

OPEN MEETING MINUTES

Name of Governmental Body: Family Caregiving Workgroup Governor's Task Force on Caregiving		Attending: : Task Force Members: Lisa Pugh, Todd Costello, Representative Deb Kolste, Jane Mahoney, Susan Rosa, Helen Marks Dicks, Carol Bogda, Senator Kathy Bernier	
Date: 12/11/2019	Time Started: 1:00 pm	Time Ended: 4:00 pm	Guests: Laverne Jaros State Staff: Faith Russell, DHS, Lynn Gall, DHS, Andrew Evenson, DWD
Location: Dane County-UW Extension, 5201 Fen Oak Dr., Suite 138, Madison, WI 53718		Presiding Officer: Lisa Pugh and Todd Costello	

Minutes

The goal today was to identify key strategies that the workgroup will continue to discuss and prioritize at the January 14 workgroup meeting. Strategies chosen on January 14 will be forwarded to the full Task Force on January 30, 2020 for further consideration.

Workgroup members were instructed to identify the top three issues from the Synthesis and Other States documents that should be priority topics.

Items identified as missing from the Family Caregiving Synthesis document included:

- Adopt an expansive definition of respite that allows people broad access to a variety of services.
- Caregiver needs assessment, education, outreach and onboarding could be done at home instead of making people go to an ADRC or other agency – Make it similar to visiting nurse services/community health nurses.
- Senator Bernier talked to her county administrator in Chippewa County about an ADRC staffperson who was scheduled to conduct a home visit with her father but did not show up, so it required transporting her father to the ADRC. She was told that it is a requirement for the ADRC to conduct a home visit. It was clarified that a home visit is not required, but home assessments are available to those who request them. She suggested that home visits be offered by the ADRC/agencies instead of having to ask one because these are home-based programs.
- Legislative items are missing, which could be bundled into a legislative package for consideration: Caregiver Tax Credit, The CARE Act, Family Medical Leave expansion, the expansion of the definition of respite, and increases for respite funding.
- Propose a caregiver support services add-on option that would allow buying full or partial benefits of a program by those otherwise not eligible. (Example: Caregivers at the End of Life program.) Develop a private pay buy-in model for providing caregiver supports for people who are over-income or not eligible due to age restrictions or other reasons but would like to access. Would allow services to reach segments of our population currently being left out.
- Future planning and end of life care – services through hospice

Research Reports

At the November meeting, several workgroup members offered to collect information about the following topics and share with other members:

1. Helen Marks Dicks, AARP: UW School of Nursing doing a lot of outreach to caregivers. Right now, Wisconsin does not have a comprehensive centralized statewide website or office where families can go to find resources online. The UW Center for Aging Research and Education is involved in several initiatives. Of great interest are efforts to support aging populations in rural communities – Currently running three pilot programs. (HeART project <https://care.nursing.wisc.edu/2019/04/29/aging-in-the-heart-of-rural-wisconsin/>)

People don't naturally think of an ADRC as a place for caregivers. The concept most people have in their minds is that an ADRC is more a place to go for public benefits, not a resource for caregivers. She found the information available through the UW School of Nursing very practical and very user friendly. Suggested that citizens need one place for people to go to for caregiver resources, including how to find information on how to correctly complete a care task (more than wisconsin caregiver.org), training programs for CNAs, and others. Questioning the marketing/connection to become a CARE-U trainer – dementia training for CNAs and offering CEUs. Would like to see a website or clearinghouse where caregiver trainings and resources are better connected, and a resource page where the average person can go. The state should pay someone to know all of it. Local and statewide lists would have to be kept. DHS should have a page.

SAIL – Supporting Aging in the Community – A program that focuses on remaining active in the community. Helen stopped researching because SAIL did not seem designed to support family caregivers, from what she found.

