

Wisconsin Long Term Care Advisory Council
Meeting of September 8, 2015
Lussier Family Heritage Center, Madison

Minutes

Members present: Beth Anderson, Jonette Arms, Heather Bruemmer, Ken Grode, Tom Hlavacek, Dan Idzikowski, Robert Kellerman, Mary Krueger, Barb LeDuc, Lauri Malnory, Tom Moore, Audrey Nelson, Denise Pommer, Maureen Ryan, John Sauer, Beth Swedeen, Sam Wilson, Christine Witt

Members absent: Cynthia Bentley, Teri Buros, Carol Eschner, Ginger Reimer, Barbara Peterson

Others present: Megan Acheson, Patti Becker, Heidi Chada, Janet Estervig, Wendy Fearnside, Erin Fabrizius, Lynn Gall, Anne Gryphan, Julie Hyland, Lea Kitz, Stephanie Mabrey, Carrie Molke, Charles Morgan, Cindy Ofstead, Gerianne Prom, Deb Rathermel, Brian Shoup, Kelly Von Oepen, Amy Weiss, Angela Witt

Call to Order and Welcome.

Heather Bruemmer called the meeting to order at 9:35 am, welcomed members and guests, and had Council members introduce themselves.

Family Care/IRIS 2.0

Brian Shoup, Administrator of the Division of Long Term Care, gave an update on the changes to Family Care and IRIS mandated by the 2015-17 biennial budget and the process the Department will follow for developing the system to implement these changes, called Family Care/IRIS 2.0.

- The Department's process for obtaining public input on Family Care/IRIS 2.0 will include a series of public hearings, meetings with Governor appointed Councils and stakeholder groups, and an opportunity to submit written testimony. The Long Term Care Advisory Council is appointed by DHS, not the Governor, and will not be part of this process. Council members are encouraged to attend hearings and submit comments.
- Act 55 requires the Department to develop a concept paper describing how system changes in the budget would be implemented to the Joint Committee on Finance by April 1, 2016. Joint Finance will review the plan and hold an up or down vote, with no amendments. If approved, the Department will submit a waiver amendment to CMS to implement the plan.

- There will not be an opportunity for public comment on the DHS Concept Paper on Family Care/IRIS 2.0 before it goes to the Joint Committee on Finance. However, there will be an opportunity for comment on the more detailed waiver application that DHS submits to CMS to implement the plan.
- Secretary Rhoades asks that the Long Term Care Advisory Council focus on the elements in her charge and keep moving forward with those. While some of the issues in the Council's charge could potentially relate to Family Care/IRIS 2.0, that is not its primary focus.

Supporting Family Caregivers

Carrie Molke, Director of the Bureau of Aging and Disability Resources introduced the topic, noting that approximately 90% of long term care is provided by family caregivers and that caregiver issues will be a focal point for the recently created Speaker's Task Force on Alzheimer's and Dementia. Background information was provided by Department staff Lynn Gall and Angela Witt and by Council members Sam Wilson (AARP or Wisconsin), Tom Hlavacek (Alzheimer's Association of SE Wisconsin), and Beth Swedeen (WI Board for People with Developmental Disabilities). Very briefly:

- People in the formal long term care system are often supported by family caregivers in addition to receiving formal support.
- Many caregivers (by some estimates over 50%) are also employed.
- The large majority of family caregivers find caregiving more difficult, more stressful and more time consuming than they expected.
- AARP's 2014 national long term support scorecard ("Raising Expectations") ranks Wisconsin 14th in terms of family caregiver support and 20th on caregiver stress. DHS is developing its own long term care performance measures.

Council members offered the following observations and suggestions:

- People don't know where to start. ADRCs should be identified and marketed as a first place for caregivers to go for help.
- Caregiver education is very important. Consider creating an outreach campaign with information for caregivers. Recognize that it is hard for people to ask for help and that people often don't know what to ask.
- Information and support needs change over time.
- There is a significant payoff from training families of children with disabilities early, at the beginning of what can be a many decades journey. Provide assistance with futures planning for people with disabilities. Set high expectations and build skills incrementally.

