

Wisconsin Long Term Care Advisory Council

Meeting of July 14, 2015

Lussier Family Heritage Center, Madison

Members present: Beth Anderson, Cynthia Bentley, Heather Bruemmer, Teri Buros, Ken Grode, Dan Idzikowski, Mary Krueger, Barb LeDuc, Lauri Malnory, Audrey Nelson, Denise Pommer, Ginger Reimer, Maureen Ryan, John Sauer, Beth Swedeen, Sam Wilson, Christine Witt

Members absent: Jonette Arms, Carol Eschner, Tom Hlavacek, Robert Kellerman, Tom Moore (represented by John VanderMeer), Barbara Peterson

Others present: Patti Becker, Michael Blumenfeld, Vicki Buchholz, Julie Burish, Mary Delgado, Wendy Fearnside, Julie Hyland, Darla Keuler-Gehl, Stephanie Mabrey, Helen Marks Dicks, Chris McElgunn, Forbes McIntosh, Kellie Miller, Carrie Molke, Cindy Ofstead, Gerianne Prom, Kitty Rhoades, Camille Rodriguez, Faith Russell, Brian Shoup, Amy Weiss, Ramie Zelenkora

Call to Order and Welcome

Heather Bruemmer called the meeting to order at 9:30 am and welcomed members and guests. Several new members are joining the Council as it reconvenes with a new charge following a six month hiatus. New members include Jonette Arms, Cindy Bentley, Ken Grode, Barb LeDuc, Denise Pommer and Sam Wilson.

Charge to the Council

Department of Health Services Secretary Kitty Rhoades described her vision for the reconvened Council. The Council will be asked to provide guidance in three major focus areas: strategies for building dementia-capable system of services and supports, strategies to increase employment of people with disabilities and long-term care needs, and community supports to keep people safe in the community as long as possible. The goal is to help people remain independent and in their own homes as long as possible.

Council Procedures

Division of Long Term Care Administrator Brian Shoup reviewed the procedures for the reconvened Council. Terms have been shortened from three years to two, to allow for diversity of opinion and increase the ability to bring in new people. Secretary Rhoades has indicated that she would like to give more voice to consumers on the Council. The Department values the participation of all members and will have the Council work as a group, rather than through subcommittees. Attendance at meetings is expected. The Council will have a Chair and a Vice Chair, and no other officers. Members will be expected to recuse themselves when the Council takes formal action on a matter that could be seen as involving a conflict of interest.

Council members asked the following questions:

- Will there be a permanent seat on the Council for advocacy groups, even if the individual representative changes? Secretary Rhoades indicated that this would generally be the case but that she did not want to lock into particular numbers or groups.
- Can members send a substitute when unable to attend a meeting? Secretary Rhoades said she prefers that members participate in person in order to provide continuity. Brian Shoup said that substitutes may attend but cannot take part in Council actions.
- Will Council members' terms be staggered? Secretary Rhoades said yes.
- Will meetings be held at different locations around the state? Traditionally, the Council has met in Madison. Meetings in other locations could be considered, if practical.
- Does the charge to the Council include Family Care? The charge does not include Family Care.

Background on the Three Council Focus Areas

Heather Bruemmer indicated that today's agenda will provide an orientation and background information on each of the three focus areas, to lay the foundation for future discussions. Future meetings will emphasize obtaining guidance and perspective from Council members.

The Dementia Care System

Carrie Molke, Director of the Bureau of Aging and Disability Resources, and Cindy Ofstead, Director of the Office on Aging, gave the orientation.

Cindy Ofstead reviewed the demographic trends: a doubling of the household population with dementia over the next 25 years, a number of age-related chronic diseases that are correlated with dementia, and disparities in the incidence of dementia among different population groups and among different areas of the state. Together, these underscore the need to address issues relating to the quality and capacity of the dementia care system. Cindy also reviewed the Department of Health Services' process for addressing dementia care needs, including a stakeholder summit in October 2013, publishing a state Dementia Care System Redesign Plan in February 2014, and holding five listening sessions around the state in July 2014.

