DEPARTMENT OF HEALTH SERVICES
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DRAFT

STATE OF WISCONSIN

OPEN MEETING MINUTES

Instructions: F-01922A

Name of Governmental Body: Governor's Task Force on Caregiving Public Input Session			Attending: Registration was not required
Date: 6/29/2020	Time Started: 9:00 a.m.	Time Ended: 4:00 p.m.	
Location: Virtual meeting via Zoom			Presiding Officer: Todd Costello and Lisa Pugh

Minutes

Governor's Task Force on Caregiving
Public Input Session Minutes
Monday, June 29, 2020

I. Welcome and Guidelines for Public Input Session

Materials on a set of draft proposals under consideration by the Task Force have been posted to the Governor's Task Force on Caregiving website under the Policy Proposals menu tab. In addition to today's public input session, public comments are also being accepted through July 14 using a survey, which is available on the Governor's Task Force on Caregiving website.

During today's session, members of the public were provided up to five minutes to speak on one or more item within each of the four draft proposal groups.

II. Family Caregiving Proposals

1. Caregiver Assessment: TCare – Tailored Caregiver Assessment and Referral
2. Aging and Disability Resource Center (ADRC) Reinvestment/ Caregiver Support
3. Legislative Change: Family Medical Leave Act Amendments
4. Legislative Change: WI Credit for Caring
5. Legislative Change: The Care Act

- Vicky Wedig from Aptiv (Resources for people with disabilities): Has questions about TCare: What is done with the information? Will families be provided individualized relief or services? Will information collected be used to make systemic changes? There is currently great variation in resources available through ADRCs. Who will ensure consistency and quality across the state?

- Tami Jackson – Survival Coalition: Supports the Care Credit and FMLA expansion as drafted. Also supports ADRC reinvestment as part of the annual assessment and checkpoint for people's physical ability to continue giving care, which changes over time. Sometimes we need to plan a transition where family caregivers require care themselves. She often hears that there are an insufficient number of caregivers available for hire.

- Sam Wilson – State Director AARP Wisconsin: Highly recommended the "Caregiving in the USA" report to task force members. We are experiencing a large increase in the number of Americans who are caregivers, and the biggest generational jump in caregivers is for Gen-Xers.
  Three task force recommendations he supports:
  1. The CARE Act assisting in transition from hospital to home.
  2. WI Credit for Caring Act. It will not completely offset expenses but the credit would provide some relief and acknowledge the expenses that caregivers face.
  3. Medical Leave Act: Expand to include grandparents, in-laws and siblings.

- Michael Bruin, Director of public policy at Alzheimer's Association: Supports the CARE Act because Alzheimer's family caregivers provide the overwhelming amount of care for dementia patients. Receiving information on the disease and how to provide care is imperative. It also helps reduce recidivism rates for hospitalization. Elder benefits specialists and dementia care specialists are important to families with dementia. He hopes that an expansion of the dementia care specialist program is included in Task Force recommendations. He also supports re-investment in ADRCs because ADRCs play an important role in the home and community based system. People know that the ADRC is the first place to go when they see their family member's needs changing and getting harder to handle. ADRCs are also a connector to services, which 80% of the time can delay going into a nursing home or enrolling in a publicly funded program. Supports the Credit for Caregiving Act because it will shrink the economic burden placed on family caregivers. There are currently 195,000 unpaid caregivers in Wisconsin, and as the prevalence of Alzheimer's grows that number increases. The estimated cost to care for a person with dementia is $350,000. Family caregivers need assistance to provide this care, which is why it is important that the recommendations be sent to the governor.

- Beth Fields: Researcher UW Madison – Care partners are critical to older adults after an onset of new condition, especially if requires hospitalization. Policy makers are realizing this, as evidenced by reauthorization of the Older Americans Act and RAISE Advisory Act. Forty-three states have already enacted the CARE Act. Despite advancements, I believe Wisconsin has fallen behind in implementing critical health policies like the CARE Act. While she was out of state working on project, her brother was hospitalized in Wisconsin and moved to an intensive care unit. While there, her family received little information, training or notice of discharge so the family could plan. As a result, her brother had to be re-hospitalized, causing the family stress and frustration.

- Elaina Seep - CEO and Project Lead at Aniwahya Consulting Services working with the Lac du Flambeau Tribe and others. Health disparities faced by Native Americans are well known. Current data shows that in Bemidji Region, subjective cognitive decline is affecting about 20% of tribal members, and there is an increased risk of Alzheimer's specifically. Presently, there is no funding to tribal nations for caregiving to nations for anyone with a disability for anyone under 55 years old. *(Note: The State of Wisconsin does provide tribes with a small Alzheimer's Family and Caregiver Support Program grant averaging about $5,500 per year.)* Task Force work is very important because the only support tribes have is the tribal dementia care specialist program for three tribes, and the other tribes share. Tribes are generally unfunded and there is a significant unmet need when it comes to caregivers and caregiver services in a population with a large percentage of trauma and disabilities related to trauma. Nationwide, any tribal elder who went into an Indian boarding school is an elder today. These are trauma survivors who have heightened trauma-related disabilities.

