

**Evaluation Report to the
Centers for Medicare and Medicaid Services**

Wisconsin Comprehensive Systems Change Grant

No. 11-P-92498/5-01

December 2008

Submitted by

APS Healthcare

10 East Doty Street

Suite 210

Madison WI 53703

608-258-3350



APS Healthcare Evaluation Team Members

Ruthanne M. Landsness, MA, Project Manager

rlandsness@apshealthcare.com

Reed Bonner, MM

rbonner@apshealthcare.com

Scott E. Coley, MS, MPH

scoley@apshealthcare.com

Heather Goldberg, MA

hgoldberg@apshealthcare.com

Bob Kinderman, MSW

bkinderman@apshealthcare.com

Scott Orme, PhD

sorme@apshealthcare.com

Renee Railey, MPH

rrailey@apshealthcare.com

Boni Westover, MSPH

bwestover@apshealthcare.com

The authors gratefully acknowledge Kathleen Luedtke, Wisconsin DHS Project Manager, the many State and county planners, and Wisconsin consumers and stakeholders who provided information for this report.

Table of Contents

Executive Summary

I. INTRODUCTION	I:1
II. BACKGROUND	II:4
III. METHODOLOGY	III:5
A. Document review	III:5
B. State Interviews	III:5
C. Evaluation Plan	III:5
D. Mixed Methods	III:6
E. Surveys	III:6
F. Stakeholder Interviews (Individual & Group)	III:9
IV. STRATEGIC PLANNING FOR STATEWIDE IMPLEMENTATION	IV:11
A. Background	IV:11
B. Setting the Tone – The Council on Long-Term Care	IV:11
C. State Outreach Strategies and Secretarial Leadership	IV:13
D. Individual County and Consortia Planning	IV:17
E. County and Consortia Planning – Lessons Learned	IV:19
F. Family Care High Level Program Elements	IV:30
V. THE ROLE OF STAKEHOLDERS IN LONG-TERM CARE PLANNING	V:37
A. History of Consumer and Stakeholder Involvement in Wisconsin	V:37
B. Consortia Outreach to Consumers	V:37
C. The Consumer Perspective of the Planning Process	V:40
D. Consumer Involvement from a Non-Consumer Perspective	V:44

E.	Advocacy Presence and Views	V:45
F.	Variation among Consortia	V:46
G.	Other Stakeholder Involvement in the Planning Process	V:47
H.	Conclusion – Consumer and Stakeholder Involvement	V:54
VI.	IMPROVING CONSUMER ACCESS TO INFORMATION	VI:55
A.	Virtual Resource Center and Information Campaign	VI:55
B.	Aging and Disability Resource Centers	VI:56
C.	Evidence-based Prevention and Early Intervention Strategies	VI:71
VII.	LONG-TERM CARE SYSTEM ACCESS	VII:73
A.	Background	VII:73
B.	Ending Wait Lists in Wisconsin	VII:73
C.	The Wisconsin Long-Term Care Functional Screen (LTC FS)	VII:75
D.	Conclusion	VII:82
VIII.	INCREASING SERVICE OPTIONS WITHIN THE CONTEXT OF LONG-TERM CARE REFORM	VIII:84
A.	Background	VIII:84
B.	Institutional Care in Wisconsin, Background and Trends	VIII:84
C.	Relocation Initiatives	VIII:87
D.	Relocation Stories	VIII:89
E.	Culture Change and Repositioning the Wisconsin Nursing Home Industry	VIII:91
F.	Self-Directed Supports	VIII:94
G.	Workforce	VIII:100
H.	Conclusion	VIII:103
IX.	QUALITY AND COST	IX:104

A. Background	IX:104
B. Quality and the ADRCs	IX:104
C. Regional Advisory Committees	IX:111
D. PEONIES	IX:112
E. Consumer Perception of MCO Quality	IX:115
F. Cost Strategies	IX:123
G. Conclusion	IX:126
X. REFERENCES	X:128
XI. SOURCES CONSULTED-BIBLIOGRAPHY	XI:139
XII. APPENDICES	XII:139

List of Tables and Figures

Table 1.	Areas of Inquiry for Each County Cohort.....	6
Figure 1.	Stakeholder Survey Respondent by Planning Role.....	7
Figure 2.	Implementation Map	28
Figure 3.	Wisconsin ADRCs.....	31
Figure 4.	Family Care Benefit.....	33
Figure 5.	Family Care Partnership Benefit	33
Figure 6.	Percentage of Consumers Aware of Planning Meetings Prior to Survey	40
Figure 7.	Sources of Planning Meeting Information.....	41
Figure 8.	Frequency of Participation in Planning Meetings.....	42
Figure 9.	Reasons for Non-Attendance at Planning Meetings.....	43
Figure 10.	Beginning of Involvement with the LTC Planning Process	47
Figure 11.	Extent to Which People Listened in Planning Meetings	48
Figure 12.	Impact of Planning Meetings on Quality of Life for LTC Consumers.....	49
Figure 13.	Percentage of Stakeholders Willing to Participate in Planning Process Again	50
Figure 14.	Balance of ADRC Activities.....	62
Figure 15.	Reasons Given for Contacting ADRCs (by percentage).....	65
Figure 16.	ICF/MR DD Residents– 1999-2007	83
Figure 17.	Number of Wisconsin Nursing Home Beds – 1995-2007	84
Figure 18.	Community-Based LTC & Nursing Home Utilization – 1995-2005	85
Figure 19.	Relocations from Institutions to Community Setting under DHS Programs.....	86
Figure 20.	SDS Choices in Family Care Expansion	94
Figure 21.	Expected Increase in the Number of Persons Aged 65+ & Women Aged 25-54 in WI – 2005-2030	99
Figure 22.	Percentage of Consumers Who Would Contact the Following with Disability- Related or Long-Lasting Health Problem Question.....	103
Figure 23.	Percentage of Consumers in Each Consumer Group Who Had Previously Heard of ADRCs.....	104
Figure 24.	Percentage of Consumers Who Heard of ADRCs and Contacted One	104
Figure 25.	Extent to Which ADRC Staff Were Perceived to be Listening Carefully by Consumers.....	105
Figure 26.	Extent to Which ADRC Staff Were Perceived to be Listening Carefully by Consumers.....	106
Figure 27.	Percentage of Consumers Who Would Recommend their ADRC to a Friend of Relative	107
Figure 28.	Percentage of Members Who Indicated Having an IDT	113
Figure 29.	Percentage of Members Satisfied With Amount of Input	114
Figure 30.	Effect of Family Care/Partnership on Consumer Perceived Quality of Care	115
Figure 31.	Effect of Family Care/Partnership on Consumer Perceived Quality of Care by Elderly and Non-Elderly Respondents.....	116
Figure 32.	Effect of Family Care/Partnership on Consumer Perceived Quality of Care by Respondents from Family Care Expansion and Family Care Pilot Counties.....	116
Figure 33.	Frequency that Respondents to PACE/Partnership Survey Felt They Were Treated With Respect by Their Team	117
Figure 34.	Percentage of Consumer Survey Respondents Who Would Recommend Their MCO to a Friend or Relative in Need of LTC Services	118

List of Appendices

Appendix A: Grant Proposal Work Plan

Appendix B: Conceptual Framework and Research Questions of the Evaluation Study

Appendix C: Family Care Expansion Counties Survey

Appendix D: Family Care Pilot Counties Survey

Appendix E: ADRC-Only Counties Survey

Appendix F: Consumer Survey Cover Letter – First Mailing

Appendix G: Consumer Survey Cover Letter – Second Mailing

Appendix H: APS E-mail Message Announcing Online Stakeholder Survey

Appendix I: Online Stakeholder Survey

Appendix J: Individual and Group Interview Guide

Appendix K: Respect Guiding Principles

Appendix L: Quality Framework

Appendix M: Grant 4-Year Budget Actuals as of 7-16-08

Appendix N: Acronyms

Executive Summary

The purpose of this report is to describe the outcomes of the Wisconsin Comprehensive System Change Grant awarded to the Wisconsin Department of Health and Family Services on October 1, 2004. The report tells the story of how the State of Wisconsin maintained a consumer-centered approach while expanding a managed care long-term care system within a historically county-based State.

The Wisconsin CMS Comprehensive Systems Change Grant outlines five major goals:

1. Conduct strategic planning for statewide implementation of long-term care reform;
2. Improve citizen access to information;
3. Develop tools to manage access to the long-term care system;
4. Develop systems and processes that will enhance the availability of service options; and
5. Develop strategies to improve the quality, consistency and cost-effectiveness of LTC services in Wisconsin.

This report heralds the extraordinary accomplishments of the Wisconsin Department of Health Services in each of these areas. Through planning and implementation activities funded by the grant, as of November 2008, Wisconsin:

- Eliminated long-term care wait lists in 6 counties;
- Developed a strategic vision and a plan to reform long-term care systems, that will eliminate waiting lists statewide, create a network of statewide Aging and Disability Resource Centers and use managed care to provide comprehensive, person-centered services to all who are eligible.
- Increased the number of Aging and Disability Centers from 9 to 28;
- Contracted with ten managed care organizations (MCOs) for long-term care services;
- Enrolled 21,620 members in long-term care MCOs;

- Developed and implemented tools to ensure consistency of service eligibility throughout the State; and
- Implemented a fee-for-service self-directed supports waiver (IRIS) as an alternative to managed long-term care.

The challenge of the long-term care reform strategy was to transition the 25-year old patchwork of county-based fee-for-service Medicaid long-term care benefits to an integrated managed care system. This transition required a paradigm shift in the thinking of policy-makers, stakeholders, and consumers, a shift from services to outcomes, and prompted a set of policies and procedures and far-reaching changes in the relationship between counties and between counties and the State.

Setting the tone for the transition was the Wisconsin Council on Long-Term Care, the oversight body of the grant and the advisory body to the DHS Secretary. The tone was one of collaboration and inclusivity, embodied by a set of consumer-centered principles that guided the entire work of the grant. The Council had many subcommittees that contributed to reform efforts statewide. The State implemented several outreach strategies to encourage consumer and stakeholder input. Primary among these was the Consumer Training Corps, a collaboration of Wisconsin advocacy groups and Wisconsin DHS. The work of the Consumer Training Corps was complemented by that of the University of Wisconsin Extension staff, who proved themselves gifted at hands-on assistance with planning.

Another significant factor in leadership of the planning effort was the intense involvement of the DHS Secretary who provided credibility and legitimacy to the reform effort to uneasy county officials. As a result of the planning process, long-term care delivery underwent a dramatic transition from individual counties to multi-county consortia and non-profit managed care organizations that took on the financial risk of the managed care organization.

The evaluation team conducted 26 interviews with stakeholders. Based on these interviews, the team drew 12 Lessons Learned. The data from the interviews is presented in this form in particular as items for consideration by other states who may be considering a similar effort.

Wisconsin has a long and lauded history of integrating consumer participation and choice into community-based, long-term care. During the grant period, Wisconsin continued its rich history of consumer and stakeholder participation during its long-term care reform process. A vast array of strategies were employed to ensure consumer

input, substantiated by data from the consumer and stakeholder surveys conducted by the evaluation team. There was a wide range of views as to the success of these strategies, particularly from the point of view of advocates, and lessons learned were drawn from consumer and stakeholders interviews. Perhaps most important among them: “Early and continuing education was a must in order to ensure knowledgeable and consistent participation from consumers.”

The expansion of Aging and Disability Resource Centers (ADRCs) is a Wisconsin success story. One of the major accomplishments of the ADRC planning process was the development of statewide ADRC policies and procedures and a clearly articulated ADRC contract. The end result of the planning during the grant period was the increase in the number of centers from 9 to 28. The resource centers have become visible and trusted one-stop shops for long-term care information and assistance.

An issue that arose during the expansion effort was that of maintaining the organizational separation between resource centers and MCOs to ensure independence and avoid conflict of interest. The State developed policies designed to avoid this issue, and ADRC and MCO staff employ strategies to resolve it when it arises. A complementary issue was inherent in the interdependency of the two organizations in the sense that the expansion of the managed care organizations initially created heavy work loads for ADRC staff performing enrollment consultation and enrollment-related functions. This overshadowed the information and assistance function of the ADRC. The State addressed this problem through a staggered enrollment policy. However, the issue underlines the degree to which ADRCs must be given the latitude to fulfill their mission as community resources and that mission must be kept in balance with the need to serve as the access point to managed long-term care services.

The stellar accomplishment at the heart of Wisconsin long-term care reform is the elimination of wait lists. To date, 6 counties have eliminated their wait list with several others currently in the process of enrolling individuals from the wait list into managed care organizations. There were impressive advances made during the grant period to ensure equal access to long-term care services through application of the long-term care functional screen. The screen received several technical upgrades and was expanded into new service areas as a direct result of CSC grant funding.

Several functional screen issues arose during interviews, such as implications of the standardization of functional eligibility, training to ensure consistency and accuracy, and how discrepancies between ADRC and MCO determinations are handled. Despite

issues related to screen advancements, it was clear from interviews that a spirit of collaboration and innovation guided the development of the screen since its inception. Plans for future adaptation of the screen to determination of level of care in nursing homes forecasts the time when the long-term care functional screen will provide consistency throughout all Wisconsin long-term support programs and options. Wisconsin DHS met and exceeded the grant objectives related to the improvement and expansion of functional screen capabilities.

Another goal crucial to the long-term care reform effort was to increase the availability of service options, especially as it relates to the balance between institutional and community-based care. Access to and utilization of home and community-based services for long-term care is increasing in Wisconsin, while the role of institutions is changing to meet new demands. As a way of highlighting the changes during the systems change grant period, the report compares information provided in the project narrative of the grant proposal with updated statistics. As part of the rebalancing effort, the State coordinated funds from the CSC grant with that of "Money Follows the Person" funds to develop and sustain relocation initiatives. An outcome of the rebalancing effort is that, on November 19, 2008, the number of licensed and certified assisted living beds surpassed the number of nursing home beds in the State for the first time (38,775 beds compared to 38,679 nursing home beds).

The State also developed strategies to reposition Wisconsin's nursing home industry and encourage adoption of the culture change model. Wisconsin DHS achievements can be grouped into five major areas: a) access data; b) acuity-based payment system; c) quality measures; d) private sector restructuring; and e) property allowance incentives. Successes in these areas are testimony to the collaboration between DHS and the nursing home industry during the grant period.

Wisconsin developed and implemented a CMS-required, fee-for-service, self-directed supports option called IRIS during the grant period. Stakeholder interviews confirmed that support for SDS is strong, despite apprehensions expressed especially by DD advocates, and that the State has successfully addressed initial implementation and training issues.

