is not aware of any groups that have registered opposition to it. This tax credit also seems to be a relatively low-cost solution. It might be a feasible request it be included as part of the budget request because it seems unlikely to pass as a stand-alone item. At this time, elected representatives are not necessarily hearing from constituents that this is a crisis.
   - Helen Marks Dicks provided additional information about the bill. The initial fiscal estimate associated with this bill (as introduced) was incorrect. The Wisconsin Department of Revenue (DOR) has since adjusted its estimate to ~$110 million. This figure was released with high/conservative assumptions regarding the number of people who would apply for it. It was recommended that the Task Force endorse the original version of the bill.
   - Helen requested data for the number of people receiving care in Wisconsin (since the credit cap is per care recipient, not per caregiver); DHS does not have a total statistic of all people receiving care, just those enrolled in DHS programs. Estimates could be generated based on what is known nationally.

Remaining questions:

- How would the state prevent fraudulent claiming of the caregiver tax credit?
  Noted that tax fraud is distinct from Medicaid fraud. Tax fraud can be addressed by DOR audits.

Proposed next steps:

f. ***Legislative Change: Support Wisconsin Family Medical Leave Act (FMLA) Expansion.*** This legislation updates when leave can be used, for example, by allowing leave for chronic conditions, and ensures that caregiving is a covered reason for leave.
    - Work to clarify who is eligible to take leave.
    - Advocate for Governor Evers to expand Medical Leave policies.
    - There are separate distinct FMLA proposals relating to leave insurance (including employee-paid insurance and matching), but these proposals have a much higher price-tag.
    - Workgrop agreed with the proposed approach of recommending the smaller step of expanding unpaid FMLA to more people under more cicumstances, which might be more politically feasible.

Remaining questions:

- Questions remain regarding costs to the state and employers/businesses.
- Some members still have questions regarding a separate but related proposal regarding FMLA insurance.
- Get clarification/reframing around what part of FMLA the Task Force would be proposing to expand: e.g., (1) modernizing the policy to recognize population changes that require more people to take-on caregiving roles now and into the future; (2) Expanding the list of care recipients to include siblings of individuals with IDD who step into guardian/caregiver roles, or caring for a friend); (3) ensuring that leave can be taken when caregiving for someone with a chronic disease, not just acute care needs; (4) including time needed to participate in care planning and discharge meetings.
- The workgroup is not recommending changes to the amount of leave available or which employers it would apply to.

Proposed next steps:

- Draft a clarifying proposal that includes a comparison with existing FMLA policy. Helen Marks Dicks volunteered to draft the proposal, possibly using existing publications on FMLA from DWD and Governor Evers' last proposed budget, which included a proposal for FMLA expansion.

g. ***Caregiver Assessment: (i) Pilot the adoption of the TCare caregiver assessment, and (ii) collect additional caregiver data for the state of Wisconsin.***
    - Is the assessment designed to 'weed out' individuals as not appropriate caregivers? *Absolutely not.* T-Care is an evidence-based (pre-packaged) assessment of the caregiver themselves and how comfortable they are in their role. This model kept coming up when the subgroup was undertaking research of caregiver assessments, and it has received endorsement by CMS. When undertaking research, Lisa Pugh

  was informed that T-Care developers are looking to expand its evidence-base tool for use with for caregivers of people with IDD, and they would be excited to partner with Wisconsin on this.
  - There are at multiple versions of the T-Care assessment, including a 'skinnier' (shorter) screen and a more thorough assessment, which can be used if merited and the participant is willing.
- Some Task Force members remarked that T-Care seems to create a separate process. Some wondered if existing processes could be built on instead. Might a hybrid recommendation be possible — for example, taking the existing 'functional screening' process (designed to ask questions about the person needing care) and adding triggers relating to caregiver questions and concerns?
  Responses: The functional screen is not applied when an individual is not interested in, or qualified for, a publicly-funded program.

  Remaining questions:
  - Is there a way to fold in a caregiver assessment into the current LTC screening process?
  - Which version of TCare is being recommended?

Proposed next steps:

- Ask Carrie Molke if it would be possible to include a caregiver assessment as part of the LTC screening process.

V. NEXT STEPS

- Reschedule the Feb. 20 Family Caregiving Workgroup meeting to take place from 1:00-3:30 pm so that members attending in person can view a "Family Caregiving Policies and Innovations Webinar" hosted by the RAISE Family Caregiver Resource and Dissemination Center from 1-2 p.m. [Those not attending in person who wish to view the webinar should register for the webinar directly (Register here).
- Invite Carrie Molke to present in person or virtually at the workgroup's Feb. 20 meeting beginning at 2:00 p.m. to discuss ADRC requirements and possibilities for including caregiver assessments into the LTC screening process.

VI. PUBLIC COMMENTS

- There were three members of public in attendance who thanked workgroup members for their work.

VII. ADJOURNED AT 4:00 P.M.

Prepared by: Lynn Gall, DHS Office on Aging on 2/12/2020.

These minutes are in draft form. They will be presented for approval by the governmental body on: 2/20/2020