DEPARTMENT OF HEALTH SERVICES **STATE OF WISCONSIN**
F-01922 (12/2019)

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, Denise Richter for Sen. Kathy Bernier, Rep. Deb Kolste Phone Participants: Carol Bogda, Irma Perez State Staff: Faith Russell, DHS, Lynn Gall, DHS, Allie Boldt, DHS
Date: 3/5/2020	Time Started: 9:00 am	Time Ended: 12:00 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

March 5, 2020

I. THE MEETING WAS CALLED TO ORDER AT 9:00 a.m.

II. APPROVAL OF MINUTES FROM 2/20/20

Sue Rosa motioned to approve. Jane Mahoney seconded.
Approved unanimously – Comment that members appreciated the level of detail in the notes. Also a request to have documents that are posted on the public meetings website sent as attachments to members' emails because there has been some difficulty downloading documents.

III. WELCOME AND OVERVIEW

Co-chairs provided welcome remarks and an overview of meeting agenda.

IV. WISCONSIN FAMILY CAREGIVER SUPPORT PROGRAMS CAREGIVER NEEDS ASSESSEMENT – Presented by Lynn Gall

- The caregiver needs assessment used by the Wisconsin Alzheimer's Family Caregiver Support Program (AFCSP) and the National Family Caregiver Support Program (NFCSP) is one part of a three-part assessment and quality improvement process for these two non-Medicaid programs. The tools include:

  1. Caregiver Needs Assessment (attached)
  2. Program Evaluation, which compares changes in caregiver ability and health upon enrolling in the program and after receiving support services.
  3. A Customer Satisfaction Survey, which measures the whole experience of accessing and receiving services.

- The Caregiver Needs Assessment is used by county and tribal program coordinators to help caregivers self-identify their most pressing needs, and then approve services to meet those needs. The DHS has been piloting the three assessment tools for two years and received its first full year of data at the end of 2019.

- Data being collected goes beyond federal program requirements.
- The AFCSP and NFCSP offer limited, shorter-term or occasional caregiver supports compared to more intense Medicaid long-term care programs for children and adults. The AFCSP requires that the person receiving care has a dementia diagnosis. The NFCSP requires that the person receiving care is age 60 or older, or age 55+ and the primary caregiver for a minor child or adult with a severe disability. The NFCSP restricts the number of respite hours a caregiver is eligible to receive to 112 hours per year, which is 4 ½ days of 24-hour coverage or 14 days of 8-hour coverage.
- Other services available include information and assistance to access caregiver supports, participation in support groups and counseling, access to goods and services, including minor home modifications that allow the person in their care to remain living at home.
- The AFCSP has no hourly time limits on respite but does limit per person expenditures to $4,000 per year. More than half of Wisconsin counties have lowered their allowable spending limit to less than $4,000 in order to serve more families in need.
- The DHS caregiver needs assessment tool is not given directly to caregivers; rather it is used by Family Caregiver Coordinators to guide discussions with caregivers. Training on how to conduct a quality caregiver needs assessment has been, and continues to be, provided to local program managers as part of DHS and GWAAR sponsored training.
- One result that stands out from the from assessments done so far is that Wisconsin caregivers are saying they need more time to themselves (see attached compilation of responses from January 2019 through mid-February 2020). As a measure of caregiver burden, this translates into a need for more respite. Respite was identified as the number one service requested in almost every section of the assessment.
- Another noticeable finding is that the needs of caregivers and care recipients' needs do not always match, even though these needs are connected to one another.
- Data from a needs assessment can be connected to data from the same person's pre- and post-program evaluation data, but not their customer satisfaction survey. Customer satisfaction surveys are anonymous and sent directly to the state office.
- DHS is able to provide caregiver needs assessment data by county, tribe or ADRC, or the state as a whole.
- DHS has learned that the easiest bar to move is the caregivers' educational levels and awareness of resources. It is harder to move the caregivers' actual physical/emotional well-being, but improvements are being documented. [DHS has attached a 2019 pre- and post-program evaluation to these minutes.]
- There are differences between Wisconsin Caregiver Needs Assessment and TCare. TCare has been used mostly in longer-term care situations. If a TCare assessment can be completed within half an hour it may be a suitable replacement for the DHS system.
- One thing TCare does better than the DHS assessment is measure the level of risk a caregiver faces – noting indications that a caregiver is at risk of moving an individual to

a nursing home or skilled care facility. TCare directly asks a question similar to: “Have you ever considered, or how close are you now to, putting the person you care for in a nursing home?”