- Donna McDowell – AARP member and volunteer has been a caregiver for her father with brain tumor, who lived with her and her husband. Then her mother suffered an aneurysm and the family was unable to care for her at home. As someone who has been through the caregiving journey, she recommends two things: The strongest possible recommendation to pass The CARE Act in Wisconsin. Our state has the embarrassment of being one of only a few states that have not passed it, which is inexplicable because there is no reason not to pass it. She is very aware how complicated it is to move a significantly disabled family member out of the hospital back to home. She stressed the importance of understanding and emphasizing the importance of people having the choice to live at home with their families and in familiar surroundings. She urged Task Force members to help Wisconsin make good decisions by offering home and community based care as an alternative to institutional care, adding that separation from family caused by COVID-19 is especially stressful. Having ADRCs is a tremendous gift to families. She urge the recommendation that commits Wisconsin to supporting and funding the big load placed on ADRCs.

- Ramsey Lee – Hudson, WI: Wisconsin needs adequate caregivers because they are essential. Caregiving can be a heavy burden for families, and we need to do what we can to support individuals with disabilities, but we also need to support the caregiving workforce.

- Stan Hensley: Part of State Dementia Group – Supports ADRCs and has been active with WITC (Wisconsin Indianhead Technical College) caregiver conference planning committee. ADRCs are so helpful, especially to rural people during the COVID-19 pandemic because many do not understand. Somewhere in the state plan we need to reach out to rural people, who often won't ask for help. Most often when rural residents do ask for help, it is usually very hard to get because of a lack of providers.

- Sharon Cornell: Caregiver for a veteran and originally appointed to serve on the Governor's Task Force on Caregiving. She is in her 80s and has had a couple of strokes, and her husband is 85 in a wheelchair with spinal cord injury. She receives help from the Green Bay Veterans Administration at home and two people from Bright Star Care Agency who provide her husband and herself with two hours of help in the morning in two hours in the evening. (4 hrs. per day) Since the COVID pandemic, it has become very difficult to find affordable care to stay with her husband for a few days. She is very thankful for the VA.

- Douglas Shackelford: Is providing 24-hr care for a son with traumatic brain injury. He called-in today because he hoped there may be support available for someone in his situation. His son has physical challenges that require continuous physical therapy, and he has used all of the Medicare-funded resources that were available. Out of benefits, he is trying to provide his son's therapy himself as a non-professional. He called today to learn more than to speak on a proposal.

- Claire Zautke at Citizen Action of Wisconsin: Her organization has members who support many of these ideas; members who are concerned about being able to afford the cost of LTC or the ability to provide care for people down the road. She supports the CARE Act in particular. Second, support the tax credit. Most CAW members have concerns about affordability. A tax credit is a really big deal and a good place to start even if it is only $1,000. The organization conducted a survey at the end of 2019, which shows that 71% of Wisconsinites are concerned about the cost of LTC. She is willing to share survey results with Task Force members.

- Henry Anderson: Standard for Excellence Training Center, which provides training to get people certified to provide care. For a privately owned company, what vision to you see us playing in the continuing training of caregivers? There are a few things that are different around the state vs. in Milwaukee where we are. He would like to continue talking about how to make the Task Force's current proposals better, and is putting his hat in the arena to help. He is part of a consortium.

- Nadine Davis: The ADRC is a great resource for providing/coordinating care and resources, but it is difficult if you don't fall within certain age groups. Wisconsin should expand ADRCs to provide more broad-based resources. Hospitals are key to coordinating a lot of this care and getting people connected. There is overlap, in her experience when one person has five nurses, each with their own specialty or agency connection. From a patient perspective, they cannot keep track of who is providing care for what. Family caregivers lacking the skills to care for someone at home leads to burnout. Someone has to pay for that training.

II. Rates Proposals

1. Rates Band
2. Nursing Home and Personal Care Payment Reform
3. Medical Loss Ratio
4. Direct Care Worker Fund

- Greg Von Arx – CEO of Recover Health and representing the WI Association for Home Health Care Spoke in favor or a 10% Medicaid rate increase, but does not see a 10% increase in the current policy recommendation. Asked that it be included in what the Task Force recommends to the governor. In other states where his company operates, Medicaid rates are substantially higher.

