

2002
Annual Report
Wisconsin
Council on
Long Term Care

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Background

The Wisconsin Council on Long Term Care was first created through the 1999 Wisconsin Act 9 with the responsibility to report annually to the legislature and to the Governor on the status of Family Care. Family Care, created by the same Act, was a new pilot approach to redesigning the long term care system in Wisconsin for frail elders and adults with developmental or physical disabilities. The Council was also directed to assist the Wisconsin Department of Health and Family Services in developing broad policy issues related to long term care services. Wisconsin Act 9 sunset the Council as a legislative council as of July 21, 2001.

On September 10, 2001, Secretary Phyllis Dubé, of the Wisconsin Department of Health and Family Services, reappointed all 15 original members of the Wisconsin Council on Long Term Care, as an advisory group for the Department on the emerging issues in long term care. She expanded the membership to 17 through the addition of two additional members to represent the interests of children with long term care needs and individuals with mental health concerns.

Members of the Council include: Tom Rand (chair), Carol Eschner (vice-chair), Chuck Wilhelm (secretary), Dale Block, Lynn Breedlove, Beth Christie, Tom Frazier, Diane Hausinger, Marlea Linse, Julie Litza, Rita Maher, Ella Pious, George Potaracke, Ruth Roschke, David Slutterback, Melvin Steinke, and Alice Westemeier. The Council meets monthly, except in December, usually on the fourth Friday of the month. Most meetings are in Madison, although the Council does travel to make site visits.

See Appendix 1 of this report for the Council's charge and detailed membership information. Agendas and minutes for all meetings, as well as reports, the Council's membership and charge, as well as other information, are updated regularly on the Council's web site at <http://www.wcltc.state.wi.us/>.

Major activities in 2002

During 2002, the Council was briefed and had lively discussions about a number of facets of the state's long term care system. Family Care implementation was a major focus, but the Council also was updated on the Partnership Program, the Mental Health system and efforts to redesign it, the Community Options Program and its related Medicaid waiver programs, children's long term care redesign, complaints and court cases related to the Americans with Disabilities Act, testing procedures for nursing assistants, and many other issues.

The Council visited Richland County in June, where members discussed Family Care implementation with county officials, consumers, and members of the Richland County Long Term Care Council. In September, the Council traveled to Jackson County, where representatives from Jackson, Trempealeau, Kenosha and Marathon Counties discussed their experiences operating Aging and Disability Centers in the absence of the Family Care benefit and Care Management Organizations (CMOs). In October, the Council met with directors and other staff of Resource Centers and CMOs from all five of the full Family Care Pilots.

The ADA Title II Committee of the Council, chaired by George Potaracke and including several members of the Council and broad representation of the public, continued a major effort to develop recommendations on how Wisconsin can progress toward full compliance with the requirements of the federal Americans with Disabilities Act. The Committee's completed its

work in November, 2002, with their Phase 2 (2002) recommendations, which centered on three areas:

1. Improving and expanding Medicaid's personal care benefit.
2. Restructuring the State's budgeting process for long term care.
3. Monitoring and guiding the use of new funds to implement Phase 1 and Phase 2 ADA Plan recommendations.

Detailed recommendations and discussion of them from both Phase 1 and Phase 2 of the ADA Title II Committee's work have been published as separate reports, available through the Council's web site at <http://www.wcltc.state.wi.us/>.

The charge of the Council's Committee on Local Long Term Care Councils is to bring recommendations to the full Council about how to improve stakeholder and citizen oversight and input. Their first task was to provide advice to the Department and its contractor, Employment Resources, Inc., in the development of training and support materials to strengthen Local Long Term Care Councils. This Committee will be ongoing in 2003.

Two other Council Committees were active during 2002, on a more short-term basis. The Committee on Future Policy Directions gathered information and framed issues to help the Council make recommendations about the direction Wisconsin should take to continue to improve the long term care system. The Funding Issues Committee gathered data and framed issues to help the Council make recommendations regarding the State's budget.

A new Committee was formed at the end of 2002, to continue the Council's role of advising the Department of Health and Family Services on federal Real Choices grants. Membership will come from the ADA Title II Committee, whose work is otherwise completed.