It was clear from the Wisconsin grant proposal that the State recognized workforce recruitment and retention as significant issues. However, the grant objectives and tasks in this area were challenged when staff and funding were redirected to other expansion efforts. Workforce challenges remain as a major issue in Wisconsin's long-term care

system. With the exception of this area, the State was successful in meeting its stated objectives in regards to system level change in the area of service delivery options.

The final goal of the CSC grant focused on quality and cost. Objectives of this goal addressed measuring ADRC quality, support and training of local advisory groups, implementation of performance monitoring of consumer outcomes, and improvement in the capacity to collect and use information. The report chronicles the data collection issues of the ADRCs, and the development of the PEONIES tool to identify and assess Personal Experience Outcomes of consumers by the CMOs. Multiple surveys confirmed the consistently high level of consumer satisfaction with both the ADRCs and CMOs.

Cost concerns emerged as a major issue in stakeholder interviews and survey responses, and were consistently high on the radar of both the State and counties since the inception of Family Care. Transitioning to a carefully-conceptualized “franchise model” is designed to address these concerns, especially those related to IT. Cost concerns have been exacerbated by the nationwide economic downturn and State budget woes. The commitment by State and the long-term care managed care organizations to the operational and financial success of the program will be tested during the next few years. The state level commitment to taking reform statewide is strong, but the expansion of the program may be slowed some due to current budget constraints. Nevertheless, the successes of the effort thus far are testimony to the dedication, perseverance, and leadership of Wisconsin DHS, counties, advocacy organizations and provider agencies. These characteristics will no doubt carry them through the highs and lows of further expansion.

In conclusion, this report confirms that, with few exceptions, Wisconsin DHS met and exceeded the goals and objectives of the CMS Comprehensive Systems Change Grant.

I. Introduction

The purpose of this report is to describe the outcomes of the Wisconsin Comprehensive System Change Grant awarded to the Wisconsin Department of Health and Family Services on October 1, 2004. (The Department of Health and Family Services is now referred to as the Department of Health Services (DHS) due to a name change in July of 2008.) The evaluation study that is the basis of this report was conducted by APS Healthcare (APS), a leading, national specialty healthcare company based in Madison, Wisconsin.

This report tells the story of how the State of Wisconsin maintained a consumer-centered approach while expanding a managed care long-term care (LTC) system within a historically county-based State. Through planning and implementation activities funded by the grant, as of November 2008, Wisconsin:

- Eliminated long-term care waiting lists in 6 counties;
- Developed a strategic vision and a plan to reform Wisconsin's statewide long-term care system that will eliminate waiting lists, create a statewide network of Aging and Disability Resource Centers and use managed care to provide comprehensive, person-centered services to all who are eligible.
- Increased the number of Aging and Disability Resource Centers (ADRCs) from 9 to 28, which serve 38 of Wisconsin's 72 counties and provide services to 2/3 of the Wisconsin population over age 18;
- Contracted with ten managed care organizations (MCOs) for long-term care services;
- Enrolled 21,620 members in managed care organizations¹; and
- Developed and implemented tools to ensure consistency of service eligibility throughout the State.^{2,3}
- Implemented a fee-for-service self-directed supports waiver (IRIS) as an alternative to managed long-term care.

This report focuses on the core issues of access, choice, quality, and cost-effectiveness, and is presented in nine chapters plus references, bibliography, and appendices. Each chapter is self-contained and includes the following:

- I. Introduction – presents an outline of the report;
- II. Background – presents historical information surrounding long-term care in WI;
- III. Methodology – describes the mixed methods study design;
- IV. Strategic Planning for Statewide Implementation – describes the role of State and Secretarial leadership in the planning process, lessons learned in the local design and development of the managed care organizations, and high level Family Care program elements;
- V. The Role of Stakeholders in Long-Term Care Planning – describes the consumer and stakeholder involvement strategies of the State and counties, and the consumer and stakeholder perspective of the planning process;
- VI. Improving Consumer Access to Information – presents an in-depth look at the Aging and Disability Resource Centers, their development challenges and successes;
- VII. Long-Term Care System Access – presents the story behind the elimination of wait lists and the advances in the application of the long-term care functional screen;
- VIII. Increasing Service Options within the Context of Long-Term Care Reform – describes the cultural shift from institutional to community level care, relocation initiatives, managed care and fee-for-service self-directed supports, and workforce issues;
- IX. Quality and Cost – presents data on consumer perceptions of ADRC and MCO quality, and a brief look at Family Care cost issues;
- X. References.
- XI. Sources Cited – Bibliography.
- XII. Appendices

The report frequently references the work plan with the goals and objectives of the original grant proposal. This work plan is included as Appendix A.

II. Background

The building blocks of the Wisconsin long-term care system are grounded in the values of the Wisconsin Community Options Program (COP). This highly respected State-funded community-based program was one of the first in the nation to demonstrate flexible funding for social supports as an alternative to nursing home placement. The program led to the development of six community-based waivers in Wisconsin. The challenge of the long-term care reform strategy was to transition the 25-year old patchwork of county-operated fee-for-service Medicaid long-term care benefits to an integrated managed care system that combined all Medicaid long-term care fee-for-service benefits with long-term care waiver services. This transition required a paradigm shift in the thinking of policy-makers, stakeholders, and consumers, a shift from services to outcomes, and prompted a new set of policies and procedures and far-reaching changes in the relationship between counties and between counties and the State. It also forced collaboration between two powerful yet previously separately-funded worlds: aging and long-term care.

Wisconsin spent nearly a decade prior to the systems change grant developing and pilot testing a comprehensive long-term care reform strategy. Several years were spent in a thorough examination of the system and development of pilot programs that used managed care strategies to improve access, broaden consumer choice, enhance quality, and improve cost-effectiveness. Early implementation of the Program for All Inclusive Care for the Elderly (PACE) program (1985 - current), Partnership Program (1996 - current), and Family Care pilots (2000 - current) are evidence of these efforts.^{1,2}

The original purpose of the systems change grant was to translate lessons learned from the pilot programs to strategic planning for comprehensive, long-term care system reform statewide. However, the purpose of State strategic planning changed dramatically when, in January 2005, the Governor of Wisconsin announced that the implementation, not the planning, of these reform efforts was to be the hallmark of the next four years of his administration. That announcement and the ensuing directive changed the focus of the systems change grant, increasing the pace of some activities while decreasing the emphasis of others. These specific changes are noted in the appropriate sections of the report.

III. Methodology

The methodology employed in this study was one of mixed methods preceded by formative research to guide the development of the overall study. While formative research is traditionally viewed as a method for informing program or intervention design, extending its use to this particular evaluation study was relevant because of the way the APS evaluation team conducted and compiled data to inform the design of the comprehensive systems change (CSC) grant evaluation study. Both document review and interviews with Wisconsin DHS staff were conducted to help inform the design of the CSC grant evaluation study.

A. Document review

The APS evaluation team reviewed more than 100 historical and current hardcopy documents and websites to provide insight into the history, current status, and potential plans, of long-term care services in Wisconsin. Documents included grant proposals, meeting minutes, reports, presentations, work plans, memoranda of understanding, and much more. Documents were reviewed and categorized according to topic areas, types of documents, and the intended audience for the material. They were then rated according to usefulness for informing study design. The document review proved particularly useful as the team developed the research questions of the study.

B. State Interviews

Simultaneous with document review, APS staff conducted 17 interviews with State of Wisconsin staff involved in the long-term care planning process. The bulk of the interviews were conducted by two APS team members with extensive experience in long-term care. Interviews were informal, yet sought to help define exactly what the most important research questions were to ask in the evaluation of the grant. Many interviewees suggested documents and websites that would bolster understanding of the history and future of long-term care in Wisconsin. At the same time, APS interviewers were able to use the information gleaned from document review to query the interviewees and gain greater insight into the secondary data documents that would be helpful in preparing a comprehensive evaluation report.

C. Evaluation Plan

Information gleaned from document review and interviews with Wisconsin DHS State long-term care staff helped the APS evaluation team identify areas of inquiry most

important for meeting the reporting specifications of the Centers for Medicare and Medicaid Services (CMS), as well as providing in-depth insight into the comprehensive State planning process. Five overall study objectives were articulated with 19 specific research questions. The objectives set forth in the evaluation plan were consistent with those in the original grant proposal to CMS. An evaluation plan overview with the conceptual framework and research questions of the study was prepared and submitted to the State for CMS review (Appendix B).

D. Mixed Methods

Following the development of the evaluation plan, the APS team determined the most appropriate study design to address each objective and research question. A mixed methods design was determined to be the best fit for collecting information from a large number and variety of stakeholders around the State, as well as for garnering in-depth information about their personal experiences. The APS team determined that quantitative instruments and data would help to best answer questions about the number of persons, services, and fiscal issues of the effort, while qualitative data from interviews and group discussions would inform an understanding of the process of long-term care reform, the relationships between individuals and entities, and the challenges and lessons learned during the planning process. Therefore, in this report, mixed methods design, quantitative and qualitative data collection instruments, analyses, and the triangulation of quantitative and qualitative findings in reporting, converge to present a rich “story” of the data and personal experiences of the State and its stakeholders. To this end, based on information gathered from document review, State interviews, and the evaluation plan, a series of surveys and a combined interview/group discussion instrument were developed.

E. Surveys

1. Consumer Surveys

A series of three consumer surveys were developed to elicit the views of long-term care consumers in publicly-funded LTC programs. The surveys were mailed to randomly selected consumers of three different county cohorts: 1) Family Care expansion counties (counties that had initiated a Family Care program following grant funding; 2) Family Care pilot counties (pre-grant award Family Care pilot counties); and ADRC-only counties (counties that had not implemented Family Care, but had functioning ADRCs (Appendixes C, D, E). The surveys contained questions on consumer satisfaction with the long-term care planning process, Family Care and Partnership organizations,

ADRCs, and self-directed supports. Table 1 summarizes the areas of inquiry covered in each of the three consumer surveys.

Table 1. Areas of Inquiry for Each County Cohort

Area of Inquiry	County Cohorts		
	FC Expansion	FC Pilot	ADRC Only
Long-Term Care Planning	X		X
Managed Care and Partnership	X	X	
Aging & Disability Resource Centers	X	X	X
Self-Directed Supports	X	X	X

The APS team conducted two mailings for each survey. Each mailing contained the survey and a cover letter, and was mailed through the US Postal Service. The first mailing was sent August 29, 2008 (Appendix F). A second copy of the original survey and a new cover letter (Appendix G) were sent September 30, 2008, to those who had not yet responded. No survey responses were accepted after October 21, 2008. A total of 1,395 surveys were completed and returned, with response rates of 46% from expansion counties (409 surveys), 41% from pilot counties (462 surveys) and 52% from ADRC only counties (524 surveys), yielding an overall response rate of 47%.

Statistical significance testing was done with chi-square tests for the three survey groups on each survey question. Age and county of residence information was obtained from eligibility records and grouped consumers into elderly (all Milwaukee consumers, and 65 and older for all other counties) and non-elderly (under 65 years of age for all counties except Milwaukee, composed of physically and developmentally disabled individuals). ANOVA tests were done to determine whether differences between survey groups were dependent on the functional eligibility status, defined here as elderly and non-elderly.

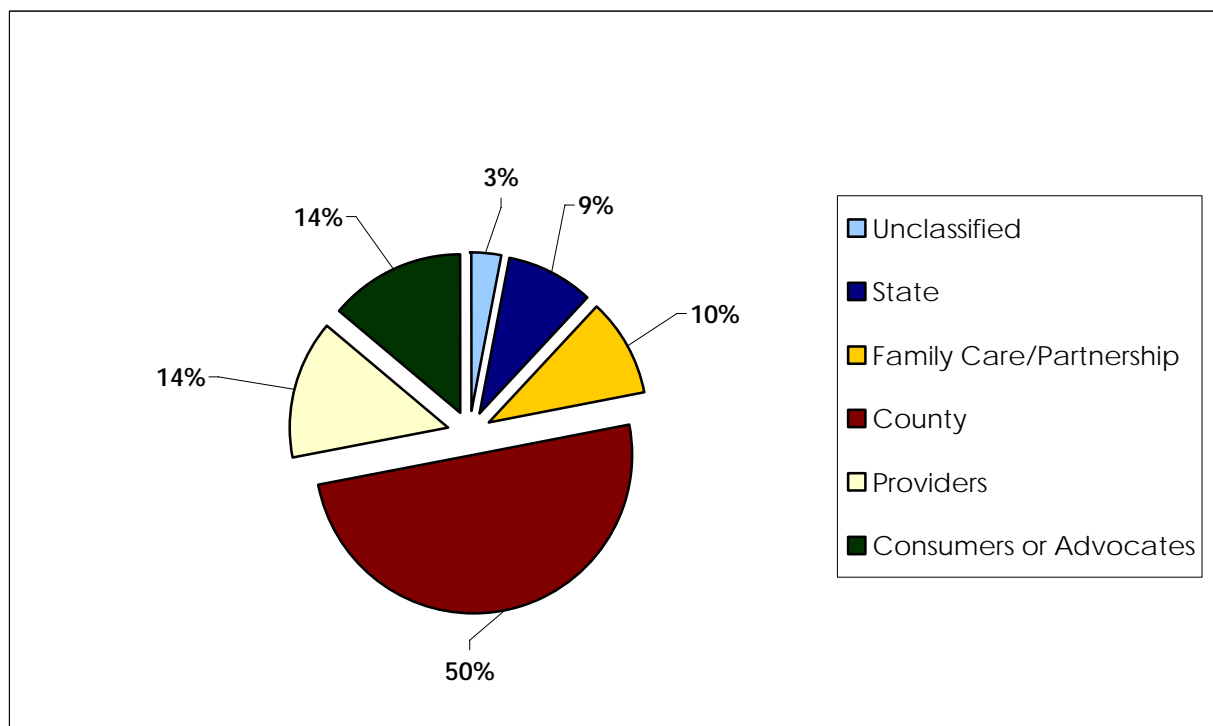
2. Stakeholder Survey

In addition to the consumer surveys, an online survey was developed and distributed to stakeholders in the LTC planning process. Over 1,000 individual e-mail addresses were compiled through document review, websites, and

requests for stakeholder contact information from key contacts. An email containing a hyperlink to the survey was sent directly to this stakeholder list and to recipients of the “Expanding Managed LTC in WI Listserv” administered by Wisconsin DHS. The email contained a request to complete the survey and to forward the email and link to others involved in long-term care planning. Undeliverable e-mail messages resulting from the direct e-mail were investigated and, if found, the survey hyperlink was sent to an updated address. Appendix H contains the email announcing the survey, and Appendix I contains screen shots of the online survey instrument.