- A member commented that one benefit with using a more widely used assessment tool like TCare is that it would allow Wisconsin to compare our results with other states using T-Care.
- Another mentioned that the assessment is related to Senator Bernier’s point that legislators need to see evidence regarding return on investment—e.g., how can we support that caregiver to be healthy longer. Should we be limiting preventative supports if those services keep people out of the Medicare system?

WI Family Caregiver Support Programs Caregiver Needs Assessment: Questions & Comments

Q: Can you disaggregate data by county? Are the needs consistent across the state?

A: Yes, we can disaggregate and can run this data by county, by ADRC or statewide. In depth-analysis has not yet been completed on the first year of data.

Q: In the question regarding unmet caregiver resources needs – what is meant by the finding that 28% chose “does not apply?”

A: The respondent either said that they didn’t need that service, or it did not come up in conversation. It could also indicate individuals who were not open to having an in-depth conversation about their needs.

- A member emphasized that respondents were willing to say that they need more time to themselves—not necessarily more resources/education. We have to keep in mind that being in a state of crisis is not the best time to learn.
- Member Carol Bogda, who works with members of the Oneida Nation, reported that she doesn’t get a lot of participation from community members when she holds classes for Oneida Nation members. For many people the real need is more respite.
- DHS will need more time to analyze the first year’s data before in-depth conclusions can be drawn about which service gaps appear to be universal or which might be localized. At this point, DHS does not have data as to how many people ask for respite and are turned down.
- It is important to remember that caregivers enrolled in NFCSP are limited to 112 hours of respite over the course of the year, and some people do turn it down. Some caregivers turn it down because the hours offered seem too small to make a significant difference. Others refuse respite because the care recipient only wants to receive care from the caregiver. Also, given shortages in the direct care workforce, respite services may not be available when people really need them (e.g., may only available between 8 a.m. - 4:30 p.m., not in the evenings when people need it).
- Sometimes, program staff encourage families to try respite once, which gives them an opportunity to see the value and perhaps be less reticent in the future.

- Wisconsin needs to think more expansively about what constitutes respite; it doesn't necessarily have to look like someone coming into the home while you are gone. It could look like someone doing your grocery shopping.
- Member Carol Bodga has a client who attends an adult day center, providing the caregiver with two days respite per week. Because this person is an Oneida tribal member, some days of service are paid for by the tribe if the need exceeds AFCSP or Older American Act guidelines. Carol does occasionally provide in-home respite herself (e.g., sit with the care recipient while the caregiver goes shopping), but she can only offer an hour or two at a time because of the demands on her time from other clients.

TCare Needs Assessment

- Member Jane Mahoney reported on a TCare assessment used by Washington State for NFCSP, using federal Older Americans Act funding and state funding
- Caregivers are given a preliminary assessment and then receive a second assessment that is more in-depth.
- A next step for this workgroup is to have a representative from TCare participate in a future workgroup meeting for a discussion about what TCare can and cannot do. Our state assessment is very practical, whereas TCare is more about how the caregiver is feeling.
- Cost to implement TCare: $10,000 one-time set up fee and $2,000 annual license fee per care manager. If it were implemented as a pilot, the cost would be minimal.

DISCUSSION:

- We must recognize that people are not at their best when they take the first assessment. Many caregivers are in survival mode by the time they request help.
- TCare trainers provide intensive training for county/tribal staff who will be asking caregivers assessment questions, and they teach how the TCare assessment connects to supports that are ultimately recommended for caregivers.
- How can we help caregivers tap into and mobilize the people around them, especially other family members? Many caregivers feel very isolated. Asking for help can be a difficult discussion to have with others.
- It's important to catch caregivers before they are in crisis, to teach them to recognize if they're in, or headed for, a crisis.
- Washington State's personal family caregiver survey (attached) places caregivers into tiers of basic risk, which allows them to calculate state savings from delaying or avoiding enrollment in Medicaid programs. The closer a caregiver is to placing someone in out of home care, the more TCare targets wraparound of services.
- We don't know if TCare will allow Wisconsin to modify these tiers. Tier two showed most savings and extended the ability of a caregiver to continue