- Leah Perras: Executive Director, Transitions at Home: Home agencies regularly lose employees to other professions. The number in WI is well below the national average for registered nurses working in a home setting. Attracting and retaining staff to home health care even with a $5,000 bonus resulted in no responses. Her agency cannot compete with hospitals and other sectors of the health care industry because her sector pays below what others receive, even though home care is the type of care that people prefer.

- Mark Hagen – Director of Public Policy, Bethesda Lutheran Communities: Supports the Medical loss ratio and Rate Band proposals. He has long been frustrated in the lack of transparency in the rate setting process used by Wisconsin MCOs. He sees big discrepancies between rates paid to care for similar individuals in different Bethesda locations. When cuts are made, his agency is told they are rate cuts not service cuts. But no reasonable person could think a 17% rate cut wouldn't result in loss of services. Steady increases in labor costs are one of the main reasons Bethesda supports these proposals. The agency is expected to lose $1 million this year. Wisconsin is by far the lowest paying state of any state where they operate.

- Sue Seegert, Villa St. Francis – South side of Milwaukee. It has been 12 years since they received a rate increase. Costs are $40 per day over current rate payments. Negotiations with MCOs have been slow, if happening at all, and the methodology has not been transparent. Rates should be based on acuity needs and the cost of care for each resident. She supports the Medical loss ratio, rate bands, and the direct care worker fund proposals. The direct care worker fund is in need of restructuring because providing quarterly payments makes it difficult to provide ongoing hourly wage increases to staff.

- Tami Jackson – Survival Coalition: The organization has submitted four concrete recommendations in a letter to the Task Force. She is concerned that the nursing home proposal will benefit only a subset of care workers and leave home and community-based service workers out.

- Paul Treffert – CEO of Sheboygan Senior Community: There have been no significant changes to the Family Care program for 20 years. Wisconsin was forward thinking back then, but he is not sure that is the case now. Our state needs transparency in rate setting and how what providers are paid is determined. MCOs are profit driven and providers have no say. The state needs to address the "mystery component" of the funding.

- Chris Cohen: MCOs are not what we need. They act as an insurance company and we do not need an insurance company driving LTCS. This Task Force is about the direct care worker first and foremost. We need to pay caregivers. That is what is at the head of this problem, and the MCOs are not interested in addressing that. They are interested in lining their pockets. The rates band proposal is the first and only thing that addresses this.

- Zach Ziesmer – Administrator for Pinecrest in NW Wisconsin: Wisconsin has been one of the top three worst Medicaid reimbursing states for nursing homes for the last 10 years. We are at a tipping point now with nursing homes closing. He supports the rates policy as recommended by the Task Force.

- Kris Krentz – CEO Skaalen Retirement Community Services: Supports the rate bands proposal. There is no negotiation with FamilyCare MCOs on anything. Skaalen currently has to limit the number of FamilyCare recipients it accepts due to the shortfall of funding. The downsizing that results leads to a loss of access for all types of payers.

- Tim Conroy – Executive Director of Capitol Lakes: Supports rates proposals. His facility loses $200/day on Medicaid clients.

- Holly Pitas – Adult Family Home: Asked the Task Force to remember the role of thousands of smaller adult family homes that do not have the power/voice of the larger organizations behind them. FamilyCare needs to be updated, especially for people in independent living. It has become simply a payer and does not provide any benefit to the person.

- Craig Ubbelohde – CEO of Bethany St. Joseph Corp. representing a three county service area in and around La Crosse. Supports the rate band proposal. Medicaid payments have gone from bad to worse with rate reductions on the room and board side. The negotiating process with MCOs is farcical. They just send a letter that there will be no rate increase. The impacts of FamilyCare include: Limiting the mix of clients with regard to who pays because the agency is trying to remain affordable and they do not have private pay rates to supplement the FamilyCare rates. His agency tries to limit their exposure to FamilyCare, which also means that they have to limit opportunities to develop new services, like memory care. They know that there is always a potential for rate cuts in the non-negotiating model we have now with MCOs. The rate band proposal allows some certainty to plan for the future. He supports the requirement that 85% of funding must be spent on care. The direct care worker fund has been a blessing because it has been the only way to provide wage increases.

- Sondra Norder – CEO of St. Paul Elder Services (Kaukauna and Green Bay): Cited the same problems with lack of transparency related to rate negotiations. She is in favor of adopting the rates band proposal in the interest of fairness and standard practice. Their organization loses more than $100 per day for residents in nursing homes. The wages and staffing needs required to meet the needs of residents have been difficult to provide. They also are limiting Medicaid patients, which is not part of their mission.

