

Wisconsin Long Term Care Advisory Council
Meeting of November 10, 2015
Lussier Family Heritage Center, Madison

Minutes

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

Members absent: Cynthia Bentley, Tom Hlavacek, Barbara Peterson, Beth Swedeen

Others present: Michael Blumenfeld, Janet Estervig, Wendy Fearnside, Lynn Gall, Katie Geiger, Ann Gryphan, Tami Jackson, Robert Lefeber, Stephanie Mabrey, Katelyn Marschall, Carrie Molke, Charles Morgan, Andy Nelson, Cindy Ofstead, Gerianne Prom

Call to Order and Welcome.

Heather Bruemmer called the meeting to order at 9:30 am and welcomed members and guests. Minutes of the September meeting were unanimously approved on a motion from Bob Kellerman, seconded by Mary Krueger.

Supporting Family Caregivers

Carrie Molke, Director of the Bureau of Aging and Disability Resources, opened the discussion with a recap of key takeaways from the Council's September meeting. Caregiving is an issue across the lifespan, and many different approaches were identified in the Council's discussion. Suggested solutions can be grouped into the following categories:

- *Community awareness*, including outreach to help caregivers identify themselves, know what support is available, and overcome the perceived stigma of asking for help.
- *Program services and resources for caregivers*. While many resources are available, significant gaps exist. We need to look for opportunities to work together to address the gaps.
- *Education and training* to help caregivers develop the knowledge and skills to carry out their caregiving roles.
- *Research and data* to help better understand and appreciate the return on investment from paid and unpaid caregiving and to identify opportunities for improvement. Wisconsin ranked 14th on AARP's long term support caregiver scorecard, with relatively low scores on caregiver assessments and pay for family caregivers.

The next step is to develop a Wisconsin strategy for caregiving and identify the roles that members of the Council and other Department partners can play in its implementation. Cindy Ofstead, Director of the Office on Aging, described the process as an effort to bring partners and stakeholders together to develop a strategic approach that is more than a state plan or work plan for state staff, where all stakeholders have a role and bring their resources to bear in a joint effort to promote and support family caregiving.

As a starting point for development of the caregiving strategy, Cindy Ofstead led the Council in a brainstorming exercise to “map” the current system of caregiver supports. A grid was distributed to provide a framework for identifying the different types of family caregivers, the resources that are currently in place to provide support for each group, the remaining gaps and needs, and some broad ideas for strategies to address the identified needs.

Caregiver Populations. Council members requested that a working definition of the term “caregiver” be developed for the project. The definition should be broad enough to include family, friends and neighbors providing any type of support, including transportation, chores, personal cares, or other forms of direct care. Professional caregivers may provide similar services but are paid and have training.

Members identified a number of caregiver groups to include in the mapping exercise, in addition to the scenarios that were included as examples on the grid template (families of people with developmental disabilities, chronic health problems and dementia; community/neighbor caregivers; and children as caregivers. Additions included: grandparents caring for grandchildren; caregivers of people with physical disabilities, mental illness, or AODA; people without family or community supports; and people with LTC needs released after incarceration.

Current Caregiver Support Services. A wide range of community supports are currently available to caregivers. Resources vary considerably from one community to another depending on the size of the community, its geographic location, the local economy, the population group served, and other factors.

The following chart lists resources that were identified as being currently available, at least in some locations in the state, for caregivers of people with intellectual and developmental disabilities (ID/DD), caregivers of older adults, and grandparents raising grandchildren. This listing is a starting point, not an exhaustive list. Resources for other caregiver populations will be discussed at future meetings.

Caregiver Group	Current Programs, Services, Providers, Resources
Parents of Children with ID/DD	<ul style="list-style-type: none"> • Informal community networks, including family co-ops and groups that share childcare and other self-help resources • Parent support groups sponsored by nonprofit agencies, school systems, faith-based organizations, etc.