- NECESSITY: The Task Force proposal should show the value of implementation and benefits and cost to the state in the long run. Washington does not have enough information yet to provide the Task Force with information on the costs versus the savings of implementing TCare, but they may be able to show if they were able to extend caregiving longer, and indicate if there was a reduction in Medicaid services and savings in other areas related to caregiving.
- Workgroup members support an assessment process that makes a connection between identified needs and actual resources provided. Right now we're not sure whether, once a need is identified, current programs and community resources are able to meet those needs.
- We also lack a way to track whether or not meeting those needs delays entrance into the Medicaid system.

Next Steps:

1. Have a TCare representative present and answer questions during the next meeting. (Jane Mahoney will arrange)
2. Reframe the recommendation in the Next Steps Document.
3. Use March and April to decide if a recommendation is ready to be submitted to the full Task Force.

V. REFRAMING CLEARINGHOUSE TO EXPANDED ROLE OF ADRCs

- Revisions were made to the initial policy idea after the last meeting to link the clearinghouse items to ADRCs. The initial clearinghouse idea is being reframed as a recommendation to improve the one-door connection to a local ADRC. Part of marketing will be to tell people to look locally for resources. Should the public outreach and marketing recommendation be included in this as well?
- It was pointed out that setting up a statewide toll-free number forces callers to re-tell their story when transferred to their ADRC, which should be avoided. The best first contact for a person to speak with is their ADRC.
- It was noted that the AFCSP and NFCSP once had a toll-free statewide phone line, but it wasn't used very often.
- Members want to find out if there is an automated toll-free system that can get callers to where they need to go – connecting them to their local ADRC by touchtone, perhaps by entering their zip code, or something similar?
- Additional questions to pursue include:
  - What other toll free numbers connect people to local resources?
  - How do they do it?
  - Can we learn from them?

  Examples mentioned included 411, the suicide hotline, and Amber Alert. An elder abuse hotline is being designed right now to connect individuals to their county Adult Protective Services (APS) unit.

- An additional consideration concerns the best use of time and money, an internet map or a toll-free number? Older people and those in rural areas may have limited access to, or comfort levels, using the internet.
- Task Force member Irma Perez was asked to share her experiences with how Hispanic families and Spanish speaking families access ADRCs and caregiver supports.
    - Irma said not a lot of families do not know what resources are available through the ADRC and even if they do, many are afraid to call. They are more comfortable interacting with an agency that is closely connected to, and has a good reputation of serving, their community.
    - Also, many Hispanic and Spanish-speaking caregivers are worried they will get overloaded with information from an ADRC and prefer to hear directly from people they already know. There is fear that families are going to get the runaround at an ADRC because that's what often happens, especially when they are Spanish speakers. In her experience, only a minimal number of Hispanic families connect with ADRCs. It is believed these families get lost or in some instances become overwhelmed.
    - When a person opens the ADRC website, there is no button for languages or related services; translation information did not appear to be available from a search of the ADRC website.
    - Families find Irma's agency and services through word-of-mouth from their friends or connections with other community groups or clinics they use.
- The co-chairs emphasized that the workgroup needs to pay attention to the cultural competence piece when thinking about building out ADRCs. One of the goals is to better reach underserved populations.
- Irma was asked to think about what ADRCs could to do make them more inviting and welcome for Spanish-speaking families. Co-Chair Lisa Pugh will send Irma specific questions. Language barriers are real and huge for families.

ADRC-RELATED QUESTIONS FOR DHS:

1. What ability do ADRCs have to handle an increase in customers, identify and fill current gaps, and improve marketing? What funding would be needed to support such efforts? Needs follow-up from DHS.
2. What have ADRCs done to address the issue of reaching underserved populations and making ADRCs a welcoming space for them? Needs follow-up from DHS.
3. AFCSP and NFCSP participants do not have access to the same level of case management support available to TCare participants, who receive continual connection with a care manager. Could the AFCSP and NFCSP assessment tool be modified to identify at-risk caregivers better, especially those at risk of placing a person in a nursing home? DHS staff answered that the current caregiver needs assessment for AFCSP and NFCSP was developed by the DHS Office on Aging, so it can be changed without involvement of an outside vendor.