- Molly Olson, Private Citizen – A social worker who used to work for an MCO, and her father has dementia: All of these proposals are absolutely necessary. When working for an MCO, the way they calculated which tasks could be reimbursed was so much less than you knew the person needed. It was soul crushing to have to tell the provider and the families. It sucked. We were only looking at specific tasks for that person, not taking into account any kind of supervision that is provided day to day, which amounts to essentially peanuts that family caregivers are able to be paid. Eventually they get burned out and have to look to some sort of placement. Our system is not recognizing when caregivers are getting burnt-out and providing needed respite. She is terrified for the day she is going to have to enroll her father in FamilyCare because she has seen how it works. He will not be getting the amount of care he is getting right now and needs. There needs to be a standard in place and for agencies to be paid the actual market rates that it takes to provide it.

- Rob McIntyre: Has a son with special needs. St. Colletta's is probably where his son will end up. Without substantial private donations, the facility would not exist. His mother is in a facility in Columbus, which he sees as very much a money driven operation where change needs to happen even though the staff is great. He is also chairperson of a small group home, "Heartfelt House" in Menominee Falls, which has been recruiting people to take over as part of succession planning. During the process, he learned that the group home has been underfunded for 10-12 years, with a shortfall of 30% mostly as a result of their inability to negotiate with MCOs. Some people have not been taking salaries, and they cannot make a succession plan with that reality going forward. He warned that Wisconsin will not have these facilities if we believe that paying staff less than minimum wage is the way to go.

- Jane Grantham – Registered nurse working independent duty for people who have chosen to stay in their homes and president of Wisconsin Professional Home Care Providers: Said rates have not gone up for independent duty nurses. The difference in pay has created a crisis for nursing care –

especially for those who are non-ventilator cases because ventilator cases pay more. Some nurses are thinking of leaving or going into another line of work due to a recent court case. She asked the Task Force to add these concerns to the list of issues being considered.

- Shanda Hubertis – Former president of Professional Home Care Providers before Jane Grantham: She had many discussions with DHS when this rate differential actually occurred and was told that we cannot put the toothpaste back in the tube. How do we fix it now? She has six disabled siblings that need 24 hr. supervision, which is being managed by her mother who is in her 70s. Eventually that responsibility will fall on her. She is asking that caregiver reimbursement rates actually reflect the care that professional caregivers are providing. Also, look at the skilled nursing tasks that MCOs are pushing to be done by non-licensed individuals. It is becoming the standard instead of the exception. This can have detrimental results when mistakes are made. She agreed that there is limited instruction when people are discharged from the hospital or care facility, especially for those that are not private pay. There is an expectation that family members will do all caregiving needed. Providers are trying to use technology instead of skilled nursing services, which is actually a reduced quality of care that can have detrimental outcomes. Paying a lower rate results in hiring lower quality caregivers. She asks that the Task Force take steps to stop the delegation of skilled tasks to unlicensed caregivers.

- Art Keup – Luther Manor: In favor of rate bands. Stated that MCOs are not negotiating in good faith, which forces agencies like his to limit access to care for vulnerable adults. He questions the case management function of the MCOs, especially after a person has been in a skilled nursing facility for a long time. Luther Manor struggles to attract and retain direct care workers, including dietary and housekeeping staff, because they are not only competing with hospitals and health care providers but they are competing with Target and Home Depot. Receiving the required certification can be difficult, and benefits are difficult to provide as well. The chronic underfunding of Medicaid is a hidden tax on private patients. It is an unsustainable model that is resulting in fewer facilities operating and less access for Medicaid patients.

III. Benefits Proposals

1. Medicaid Expansion
2. Earnings Disregard

- Lynn Carey from Germantown – Supports Medicaid expansion. Is a registered nurse with 45 yrs experience and a caregiver for mother and father as they aged. Badgercare expansion would help caregivers earn more and work more hours without worrying about losing their health care. Losing benefits is a huge challenge for family caregivers and professional caregivers without employer-based insurance who have to cut back hours in order to be eligible for publicly funded insurance. It is a no-win situation for many because if they cut back their work hours, they then have less money to purchase other things they need as well.

- Tami Jackson –Survival Coalition: Supports all of these proposals because a benefit package goes a long way to addressing hiring and retention issues. The earnings disregard proposal is a smart and

strategic way to incentivize working more. Expanding BadgerCare provides similar benefits to allowing direct care workers to earn more.
Items missing from the proposal include:
  a. Paid sick leave: Is not part of Medicaid expansion or earnings disregard proposal.
  b. Overtime and hazard pay: Professional caregivers often work extra hours and take on additional clients because of the current worker shortage, which should be factored into their pay especially if the caregiver is specializing more.
  c. Transportation – Many potential care workers are unable to take job that do not provide a company vehicle because they cannot afford to own and maintain a personal vehicle. Employers should maintain a fleet.
  d. Daycare – Offering tax credits and child care benefits that make it possible for parents to afford working.
  e. Retirement Plan: Offering a retirement plan adds overall value to the job.