Caregiver Group	Current Programs, Services, Providers, Resources
	<ul style="list-style-type: none"> ● Formal, organized networks such as Parent to Parent of Wisconsin and the NAMI (National Alliance on Mental Illness) provide training and support ● Certified Parent Specialists (paid positions, certified by DMHSAS and employed by agencies to work parent-to-parent) ● Training programs and conferences (Parents in Partnership sponsored by DPI, Circles of Life, Children Come First, WBPDD Self-Determination Conference) ● Centers for Children with Special Health Care Needs-- Guardianship support ● Programs such as Birth-to-3, Katie Beckett, Youth in Partnership with Parents (funded by DPI), and school district special education programs provide early education and training, in-home support, resources and referral to other care ● Easter Seals Camp, Boys and Girls Clubs and other programs for kids.
Parents of Transitioning Young Adults with ID/DD	<ul style="list-style-type: none"> ● DPI special programs: Parents in Partnership, Youth in Partnership with Parents for Empowerment ● Formal waiver resources ● Boys & Girls Club ● Wisconsin Transition Conference ● Private planning resources ● Movin' Out helps families provide housing for an adult child with disabilities ● Work incentive benefits ● National Family Caregiver Support Program (NFCSP)
Aging Parents of Adults with ID/DD	<ul style="list-style-type: none"> ● Interfaith provides one-on-one support to aging caregivers in Milwaukee: ● Profit and non-profit agencies ● NFCSP
Siblings of Children with ID/DD	<ul style="list-style-type: none"> ● Wisconsin Sibs
Caregivers of Older Adults	<ul style="list-style-type: none"> ● Hospice Services ● Personal care agencies (respite, direct care, care sharing) ● Interfaith: Neighbor to Neighbor program ● Share the Care

Caregiver Group	Current Programs, Services, Providers, Resources
	<ul style="list-style-type: none"> • Faith-based programs/member support • Adult day care and adult day programs for respite or to allow the caregiver to work • Aging network services (transportation, home-delivered meals and other nutrition, support groups, training, telephone reassurance lines, senior companion programs) • Powerful Tools for Caregivers, Memory Care Connections and other programs designed to support caregivers and provided by ADRCs, county aging offices, and other community organizations • Aging and Disability Resource Centers: resource directories; information and assistance, options counseling, access to programs and resources • ADRC Dementia Care Specialists • Memory Cafés • Alzheimer's Association 24 hour helpline • Adult day programs at facilities • Electronic monitoring (Lifeline, GPS, in-home video monitoring) • Online trainings (UW-Oshkosh, AARP and others) • On-line information resources • UW School of Nursing online caregiver support project (eCARE) • Alzheimer's Family Caregiver Support Program (AFCSP) and NFCSP • Employee Assistance Programs for working spouses or adult children • Veteran Caregiver Support (hotline & coordinator at each VA hospital) • Condition-specific organizations (e.g., Cancer Society, Alzheimer's Association) • Guardians, Guardian Support Center, Wisconsin Guardianship Association and WINGS (Working Interdisciplinary Networks for Guardianship Stakeholders) • AARP (phone support line, training, resources) • 211 Systems • DHS & Alzheimer's Association "Employed Caregiver" support • Eldercare Locator, national 800 number for local resources and contacts • Supporting Active and Independent Lives (SAIL) provides in-home support for a monthly membership fee. Attic Angels and Oakwood co-sponsor program in Madison. • Community Life Enrichment program (training for caregivers,

Caregiver Group	Current Programs, Services, Providers, Resources
	<p>exercise, computer lab, fraud awareness, etc.) through Lutheran Homes of Oconomowoc</p> <ul style="list-style-type: none"> • Senior Centers • Law enforcement and fire departments for well checks and emergency services • Elder transportation programs
<p>Grandparents Raising Grandchildren</p>	<ul style="list-style-type: none"> • Grandparent support groups • Grandparents and others As Parents (GAP) in Eau Claire provides peer support, informal advocacy, guardianships • Villard Square Grandfamily Housing in Milwaukee • NFCSP • Rainbow Project in Madison • Kinship Care from the Department of Children and Families • UW Extension GRAND manual • Tribal resources, including gaming funds and s. 85.215 transportation (Menominee)

Gaps in/Need for/Barriers to Accessing Caregiver Support

While many of services and supports are specific to a particular caregiver population, the gaps in service and barriers to accessing services tend to apply across all of the different caregiver types. Council members identified the following as issues in the current system:

- Access to resources, including the inconsistent availability of resources in different geographic areas
- Access to information – letting people know about and helping them connect with the services that are available.
- Funding for formal services, including paid in home care and respite
- Lack of transportation, a problem in much of the state
- Cultural influences – language barriers and different belief systems (such as families should take care of their own) can inhibit access to resources
- Labor shortage – too few caregivers
- Low expectations – many people believe they should just “make do.” Many people don’t identify themselves as caregivers and don’t look for help.
- Not knowing what help is needed or what is available.
- The stigma of needing or asking for help.
- Training for caregivers.
- Crisis response to provide help when the situation is more than the family caregiver can handle.