- Peer support and mentoring can be effective way to support families of children and adults with disabilities.
- The number one thing families say they need is respite. Respite should be included as a benefit in long term care programs. Consider creating a registry to help families identify people who are available to provide respite.
- Help with transportation can be very important.
- Caregiver assessments that evaluate technical skills and emotional needs can be helpful in identifying support needs.
- Develop contingency plans and transition plans for when the family caregiver can no longer continue to provide support.
- Encourage caregiver coalitions to provide mutual support and advocacy.
- Find other words or phrases to use in place of “caregiver” and “respite.” These are not things most people identify with.
- Have back up plans for when family or other caregivers are not available. Explore options for providing and funding training for backup caregivers.
- Be prepared to respond crisis situations involving people with dementia and other long term care needs. Crisis stabilization can be provided in place, where the person lives. Places with behavioral and geriatric expertise where people with dementia can go when experiencing crisis are also needed.
- Funding is needed to help family caregivers, as well as to pay for the care provided to the individual with long term care needs.
- The ability to pay family members is an important factor in increasing the amount of care families can provide and has worked well in IRIS.
- Natural support solutions aren’t realistic for all individuals, especially those who have few resources to set aside for the future, who have small families or no children, and who do not participate in civic or religious organizations. Public response and funding will be needed.
- Avoid cost and confusion by encouraging people to have a power of attorney for health care.
- Health care advocacy is a role for caregivers.
- Encourage adults to anticipate and plan for their own future needs and to talk with their children about their long term care plans.

Integrated Employment Settings

Deb Rathermel, Interim Director of the Bureau of Children’s Services, and Janet Estervig, Section Chief for the Integrated Employment Section, provided an introduction and background information, including:

- Three key areas of life satisfaction are where you live, having people who care, and having meaningful work.
- Wisconsin ranks 24th among states in employment of people age 18-64 with long term care needs.
- The Department of Health Services (DHS) is charged with assuring compliance with the CMS home and community based services settings rule in both residential and non-residential settings. The non-residential settings requirements apply to pre-vocational and employment services and to adult day care, day services for people with developmental disabilities, and children's day centers.
- The Department is currently working on a non-residential settings assessment tool.

Council members offered the following comments and suggestions during their discussion:

- Non-residential settings assessment tool
 - An assessment tool that takes three hours to complete is far too long.
 - Find a way to streamline the assessment process for organizations that have multiple employment sites.
 - Ask the about the percentage of clients who have an opportunity to work with non-disabled individuals, rather than for specific numbers.
- Community readiness for integrated employment
 - Some companies are open to the idea of integrated employment, but there is a limit to how many people they can employ.
 - Trying to find integrated employment is time consuming for guardians, especially when the ward is older and used to a sheltered environment.
 - People who are employed in fast food often work only part time during peak hours.
 - Building the capacity of employment services providers who can locate employers, ensure the match is right, and provide support services is essential.
 - Volunteer activity is good but it is not the same as work.
- Barriers to employment of people with disabilities who require accommodation or supported employment:
 - Employers are concerned about the amount of commitment involved in having to follow federal rules.
 - Public transportation to industrial parks locations is not available.
 - The rate paid for coaching is too low to support a full-time job coach.

- It is harder for people with visible disabilities to get hired.
- Federal MA rules allow payment for participants to travel to get care services but not for caregivers to travel to the person's work.
- Areas where there may be opportunities for integrated employment include supportive home care, manufacturing, agriculture, and home based work.
- Things DHS could do:
 - Enter into high level conversations about employing people with disabilities with employers, in coordination with Wisconsin Manufacturers and Commerce. The Society for Human Resource Managers is another potential resource.
 - Include language regarding employment expectations in the IHA contract.
 - Presume that adults with disabilities in the state's long term care programs will work. Change the screen questions from "Do you want to work?" to "Where do you want to work?"
 - Start the messaging early, in the Birth-Three program.
 - Recognize that many people with disabilities will not be able to work full time. Find other meaningful activities to supplement their work.
 - Find a way in Family Care/IRIS 2.0 to permit some MA personal care activities, such as assistance with toileting, to be performed at the work location, and to pay for the caregivers travel to the work site as well as for hands-on care time.
 - Many companies need
 - Work with LTC participants to get them ready for the job application process.
 - Reach out to the Department of Veterans Affairs.
 - With all the interest in youth transitions and employment, remember that people who are no longer young need work opportunities, too`.