- Carl Lock – Brookfield – Home health care workers are very important to his sister. Without them she would be in a nursing home. Expanding Medicaid will help keep workers healthy and safe to serve people like her and save millions of taxpayer dollars per year.

- Karen Kirsch of Greenfield, representing Citizen Action and is herself a caregiver. Supports Medicaid expansion. She cared for father during last five years of his life, which enabled him to stay at home until last few days in hospice. She used her personal vacation days and took days off work unpaid. She did not have any break or real vacation for five years. It was a very stressful time juggling her family, her father and her job. Reducing work hours to help deal with the stress was not an option because she could not lose access to employer-based health insurance because she has asthma. These conflicting pressures led to mental health problems, and the last moments with her father could have been more meaningful if she had not had health insurance, work and caregiving pressures weighing on her. These things also affected the time she spent with her daughter, who was in elementary school. She was not as mentally present as she could have been. “If I could have reduced hours and picked up BadgerCare, it would have been better for me. It could be one tool to help keep people in their homes and have an added bonus of saving money in the long run.”

- Anastasia Wilson – Program participant at The Waisman Center in Madison. She needs around clock care because of cerebral palsy. Aides have to work extra hours, and they are feeling overworked and overwhelmed. “Please consider raising aides’ wages so I can keep living independently in the community.”

- Shanda Hubertus – Nurse Supervisor who spoke earlier. She has staff that struggle to pay for health care and daycare. She believes there are many people out there who want to work but have to make decisions about what they can afford to do. It is important to get something in this Task Force plan that allows them to pay for their daycare or increases income limits to be able to stay on the Medicaid health insurance benefit.

- Ramsey Lee: It would allow me to hire better quality workers. I would love to become more involved.

- Stan Hensley from Menominee – Is in favor of Medicaid expansion.

IV. Untapped Workforce Proposals

1. Statewide Caregiver Training: Statewide Direct Support Professional Training
2. Recognition and Recruitment of Direct Support Professionals
3. Background Check Policies
4. Regulation & Compliance: Regulatory proposals for pre- and post-COVID-19

- Mark Hagen – Bethesda Lutheran Communities, Executive Director: His organization has a 116 year history of providing services and supports to people with developmental and intellectual disabilities, including the move to home-based services instead of institutional settings. However, pay rates for in home workers still do not compensate the direct service professional (DSP) as a professional position, and they should be treated and funded as such. He enthusiastically supports recommendations that acknowledge the skills and expertise the job requires and our citizens deserve. The greatest cost of the workforce crisis is the continual disruption in continuity of care. These proposals will create an awareness of the need for DSPs and jobs with a rate structure that compensates DSPs and acknowledges those with advanced certification. Adequate recruitment is needed and ways to offer career advancement of existent DSPs. He supports the proposal to expand the WisCaregiver program to include DSP positions in home-settings, which are nearly identical to the nursing home positions currently promoted by the WisCaregiver program. Adoption of this proposal will put DSPs on equal footing with nurse aides in congregate settings.

- Tami Jackson – Survival Coalition: Agrees that background check policies should be changed. Per regulation and compliance changes, it is unclear what the direct impact of that proposal will be on direct care workers themselves. Any changes must be considered from the point of view of the people in the programs, and any changes must benefit the participants, workers and the Medicaid program as a whole.

- Nadine Davis – Echoed Mark Hagen and Tami Jackson: Has been a registered nurse for 35 years, was director of a home care agency, and cared for her 95 year old aunt in home. Continuity of care is truly an issue that most agencies struggle with, and it affects patient care. Regarding professional training and standards of practice: there needs to be hands-on training adaptability. What works in a LTC facility is not the same as what works in the home environment. A person needs hands-on training that builds confidence, and there needs to be clear regulation and guidelines without vague language about what a direct care worker can provide. Medication management is an example. When teaching in the home has been done, the feedback from the person is that they felt safer, which helps the caregiver feel confident in what they are doing. She suggested developing a fleet of mobile training units that contain qualified teaching skill labs to train home care workers, noting that what you do at home and in another person's home are often very different. Today there is care being provided in the home that could only be done by a skilled care professional not long ago. We need to catch up.

- Henry Anderson – Standard of Excellence: He is interested what the proposal means by tiers of education because there are current CEUs that are available. Would this training guide need to be created? He says he already has one, and there are already entities in Milwaukee, Racine and other places that have been doing this for years. If this would be a certificate, what entity would be issuing it? Direct caregivers can do the job of a personal care worker, but not the other way around. CNAs cannot do some of the requirements of a job that direct caregivers can do, such as handout medication. We all need to be on the same page so we can target and pay the people we must to get them into this profession.