2. Susan Rosa: DRAFT document submitted
Researched background of visiting nurse programs – The original goal of visiting nurse programs was to reduce hospital readmissions. Building trust between visiting nurses, care recipients and their families is an important part of the program - done by spending time with families and getting to know them. The household is the focus and family dynamics must be taken into consideration. Visiting nurses must be flexible in their ability to provide a variety of services. She said the Task Force should consider expanding the use of public health resources and programs such as visiting nursing services because the direct care worker shortage is a public health crisis, and families cannot always identify what they need.
Suggested educating nurses to have an expertise in caregiving households. Prioritize a comprehensive home-based model of services and a delivery system that targets people of all types of caregiving households.
3. Carol Bogda shared a caregiver survey tool and provided an overview of the Oneida Tribe's and Brown County's joint events for National Family Caregiver month in November, 2019. Survey results revealed that meeting the caregiver's own health and emotional needs requires more attention, especially more

respite care/options for family members who continue to work full or part-time. It is currently difficult to find sufficient funding to help working caregivers, especially if they are not on Medicaid. More education is needed around future planning, end of life care and respite available through hospice.

4. Jane Mahoney shared information about the Wisconsin Family Caregiver Support Program and National Family Caregiver Support Program. (attachment) NFCSP is an Older Americans Act program that has no income eligibility requirements but does have age requirements. NFCSP limits temporary respite to 112 hrs. per year. The Wisconsin AFCSP, which is funded with GPR, requires participants to have a dementia diagnosis and an income that does not exceed \$48k/yr. after dementia-related expenses are deducted. Maximum funding under the AFCSP is \$4,000 per year, but more than half of Wisconsin counties have reduced the amount available in order to serve more families.

Question: Does NFCSP only go to counties?

Answer: The federal Administration for Community Living requires that states contract Older Americans Act funding through the state's Area Agencies on Aging (AAAs). Wisconsin's three AAAs are GWAAR, Dane and Milwaukee. Those agencies can, and some do, sub-contract NFCSP to be run by another agency, but the county retains the ultimate responsibility for administration and oversight of these federal funds.

5. Lisa Pugh provided information on standardized caregiver assessments.
A standardized assessment would mean that anyone applying or receiving services through a public program would receive a caregiver assessment. The Federal RAISE Advisory Council is considering whether a standardized assessment should be used across Medicaid programs or perhaps across all programs. Lisa provided a link to a 2013 AARP article in which Wisconsin is not listed as using a caregiver assessment, however Wisconsin's NFCSP and AFCSP (non-Medicaid) programs have been requiring caregiver needs assessments for the past three years. Medicaid funded programs, such as Family Care and IRIS - where family members are doing a lot and often default to doing tasks because they can't find workers, do not currently use a standardized caregiver needs assessment. Lisa believes adopting one would help prevent caregiver burnout. Lisa would like to embed best practices and caregiver needs assessments within our system in all places/programs that touch caregivers.

Identify three priorities

Workgroup members were asked to choose three issues as the first topics the Governor's Task Force on Caregiving addresses. Included was a request to begin describing solutions that might work.

Sen. Bernier: Suggested that the workgroup should be careful not to expand certain types of programs when there is already a shortage of respite workers.

1. Clearinghouse for caregiver supports – Create one link maintained by DHS that links to all the counties that's easy to access, well promoted and disseminated.

2. Encourage, develop and strengthen the natural supports among family members and friends using existing services. Family and friends may be more willing to provide care if they knew they weren't doing alone. Education is needed, including family meetings to coordinate services.
3. Improve the role/ability of the ADRC to self-promote and educate caregivers and the general public about what ADRCs do and the services they provide or can refer.

Rep. Deb Kolste:

1. Clearinghouse or a State Office of Caregiving that would serve as a clearinghouse.
2. Caregiver Innovation Grants – Grants that allow communities to explore possibilities, invent and implement small-scale projects.
3. Expand family medical leave

Helen Marks Dicks:

1. Funding for caregiver innovation grants
2. Expand funding available for existing programs
3. Expand/Alter definitions for family caregiver support services, and amend eligibility requirements of existing of programs
4. A legislative package that includes expanded FLMA, the CARE Act and a Caregiver tax credit.