Carrie Molke described Department initiatives in each of the five focus areas in the Dementia Care System Redesign Plan: community awareness and services, facility-based long-term care, crisis stabilization for people with dementia, dementia care guiding principles and training, and research and data collection. Highlights include hiring dementia care specialists in selected ADRCs and tribes; a variety of dementia-friendly community initiatives and caregiver support projects; the Music & Memory Program; development of guiding principles for

dementia care; publishing a directory of dementia-related trainings; and creating on-line training courses for crisis responders, health care providers and family caregivers. Details are contained in the accompanying Power Point handout.

Carrie Molke described the overarching goal of the dementia initiatives as being to prevent the crises which require people with dementia to move from their familiar environment to a more restrictive setting, while at the same time recognizing that, for some people, more will be needed. She is hoping that the Council can identify things that have not yet been considered in the Department's approach and persons or organizations who could help in moving toward a more dementia-capable Wisconsin.

Council members identified the following topics for possible Council discussion at future meetings:

- ✓ Coordinating with hospitals to minimize the adverse effects of hospitalization on people with dementia
- ✓ Dementia training for personal caregivers
- ✓ Dementia crisis care
- ✓ Falls prevention for people with dementia
- ✓ Supporting family caregivers
- ✓ Ways to get to people with dementia and their caregivers earlier, to provide support when it can have the greatest impact on prevention and diversion
- ✓ Decreasing the stigma of dementia
- ✓ Ways to help people with dementia stay healthy, including the Healthy Athlete Program of the Special Olympics

Comments from the Public

Amy Weiss from the Milwaukee Center for Independence spoke about the Direct Care Competency Training program that has been developed by the Wisconsin Personal Services Association (WPSA), the Wisconsin Long Term Care Workforce Alliance and the Alzheimer's Association of Southeastern Wisconsin. This is a train-the-trainer program that includes a curriculum, manual and toolkit for training direct caregivers in a variety of hands-on and communication competencies and is available through WPSA.

Julie Burish complemented the Department on the Dementia Care Guiding Principles and said that they could apply to people with disabilities as well as to people with dementia. She suggested that the Department have guiding principles for all of the populations it supports, describing how people are to be treated in its different programs, with the addition of some principles specific to each group. Secretary Rhoades indicated that there is a set of more general guiding principles for the Department as a whole on the Department's website. (See <https://www.dhs.wisconsin.gov/aboutdhs/mission.pdf>.)

Background on the Three Council Focus Areas (continued)

Employment for People with Disabilities

Camille Rodriguez, Director of the Bureau of Children's Services in the Division of Long Term Care, provided the orientation. She began by observing that many ask why the Employment Initiative Section is in the Children's Services Bureau. Employment is an issue that crosses the lifespan. It is important to begin early to establish the expectation that employment for people with disabilities is possible, in order to develop skills, and include employment goals when transitioning youth from the children's to the adult care systems. Secretary Rhoades observed that it is also unusual for employment to be included in long-term care. People want to be independent and the Department wants to help them succeed. Employment should be a normal part of the conversation about becoming independent.

While the Department does not operate employment programs, it collaborates with other agencies on employment initiatives and provides guidance and resources. It has participated in a number of successful employment programs for youth with disabilities, including Project Search, the Promise Grant and Let's Get to Work. Wisconsin's long-term care waiver programs include employment goals in participants' individualized service plans, include work-related daily living skills training and Work Incentives Benefits Counseling in the benefit package. In addition, the Department administers the Wisconsin Senior Employment Program (WISE) and provides opportunities for volunteerism and other meaningful engagement of seniors. The goal is to use the systems we have to maximize opportunities.

Secretary Rhoades said she could use the Council's help in shaping the message about the advantages of, and opportunities for employment, and in finding ways to get the word out to people who are afraid of losing benefits if they work.

The following were identified as challenges in the employment area: getting the message about employment opportunities to families of children with disabilities, supporting people's employment choices while navigating the new federal rule on home and community-based settings, measuring the success of employment programs for people with disabilities, and creating a cultural paradigm shift regarding employment expectations for people with disabilities.