In November, the Council reviewed its findings about Wisconsin's long term care system and adopted recommendations about where the state should be heading in both the short and longer range future. A description of all the major components of the system and issues related to it was published in November, and is available on the Council's web site. The Council's major findings and recommendations are presented below.

Findings of the Council

Wisconsin has made much progress over the past two decades in developing a comprehensive array of long term care services. Twenty years ago, when the Community Options Program (COP) was started, virtually no home and community based services and supports were available to frail elderly people or people with serious disabilities, and Wisconsin had one of the highest nursing home utilization rates in the nation. As our population has aged and the need increased over the past twenty years, all growth in publicly funded long term care capacity has occurred on the home and community side of the system. Nursing home capacity has been capped for that time period, and both the number of beds and the rate of utilization have declined.

Despite this progress, the problems identified during the Long Term Care Redesign process in the late 1990s still exist in most of the state. Although the system is far more balanced than it once was, institutional funding still dominates the state budget, while there are long waiting lists for home and community programs. Many people still don't have real choices about where they will live and how they will receive services. The community service system is too complex, consisting of a confusing and administratively inefficient array of individual programs with separate rules,

eligibility requirements, payment rates and covered services. People can fall through the cracks, and care managers usually have to patch together funding from several programs to cover needed services. Access to these programs, as well as level of choice, array of services covered, and quality all vary from county to county. The system does not encourage available resources to be used in a smart way; people often have to rely on Medicaid card services that are more medical, professional, and restrictive than they need or want. Not enough effort is focused on helping people become or stay more independent, or to conserve their own resources and reduce their reliance on the public system. Quality assurance is too often about process instead of outcomes for people.

In the face of a rapidly increasing number of people needing services, available resources will not sustain the long term care system unless we become more effective and efficient. The current economic climate in Wisconsin cannot be ignored when considering how to address the long term care needs of our residents. Those who have long term care needs are among the most vulnerable of our citizens. Moreover, the choice is to manage their needs and associated costs or ignore them and pay the costs of managing and paying for health care in crisis. With careful consideration, the Council has formulated its recommendations in a way that we believe balances the long term care needs of Wisconsin's citizens within the constraints of the current economic environment.

The Wisconsin ADA (Americans with Disabilities) Title II Plan – Phase I, dated January 2002, is a more comprehensive review of our assessment of the needs in Wisconsin. Our attempt to prioritize in the following recommendations does not in any way suggest that all of the funding needs identified in the ADA Plan are not important and valid. In fact, there are three areas that we believe will need attention, but upon which the Council has not yet agreed on any concrete plans to implement changes. These three areas are: the current workforce and financial crisis in nursing homes, Children's Long Term Care Redesign and Mental Health/AODA Redesign.

Recommendations

Family Care. The Council is convinced that Family Care is accomplishing the major goals agreed to by the wide array of stakeholders involved in the Long Term Care Redesign process. We have heard from state and local managers, Local Long Term Care Council members, and consumers about their experiences in Family Care and reviewed statistical data and evaluation reports. This evidence leads us to conclude that Family Care has resulted in:

- Greatly improved access. In contrast to the rest of the state, there are no waiting lists for covered populations in Family Care counties.
- Better outcomes for people. Family Care manages for quality based on how well people achieve the outcomes that they want in their own lives, and how well they are supported to achieve those outcomes.
- Real choices. Family Care members have choices about where they live and how they receive services. The comprehensiveness and flexibility of the benefit allows for creativity in meeting needs and equal access to long term care in all settings. Care Management Organizations have enough leverage to induce providers to develop all the services that their members need.
- Cost effective methods for providing care. Family Care has reduced the per-person cost of services, compared to Medicaid Waivers and card services. Fiscal incentives

are built into the system to control costs for primary, acute and long term care services.

- A comprehensive system. Family Care provides one flexible, comprehensive, care-managed benefit that replaces an array of separate programs and services in all long term care settings.
- Improved fairness and uniformity. Access, eligibility determination, covered services, and quality assurance and improvement methods are the same across Family Care sites.
- Stronger efforts to help people stay independent. Resource Centers provide information and consultation to help people make cost-effective long term care decisions before they spend down their own resources. Care Management Organizations focus on helping their members maintain and improve their functional ability. Both organizations focus on prevention and wellness efforts.