A total of 446 individuals completed the survey, 280 of whom had participated in the long-term care planning process. For analysis purposes, participant-defined roles in the planning process were collapsed into five major categories - consumers or advocates, county, Family Care/Partnership organizations, providers, and State. These five groups encompassed all but seven respondents who did not fall into a category. Figure 1 shows the percentage of stakeholder survey respondents from each group.

Figure 1. Stakeholder Survey Respondents by Planning Role (n=280)



Statistical tests were done using chi-square and Fisher tests for independence on all relevant questions. A series of six questions with four-point Likert scales were administered to rate importance, the extent of discussion and the likelihood that discussions would lead to positive program outcomes. In an effort to control for response bias among groups of respondents, the point scores chosen by each respondent were standardized by dividing each score by the average of scores given by the same individual for that question type. T-tests were run to assess relative views by planning role on importance, discussion and perception of positive program outcomes raised in each question. A second series of questions measured participants' views of long-term care reform before and after participation in the planning process. The sign test was used to test for statistical significance of changes in opinion for each of the five stakeholder planning roles.

F. Stakeholder Interviews (Individual & Group)

A series of eight open-ended questions were developed and administered in both group and one-on-one interview settings to a variety of individuals and groups identified by the State as having been important and involved in the long-term care planning process. Interviewees included MCO directors and staff, ADRC directors and staff, case managers, advocates, consumers, and providers. Questions delved into perceptions, opinions, and experiences with the LTC planning process. Specific topics covered in the questions included, but were not limited to, motivation/resistance to involvement in the LTC planning process, extent of consumer involvement, successes and challenges, and lessons learned. A final question in each interview asked respondents if there was anything overlooked in the interview that they would like to discuss. This question yielded a large amount of valuable data and reflections not otherwise covered in the interview guide. The interview guide and questions therein are listed in Appendix J.

Individual interviews were conducted with 26 individuals. Two interviewees invited colleagues to sit in and participate in their interviews. Eight group interviews were conducted. Non-participant observation was conducted at two large meetings composed of members who had previously participated in a group interview.

Each interview was conducted by at least two moderators, one who primarily asked questions and guided the discussion and another (one or more persons) who took copious notes. Interviews were also audio-taped to ensure that the notes taken during interviews accurately reflected the content and tone of the discussions. Interview notes were then transcribed first by the co-moderator who had primary responsibility for taking the notes during the interview, then reviewed and edited by one or more persons also in

attendance at the interview. In this way, the notes and perceptions of each moderator were validated or challenged by other members of the APS evaluation team.

Interview notes were parsed into approximately 3,200 unique interviewee statements. Interviewee statements were entered into an Excel file where they underwent an iterative process of categorization. The initial categorization resulted in 136 response topics. Ultimately, through the process of repeated grouping and categorization, the response topics were condensed into 26 major (and manageable) themes or categories of information. A single APS team member, who moderated the majority of the individual and group interviews, conducted the iterative review and categorization. This approach enabled the APS team to avoid problems of inter-rater reliability, as well as to draw from the significant knowledge base of the team member who had the most experience conducting the interviews.

The 26 major themes are triangulated (i.e., interwoven) with the information garnered from the quantitative surveys and presented in the subsequent chapters of this report.

IV. Strategic Planning for Statewide Implementation

A. Background

Strategic planning for statewide implementation of long-term care reform was the primary goal of the comprehensive system change grant proposal. The three objectives supporting this goal were:

1. To build consensus among key stakeholders and partners on an implementation plan for statewide reform;
2. To assist local long-term care governing bodies to design and develop more effective local long-term care systems; and
3. To provide support to plan, design and begin to implement local county or multi-county reform efforts.

This chapter provides testimony to how the Wisconsin Department of Health Services achieved and exceeded these objectives. The first section of this chapter focuses on the State outreach strategies used to build consensus among key stakeholders and partners. It then transitions to the impact of secretarial leadership on the evolution of the role of the State in the long-term care planning and implementation process. The third section traces the redrawing of the map of Wisconsin county governance and the birth of the multi-county managed care organizations, complete with lessons learned along the way. The fourth section highlights the major program elements of the Family Care program, Wisconsin's long-term care managed care program.

B. Setting the Tone – The Council on Long-Term Care

The Council on Long-Term Care Reform (“the Council”) was the guiding, decision-making force behind long-term care reform in Wisconsin. The Council was established in 2000 by the Secretary of DHS to advise her on how best to proceed with the reform efforts. The Council shepherded the reform from its early pilot stages to its current rapidly expanding form, and was the oversight body of the Comprehensive Systems Change grant. As one council member stated, the Council on Long-Term Care “made expansion possible.”

The Council set the collaborative and inclusive tone for long-term care reform in Wisconsin. As one of its first tasks, the Council developed a set of principles which

became the guideposts against which major decisions and activities were assessed. These principles honored the past while defining the parameters of the framework for the future of long-term care in Wisconsin. The major principles included:

- The reformed long-term care system must be characterized by choice, access, quality, and cost-effectiveness;
- Organizations managing the new system must be value-driven and those values must be consistent with the four goals listed above;
- Care planning must be person-centered, one person at a time;
- Consumers must have opportunities for self-directed care;
- Consumers' views must inform the management of care management organizations;
- Organizations proposing to manage local systems must collaborate with all stakeholders, including consumers, advocates, counties, and private providers, in developing plans and proposals; and
- The State has ultimate responsibility for contracting with organizations that can and do deliver high quality services and are fiscally sound.

The Council was characterized by active, hard working, and vocal subcommittees. Subcommittee members identified, framed, and investigated many of the implementation issues of the Council. Among others, the subcommittees included Residential Options, Aging and Disability Resource Center Development, Workforce, Housing, and Vocational Services. Most committees had about 15 members and met on a monthly basis.

The subcommittees funneled recommendations to the Council on Long-Term Care who studied, debated the issues, and passed on their recommendations to the Secretary. The Council consisted of about 25 members, and included consumers, advocates, and county, managed care organization, and provider agency representatives. During the first stages of the expansion, the Council addressed 19 areas of consensus related to the reform initiative. Some of the major issues it discussed were:

- The degree of integration of medical health benefits into the Family Care model;

- The content of the request for information that would fund county planning groups;
- The rebalancing of community-based and institutional care;
- Budget provisions related to expansion of the Aging and Disability Centers and managed care organizations;
- The role of mental health services in the long-term care system;
- The role of counties in the reformed system;
- The desirability of public and private models; and
- The realignment of the State to the role of purchaser of outcomes in a new multi-county system.

Dedication to building consensus on these complex core issues generated a strong, knowledgeable, and collaborative spirit of leadership among members of the Advisory Council that continues to this day.

C. State Outreach Strategies and Secretarial Leadership

A particularly active committee of the Council was the Stakeholder Committee. As described by one Council member, this committee “took their charge to heart, learned the basics, and aggressively went about planning and obtaining consumer, public, and stakeholder input.” Described as “a cast of characters,” their work reverberated through the system. Primarily consumers, the members of the Stakeholder Committee were major vehicles of carrying and sharing the vision of the grant and of the long-term reform effort. They actively participated in State and county meetings, keeping the promise of consumer and stakeholder input in the foreground of the planning effort.

1. The Consumer Training Corps

A related vehicle for sharing the vision and building consensus was the Consumer Training Corps. The Consumer Training Corps originated from a request from the Coalition for Wisconsin Aging Groups, Wisconsin’s long-standing and celebrated advocacy organization for elders. Using grant funds, the State contracted with this advocacy group for elders to prepare and conduct a series of trainings. The Director of the Coalition for Wisconsin Aging Groups was joined by the Director of Disability Rights Wisconsin, the primary advocacy group in Wisconsin for people with disabilities, together

presenting formidable advocacy leadership to the training and the reform movement as a whole.

State Family Care leaders and the advocacy directors conducted day-long sessions in 10 Family Care implementation regions around WI. Follow-up sessions were held in many regions. Consumer demand exceeded expectations. Over 400 people attended the training sessions from an initial goal of 200.

Thoughts on the success of this collaboration between the State and advocacy groups varied by which party was speaking. Representatives from the State felt that the advocacy organizations “leaned too heavily on the State for logistics and organization in general.” On the other hand, representatives from the advocacy organizations felt that the State “was not supportive of the program,” and had “goals that focused on PR and were cheerleading the long-term care expansion rather than encouraging stakeholder education and involvement.” Regardless of the perceived failings of each group and the content of their presentations, the trainings spearheaded the multitude of education sessions held in subsequent years as the expansion proceeded.

2. University of Wisconsin Extension Involvement

The State also contracted with the University of Wisconsin Extension (UWEX) to further facilitate and support stakeholder and consumer involvement. UW-Extension has the capacity to reach local agents in every county in Wisconsin. Extension personnel brought a wide variety of skills and a long and successful history of working in the counties.

Extension staff provided a full range of services to six of the consortia funded by DHS. The services they provided were tailored to the needs and goals of each consortium, and ranged from assisting in the development of a stakeholder communication/ participation plan, preparation of a toolkit for stakeholder involvement, and dissemination of education materials. Extension staff proved themselves gifted at providing hands-on assistance with planning. The Extension work did not begin until late 2006, and most was done in 2007. The collaboration represented a true win-win relationship. The State and counties received the bounty of services from the Extension, and the Extension forged new relationships and broadened its image beyond that of issues related to land use or farming.

3. Secretarial Leadership – Bottom-Up to Top-Down

Wisconsin long-term care reform has been consistently characterized by strong, supportive, and involved leadership from the Secretary of the Department. Secretary Helene Nelson led the expansion effort. As a former Director of county long-term care services, Secretary Nelson brought first-hand knowledge of community-based care to the endeavor. This was coupled with long, established, and trusting relationships with county government officials.

Secretary Nelson provided the credibility and legitimacy needed at a critical time to calm the nerves of uneasy county officials. The Secretary conducted six forums with individuals and groups interested in responding to the planning RFI/RFP during the fall of 2005, two of which were webcast. She continued to express her support throughout the process by personally meeting with members of each consortium at least once, and maintaining regular contact with consortia leaders. As she stated in her interview with the APS evaluation team, “State leadership is important for articulating the mission and creating structure and process. The State must both sell the concept and engage positively with partners for action.”

Secretary Nelson led the Department through the first stages of a new relationship with Wisconsin counties. For the first time, counties were being asked to share risk with the State and work with the State to develop a new regional county model, a model in which they worked with the State and each other in a totally different manner. As echoed in many interviews, Secretary Nelson had the temperament and personal philosophy that lent itself to an organic process in which counties redrew the map of county governance in Wisconsin. Secretary Nelson reflected this as she said, “The ultimate motivator is to appeal to the best in people – that they really desire to better the lives of consumers...It’s important to get people involved in ways and places that are meaningful for them.”

Making the new balance of power and risk work in reality was no small feat, appreciated by some, unwelcomed by others. Many interviewees lauded the flexibility of the State and the freedom they were given to develop their own systems. This was balanced, however, with frustration by county planners who felt that they “needed clearer direction and guidance on issues that were complex and as yet unexplored by the counties. This was slow in coming.” Others stated, “The State should have been more prepared and better

organized before moving ahead on this project.” Others were frustrated that they “often got one answer from one person and another from a different person.” Many complained that much energy was spent “reinventing the wheel.” There were few interviews in which the role of the secretary, and in its more generalized form, the role of the State, was not mentioned. It is important to note, however, that even the staunchest criticism was consistently couched within or followed by a statement of empathy and understanding of what people were experiencing and was something to be expected in the evolution of such a large undertaking.

The exploratory nature of early expansion took on a new tone with the retirement of Secretary Nelson and the advent of leadership from Secretary Kevin Hayden. Secretary Hayden assumed his post as the county planning councils were completing their first year of planning. While supporting the consumer and stakeholder focus of the previous efforts, Secretary Hayden was particularly responsive to State and stakeholder concerns about duplication of effort, especially as it related to core infrastructure components like information technology (IT). The new Secretary led the movement to what is frequently referred to the “franchise model,” in which the State takes a much more prescriptive and regulative role, forcing efficiencies of scale and reducing variation in process and product. Standardization became the rallying cry of some, the core of resistance for others. A common theme among stakeholders was that, if it was going to be used, the franchise model should have been applied during the entire planning process, not affected midstream in expansion. Many bemoaned the potential loss of systems or products they had already developed. This was particularly true as it related to IT. “Consortia will have a difficult time accepting a new IT system from the State, particularly if it is not one which has already been proven in the Family Care data environment. Rather than imposing a new system, a better approach would be to require particular technical capabilities and recommend a set of proven systems for use in the counties.”

Secretary Hayden left the State for another position in April 2008 and has been replaced by Secretary Karen Timberlake. The new Secretary continues in the mode of Secretary Hayden, and plans are being carefully considered as to what will become standardized elements of the Wisconsin long-term care infrastructure, and how they will be prioritized and implemented.

D. Individual County and Consortia Planning

1. Background

Funds from the comprehensive systems change grant were allocated in the fall of 2006 to support local efforts to plan for the implementation of managed long-term care. Sixty-three of Wisconsin's 72 counties and 11 Native American Tribes/ Bands organized themselves into ten separate planning consortia. Several counties began planning with one consortium but switched consortium membership during the planning process. The nine rural counties that declined the opportunity to apply for planning grants basically took a "wait and see" attitude toward long-term care reform. All of the nine were small rural counties, with eight clustered in the northeast portion of the State and one located in central Wisconsin. The amounts of the initial planning grant funds received by the consortia ranged from \$100,000 to \$250,000, and significant additional funding was provided to cover planning and implementation costs. Counties also provided their own funds as well as extensive in-kind contributions of staff time and supplies.

In addition to funds, the State provided each planning consortium with "massive" amounts of de-identified data to use in planning, including data on case loads, service utilization, and rates. The State also provided a readiness tool against which each consortium could gauge their readiness to become a managed care organization.

The State released a Request for Information (RFI) and invited interested parties responded. The RFI was clearly non-prescriptive. For example, it left it in the hands of the respondents to clarify their intent to be a public or private entity and the degree of integration with Medicaid or Medicare primary and acute health care benefits. It also took into account issues such as the approval of Special Needs Plan authority.

The consortia that received planning grants entered into planning for long-term care delivery at various stages. Those counties that already were Family Care pilot counties, and the neighboring counties who joined them, were able to build on their pilot experience. Counties that were not Family Care pilot counties and chose to create their own managed care organization "from scratch" had much more planning to do. While a wide variety of stakeholders were involved throughout the planning process, the leading players in each consortium were consistently county human services administrators and

elected county officials. In those consortia where an existing MCO was available, the MCO administrators were also key players.