- Edna Hudson – Nurse for 24 years in private, facility and hospital settings. Has provided nursing education, training and consultation to help develop caregiving programs, as well as CNA and advanced CNA and pre-licensure programs. As a professor in nursing, she knows what it would take to give a full rounded educational service to those who want to help. If those who want to help do not feel supported or competent in their skills, they cannot do a good job. The more one understands why they are doing something, the more vested they are in doing it correctly. Students must be able to practice their skills in a safe environment, and they need time to practice. Do not cut the education to 3-5 days. Caregivers need time to practice and learn how to apply what they learn to the home setting. COVID-19 has stopped clinical rotations, but we can create simulation rooms to model what you would do in the home. It is important that the language used is correct or else risk confusing people in the community who want to do certain jobs. Make sure that home health agencies are requiring staff complete continuing education to learn the latest techniques, and promoting that a CNA become an advanced CNA.

- Michael Bruin – Alzheimer's Association. Addressed Training Proposal: Only 8% of people diagnosed with Alzheimer's or dementia live at home or in a community facility. Having Forward Wisconsin and the WisCaregiver Program to recruit new people to this field is imperative. Our increasing numbers of people with dementia is going to make this workforce shortage issue even more challenging. Adequate training is at the top of workforce issues that people want addressed. If a person feels inadequately trained, they will leave and go work somewhere else that has a lower stress level.

- John Griffith – Member of Milwaukee county commission on aging and state advisory council and state LGBT community center. Has been a caregiver for his mother and stepfather in their 90s. Groups he is in have been talking about cultural competence training, what different minority communities have to deal with, and the need to be teaching these skills in all care facilities. Many seniors go into a closet of sorts, especially LGBT seniors in care facilities. There continues to be a lack of recognition of them even though society celebrates many of the other cultural holidays. There should be cultural training as part of training provided to all caregivers. He suggested that groups be formed to go around providing cultural awareness training for the many groups that make up Wisconsin's population. He also questioned whether the Ombudsman is adequately funded and whether it is working. He believes that the Ombudsman program needs to be more assertive because the corporate dollar is so directive of activities and service provision that takes place in facilities. How many care facilities celebrated Pride Month this June?

- Amy Weiss – Wisconsin Personal Services Association (WPSA) representing personal care and home care providers. Addressed the Training Proposal – She has provided documents to the Task Force in the past with their recommendations. WPSA developed a direct care competency program in 2005 that assesses the worker and provides 1-1 competency testing. The training modules were written over two years by professionals. There are three DCC modules, and they are currently working on others. Portable training certificates have been provided to many caregivers. During the pandemic, it has been difficult to continue this training, so they have been working on creating an electronic version. She suggested that the Task Force give further attention to this existing program that already has the components the Task Force is looking for. She offered to help in anyway needed. Oversight Proposal – WPSA and member agencies agree with state regulation. What they disagree with is the perfection standard regarding audits that imposes penalties for the color of ink used, initials, etc. Agencies have been experiencing a difficult time trying to hire people during the caregiver worker shortage and now suffering through COVID-19. They would like to see cooperation between DHS and OIG and revised guidance before home care agencies completely collapse.

- Erin Fabrizius – WI Personal Services Association – Regulatory reform. This proposal does not let people off the hook for fraud. There are many inconsistencies between the two agencies that oversee Medicaid services, which makes it difficult for providers to meet current standards. Providers have experienced significant paybacks of Medicaid funding because punitive and unfair practices are driving providers out of the industry. Recouping payments for services that were provided does not prevent fraud; what it does is makes providers rethink if they want to accept Medicare because they may not receive payment for the care they provide.

- Shanda Hubertus: State of Wisconsin has transitioned the developmentally disabled population to home settings but Medicaid payment has not kept up. Technical oversight is not a replacement for the direct care that these people should be receiving. The medically and developmentally fragile population is being negatively impacted by the low pay and required schedules that human beings often do not stick to with in regard to ADLs. Skilled nursing tasks are being requested by MCOs from anyone who is "just a warm body," and this trade-off is dangerous for the clients. The perfection standard for Medicaid paperwork is absurd. We also want no fraud, waste or abuse and encourage that regulatory oversight on that. However, she does not believe penalties should be issued for paperwork mistakes by people who have proof that they provided the care. She has asked for discussions DHS about how to provide education in cases where it is needed to correct minor mistakes, but the issue remains unresolved.

- Ramsey Lee – Echoed what Shandra Hubertus said. He cannot emphasize enough the need to include those affected in the process.