For these reasons, the Council strongly recommends that:

1. **Family Care should be made available to residents of the entire state by 2010.** This objective not only addresses the growing long term care need, but is also consistent with the ADA Title II Plan to assure that the legal rights of citizens with disabilities are met. The key is to expand in a thoughtful way and to not neglect the growing long term care need in counties not currently in Family Care pilot areas.
2. **In the 2003-05 Biennium, as first steps to this long-range goal, and to further strengthen the structure of Family Care:**
 - a) Expand Aging and Disability Resource Centers to additional counties. Currently, 15% of the Medicaid population lives in counties with an Aging and Disability Resource Center. It is economical and reasonable to increase that coverage to 23%, in at least 5 additional counties, by the end of the next biennium. Expansion should focus on those counties that are committed to bringing the Family Care benefit to county residents by 2007, either through establishing a Care Management Organization or through joining with an existing CMO.
 - b) Expand the availability of the Family Care benefit. Bring a Care Management Organization on line in Kenosha County by 2004. Further expand to cover at least 29% of the state's population, as currently authorized in statute, by January 2005 by expanding to additional counties and/or extending the benefit to younger adults with disabilities in Milwaukee County, where only those ages 60 or older are currently covered.
 - c) Remove the current statutory limitation on Family Care eligibility for people with developmental disabilities. Under current statute, people with developmental disabilities are eligible for Family Care only in counties where the benefit was available before July 1, 2001. People with developmental disabilities have benefited greatly from Family Care and should be eligible as it expands across the state.
 - d) Expand the target population of one of the existing Family Care Counties to include certain Mental Health and AODA clients. About 25% of all current Family Care members have mental health and/or alcohol or other drug abuse issues. Care Management Organizations thus have considerable experience, expertise and

responsibility for these issues. They believe that they could improve services for people, currently eligible for the Community Options Program, whose primary diagnosis is serious and persistent mental illness or chronic AODA issues and who need long term care. This recommendation would allow a pilot test of that expansion in one county.

- e) Improve the pre-admission consultation system. Aging and Disability Resource Centers report that the current requirements for facility referrals and Resource Center response are not working well to reach people in a timely way and provide them with real options. The Council has not yet studied this issue enough to know what solutions would work best, but urges the Department, in consultation with Family Care counties and facility-based providers, to propose improvements in these processes and statutory requirements.

- f) Strengthen the county role. The federal government requires that CMO services be competitively procured. Wisconsin's policies should be strengthened to assure that county officials and Local Long Term Care Councils are key players in deciding how Family Care will be implemented in their counties. The Council makes the following recommendations:
 - 1) The Department of Health and Family Services may not contract with any organization other than a tribe to operate a Care Management Organization without the explicit agreement of county officials and the Local Long Term Care Council unless an existing county CMO fails to meet certification standards or does not have the capacity to serve all county residents who are entitled to the Family Care benefit.
 - 2) In future expansion of Family Care, counties should be the preferred CMO providers because of their past experience, stability and accountability to the community, as long as they can meet all certification requirements.
 - 3) New CMOs should have sufficient time to establish operations and develop the capacity to serve all entitled residents of the service area before proposals for different or additional CMOs for the area are solicited.
 - 4) If a county chooses not to apply to operate a CMO directly, or does not meet certification requirements, the Department may, after receiving advice from the Local LTC Council(s) for the county(ies) in a proposed new CMO's service area, contract for CMO services with a not-for-profit, community-based organization, at least 25% of whose board of directors are reflective of the target populations of the proposed CMO.

Partnership Program. The Council believes that the Wisconsin Partnership model provides an excellent alternative to Family Care for a subset of the long term care population, particularly those who have complex medical needs. This model uses a person-centered approach to managing a fully comprehensive, capitated benefit that includes the whole range of primary, acute and long term care services. Currently, four pilot programs serve over 1200 elderly people and younger adults with physical disabilities in six counties. These cost-effective, care managed programs have demonstrated excellent outcomes for their enrollees.