Regardless of whether the counties had addressed the issues highlighted below as part of their preparation to be Family Care pilots or first considered them upon receipt of their planning grant, counties had to face the same basic issues. Prior to the advent of managed long-term care, counties, with State oversight, were directly responsible for the provision of and budgeting for long-term care services. Many of the key service providers, particularly case managers, were employees of the counties. Funding for long-term care was based not on a capitated rate but rather on allocations to each county from the State. The State's decision to transition to a long-term care system provided by managed care organizations covering multi-county regions inherently raised questions such as: How much control could county government retain over the actual provision of services? How would this control be exercised in a public or private model? What financial risk, if any, would the county have in the future? To what extent would counties be required to contribute the local funds that they historically contributed? Finding answers to these questions ultimately resulted in new State policy and statute.

Various models of managed long-term care were available for consideration. Each model was characterized by a different level of local control and financial risk. In general, those models that gave county government a great deal of control placed a great deal of financial risk upon the counties, and models that minimized risk allowed for less control. Traditionally, county government had both a legal and moral responsibility to provide the best possible long-term care, and it would be safe to say that those individuals who made up county government were very protective of their fellow citizens who needed long-term care services. At the same time, counties were facing ever tightening budgets, and the costs of long-term care were becoming a rapidly expanding portion of those budgets. Finding the model of managed long-term care that gave each county the best balance of controlling the provision of services, while limiting budgetary burdens, became the essence of consortia planning.

2. Resulting private and public governance structures

The resulting private and public governance structures are testimony to the latitude given by the RFI of the State. The current status of the planning efforts can be described as follows:

- Four consortia completed both planning and implementation and established new publicly owned managed care organizations using the Family Care District governance model. These MCOs are governed by boards made up of county and consumer representatives.
- Three consortia opted to get out of providing long-term care services and planned for Family Care to be delivered by private MCOs.
- One consortium continues extensive planning efforts. This consortium is considering dividing into two groups. One county is very interested in implementing a private model once a new Special Needs Program application is approved; the other counties are planning a public MCO using the Family Care District model.
- Each of the remaining two consortia are unique. These two consortia include approximately 30% of the state's population. Both consortia continue to plan. In the first, their recent solicitation to the State may result in multiple MCOs where previously there was only one. The second faces significant challenges as they attempt to address the needs of Developmentally Disabled (DD) consumers in a managed care environment.

Each of the consortia produced a report of their planning activities, including the various committees formed, managed care models considered, public information and forums presented, specific individuals involved and the roles they played, and numerous other aspects of the planning process. These reports provide a very detailed description of the steps taken and decisions made by the consortia. The planning reports are posted at <http://dhs.wisconsin.gov/managedltc/grants> on the State Expansion of Managed Care website¹.

E. County and Consortia Planning – Lessons Learned

What went well? What was most challenging? What issues need to be addressed, and in what order? Interviews with dozens of key players in the planning process revealed some distinct issues that planners in other long-term care reform efforts may well profit from heeding. Those interviewed were very forthcoming when asked the questions: “If you had to do it over again, what would you do differently?” and “What would you tell your counterparts in other states that are considering a long-term care reform similar to

that of Wisconsin?” The following lessons learned are presented in no particular priority of importance. However, they were consistently mentioned by most interviewees.

1. Change is seen as threatening by some, inevitable by others, and as both by many.

Initially, there were many stakeholders who, though they agreed the existing system had many problems, felt that it nonetheless could be patched together to make it work and that a major overhaul of the system was just too big of a task to take on at this time. Other stakeholders recognized that the existing system required major changes and, as difficult as the task would be, putting off changes would only make the task more difficult in the future. Over time more stakeholders became involved in the planning because they felt if they didn't they would be left accepting decisions that they had no part in making. Comments such as “The horse is out of the barn” or “The train is leaving the station and we have no choice but to get on board” were voiced frequently. The lesson learned was that many who started out resisting the very idea of long-term care reform changed their minds if treated with patience and respect, and effective planning benefited from accepting all interested stakeholders regardless of when they entered the process.

2. It is both difficult and essential to find a balance between tightly prescribing what is expected of planners and encouraging them to be as creative and self-directed as possible.

Strong feelings were expressed in the interviews that both supported and criticized the extent to which the State laid out requirements for the use of the planning grant funds. Those who favored the relatively open-ended planning process acknowledged that planning probably took longer without specific guidelines to follow, but by having each of the members of each consortium jointly go through the knowledge-gathering and evaluation of various options, the resulting decisions received more unanimous support and were a better fit for local needs. Enabling individual counties to choose whether or not to plan at all, and which other counties they would partner with if they did plan, was seen as particularly important. Several people pointed out that in the instance where the state openly encouraged a particular county to enter into planning and pushed that county to partner with a specific neighboring county, the progress of the planning was slower and the results less conclusive.

Putting each consortium in the position of having to figure things out on their own inevitably lengthened the planning process. Some consortia who were relatively new to long-term care reform expressed in hindsight that they could have benefited from requesting more assistance from the experienced Family Care pilot counties. In a few instances, certain consortia reached out to other consortia on their own. There was general agreement that, had there been sufficient resources, a system to facilitate ongoing communication between consortia would have been valuable.

As noted earlier in the discussion of Secretarial leadership, interviewees consistently confirmed that the one area where more prescriptive guidelines clearly should have been in place was in the development of information technology systems. In order for the State to effectively manage contracts with MCOs, it is essential that the same data be collected and reported in the same format across all MCOs. A consistent IT system would also enable individual MCOs to better assess their services by allowing them to make accurate comparisons with other MCOs. Without specific guidelines in this area, consortia developed their own IT systems and it now appears possible that they will need to change their systems or purchase new ones in order bring about a more useful state-wide system. Any state that may be considering long-term care reform should make every effort to address this issue as early and completely as possible.

3. It is important to get the right people at the table, and the Project Manager is the most important position.

Implementation of reformed long-term care services works best when it has the support of all the key stakeholders. These include county officials and managers, service providers, advocates, consumers and others. Stakeholders are best able to support a new program when they feel they have had real involvement in the development of that program. Most consortia started planning with what could be considered the most obvious players, county human services directors, and this group of individuals generally played the leading role throughout the planning process. Other appropriate stakeholders were involved from the start or brought in as details fell into place. Many commented that decisions were often made by a small core of people, with some issues resolved outside of formal meetings. This aspect of planning is in no way unique to long-term care reform and can be seen in any legislative or large decision-making process. The challenge in this instance is for the core

group to be as transparent as possible, making every effort to enable input from all concerned stakeholders and assuring that all key decisions be presented for public review.

Consortia representatives consistently expressed the value of having the planning process managed by someone with the ability to be a project and change manager. These skills were not seen as the same as those needed to be a successful human services or MCO manager. There were certainly human services and MCO managers who had the skills to manage change, but most consortia eventually hired or designated someone to staff and manage the planning as a project in itself.

It should also be noted that, given the very public nature of both the funding for and participation in long-term care services, there are political aspects to nearly every decision. Planning participants needed to include not only those with experience in the management, delivery, and use of long-term care services, but those with experience in the political arena as well.

4. The importance of encouraging positive personal relationships and recognizing cultural differences between counties should not be overlooked.

This aspect of planning is often overlooked or minimized, but can be a fatal mistake if not considered. The differences in personal goals and assumptions that stakeholders bring to the table can be much greater than anticipated. Arriving at a final decision often involves very contentious discussions in even the best of circumstances. Establishing a strong sense of trust and understanding among planners as early as possible in the process goes a long way toward easing the resolution of difficult issues that will inevitably come up later. Differences between counties as unique cultural and political systems, not just the individuals who represented those counties, became apparent in some consortia. Some consortia were fortunate in that they were made up of counties that had experience working together in developing other regional services. In other consortia, however, counties with historically different politics and approaches to delivering human services formed somewhat uneasy alliances. Most of these consortia recognized and addressed this challenge early on. One of the more interesting comments on the process was that consortia where human services directors with a social work background played a key role, the process tended to run more smoothly.

5. Union and human resources issues will present unique challenges.

This may be more of a factor in Wisconsin, but it will be of concern in any situation where a significant number of staff may either lose their job or end up working for a different employer. Prior to the transition to managed long-term care, most of the services were provided by county employees. Many of these employees were union members and all had become used to a particular standard of benefits, including being members of the State retirement system. While there was no absolute requirement that their employment status be protected, there was a great and unavoidable amount of political and community pressure towards insuring that this received the utmost consideration. To address this issue, the State promulgated new statutory language that created the Long-Term Care District. Under certain circumstances, this structure extended union benefits and continuation of State retirement benefits to employees within the District.

In addition, it was widely understood that the quality of services would suffer if the training and experience of county workers was lost. Consortia addressed this challenge with a variety of approaches. Union representatives became key players in the planning process. In some consortia, the MCO contracted for services from counties who remained the employer of the staff. In other consortia, the MCO agreed to give preference to county staff when they hired for their new positions. In a larger context, the state legislature created new statutes which allowed former county employees to remain as members of the State retirement system.

It should be noted that not all of the agreements made to address labor concerns were universally supported. Concerns were expressed that the promises made to unions could result in an uneven playing field for publicly owned MCOs should they ever have to compete with privately owned MCOs.

6. Long-term care reform is a very large and complicated challenge.

Nearly everyone interviewed expressed a variation on the following theme: No matter how thoroughly you think you understand the enormity of the task at hand, you will be wrong. No matter how completely you plan for every contingency, failures will occur and challenges will arise that you never anticipated. The only realistic approach is to expect the unexpected and be confident that you will be able to handle it when it occurs. This theme is

addressed in answers frequently received to the question, “What would you do differently if you had to do it all over again?”

Two key lessons emerged as important for other states to consider. The first was: Don’t enter into this process unless you are ready to see it through to the end. This means insuring that there is sufficient staff and funding to coordinate a major, possibly years-long effort. Ideally, there will be extensive pre-planning completed before a commitment is made to undergo statewide long-term care reform. There is an extensive body of knowledge regarding managed long-term care services and related business practices that would be beneficial for all planners to know. Having this knowledge would not overly influence the decisions of the planners but would make their process more efficient. Wisconsin consortia spent considerable time building this body of knowledge on their own.

The second lesson was: Don’t let the perfect be the enemy of the good. Wisconsin entered into its planning effort with a total commitment to implement managed long-term care. While consortia were not given firm deadlines as to when they should be ready to move to implementation, there was a clear message that planning couldn’t go on forever. Planning was not intended to be an exercise in exploring possibilities but was to be the first step in building a new system. The desire on the part of some to have every aspect of the new system spelled out in detail before it was put into operation can result in unneeded delays to implementation. The lesson from those who have proceeded to implementation is that there will always be more details to be worked out. The first few weeks of implementation may seem like chaos, but it can be controlled chaos.

A third message for other states is not so much a lesson as words of encouragement. Despite the intense efforts needed to change long-term care services, the consensus of those involved was that it is definitely worth it. Depending on the county, the existing system was seen as broken or about to break. Tinkering around the edges was not going to solve the problems and doing nothing was not an option. Failing to invest in change now will only bring about greater challenges in the future.

7. Long-term care reform can have serious implications for local human service units, especially in terms of staffing and traditional county services.

The planning effort required a great deal of time and staff resources from county human services departments. This was particularly true for smaller counties. Some human services directors described the planning process as like having a second job. While there were no overt policy changes to other human services, planners acknowledged that there were only so many hours in the day and their attention had to shift more to long-term care than ordinarily would have been the case.

At the same time, planning for ADRCs sometimes created tensions within counties because of state and federal expectation that aging agencies would have a significant role in the development and operation of ADRCs. In settings where no history of collaboration between aging and human services/ long-term support programs was established, planning was delayed by lack of clarity and direction about how much aging units could or should be involved. There was also some confusion about whether ADRCs were the same as intake units, rather than new organizations with hybrid roles (drawing from long-term support and aging). Ultimately, many counties decided to build their ADRCs through a combination of elements of aging units and long-term support agencies.

Long-term care reform also had implications for funding and staffing of traditional county-delivered services other than long-term care. As the legacy fee-for-service waiver programs ended, the county no longer received the waiver administrative dollars that supported the infrastructure of these programs. As a consequence, there was a lack of staff to provide certain programs, such as Adult Protective Services and guardianship. An entirely new infrastructure had to be developed.

A consequence unrelated to limited resources may be thought of as a conceptual spillover. As policy makers and administrators got used to planning on a more regional basis and experience the efficiencies of delivering services on a larger scale, they began to consider this approach for more human services than just long-term care. Child welfare services in particular have been suggested as an area that could benefit from a more regional approach than currently exists.

8. Managed care's generally poor reputation will need to be addressed.

Right or wrong, many stakeholders came to the planning process with the belief that managed care was more about saving money than delivering quality services. This attitude was particularly prevalent among developmentally disabled consumers and their advocates, but it was hardly unique to this group. Many older people also expressed concern about managed care. This concern was primarily based on an unfortunate experience several years ago when a large Medicare managed care program abandoned the State and its 16,000 Medicare members. This led to natural suspicion by elders about the potential impact on Medicare fee-for-service benefits presented by managed care organizations.

Much of this apprehension was based on the assumption that managed care meant turning the system over to private, for profit organizations. Addressing this concern was an important part of the many public fora of consortia planners. To some extent, this involved defending some existing private MCOs and showing that they had not been detrimental to the quality of services. To a larger extent, this concern was addressed through the consortia developing governance models that included publicly owned MCOs controlled by boards appointed by elected county officials. In those consortia where a private MCO was contracted, at the direction of the planning group, a community advisory committee with clear lines of influence was put, or kept, in place.

9. Recognition of values should be a top priority.

This is an issue, like positive personal relationships, that can be taken for granted but clearly deserves recognition. While most, if not all, stakeholders enter into the process with the best interests of the consumers in mind, giving time to discussing exactly what this means in practice is a worthwhile investment. Consortia that began planning by focusing on defining a shared mission and guiding philosophy found that when such principles are determined early on, they are very useful in resolving differences over the more mundane, but often contentious, issues of managing personnel and resources. Recognition of values was seen as a particularly important basis for designing quality oversight systems. Oversight was seen as a process of holding organizations accountable for adhering to the basic values of the community as well as the usual expected business practices. These values

were also seen as the primary motivator for implementing self-directed services.