V. Home Care Provider Registry Proposal or Any Other Proposal

- Tim Carey: Kayla speaking on his behalf – He has muscular dystrophy DMD and is on a ventilator 24/7, yet he has to fight for benefits continually. Example was when a clerical error caused an agency not to be paid. He has also had to fight and appeal denials of benefits. Forward Health providers rarely can answer questions. DHS seems more interested in catching fraud than providing services. Having two PAs a year wastes time for me and the state of Wisconsin would like to have Medicaid renewals twice a year. I have to go through this review even though my condition never improves and never will. The state should have a list of conditions where the PA becomes a formality so as to not waste time on this.

- Tami Jackson: Have long been a proponent of a caregiver registry and agree that a participant interface is needed. There have been previous attempts at this, which have been very useful in allowing participants to self-direct. Adequate pay rates would allow agencies to invest in technologies and automate several aspects of their business, including timekeeping. She suggested establishing a statewide contact system that would be used by all of the MCOs and help track caregiver time.

- Kathryn Wilson: Brookfield – Has taken care of three elderly parents and an adult child with cognitive disabilities that will require care. Supports the rate band proposal. It is extremely difficult to recruit someone when directing yourself. We really need to pay them a better wage. They make our society function.

- Barbara Katz: Family Voices of Wisconsin – Parent and guardian of 29 year-old son with intellectual disabilities who has grown up using different aspects of Wisconsin's LTC programs his whole life. She encouraged members to think about children who have extraordinary needs in the LTC support program from birth through age 18 as these proposals move forward. She makes her comments through the lens of children and families whose caregiving greatly exceeds typical caregiving. When paid caregivers are not available, it is the family that is doing caregiving. She asked the Task Force to think about how Wisconsin can support these family members.
  Comments re other Task Force Proposals: TCare Assessment: Include evidence-based tools including those eligible for children's LTS; supports the FMLA proposal; The Credit for Caring proposal should include families caring for child in the children's LTC program. She supports nursing home and payment reforms for children under age 18, the Medicaid expansion and earnings disregard, and the statewide training and homecare provider recommendations.

- Todd Wilson: Bethany Eagle Crest, serving communities around La Crosse. He supports pretty much everything that the Task Force is recommending. There is a lot of complexity to it all. There may be too much to handle all at one time. His agency serves people across the whole range of the system.

Bethany was an early Family Care participant, which started out as a great program. It didn't underpay at the time, and we were willing eagerly to serve an additional population. The money originally came from nursing home funding budget, and nursing homes took the back seat. We did not anticipate that would last forever, but it has. Over the course of the longevity of the FamilyCare program, the nursing home side of the equation has basically been left out. Last year it got about 6% and will get 1% this year, but in last 12 years, increases have been negligent. This puts us at the bottom of nursing home payments in the nation. It is a symptom of a system of payment that is really out to sync. FamilyCare has continued to grow and expand and provide additional services, but a symptom of the disease is that now everyone is underfunded. There have been multiple funding cuts of 10% to implement a new rate setting methodology that we have no input into. It is a secrecy system. The process needs provider input that allows them to have a substantial say into the way we develop the acuity for the base of the model. We have system that underfunds assisted living, memory care, nursing homes – This can't continue. You have been expanding the Medicaid budget on the back of the provider base, and providers can no longer do this while sustaining losses. We do not need hundreds of millions of dollars to go into the infrastructure and administrative costs of the Family Care program.

- Ruth Adix: The recommendations that come from this Task Force need to go forward based on best practice, not based on what political parties will accept. This is an issue for every individual in this state regardless of political party. She has a 39 yr. old with a disability and attended a local meeting of this Task Force. She likes the ADRC reinvestment proposal for improving caregiver support. Fundamentally, the Task Force has to keep the focus on the caregiver and what keeps caregivers in their jobs. She does not feel strongly about supporting the TCare proposal. It sounds like one more thing we're asking caregivers to do when what they really need is resources. ADRCs are in the best position to do that. FMLA is important to care for family members. She experienced the need for The CARE Act when her mother was hospitalized and she did not receive clear instructions upon discharge. Her experience is that caregivers aren't always being trained or told how to provide needed care. She urged the Task Force to be careful not to favor one of the modes of providing care on the back of another. Recognize the uniqueness of different services to care for different people in different circumstances at different points in life. Medical loss ratio: supports. Medicaid expansion is a critical for caregivers and is desperately needed to keep people in jobs that do not pay adequately. Adopting the earnings disregard is a really big piece of the solution. As we look at getting these wages up, we need to have ways to relive stress on our caregivers. The Home Care Registry should be made available to everyone and statewide, and be equitable. She likes the survival coalition's ideas for transportation and caregivers being paid for traveling from one client to another, plus childcare, pensions and retirement programs.