1. The Council supports the proposal by the Department of Health and Family Services to provide sufficient funding to allow every eligible person in areas of the state where Partnership is available to join if he or she chooses to do so.
2. The Council recommends that the Department actively seek to expand the availability of Partnership to additional areas of the state.

Community Options Program and Medicaid Waiver Programs. Expansion of Family Care and Partnership to additional parts of the state will take time. Meanwhile, waiting lists for the Community Options Program (COP) and its related Medicaid Waiver programs continue to grow. In some counties, estimated waiting times for some target groups are decades long. In addition, some best practices in the Family Care pilots can be exported to other counties to strengthen COP and the Waivers.

1. The Council recommends that, at a minimum, sufficient funds be provided for COP and the Waiver programs to reduce waiting lists and to address demographic changes that will increase the need for these services.
2. The Council recommends that the Department encourage and assist counties to adopt the following features of Family Care that have proven beneficial:
 - a. Care planning and quality monitoring practices that are based on self-identified outcomes for participants.
 - b. Care planning by a team that includes a nurse.
 - c. Uniform, web-based training for those who administer the functional screen to determine eligibility.

Independent advocacy. Members of Family Care and Partnership have access to a confusing array of avenues for resolving complaints and problems. The absence of independent advocacy services in these managed care programs compromises the ability of enrollees to understand their rights and to resolve differences with their care managers in the choice and delivery of services. In addition, an opportunity is lost for the independent advocates to identify patterns of systemic problems that could assist state and local agencies to improve overall quality. A second issue is that the Ombudsman program in the Board on Aging and Long Term Care is available to help resolve problems for residents of most long term care facilities. However, this assistance is not available for residents of Residential Care Apartment Complexes.

1. The Council recommends that independent advocacy services be made available to both Family Care and Partnership enrollees.
2. The Council recommends that the authority of the Ombudsman be expanded to cover residents of Residential Care Apartment Complexes and that funding and position authority be provided to allow it to fulfill that function.

Budgeting for Long Term Care. Budgeting for long term care has previously been done in a piecemeal manner. Legislators and other policy makers were presented with many budget items on long term care programs and services and make these decisions separately, without benefit of seeing how these items fit into a big picture. Several other problems exist with respect to how these decisions are made. The Council recommends the following reforms to the state budget

process and related policies for long term care, and commends the Department of Health and Family Services for including some of these reforms in its 2003-05 biennial budget request dated November 15, 2002:

1. Present and decide on the wide range of long term care funding and policy issues as a whole, with a view toward improving the overall system over time.
2. Base budgets for COP and Waiver slots on the actual average costs of providing services.
3. Use the same decision-making process for determining annual rate increases for the Waivers as is used for other Medicaid non-institutional and nursing home providers.
4. Anticipate and budget costs for acute and primary health care services for newly Medicaid-eligible Waiver participants.
5. Budget prospectively for nursing home phase-down agreements.
6. Revise the Medicaid base re-estimate and Waiver budgeting methodologies to: assume no Waiver increase in base re-estimate (rather than implicitly assuming historical increase); and budget nursing home savings when Waiver funding is increased.
7. Better prepare for nursing home closings to maximize community placements.
8. Create incentives to promote resident relocations from nursing homes and ICFs-MR:
 - a. Change the bed banking policy by eliminating it or shortening the number of allowable “banked” years.
 - b. Provide the enhanced CIP-IB rate for each relocation from an ICF-MR.
 - c. Create an enhanced CIP-II rate and provide it for each relocation from a nursing home.

Support for proposals included in the Department of Health and Family Services’ biennial budget request. The Department’s 2003-05 biennial budget request dated November 15, 2002 contains several items for which the Council wishes to express its support. These include:

1. ICF-MR downsizing. This initiative would improve access to community based services for individuals with developmental disabilities and assist Intermediate Care Facilities for the Mentally Retarded (ICFs-MR) in streamlining their facilities. Under the proposal, funding for ICF-MR services or alternatives to them would be moved from the state to the county level.
2. Nursing home downsizing. This initiative would improve access to community based services for elderly, physically disabled and brain injured nursing home residents wishing to relocate to the community and assist nursing homes interested in streamlining their facilities.