10. Reaching agreement on an appropriate capitated rate will be one of the greatest challenges.

While setting a capitated rate for the delivery of managed long-term care services was not the role of the consortia, developing a service delivery system that could operate within the rate projected by the State was one of their greatest challenges. Some consortia did their own accounting of costs in an effort to refute the rate projected by the State. Stakeholders expressed the opinion that rate setting was too much of a “black box” in which actuaries and data analysts did their best work but the details of how they arrived at their conclusions were not readily available. Stakeholders acknowledged that it was a very complicated process but felt that they should have more information about it and be given the opportunity to understand it to the best of their abilities. The better they understood the process the less they would challenge the result.

11. There will not be agreement as to the pace of planning or speed of implementing reform.

Interviewees expressed strong opinions about the pace of the planning and implementation. For some, change was happening too quickly. For others, change was not happening fast enough. County staff who found themselves employed by an MCO expressed concern that they had too little training regarding the new system in which they were working. Some MCO staff found that during the process of transitioning recipients of the Community Options Program (COP) and Community Integration Program (CIP) to the managed care organization, they could not give members the opportunity to express their opinion about the adequacy of the level of services they were getting or would be receiving. Because staff were overwhelmed with just getting members into the new system, there was little opportunity to review their service plan. This had been a stated expectation of the “rollover” process. In general, there was concern that managed care was being implemented so quickly in some counties that the full benefits of the new system may not be realized as a result. Again, the installation and effective use of IT systems was described as lagging behind the implementation of services.

In contrast, consumers and advocates frequently expressed concern that change was occurring much too slowly. Implementation to them meant an end to wait lists and it was difficult for anyone on these lists to see a good reason for them to continue. Other stakeholders expressed dismay that efforts to achieve consensus during planning meant that a very small number of resistant individuals could significantly delay the process. The lesson for project managers was that the anticipated differences over values and structural details were not the only sources of friction. Sensitivity to expectations regarding the process itself also had to be kept in mind.

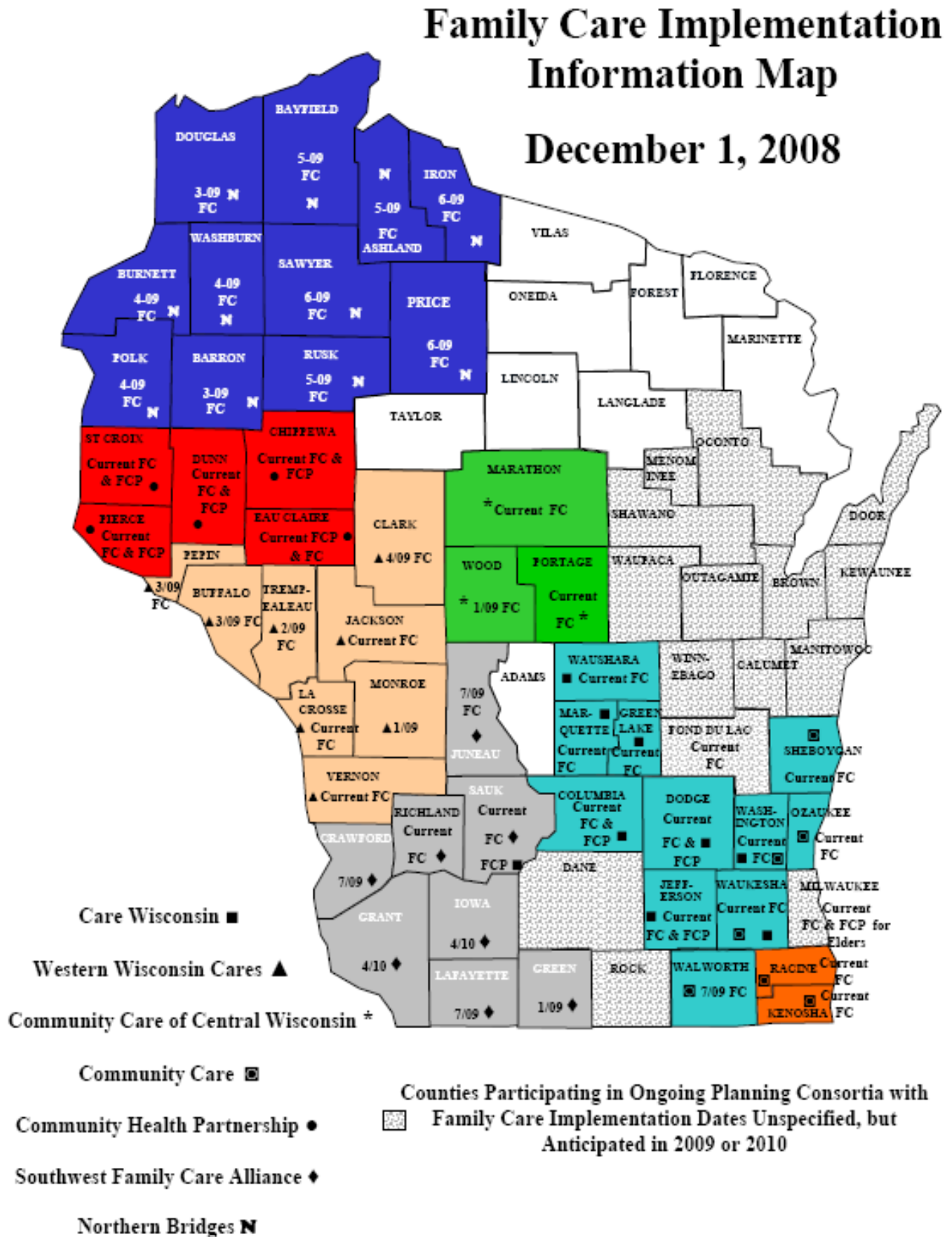
12. The advantages of long-term care reform should not be oversold.

This is an issue that is easy to understand in principle but is much harder to carry out in practice. Stakeholders who develop a positive impression of managed long-term care based on a description they first heard at a public forum or at an initial presentation to a planning consortium, and subsequently find that further experience is less than positive, tend to hold a negative attitude over the long term and resist further efforts at expanding managed long-term care. This is a particularly detrimental dynamic when consumers are involved. In the example cited above, the new members who did not experience the consumer choice they had expected were much less likely to encourage their peers to enroll in a managed care organization.

The desire to paint managed care in the best possible light, given that many came to the discussion with a negative attitude to begin with, is understandable. While the descriptions frequently presented were in no way inaccurate, they tended to picture managed care as it could be when everything was in place and running as intended. The fact that there would be difficulties during at least the first few months of implementation was often minimized or overlooked entirely. In hindsight, future promoters of managed long-term care would be wise to acknowledge that good things take time, and while the benefits will be worth the time and effort it takes to achieve them, those who are first in the system may have to put up with its growing pains.

The Family Care Implementation Map² (Figure 2) on the following page displays, by color, the current stage of Family Care implementation by consortia.

Figure 2. Implementation Map



F. Family Care High Level Program Elements

An overview of the Family Care program elements is included here to provide context for the remaining chapters. The Wisconsin Family Care program was authorized by the Governor and Legislature in 1998, and serves people with physical disabilities, people with developmental disabilities, and frail elders. Family Care has two major organizational components, Aging and Disability Resource Centers, and Managed Care Organizations. Wisconsin provides self-direction of services through the Family Care self-directed supports managed care option and the fee-for-service waiver option entitled IRIS (an acronym for Include, Respect, I Self-Direct).

1. Overview of Aging and Disability Resource Centers (ADRCs)

Aging and Disability Resource Centers offer the general public a single entry point for information and assistance on issues affecting older people, people with disabilities, and/or their families. The centers strive to be welcoming and convenient places to get information, advice and access to a wide variety of services. They are a clearinghouse of information about long-term care. Services are provided at the centers themselves, by telephone, or in visits to an individual's home. The expansion of ADRCs was a stellar achievement of the long-term care effort during the grant years. The following bulleted points provide a general description of ADRC services. (See Family Care General Information Web site: <http://dhs.wisconsin.gov/lcicare/pdf/FCoverview.pdf> for more information.) Issues surrounding ADRC implementation are covered in Chapter VI, Improving Consumer Access to Information.

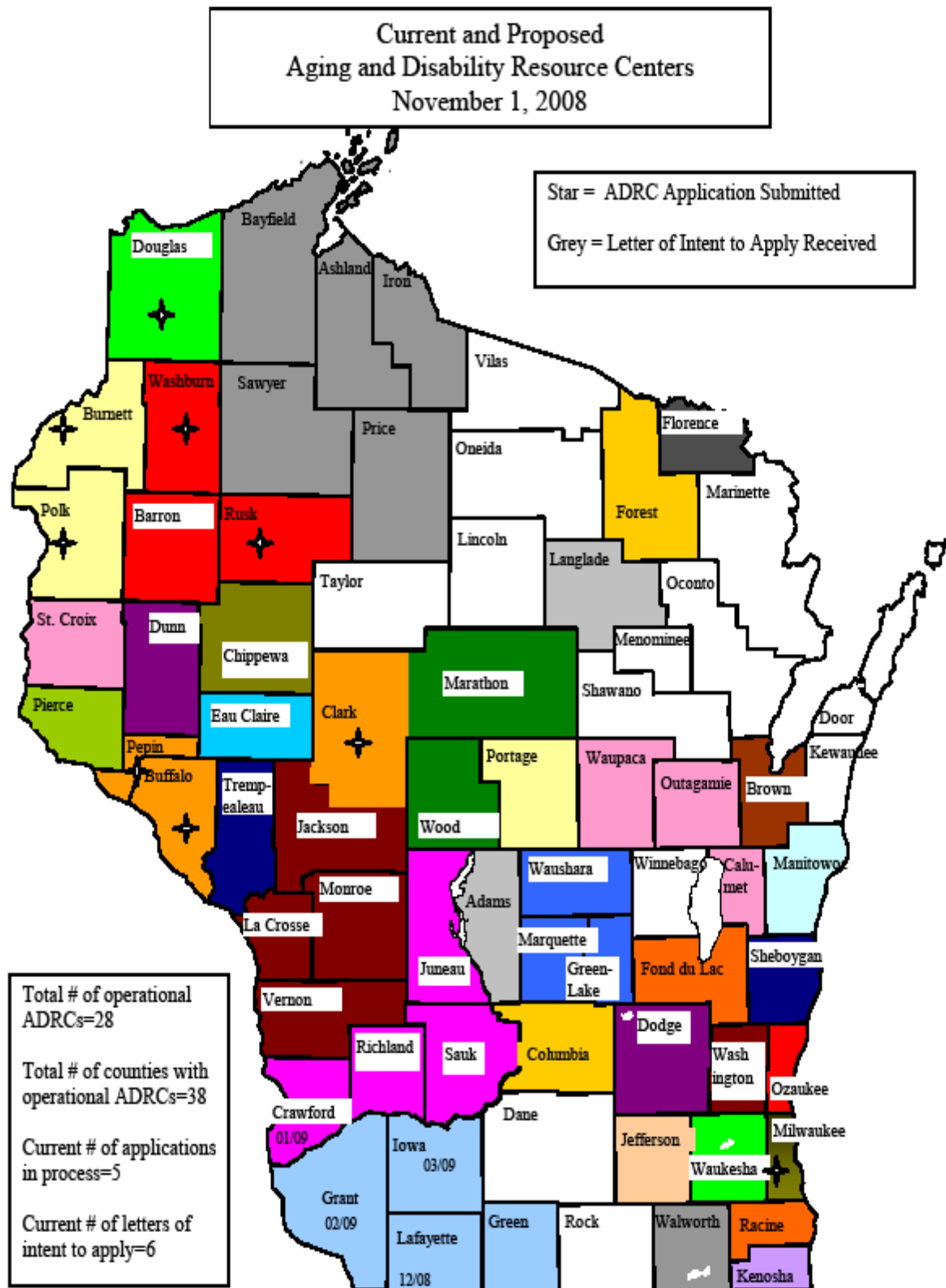
- Information and Assistance. ADRC staff provide a wide range of information to the general public about services, resources and programs in areas such as disabilities and long-term care related services and living arrangements, physical and behavioral health, adult protective services, employment for people with disabilities, home maintenance, nutrition, and Family Care. Resource center staff provide help to connect people with these services and also to apply for Supplemental Security Income (SSI), DHS FoodShare benefits, and Medicaid as needed.
- Long-Term Care Options Counseling and Enrollment Consulting. ADRC staff provide consultation and advice about the options available

to meet an individual's long-term care needs. This includes information about the range of options available through the Family Care program.

- Benefits Counseling. ADRC staff provide information on private and government benefits and programs, including Medicare, Social Security, or other benefits. Elderly and Disability Benefit Specialists are available to assist and counsel individuals in how to obtain and keep public benefits.
- Emergency Response. Staff at the ADRC help ensure that people are connected with someone who will respond to urgent situations that might put someone at risk, such as the sudden loss of a caregiver.
- Prevention and Early Intervention. ADRC staff collaborate with public and private health and social service partners in the community to provide information and intervention activities that focus on reducing the risk of disabilities.
- Access to the Family Care Benefit. For people who request it, ADRC staff administer the Long Term Care Functional Screen (See Chapter VII, System Access) to assess an individual's level of need for services and eligibility for the Family Care benefit. Once the individual's level of need is determined, resource center staff provide advice about the options available, whether it be Medicaid managed care services, Medicaid fee-for-service, or private pay for services. If the individual chooses Family Care, the resource center will enroll that person in an MCO. The level of need determined by the Long-Term Care Functional Screen triggers the monthly payment to the MCO for that person.

The map on the following pages (Figure 3) displays the stage of expansion of the Aging and Disability Centers as of November 1, 2008.³

Figure 3. Wisconsin ADRCs



2. Managed Care Organizations and the Family Care Benefit

Family Care is a managed care program designed to provide cost-effective coordination of long-term care services by creating a single flexible benefit that includes a large number of health and long-term care services that otherwise would be available through separate programs. The philosophy of Family Care is frequently described by State planners as: “Access, choice, quality, and cost-effectiveness and the right service, in the right amount, at the right time.”³ Family Care is person-centered and outcomes-driven.

In some counties, the Family Care benefit includes the Partnership benefit. Family Care operates under federal authority provided by 1915 (b) and (c) waivers; Family Care Partnership operates under a 1915(c) waiver and state plan amendment 1932(a). The relationship of the Family Care and Family Care Partnership benefit packages are well displayed in the graphics on the following pages. The Family Care benefit includes all Medicaid long-term care services and partially integrates health care (as represented in the first of the following graphics, Figure 4⁴). The Family Care Partnership benefit includes all Medicaid primary and acute and LTC services and Medicare primary, acute, prescription and LTC benefits. Family Care Partnership fully integrates health care (as represented in the second of the following graphics, Figure 5³).