- Janet Stockhausen: Supports all of the Task Force recommendations, but the ones about pay and benefits are at the forefront. Without adequate pay and benefits, there is no way we can resolve the workforce shortage. Adequate and consistent care by reliable caregivers lowers costs because it reduces emergency room visits, and individuals get to establish relationships. She hopes the governor and legislature will look to implement all of these recommendations.

- Molly Olson – Social worker used to work for an MCO and has a father with dementia. Agreed that MCO rate increases are not necessarily going to providers. Feels MCOs are organizationally top heavy and would benefit from some restructuring. The rate setting comes from functional screen that does not catch the whole range of a person's needs, and the way it is used to set rates is so much different than it is for younger and older people. When she worked for an MCO, it was incredibly hard to find placements for people with the low rates. Much of her time was taken from care managing to just telling people that they aren't going to get the rate they wanted and then we would have to keep looking for providers farther out from their town. Rate banding would help. Consider adding caregivers providing care to funding specific through ADRC, which would allow paying friends, family members and others the person knows. Families currently have to go through an agency in our county. Recognizing what informal caregivers do and working to reimburse them so they can keep providing the care they need will reduce hospital and ER admissions, and cases of unintentional neglect and abuse.

- Claire Zautke: Health Care Director, Citizen Action of Wisconsin – Supports Medicaid expansion for increasing access to health care and supporting direct care workers so they can work more in their communities. Earnings disregard - Commended the Task Force for taking this thoughtful and strategic move which will let people keep health care benefits without losing income. She strongly supports bringing added respect and professionalization to the direct caregiver profession, and providing additional benefits like paid sick leave and vacation time so staff can care for their own family members and tend to their own self-care.

- Ruth Kantrowitz – Milwaukee residential adult family homes and CBRF provider. She is also a volunteer guardian. "Family care is a waste." She has seen first-hand that nothing a family member wants is what happens. It is abuse. She said that MCOs see how little they can pay for services and do not allow for resident choice. They are always looking to get the most services for the lowest cost, and the residents suffer. Family Care has become a monopoly, and case managers do nothing for patients. The so-called care team changes faster than anyone can keep track of. They cause more harm to everyone with their lack of respect for providers. They function as babysitters and it is obscene for a provider who has been taking care of someone for years to have a care manager right out of school tell them what that person needs. Who is overseeing Family Care? The state says MCOs can do whatever they want. Case managers have no decision-making ability. The coronavirus gave us a chance to take a look at the whole system. The case managers are all sitting at home, not in the person's life. The ones who deal with a person's daily care get paid $10 and get no support. She urged the Task Force to do away with Family Care and rethink what case managers are doing. If nurses cannot touch the residents, then what is the purpose of a nurse?

- Sondra Norder – The Covid-19 pandemic has thrust nursing homes into the spotlight, and residents are keenly aware of how interested people suddenly are in their lives. The time is right for looking at how we fund them. At a time when we are expected to protect their lives, there has never been a more compelling reason to reform and reimburse for the actual cost of care. We need the Task Force to continue to advance nursing home payment reform. It is unreasonable to pay 68% of the cost and expect perfect care.

- Shanda Hubertus: Nurse in home care setting and critical care. Seconds everything Tim Carey said related to private duty nursing. The documentation to get a PA approved is “absurd.” Medicaid already has access to this information since they paid for the service. Tools used to determine care hours needed are cumbersome and unnecessary. Return to an annual PA approval in cases where a person’s health condition is not expected to improve, perhaps ever. There is too much red tape for those who require care, and then nurses are not reimbursed for the case coordination. A pay differential should be fixed between vent and non-vent cases. Audits should only go back one year from when a clam was submitted. This will keep nurses in the field without worrying about losing their income. MCOs are a waste of taxpayer dollars. We are paying a for-profit company to provide a service with taxpayer dollars, which is paying a middle-man. MCOs try to cut costs in any way possible, and cost over quality is a huge issue for MCOs. Travel reimbursement above the hourly rate is needed. As caregivers, we should not be going to work if we are ill. Training is a necessity for providers and those overseeing prior authorizations.

- Ramsey Lee: The IRIS program is a wonderful program for individuals in the community. Will this meeting be available to somewhere to listen to for those who missed today?
  Faith Russell, DHS staff: WisconsinEye (wiseye.org) is recording this public input session and will have it on their website. Address was included in Zoom chat.

- Stan Hensley : Retired farmer – Spoke about need for internet access in rural areas. He is still on a copper wire even though he is two miles from Stout University. Neighbors behind him have access to fiber optics but the power company will not hook him up from that cul-du-sac. Farmers need technology, and they would use it if they had access to it. This applies to caregiving options as well.

Prepared by: Lynn Gall, DHS Office on Aging on 7/14/2020.
These minutes are in draft form. They will be presented for approval by the governmental body on: 9/10/2020