Council members identified the following employment-related topics possible for Council discussion at future meetings:

- ✓ Creating employment opportunities for people with disabilities in areas related to long-term care, where there is a serious workforce shortage.
- ✓ Overcoming disincentives to work, especially the fear of losing benefits.

- ✓ Helping families navigate the variety of employment programs and options.
- ✓ Helping Community Rehabilitation Programs build capacity to provide integrated employment services.
- ✓ Increasing the number and capacity of employers for people with disabilities, especially in the area of Supported Employment.
- ✓ Messaging for families of people with disabilities, starting with Birth to 3 , to encourage engagement in normal community activities and, ultimately, in employment.
- ✓ Including performance expectations in the MCO contract relating to employment.
- ✓ Targeting the employment funding and resources are available through the state.

Community Supports to Keep People Safe in the Community

Carrie Molke, Director of the Bureau of Aging and Disability Resources (BADR) gave the orientation. She reviewed how the Bureau is organized and the various roles it plays in providing community support for older people and people with disabilities. The Office on Aging oversees Older American Act programs such as meals, caregiver support, prevention and health promotion, together with elder benefit specialists, adult protective services, senior employment, and others. The Office for Resource Center Development administers the program that funds aging and disability resource centers and tribal aging and disability resource specialists throughout the state. The Office for the Deaf and Hard of Hearing provides outreach, education, information and referrals for people with hearing impairments; access to assistive technology and communication aids; and administers the test for sign language interpreter certification. The Office for the Blind and Visually Impaired helps people learn the variety of skills needed to obtain independence, including orientation and mobility and how to communicate, cook, perform personal cares, travel, use adaptive equipment and perform other activities of daily living. The Physical Disabilities Resources Coordinator is the Department's focal point for policies affecting people with physical disabilities. In addition, the management of Independent Living Center contracts and the WisTech assistive technology training and loan programs will be moving to BADR soon.

A variety of factors that could put a person at risk for not meeting the goal of living a happy and healthy life in the community were identified, including: living alone, being homebound, lack of family support, lack of transportation, nutritional risk or living in a food desert, physical disabilities and chronic conditions, mental health issues, poverty and retirement insecurity, caregiver burnout, hidden disabilities that isolate the person, and family dysfunction and violence.

Council members identified the following topics for Council discussion at future meetings:

- ✓ Behavioral health services for people with hearing impairments
- ✓ Need for accessible medical equipment (MRIs, etc.)
- ✓ Falls prevention for people with disabilities
- ✓ Workforce capacity to meet long-term care needs
- ✓ Outreach and gaining access to people in need
- ✓ Livable communities
- ✓ Accessible housing supply
- ✓ Transportation
- ✓ Interface between law enforcement, corrections and the long-term care system
- ✓ Coordination with other Councils dealing with related issues

Regarding Future Meetings

Council members had several additional questions and suggestions regarding future meeting agendas. A question was asked about how the Department will gather input on its long-term care programs, now that they are no longer within the scope of this Council. Brian Shoup said the Department is preparing a plan for getting stakeholder input, advice and counsel on Family Care and IRIS and related changes in the budget to present to the Secretary. Council members expressed their belief in the importance of coordinating with other related councils and asked how this can be done. Secretary Rhoades said she wants input to be effective and focused on solvable issues. Council members expressed their preference to work on topics that the Department will be acting on and to have the Department identify those issues. Members also requested that the Council be provided with materials ahead of the meetings so that those who represent groups can give their constituents time to review.

The meeting adjourned at 3:30 p.m.

Handouts

- *Wisconsin Long Term Care Advisory Council, July 2015* (membership list)
- *Charge to the Wisconsin Long Term Care Advisory Council: July 2015-June 2016*
- *Wisconsin Long Term Care Advisory Council, Council Procedures*, July 2015
- *Dementia-Capable Wisconsin, July 14, 2015* (Power Point)
- *A Tool Kit for Building Dementia-Friendly Communities* (cover and table of contents only; the full tool kit is available at <https://www.dhs.wisconsin.gov/publications/p01000.pdf>)
- *Dementia Care Guiding Principles* (one page summary)
- *University of Wisconsin-Oshkosh: Dementia Training Topics*