Figure 4. Family Care Benefit

Family Care benefit includes all Medicaid long-term care services

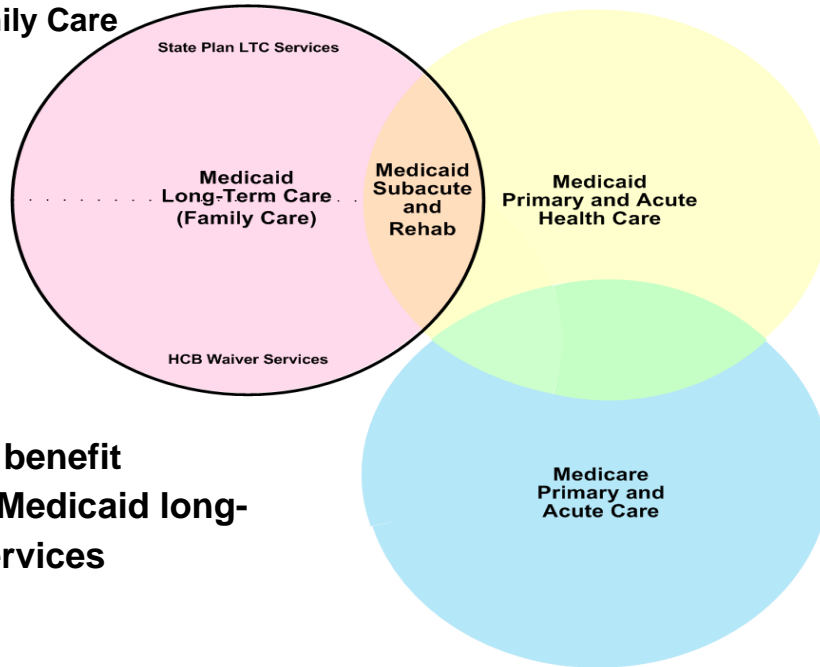
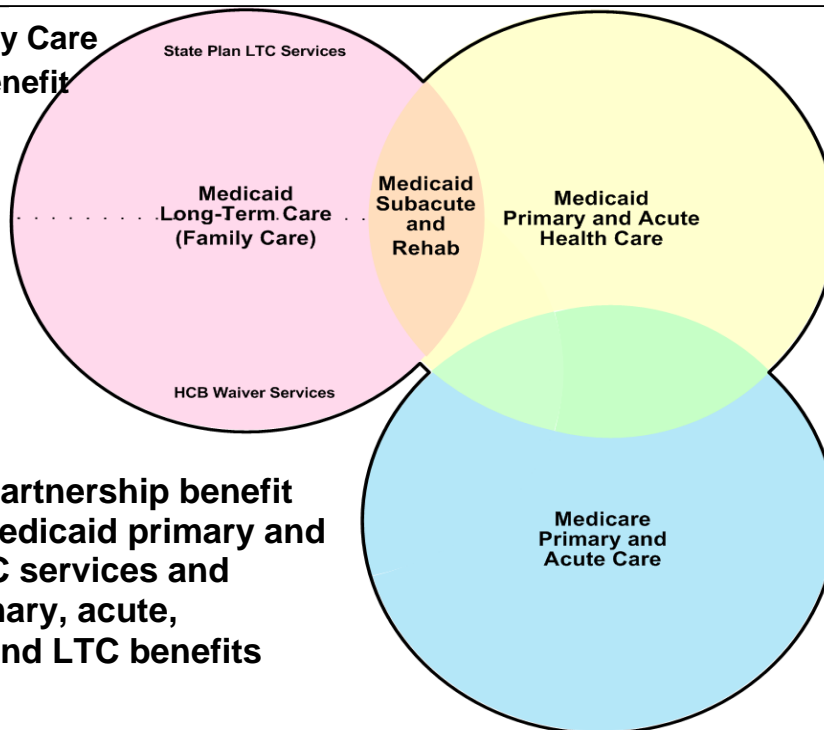


Figure 5. Family Care Partnership Benefit

Family Care Partnership benefit includes all Medicaid primary and acute and LTC services and Medicare primary, acute, prescription and LTC benefits



Core elements of the Family Care benefit include the following:

- Interdisciplinary Team. The Interdisciplinary team (IDT) is an essential component of the managed care service delivery model. The composition of the team minimally consists of the member, a care manager/social worker and a Wisconsin licensed registered nurse. Additional members, such as a mental health professional, are added to the team when necessary. The interdisciplinary team members help consumers determine the outcomes they want, and create a care plan designed to meet those outcomes. The managed care model requires that team members accustomed to the waiver program shift from “thinking in terms of outcomes rather than services.” The current social worker case load is 1-40; the nurse case load is 1-60.
- The Long-Term Care Functional Screen. The Long-Term Care Functional Screen (the “screen”) is an automated tool for assessing functional level of care. The State made exceptional progress with the screen during the grant period. The screen history, implementation, and issues surrounding its use are explored in Chapter VII, System Access.
- Quality Management and Financing. Managed Care activities are required, under contract, to include ongoing monitoring of quality measures and performance improvement projects. Progress in this area, particularly as it relates to the PEONIES project, is found in Chapter IX, Quality and Cost.
- Financing. Payments to the managed care organizations are a combination of Federal and State match. For 2007, counties contributed based on their 2006 contribution of local funds toward waiver participants. County contribution will be reduced over the first five years each county participates. The amount of the capitation rate and its capacity to provide enough money for the MCO to meet consumer needs remains a constant concern of the State and the MCOs. This is addressed briefly in Chapter IX Quality and Cost.
- Self-Directed Supports. Self-direction is alive in Family Care under the self-directed support option, delivered with support of the interdisciplinary team. This option finds its complement in IRIS, the

self-direct fee-for-service waiver option. The IRIS waiver became available in counties with Family Care as of July 1, 2008. Issues regarding the implementation of self-directed supports can be found in Chapter VIII, Increasing Service Options.

V. The Role of Stakeholders in Long-Term Care Planning

A. History of Consumer and Stakeholder Involvement in Wisconsin

Wisconsin has a long and lauded history of integrating consumer participation and choice into community-based, long-term care. Home and community-based waivers are imbued with a culture of respect for consumer choice. In years past, the RESPECT guiding principles poster (Appendix K) was a common sight in many a state and county office, and case managers took pride in their creativity in applying waiver policies to consumer needs. Traditionally, county governments administered the community-based long-term care programs, and the State required that county government build consumer and public participation into their programs. Many counties took this responsibility seriously and considered themselves advocates for consumer rights and responsibilities. Counties contributed local tax revenue to the long-term care system. This all resulted in long-term care programs with a high degree of reliability and public accountability. In addition, consumers, providers, and the counties in general were knowledgeable about the long-term care system, were experienced in providing input, and had expectations that this rich experience would be tapped as Wisconsin entered a new era of long-term care. This chapter highlights how, during the grant period, Wisconsin continued its rich history of consumer and stakeholder participation during its long-term care reform process.

B. Consortia Outreach to Consumers

1. Background

While the State assisted in facilitating consumer involvement through the Long-Term Care Council, advocacy organizations, and UW Extension, the majority of the responsibility of ensuring meaningful consumer involvement fell to individual consortia and counties. The State required that local planning groups include consumers/ stakeholders in local planning efforts, although how to involve them was not well-defined. The State also required that 25% of governing ADRC and MCO board members be consumers, family representatives or advocates. It was commonplace for consortia to develop extensive consumer communication plans, conduct surveys to discern consumer long-term care preferences, and discuss at length exactly what was meant by “meaningful” consumer involvement. According to the State, “The standard for meaningful participation will be met when well-informed stakeholders become knowledgeable observers, critics of your efforts and, eventually, positive agents of change.”¹

2. Consumer Involvement Strategies

Stakeholder interviews and consortia planning grant final reports give evidence of a vast array of strategies employed to reach consumers. Strategies were characterized by their multi-media quality. For example, many consortia created consumer-friendly websites, radio spots, newspaper articles and press releases. Consumers received invitations to planning meetings in multiple ways, from e-mail to snail mail, letters, brochures, and newsletters. Some counties provided reimbursement to consumers for travel to planning meetings. One county group utilized a common message strategy where the final agenda item for each of the subcommittee meetings was to summarize the meeting into a “common message.” Committee members would then share that message with their network of people between meetings. The first agenda item for the next meeting would be stakeholder feedback that committee members had received related to the common message.

In addition to county and consortia activities, the Council on Long-Term Care created a Consumer Advisory Council to educate consumers and provide feedback to the Leadership Committee of the Council. Some counties counted on consumers with a history of involvement to participate, while others used a more blanket approach in trying to reach all consumers.

Public comment was a fixture of many county meetings, and meetings had a myriad of names. Some were called education or information sessions; others were called input sessions, forums, focus groups, or town hall meetings. Most meetings were not designed specifically for consumers, and included other stakeholders and staff, as well. According to information learned from the interviews conducted for this report, the role of consumers at the meetings varied, from listener to active participant. There was considerable contention over whether consumers should have voting rights on committee decisions. In the end, most consortia adopted a policy such that all committee members, including consumers, had full voting rights. As captured by one interviewee, “Consumers were given the vote when committee members realized their hypocrisy.”

As diverse as the types of meetings was the variety of people who conducted them. Consortium project managers, state staff, county staff, county directors, consumer representatives and advocates, managed care organization directors, facilitators from outside consulting groups and UW Extension, and many others were tasked with spreading the word and bringing consumers to

the table. Meeting topics frequently included the basic components of managed care and an introduction to Family Care. Of note is that the Department Secretary herself was engaged in many of the early discussions with county staff and consumers, bringing credibility and high-level State endorsement of the impending changes.

3. Effective Consumer Outreach Strategies

Consortia planning grant reports and stakeholder interviews characterized several specific outreach strategies as particularly effective in reaching consumers and facilitating meaningful involvement. These strategies included:

- Speaker's bureau. One county created a local volunteer speakers bureau. The consortium provided a tool kit for speakers. The tool kit included Family Care education handouts, visual aids, and a feedback tool to evaluate the presentation. Speakers in one county alone spoke to 21 different groups over a two month period using this tool kit.
- Parent panels. One consortium held a forum described in the planning report as "a listening session consisting of a panel of parents of children with developmental disabilities." Families from the nine counties of the consortium shared their concerns and suggestions related to long-term care services for their children.
- Going to the consumers - kitchen table discussions. A theme that echoed from one interview to the next was the importance of "going to consumers rather than asking consumers to come to us." This approach took staff to the homes of consumers for informal discussions, many of which centered on the actual impact of the change to managed care on their specific services. The downside of this approach was the amount of time it took to organize the gatherings and the amount of time it took for staff to participate in them. As a result, they were not as common a practice as interviewees would have liked. Nevertheless, in situations where they did occur, interviewees cited this highly individualized approach as important, successful, and memorable.
- Combined education and feedback. One consortium changed the meeting format to include a morning educational session on a specific issue (for example, how the managed care organization contracts with the State),

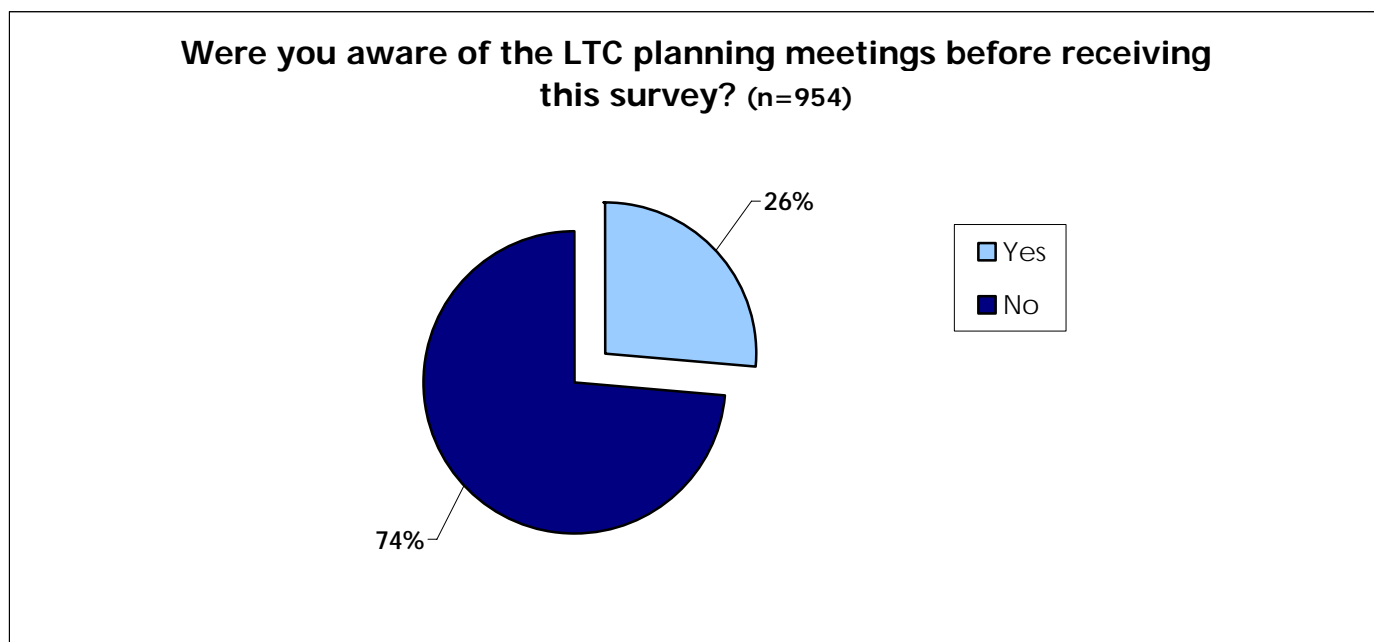
followed by an afternoon session to solicit consumer feedback on the morning issue. There was also a plan for meeting follow-up in that attendees were assigned activities in the community to do between meetings.

- Town hall meetings. One consortium held regularly scheduled town hall meetings regardless of the implementation planning stage. According to the report, this proved to be an ideal forum for consumers to ask questions, voice concerns, and provide input into the planning process. Information from the meetings was taken back to the county/consortia steering committee for action.

C. The Consumer Perspective of the Planning Process

As indicated in Chapter II, Methodology, the APS evaluation team developed and conducted a series of consumer surveys to elucidate consumer perspectives of the planning process. As indicated earlier, the overall survey response rate was relatively high at 47%. Because of the emphasis on consumer involvement at the State level, the range of strategies used to encourage consumer participation, and the amount of energy put into this effort, the survey included question on the extent to which consumers were aware of the planning process prior to receiving the survey, and how consumers heard about the planning meetings. Findings from all three consumer surveys combined indicated that 26% of consumers who responded to the survey had heard about the planning meetings (Figure 6).