3. Consumer directed personal care. This proposed pilot program would allow some Medicaid recipients of personal care services to hire and schedule their own personal care workers.
4. Children's long term care redesign. This proposal would implement a new Medicaid waiver that offers family centered services and a single entry point for eligibility determination.
5. Mental health/AODA redesign. This proposal would provide support to implement pilots of a redesigned system for the management and delivery of mental health services and alcohol and other drug abuse services.
6. CIP IA rate. This proposal would increase the rate in the Community Integration Program (CIP IA), enabling the relocation of more residents of the State Centers for the Developmentally Disabled. Funds would be transferred from the budget for the Centers.

Related issues. Although the Council has not studied them thoroughly enough as yet to make specific recommendations, we do urge that sustained and focused attention be given by the State to several pressing issues that impact on our ability to provide needed long term care to our elderly and disabled citizens.

1. Workforce. Prolonged high employment rates in the state have contributed to a serious shortage of direct care workers in all long-term care services and settings. Turnover in many facilities is as high as 100 percent, and turnover among home care workers is often at least 50 percent annually. A stable, well-trained and caring workforce is the backbone of the long term care system, and shortages affect consumers, providers and workers. The workforce issue will become increasingly difficult as elderly age groups grow far more rapidly than those of working age during the coming decades. The Governor's Health Workforce Shortage Committee recently made a number of recommendations in this area and several other efforts are underway.
2. Affordable and Accessible Housing. People cannot receive services in the community unless they have an affordable place to live. For people with physical limitations, housing must also be physically accessible. Many areas have waiting lists for Section 8 vouchers or have little accessible and affordable housing available. Housing delays make it difficult to develop a plan for newly enrolled individuals and create frustration for community agencies working on relocations.
3. Nursing homes. Many nursing homes in Wisconsin are in financial difficulty, largely because of inadequate Medicaid reimbursement. Without sufficient funds to pay direct care workers a living wage, they have great difficulty maintaining a stable and qualified staff, which in turn affects their ability to provide high quality care. The goal of the State must be to find the right distribution of nursing home capacity across the state, and then to adequately fund nursing homes to provide high quality care.

Planned areas of focus for 2003

During 2003, the Council plans to focus on several areas of concern:

1. Continued monitoring of progress toward a redesigned long term care system, including Family Care, children's long term care redesign, and the redesign of the mental health/AODA system.
2. Improving communication and support for Local Long Term Care Councils.
3. Oversight of implementation of key recommendations developed by the Council's ADA Title II Committee and adopted by the Council, including:
 - a. Review of the status of each person in an institution, including an improved WATTS review
 - b. Full development of timely discharge planning
 - c. Development of ADA Title II training materials
 - d. Institution of pre-admission counseling and screening statewide
 - e. Expansion of funding for community services as an alternative to institutions
 - f. Amendment of any state law that conflicts with ADA Title II
 - g. Expansion of the personal care benefit under the State Medicaid plan and pursuit of Medicaid waivers to provide maximum flexibility, including consumer directed services
 - h. Monitoring and guidance of the use of newly available funds to implement the Committee's Phase I and Phase 2 plan recommendations
 - i. Restructuring the State's budgeting process for long term care
4. Long term care workforce issues, especially the acute shortage of direct care workers.
5. The shortage of affordable and accessible housing in many parts of the state.
6. Assisted living issues, including trends in the development of community based residential facilities, adult family homes, and residential care apartment complexes, and issues related to affordability, regulatory and program requirements and statutory definitions.
7. Nursing home closings and financial difficulties.
8. Transportation issues as they relate to long term care.
9. Employment issues for younger adults with disabilities.

The Council's Charge, September 28, 2001

It's important for the Department of Health and Family Services to have the advice of consumers, providers and the public in the important policy decisions that need to be made. The Council on Long Term Care is appointed to be the key advisors to the Secretary on the overall long term care system. The challenge for the Council is to provide the Secretary with advice on how we can accomplish the goal of turning our current long term care system into one that focuses on community living whenever possible within the resources available to the Department.

The Council will be responsible for the following:

Family Care Monitoring and Oversight

- Monitor the progress of the Family Care pilots.
- Evaluate the progress of the pilots on whether they are accomplishing the goals of Family Care and Long Term Care redesign, starting from a neutral stance that does not assume Family Care is the answer to all the long term care issues in the state.
- Analyze whether or not Family Care is an affordable option for the future.