Members agreed that the goal of recommending a needs assessment is to reach and help caregivers who are most at risk. In order to do that, there needs to be a more targeted question or method for measuring how at-risk a person is.

- It is believed that the same caregiver needs assessment could be used for Family Care and other Medicaid programs. The goal is to recommend an assessment that can be used broadly across participants of the non-Medicaid and Medicaid home and community based waiver systems.
- One member noted that there are two constants that he's seen in family caregivers:
  - They're afraid to die because no one can care for their family member like they can.
  - Placement outside the home is considered failure on their part.

  This member believes that much of caregivers' effort and angst is coming from that place of fear. He is interested in understanding more about the algorithm used for these kind of questions when asked by TCare.

VI. PUBLIC AWARENESS CAMPAIGN

- Several members of the Direct Care Paid Workforce Workgroup are reaching out to learn more about the impact and effectiveness of public awareness strategies. The other workgroup indicated a strong willingness to combine our efforts even if campaigns have different goals.
- It was suggested that a public awareness campaign should be run in two phases. But before any public awareness campaigns can be designed, the state needs to build capacity and increase resources available before caregivers are told to call for services. In California there was an "Age On, Rage On" campaign that was similar. The Wilder Foundation in MN had a campaign to get people to self-ID as caregivers, which they believe was successful but used soft measures used to determine success. Our group needs someone who can provide an accurate return on investment (ROI) estimate.
- When Rep. Deb Kolste served on the Janesville School Board, one message used was that going into professions such as welding without attending a 4-year college can be just as profitable. That message is working because one can earn a living wage in some jobs in the skilled trades. Do we/will we have that carrot in our message? If we achieve pay increases and benefits for paid caregivers, we could promote them in the same way. But without better pay and benefits, it will be a hard sell.
- DHS may have information on the impact of previous ADRC outreach campaigns on ADRC usage and public awareness.
- It was suggested that the public service message link the cost of caregiving to families and emphasis the cost to society when there are not adequate caregiver supports. Are you a family caregiver who is looking for help? Call the ADRC! Do you want to help solve the problem? This is what you can do! Marketing must understand the audiences, such as community orgs, caregivers, businesses, others. Target messages that resonate. (Notes from the last meeting listed who the target audiences could/should be. Will require a professional marketing firm to identify what type of marketing would work best.)

- One member expressed concern that given that Wisconsin is in a workforce shortage crisis, solving the paid direct care workforce shortage is going to require an infusion of funding to increase wages. Raising Medicaid reimbursement rates is the only way to increase wages because Medicaid is the main source of their pay in most cases. If the Task Force requests a lot of money for a public awareness campaign, it could take away from funding available for worker pay increases. Will it be worth it? Are there other ways to build support for caregivers and direct care workers that don't cost as much as a statewide public awareness campaign would?
- It was stated that the first goal of the Family Caregiver Workgroup should be to increase the capacity of ADRCs. Awareness is growing among local providers and in the public and private realms because more people are understanding that our society is aging and reaching a critical mass for the number of caregivers available. People of all stripes are recognizing it.
- In 2019 the Alzheimer's Association ran a statewide Alzheimer's and Dementia Awareness campaign, with the help of a state-funded grant. Some members reported seeing associated materials, while others had not. Members agreed it would be helpful to have a report from the Alzheimer's Association on the outcomes and how much advertising they did. DHS will get the report for Workgroup members. The 24/7 hotline had nearly a six fold increase over the same time the previous year.
- The Task Force can impact awareness of caregiver needs by developing a tagline for use when the package of recommendations is released. A well-worded report and announcement can bring a lot of attention without spending a dime. What we're doing is newsworthy. We need to package in a way that is exciting. DHS has communication specialists who may be able to offer assistance.
- Make sure that we're tracking where the Direct Care Paid Workforce is headed with their public awareness campaign and discuss the possibility of a simultaneous outreach effort. The co-chairs will invite interested members of the Family Caregiving Wokrgroup to join the Direct Care Paid Workgroup in discussions once this workgroup agrees on its goals. It was noted that it is not clear whether a statewide effort is worth the expense, or if there is a need to target specific areas with more need.
- The workgroup should consider developing a communication plan and elevator speech regardless of whether there will be full blown public awareness campaign. That could include a 1-page document that talks about the workforce crisis, including Dennis Winter's info. Make sure both workgroups are on the same page articulating the need and how we came to these recommended solutions. Leverage social media and other free space. Faith said that DHS communications people would be happy to meet with workgroups to discuss what could be done.