Figure 6. Percentage of Consumers Aware of Planning Meetings Prior to Survey



Of consumers who had heard about the planning meetings, 69% heard about the meetings from their care manager or social worker (Figure 7). Considering the many other means used to inform consumers about the planning process, this percentage highlights the key role of care managers in this process.

Figure 7. Sources of Planning Meeting Information

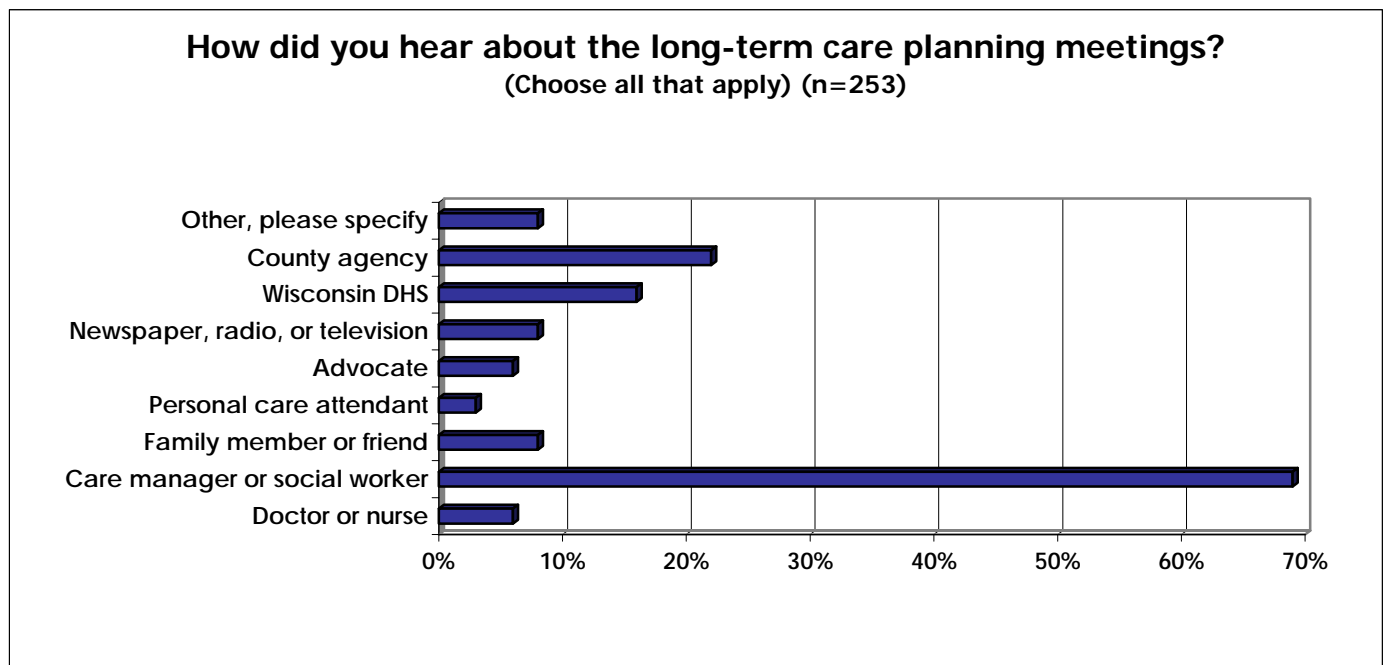
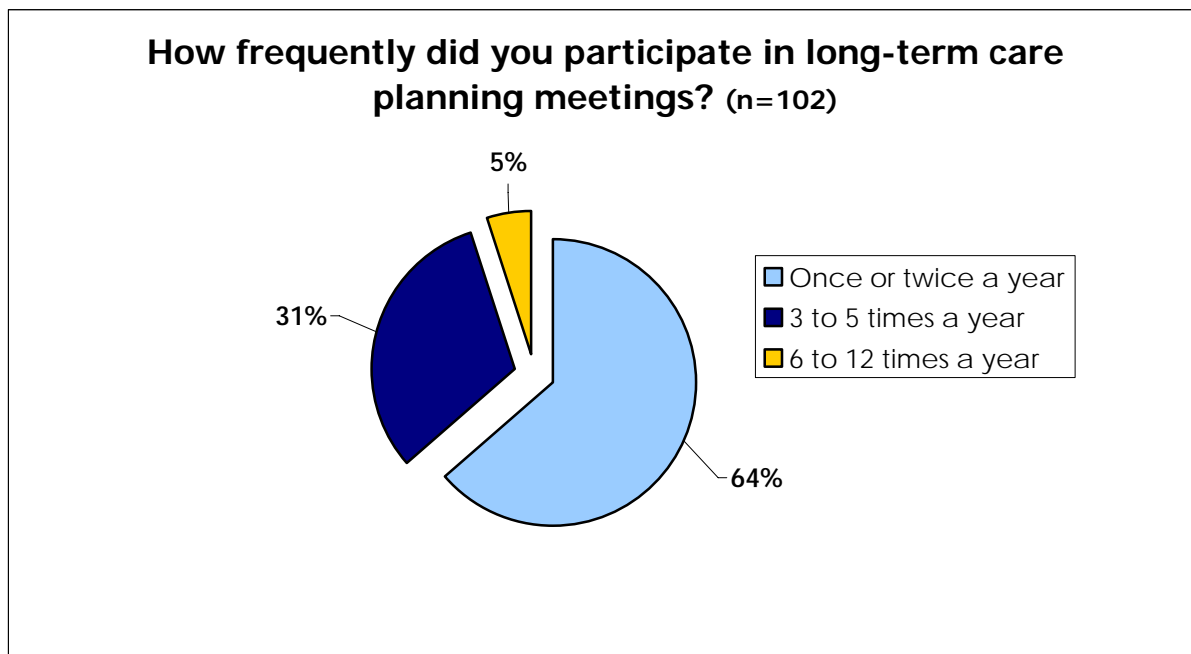


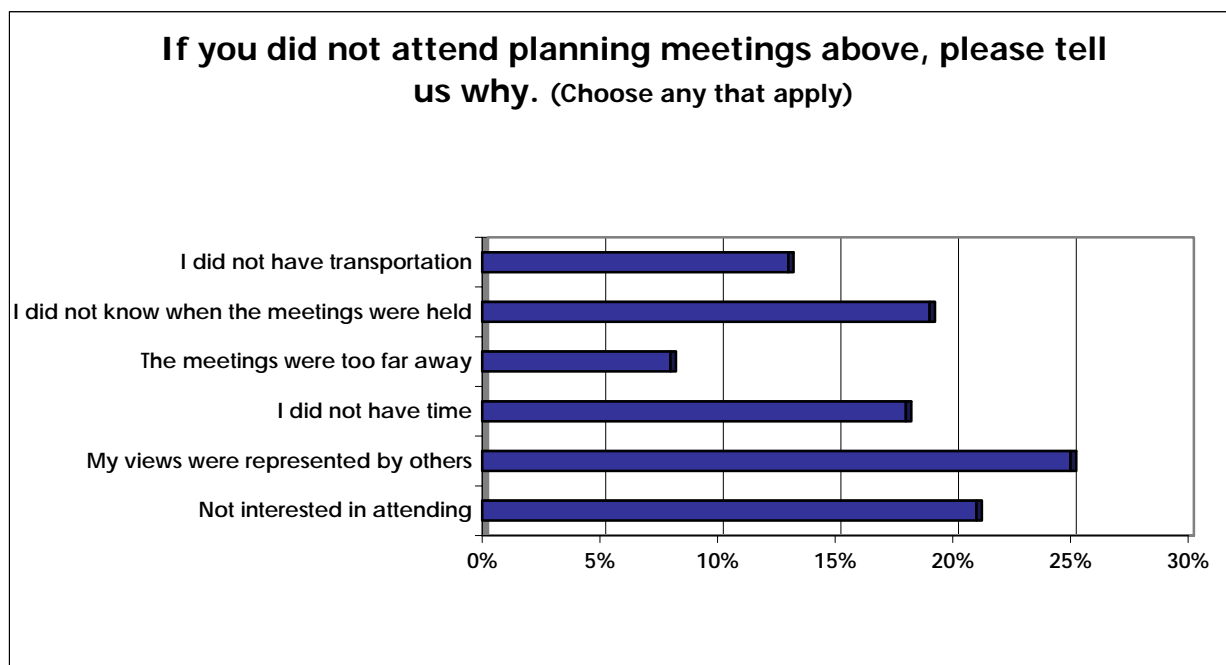
Figure 8 presents the frequency of attendance at LTC planning meetings. Forty-one percent (41%) of consumers who reported knowing about the planning meetings attended at least one meeting, an indication of the level of interest and commitment on the part of consumers. Of those who attended at least one planning meeting, 64% participated once or twice, 31% participated in 3-5 meetings, and 5% participated in 6-12 planning meetings.

Figure 8. Frequency of Participation in Planning Meetings



Why 64% of consumers who were aware of planning meetings did not attend may be of particular interest for future planners. Figure 9 shows the variety of reasons reported for non-attendance: 25% reported their views were represented by others, 21% were not interested in attending, and 19% did not know when meetings were being held. (Sum of percentages is greater than 100 because respondents were able to select all responses that applied.)

Figure 9. Reasons for Non-Attendance at Planning Meetings



D. Consumer Involvement from a Non-Consumer Perspective

1. Educating Consumers

Reasons for consumer involvement (or non-involvement) revealed by the consumer survey were echoed in interviews with other stakeholders. Additionally, stakeholders pointed out other reasons for involvement or lack thereof by consumers in the planning process. Interviews with advocates brought to focus the educational component so important to ensuring that consumers were versed in managed care terminology and issues. Interviewees consistently stated that the consumers' (as well as for many stakeholders'), lack of knowledge of technical and bureaucratic issues was paramount in the challenges of integrating consumers into substantive dialog. Many counties facilitated extensive consumer-focused education outside of regular planning meetings, paying particular attention to demythologizing managed care terminology. As one interviewee stated, "It's easy to make assumptions about long-term care lingo."

2. Meeting Formats

Another reason cited by stakeholder interviewees for lack of consumer involvement was the meeting format itself. Interviewees frequently pointed out that “Big meetings are intimidating for consumers not used to working in this kind of process.” One advocate complained that “state and local managed care planners set the agenda and fed pabulum to consumers.” Other stakeholders countered that “in our county, meetings were very well managed, consumers were asked their opinions, given an opportunity to ask question, and received thorough answers. Throughout the process, consumers were consistently treated with respect.”

Many interviewees identified ways in which their committees had addressed conventional big meeting formats. For example, many counties structured the agenda so that operational issues of greater interest to consumers were discussed in the afternoon. Conscious efforts were made to structure meetings so as not to “wear down” consumers with discussions of issues that had little direct interest to them. As stated in various ways by many interviewees, ultimately, the question from the average consumer was, “What does this change mean for me and my benefits.” The more meetings were structured such that consumers had an opportunity to address this core question, the greater their understanding of the system change overall.

E. Advocacy Presence and Views

Advocacy presence was prominent and effective in promoting consumer involvement. As mentioned in Chapter IV, advocates played a major training role, especially initially through the Consumer Training Corps. Advocacy for elders and for people with disabilities has a lauded history in Wisconsin, represented primarily through the Coalition of Wisconsin Aging Groups and Disability Rights Wisconsin. Both organizations are recognized for their representation of consumers at the local and state level, including a strong presence with the state legislature. Historically, advocacy for aging and disabled persons had operated in somewhat parallel universes. However, long-term care reform sparked unprecedented collaboration between leadership of the two groups, bringing strong consumer representation to the foreground, especially at the state level. As one advocate pointed out, “In Wisconsin, the leadership of Family Care, both past and present, knows that consumers and advocates are silent partners, because without them nothing will happen.”

At the State level, and particularly active at the local level, leadership from Wisconsin Independent Living Centers played a major role in ensuring strong consumer representation. This was especially true in large metropolitan areas. As expressed by one advocate, “We were politely in their face.” As with training in general, UW Extension staff also played an important role. One interviewee expressed, “UW Extension staffs were like ‘traveling correspondents,’ engaging with consumers in multiple counties.”

Advocates expressed a range of opinions as to the success of involving consumers in the planning process. One advocate stated that “consumer involvement in at least some of the counties was ‘extremely successful,’” while another described it as “leaving much to be desired.” Revealing the maturity of advocacy leadership in Wisconsin, one advocate stated, “With hindsight, I think we focused too much on the numbers of consumers at the table. There’s a big difference between quantity and quality. We need both.” Another advocate revealed what might be a harbinger of change relative to the meaning of consumer involvement when he stated, “Prior to the reform effort, there was an emphasis on getting ‘real’ consumers involved in the process. This was very difficult. Some of these people were struggling to get through their day rather than making a meaningful esoteric contribution. Now, I think an actual consumer is not as important as an advocate or other representative of consumers.”

Other stakeholders frequently lauded the work of the advocates. As stated by one interviewee, “Facilitating meaningful consumer involvement requires hard work, time, extensive advance planning, and is a collective responsibility. Advocates were invaluable in assisting in this process.”

F. Variation among Consortia

Interview data attested to great variation in consumer involvement between consortia. Many attributed this to a particular county’s long-term care history and the attitudes of county planners. This theme was particularly salient in interviews with MCO Directors. One director pointed out that “consortia that are developing their system from scratch will have more consumer involvement.” Another director substantiated this by saying that planners “focused much more on consumer involvement when they were first developing Family Care,” referring to the Family Care pilot experience. He continued, “Much of our planning time was devoted to developing an intergovernmental agreement, an overall process that the board did not feel lent itself well to consumer involvement.”

A major factor that affected consumer involvement, particularly in two urban counties, was the manner in which people were transitioned from COP waiver services to Family

Care. In order to expedite the transition of large numbers of people in one county, the State approved “rollovers” without requiring the individual options counseling that is the norm.

According to another MCO Director, it was often the case that the consumers who participated had a long-standing relationship with the county and were involved in issues other than Family Care prior to long-term care reform. He said, “To include consumers, we built upon what we had.” Many directors made it clear that it took a lot of time and effort to involve consumers. However, a consistent theme was that they never stopped trying.

G. Other Stakeholder Involvement in the Planning Process

1. Background

Wisconsin DHS defined stakeholder groups to include consumers, their families and information supports, services providers and their employees, care managers, program administrators, county and tribal agencies and their employees, county and tribal governments, social service agencies, health care providers and advocates.¹

Consumers, conventionally considered stakeholders in the long-term care arena, were addressed separately in this report due to their high profile in the grant proposal. Here we focus briefly on other-than-consumer stakeholder involvement in the planning process, with a particular look at case managers and providers.