Comments from the Public

Amy Weiss, President of the Wisconsin Personal Service Association, suggested that the Department hold a conference for interested businesses to encourage participation in integrated employment. Businesses need to understand what it means to hire someone with disabilities, what questions they can and cannot ask the applicant, and what the impact on their health care costs will be, among other things. Could the integrated settings assessment tool be used to provide a learning opportunity for interested businesses?

Council Business

Council members provided feedback on the new meeting format. They found the meeting informative, appreciated the more interactive format, and wanted to know how the Department will use information gathered from the discussion. Carrie Molke indicated that ideas generated at Council meetings will be used to inform Department planning and Deb Rathermel said input will be used in revising the community based settings review tool. Members also suggested adding a break in the agenda, condensing the background information presented, and providing specific discussion questions before the meeting.

Council members expressed their concern that the Long Term Care Advisory Council is not involved in development of Wisconsin's new long term care system. Several suggestions were raised and discussed regarding the Council's role in the redesign process, including asking the Department to:

- Expand the scope of the Council's charge to include advising on the design of Wisconsin's long term care programs.
- Keep the Council updated on progress with the new long term care system and involve the Council in its development.
- Identify issues relating to Family Care/IRIS 2.0 which are within the areas of the Council's charge and on which the Council could advise the Department.
- Seek input from the Council on Family Care/IRIS 2.0 following the public hearings and on an ongoing basis as the new system is developed.

Carrie Molke reminded the Council that its involvement must be within the three areas contained in its charge – building a dementia-capable system of care, employment for people with disabilities, and supports to keep people safe in their homes as long as possible. Deb Rathermel observed that long term care encompasses more than the long term care waiver programs and that the Council should have a broad focus. Julie Hyland, Communications Specialist for the Division of Long Term Care, said that she would take the Council members' suggestions back to the Department.

The meeting adjourned at 3:30 p.m.

Handouts

- *Family Care and IRIS 2.0* [Information about scheduled public hearings and opportunities for public testimony]
- *Family Caregiver Facts*, August 25, 2015
- Excerpts from *Raising Expectations: A State Scorecard on Long-Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers, 2014*
 - *Support for Family Caregivers: Dimension and Indicator Ranking*
 - *Appendix B2. State LTSS Scorecard Indicator Descriptions and Data Sources*
- *Wisconsin: 2014 State Long-Term Services and Supports Scorecard Results*
- AARP Information Packet
 - *Valuing the Invaluable: 2015 Update*

- *Valuing the Invaluable: Putting a dollar Value on Family Caregiving*
- *Home Alone: Family Caregivers Providing Complex Chronic Care*
- *Support Wisconsin Seniors and Their Family Caregivers (CARE Act)*
- *AARP Wisconsin Caregiving Resource Guide*
- *Dementia Friendly Communities* [excerpt from *A Tool Kit for Building Dementia-Friendly Communities*]
- *Making Connections and Finding Solutions Together*, Wisconsin Board for People with Developmental Disabilities [Recommendations to support families of people with disabilities across the lifespan]
- *Fact Sheet: Summary of Key Provisions of the 1915(c) Home and Community-Based Services (HCBS) Waivers Final Rule (CMS 2249-F/2296-F)*
- *Exploratory Questions to Assist States in Assessment of Non-Residential Home and Community Based Service(HCBS) Settings*
- *Questions and Answers – 1915(i) State Plan Home and Community-Based Services, 5-Year Period for Waivers, Provider Payment Reassignment, setting Requirements for Community First Choice, and Home and Community-Based Services Waivers – CMS 2249-F and 2296-F*