Long Term Care System Monitoring and Oversight

- Serve as the overarching advisory group that will review the long term care system as a whole. In particular, the Department will be looking to the Council for advice on how to structure changes in the long term care system in an affordable manner, with special attention to how the various long term care programs intersect. People often do not fit neatly into one category or another and may need to transition from one system to another. All the systems need to work together and the Council is to monitor how that is happening.
- Review and monitor the progress of the Children's Long Term Support Redesign and issues affecting children as well as adults that need long term support.
- Review and monitor the progress of the Mental Health/AODA Managed Care pilots and the mental health system in the state.
- Provide advice as to how well the various components of the systems are integrated. The Department has received excellent input from the Blue Ribbon Commission on Mental Health Implementation Committee as well as from the Children's Long Term Support Redesign Committee and will continue to receive their advice. However, it is important for the Secretary to have one body that integrates the various pilots and proposals for long term care systems change.
- Identify the current unmet need for long term care services and develop recommendations to the Secretary on how to address the challenge of serving individuals in the most integrated setting appropriate to their needs. The Council will involve key stakeholders in an evaluation of the current long term care system and how it can be improved to assure the state continues to meet the requirements of the ADA T.II and recent court decisions that clarify the state's responsibilities. Where the courts haven't provided clarity, advise the Department on your ideas for the best approach for Wisconsin.

- A particular challenge will be to advise the Secretary on how to accomplish the goal of turning our current long term care system into one that focuses on community living whenever possible and to do so within the challenging state fiscal environment. The Council will help the Department prioritize the unmet needs in the area of long term care within the resources provided to the Department, as well as ideas on how we can use the current state resources to generate additional federal revenue to meet those needs.
- Investigate and analyze why Wisconsin spends so much more on community based long term care, compared to other states, and yet has such long waiting lists for the Community Options and the Home and Community Based Waiver programs. How are the systems in those states different from Wisconsin?
- Investigate the major emerging issues in long term care. How can the Department better promote prevention efforts for the population in order to reduce the burden of long term care in the future? How can Wisconsin better support the families who make extraordinary sacrifices of time, opportunities and money to care for a frail parent, spouse, or child with a disability?

Vehicle for Stakeholder Input

A seventeen-member group is still too small to have all the long term care stakeholders at the table. For this reason, the Council will need to tap into the other state councils and committees that work on issues related to long term care. This group may also want to make use of a number of other vehicles to get increased representation of the many voices of the long term care stakeholders in Wisconsin. This could include adding subcommittee members to address areas where additional expertise is needed, sponsorship of community forums or focus groups, and getting input from the Local Long Term Care Councils. The Council members are asked to be a resource and link to other stakeholders and groups.

Council Duties

Specifically, the Council will be responsible for reviewing and commenting on the following:

- The development of future contracts with the Family Care Resource Centers and Care Management Organizations (CMOs).
- The Family Care benefit package and rate structure.
- The patterns of enrollment and disenrollment from Family Care, Partnership, PACE, COP and the Waivers as well as the Medicaid fee-for-service programs.
- The quality of the long term care system, including complaints, grievances and appeals related to Family Care, as well as other long term care services and programs.
- The development and implementation of the Children's Long Term Support Redesign and the children's waiver and how it will fit into the overall long term care system in Wisconsin.
- The development and implementation of the Mental Health and AODA pilots and how they fit into the overall long term care system in Wisconsin.
- Workforce strategies for addressing the workforce issues in long term care.
- Future budget proposals for long term care programs and services.

In addition to advice on policies, the Council will:

- Serve as a conduit for input from and support to the local long term care councils.

- Evaluate the progress and affordability of Family Care in light of the current fiscal realities of the state budget.
- Monitor the overall long term care system.
- Develop recommendations for system improvements to ensure that older people and people with disabilities are served in the most integrated setting appropriate to their needs.
- Recognizing that the demographic bulge of baby boomers are entering their retirement years, review how the current system supports prevention of long term care, as well as the informal caregivers who are the backbone of the long term care system.
- Produce an annual report to the Secretary on the key findings of the Council.

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