Sue Rosa:

1. Development of a comprehensive home-based caregiver model focused on the family.
2. Eliminate program “categories” related to age and population restrictions. Instead have “age 0 to death” (Lifespan) programs that don't deny people based on predetermined criteria. Would require redesign and improving coordination of existing caregiver supports to eliminate fragmentation.
3. Fund a public service campaign that elevates the role of caregiving, gets people to identify themselves as caregivers, and helps everyone recognize the value caregivers provide to society.

Carol Bogda:

1. Legislative package CARE Act, Caregiver tax credit, and FLMA expansion.
2. Support a comprehensive home-based model service delivery, including annual caregiver assessments
3. Expand the definition of respite to include home chores and related items.

Jane Mahoney:

1. Standardized statewide caregiver assessment across multiple domains, including doctor office, senior center and others. Will raise awareness and help caregivers self-identify as individuals.
2. Expand the definition of respite – Will require training of people who approve respite payments.
3. Public media campaign elevating the role and value of caregivers, self-ID, etc.

Todd Costello:

1. Public awareness campaign is the one thing that can normalize this conversation. We will one day all be in this situation. Expose the messy reality of the relationships of caregiving in way that doesn't shame or blame.
2. Strengthen natural supports – self-defined by each individual. Build a community around a person. Build a deeper bench.
3. Innovation grants

Lisa Pugh:

1. Standardized caregiver assessment
2. Statewide 800 number that connects with clearinghouse and resources
3. Improve the role of ADRCs

Workgroup members were asked to look at the list of all priorities mentioned and choose their top three items using Post-It Notes.

Winning ideas

1. Standardized caregiver assessment model to connect to what they need across multiple domains (4 votes)
2. Comprehensive awareness campaign (3 votes)
3. Clearinghouse for statewide county/tribal supports and a toll free number (4 votes)
4. Legislative package of bills (3 votes)

Sub-groups to gather additional information on the four winning ideas:

- Sen. Bernier, Rep Kolste, Carol and Helen will work on the clearinghouse idea
- Lisa and Jane will work on the standardized assessment idea
- Sue, Jane and Todd – Public awareness campaign
- Helen and Sen. Bernier and Susan Rosa will work on the Legislative package

Expanding the definition of respite did not make the final list but can be included as part of the narrative when the final report is made.

Public Comments

Stan Hensley: A retired farmer who serves on the community leadership team as part of State Dementia Plan. Said he is pleased to hear that the ADRC is very active in the community and will be a big help in implementing Wisconsin's dementia plan. Noted that the state has been doing more with less for a long time, but that has to change. We need more money and more people to meet the growing needs. Wisconsin needs an outside resource in the worst way, perhaps someone like caregiving expert Teepa Snow to bounce ideas off of. We don't have time to do it all ourselves. "Country people" are very tough. We take care of, and do everything,

ourselves. It's going to be hard to break this attitude of self-reliance down with caregiving needs. Words to die by are, "Don't ever put me in a nursing home," but it is the caregiver who often dies trying to provide all the care because we are so dog-gone independent.

Laverne Jaros: Believes the State of Wisconsin should simplify Family Care. Caregivers get very frustrated by the complexity of Family Care and IRIS, etc. Also, offering no-interest home modification loans and grants would be a good idea. A Caregiving Clearinghouse is going to need connections to the ADRCs database/s. That person should be contacted and be part of the discussion of this workgroup. (Lynn Gall will identify who at DHS is working with the ADRC database.)

Next workgroup meeting: January 14th Location TBA

Meeting adjourned at 4:00 pm

Prepared by: Lynn Gall, DHS Office on Aging on 11/13/2019.

These minutes are in draft form. They will be presented for approval by the governmental body on: 1/14/20