VII. FMLA LEGISLATION

It was felt the workgroup couldn't move forward too far without Helen Marks Dicks present. Keep this discussion for a future meeting because there is less that would need to be done to move this forward.

VIII. CAREGIVER REGISTRY WORKGROUP

- Volunteers from this workgroup to participate: Lisa Pugh, Todd Costello and Jane Mahoney.
- DMS will be meeting with the Direct Care Paid Workgroup later today to discuss how what they are working on may be able to feed into a registry for new Electronic Visit Verification (EVV) requirements. Provider numbers, skills, availability, etc. are federally required to be included for all Medicaid-funded providers. Also, registries already exist that can be purchased and/or modified.
- Ask people at time of licensure or graduation from programs to enroll.

IX. NEXT STEPS

- WHA is coming on March 19 to hear what hospitals currently do in terms of discharge assistance, including a description of the caregiver support available to help them understand what is needed and required of the caregiver. The presentation will include people who are in the role of providing discharge assistance in hospitals.
- Subgroup meetings in March and April: Subgroups can schedule additional times to meet in April. If they want more information provided to them, it could be scheduled during these months.
- April 2 and 16 coming together as a group – the Workgroup can configure these meetings anyway you want. Subgroups must have proposals for the full Workgroup ready by April 22nd for the May 6 Workgroup meeting. That will be a critical meeting where all questions must be answered and consensus reached on what to recommend to the full Task Force, how to be ready to answer anticipated questions, and how to be prepared with convincing support for the recommendations.
- The Task Force should decide if there will be a Phase II and what the focus will be. It could make putting some of the group's initial ideas aside temporarily easier to do.
- After reframing the Next Steps document, the Workgroup will need to decide which items are recommendations, which need more research, and which should be permanently put aside/removed from consideration.
- Sub groups should work through the policy development template that has been developed, including the question related to equity, to be ready for May 6.
- DHS is gathering figures to determine how much funding is currently needed to fully fund ADRCs. DHS will identify gaps in services that people seek but which ADRCs are not able to deliver at this time. The final estimate to operate fully funded ADRCs will include an estimate for 2020 and an estimate for future funding needs based on the growing number of older adults.
- Should administering a caregiver assessment be included as a core ADRC service?
- It was suggested that Task Force recommendations should not be sent to the Legislature as separate bills. Doing so risks that they be put aside by legislative leaders. It would be more productive to have the Task Force's recommendations included as part of the governor's budget.
- Do not put forth unfunded mandates. The final Task Force report should reflect only ideas that work on their own, or ideas with funding attached. There is bipartisan support

that caregiver issues are important and need to be addressed.

X. PUBLIC COMMENTS

- Comments from a member of the public using the chat function on Zoom.
  Name: Karl Kopp
    - If you Google “need a caregiver,” Care.com is first on list and the local ADRC was 9th. Those between #1 and #9 were private pay agencies.
    - Maybe try ideas like offering incentives if someone recruits a new person to be a caregiver. Or offer some kind of pay for performance system, like job coaches.
    - What about a survey to find out who caregivers are (profile) - why they are doing it, age, household income, what they read, eat, etc... so help to develop marketing plan - where to recruit.
    - Additional ideas:
        - Hire a full-time recruiter at each ADRC.
        - Use inspiring slogans:
            - Doing good does you good, Be a caregiver.
            - From compassion to action. Be a caregiver.
            - There is a need, take the lead. Be a caregiver.

ADJOURNED AT 12:00 P.M.

Prepared by: Lynn Gall, DHS Office on Aging on 3/10/2020.

These minutes are in draft form. They will be presented for approval by the governmental body on: 3/19/2020