- Social isolation of caregivers.
- Community “movers and shakers”, people who can organize informal supports
- Difficulty in accessing medical and mental health care for the caregiver
- Help with transitions – training for caregivers when their family member is discharged from the hospital, for taking on unfamiliar tasks (such as a husband cooking), or relearning roles
- Grief support. Family caregivers mourn the diminished capacity of their loved one and the loss of that person. Their grief needs to be recognized and supported.
- Work schedule flexibility for working caregivers.
- Legal documents – POA for health care, facilitation for difficult conversations and document preparation in advance of a health care crisis.
- Support for male caregivers.
- Lack of mandatory leave for family caregiving
- Need for advance planning, without waiting for a crisis situation to occur.

Strategic Approaches to Supporting Family Caregivers. Council members identified the following strategies with potential for increasing the support available to family caregivers:

- Work with employers’ human resources departments to facilitate caregiver-friendly workplaces.
- Use tele-health, apps and other technologies to bring health care to people, reducing time commitments and the need for transportation.
- Educate physicians, nurses and medical assistants to increase awareness of caregiver needs and the availability of ADRCs and other local resources to which they could make referrals.
- Work with insurance companies to encourage coverage of caregiver support services.
- Make outreach materials available in clinics and public places.
- Emphasize follow-up after information has been provided. ADRCs, aging units and health care providers should develop ways to follow up with caregivers. It takes time to build relationships, get the message across, and have an impact.
- Build capacity for advocacy and informal support programs.
- Address cultural barriers that make people reluctant to seek help, such as the emphasis on self-reliance.
- Work toward improving caregiver compensation. Workforce shortage is a crisis throughout the long term care sector, largely because of compensation. A livable wage, health insurance, paid leave and time off are essential if we are to have a consistent and quality caregiver workforce. Without these, the stage is set for failure.
- MA and Family Care need to be part of the solution. Build expectations for caregiver pay into Family Care/Integrated Health Agency capitation and nursing home rates.
- Establish adequate provider rates for nursing homes and assisted living facilities.
- Promote the availability and use of respite care.

- Provide information about what is available and what works. Awareness campaigns need to be kept continually updated.
- Invest in building community services that help people avoid and delay the need for institutional care.
- Make ADRCs the single entry point for caregiver questions.
- Establish a Wisconsin Family Caregiver hotline that routes calls to the local ADRC.
- Market the ADRC (people don't know the acronym) and establish a statewide toll free line and website.
- Have places that ADRCs can refer caregivers to.
- Have ADRCs problem solve with caregivers and put together a plan for the family.
- Consider legislation to require mandatory leave for family caregiving

Integrated Employment Settings

Janet Estervig, Employment Initiatives Section Chief, addressed questions raised at the September meeting and presented information on employment for people with disabilities in the long term care system.

Personal Care in the Workplace. The Council has identified lack of access to personal care in the workplace as a major barrier to employment for people with physical disabilities. Currently the Medicaid (MA) card cannot pay for personal care anywhere outside the recipient's home. Wisconsin statutes, MA State Plan, MA handbook, and MA updates do not allow for MA fee for service coverage for personal care in the workplace.

Council members observed that IRIS waiver allows participants to self-direct their MA personal care in the workplace. They asked what federal rules apply and suggested that the Department explore what could be done to make it possible for others to have the same ability. Pursuing a "j" waiver for all long term care was suggested as one possibility.

While we do not know the number of people with disabilities who are unable to work because they cannot get personal care in the workplace, there are several known factors that limit the availability of personal care in any setting. One is the number and distribution of personal care providers. There are 199 agencies that provide personal care in Wisconsin: 102 in Milwaukee, 9 in Dane County, 9 in Brown County, and 72 in the rest of the state. Another limiting factor is reimbursement. The MA rate for personal care is \$16.08 per hour. This rate was established in 2008 and has not been increased since. Another factor is unpaid travel time, especially when the worker is performing care that may take only 15 minutes to provide.

Employment Service Provider Capacity. Janet Estervig provided the following profile of employment service provider capacity in Wisconsin.

- *Types of Employment Services.* Three types of employment services are tracked in the Department's Program Participation System (PPS): individualized supported employment, group supported employment for three or more people (also known as "enclaves"), and facility-based pre-vocational services, where employees are paid for piece work. Community based pre-vocational services are typically not paid and include volunteer, career development, business shadows or day services, rather than employment.
- *Number of Employment Service Providers.* There are 82 providers of supported employment and/or pre-vocational services in Family Care counties and Dane County. Data is not available on employment in legacy waiver counties other than Dane County or on employment service provider wait lists. DVR has expressed concern about having enough provider capacity to comply with work experience and opportunity requirements for youth with disabilities required by the 2014 Workforce Innovation and Opportunity Act (WIOA), and DHS and DVR are meeting to discuss the future needs of integrated employment service providers.
- *Numbers of People Employed.* Approximately 3,600 Family Care members participate in integrated employment, 400 in enclave employment, and 5,500 in facility based pre-vocational programs.
- *Data Sources.* The Department of Health Services (DHS), Division of Vocational Rehabilitation (DVR), and the Department of Public Instruction (DPI) report employment data annually. Approximately 30% of (DVR) clients are in the long term care system. The Institute for Community Inclusion (ICI) also has Wisconsin data (to access, go to <http://www.statedata.info/>).

Barriers to Employment for People with Disabilities. Council members identified the following as barriers to employment for people with disabilities:

- Transportation for the person with disabilities to get to work. Employers may need to be flexible on hours in order to facilitate transportation.
- Fear of losing benefits. People with disabilities often incorrectly assume that they will lose their MA benefits if they work. Work Incentives Benefits Counseling can help with this.
- Prospective employees need help in developing the skill set for finding a job.
- Limited capacity of employment services providers. Demand will increase when new federal requirements go into effect in July 2016, mandating that people in facility-based programs and high school students transitioning to work be given opportunities for integrated employment. Employment service providers will need to increase their overall service capacity and develop better skills in recruiting employers for people with disabilities.
- The bottleneck created by the shortage of DVR counselors and inexperienced DVR staff who don't "know the ropes" and aren't familiar with the businesses and employers in the community. Prospective employers can't wait for DVR to "come through."
- Job coach shortage.

- Low expectations for employment of people with disabilities. Many people with disabilities don't believe that they can work. Many employers share that view and do not know enough about employing people with disabilities to be comfortable doing so.
- Lack of access to MA personal care in the workplace.
- Difficulty created for prospective employers when hiring a person who can only do part of a job, especially when there are labor shortages.
- Lack of compensation for employment service providers' job development work. It is easier for service providers to place people in a facility setting than to locate integrated employment opportunities.
- Communities that lack the infrastructure needed to support integrated employment: transportation, behavioral support, a large employer base, and a low general unemployment rate, and experience with employment programs for people with disabilities. These features are more available in Dane County than in many other areas of the state and may explain why it has a better track record in employment.
- MCOs limiting the amount they will pay employment service providers for follow-up with the people who they have placed in community employment. Some MCOs limit the amount of follow up to two hours per month, too little for the employer service provider to know what is going on and be proactive solving problems. This results in placement failures that otherwise could have been avoided.
- Difficulty in getting employment services for people with disabilities who are over the age of 24.

Preliminary Recommendations on Employment

Council members generated the following ideas for addressing employment needs of people with disabilities:

- Increase the \$16.08 rate for MA personal care.
- Allow provision of MA personal care in employment settings.
- Adequately cover the cost of caregiver transportation. Either allow MA billing for caregiver transportation to the locations where they provide supportive home care or have the SHC rate reflect the real cost of caregiver transportation.
- Account for caregiver vacation and sick time in the MA rate.
- Mandate that MCOs pass through rate increases so that caregivers benefit.
- Include MA rate solutions in both the MA card and in MA managed long term care.
- Have a goal of increasing the percentage of LTC enrollees with disabilities who are employed in the community
- Promote an expectation that Family Care MCOs and IHAs focus on job development
- Find a way to pay employment service providers for job development, such as by building job development into their rate

- Ascertain and reimburse the real cost of having employment services agencies provide the needed level of follow up with the people they have placed in integrated employment.

Comments from the Public

Heather Bruemmer asked for any comments from the public. There were none.

Council Business

Council members requested the following:

- To continue discussion of employment recommendations at the January meeting.
- That representatives of the Division of Vocational Rehabilitation (DVR) and the Department of Public Instruction (DPI) be invited to participate in the Council's discussion of employment issues.
- That Community Care Connections of Wisconsin be invited to present on its employment initiatives at a future Council meeting.
- That a recap of today's discussion be distributed in advance of the next meeting for members to review and come with additional ideas.

The meeting adjourned at 2:40 p.m.

Handouts

- *Statewide Caregiver Support Strategy Starting Point: Mapping the Current System*, a format for the family caregiver discussion
- *Non-State Employee Expense Report* form
- *2016 Meeting Dates for the Wisconsin Long Term Care Advisory Council*