2. Consortia Outreach to Other Stakeholders

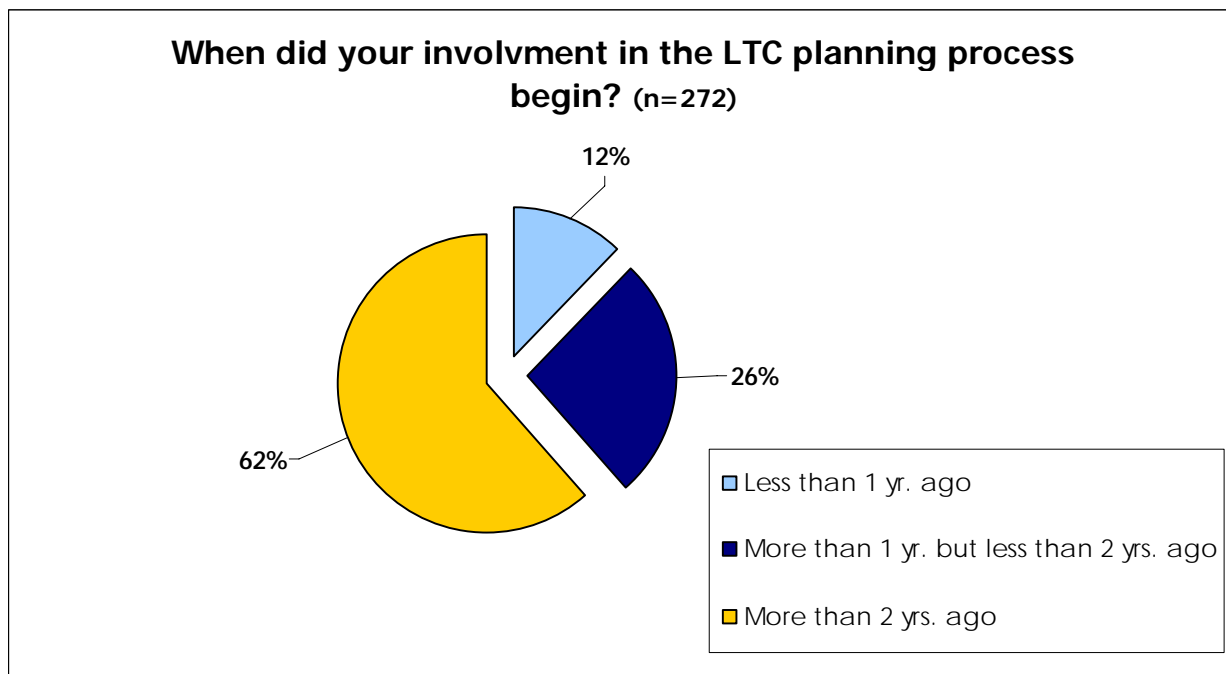
Many consortia conducted stakeholder assessments and contracted with the UW Extension for assistance with stakeholder identification, involvement, and communication. Consortia regularly held information meetings and forums that were open to the community at large to help ensure stakeholder input. The previous sections of this chapter attest to the many strategies employed to engage consumers. Many of these same strategies were used to invite other stakeholders to the table. Interviewees confirmed over and over that stakeholders across Wisconsin dedicated innumerable hours and energy to the reform effort through their participation in the planning process.

The stakeholder survey conducted by the APS evaluation team confirmed the amount of time involved in planning, reflections on the planning process, and

the willingness of stakeholders to participate again. In the survey analyses included in the charts below, “stakeholder” refers to advocates, county staff and directors, Family Care MCO and Partnership organization directors and staff, providers, and some state staff (Of the 446 respondents, 25 State staff who were involved in planning took the survey). The analyses also included a few respondents who identified themselves as consumers. These consumers were included in the “advocates” category.

When asked how they learned about the planning process, 73% of stakeholders reported that they learned about the planning process through their job. The most commonly cited means of participating in the planning process was through participating in planning meetings (75%). The majority of stakeholder respondents had been involved in planning for an extended period of time. Regardless of their role, 62% reported having been involved in planning for more than 2 years (Figure 10).

Figure 10 – Beginning of Involvement with the LTC Planning Process



3. Stakeholder Reflections on the Planning Process

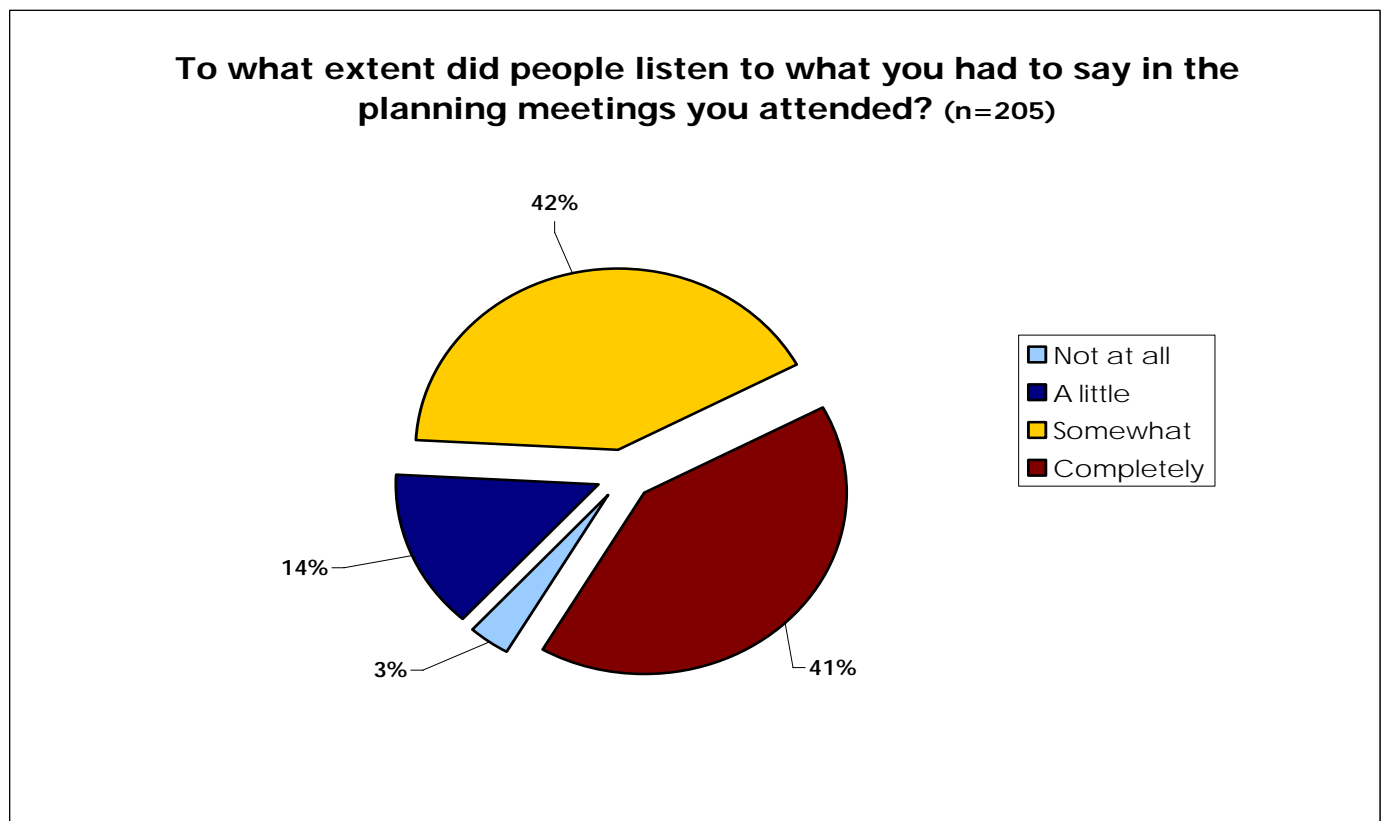
In general, county planners held a more positive perception of the consumer role in the planning process than that held by consumers. Specifically, county planners were more likely than consumers/ advocates and providers to

indicate that consumer involvement was “somewhat” or “completely” meaningful.

Two measures of involvement were the ability to ask questions and to feel heard. County planners were significantly more likely to report having had “ample opportunity” to ask questions about the proposed LTC changes (70%). This stands in contrast to 50% of consumers/ advocates who reported having had “ample opportunity” to ask questions.

In response to whether people listened to what they had to say in the planning meetings, over 80% of all groups responded “somewhat” (42%) or “completely” (41%). Figure 11 summarizes these data.

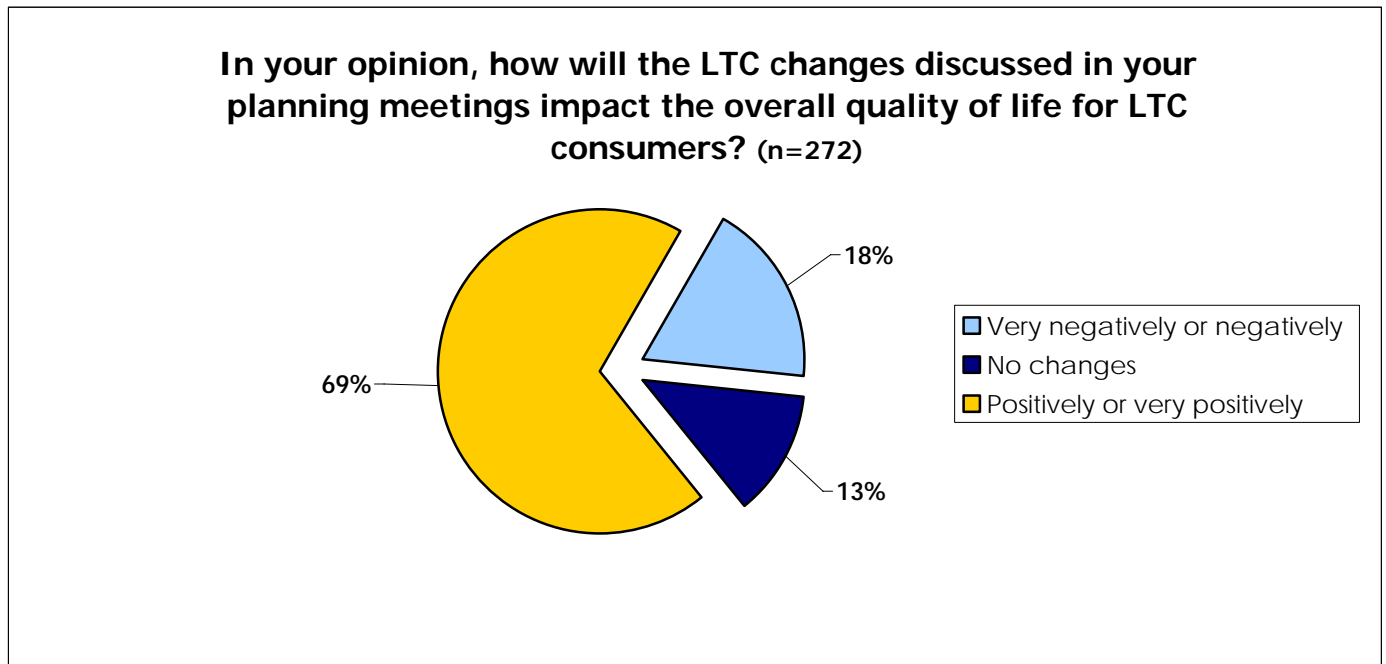
Figure 11. Extent to Which People Listened in Planning Meetings



Interviews with county, MCO, and ADRC staff consistently highlighted stakeholder concerns for the quality of life of Wisconsin long-term care consumers. Survey findings showed that 69% of respondents felt that the

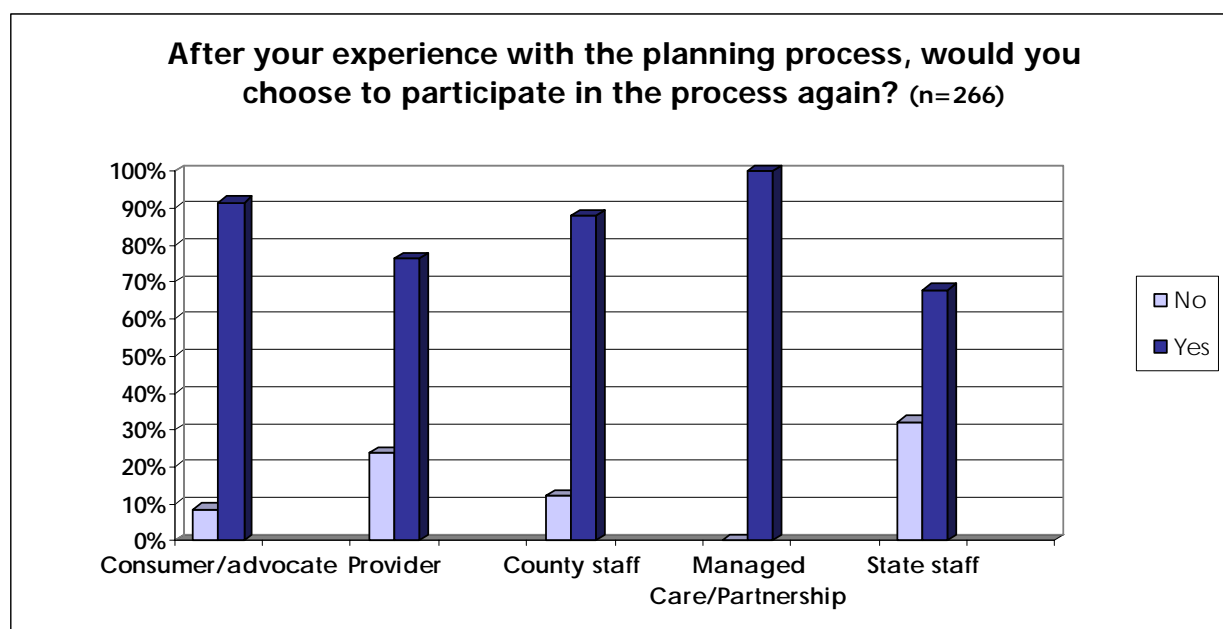
long-term care changes would affect consumer quality of life “positively” (55%) or “very positively” (14%) (Figure 12).

Figure 12. Impact of Planning Meetings on Quality of Life for LTC Consumers



The stakeholder survey also queried whether or not stakeholders would participate in the planning process again (Figure 13). Significant differences emerged between stakeholder groups. Providers (76%) and state staff (68%) expressed less willingness to participate in the planning process again than consumers/advocates (91%), county (88%) and Family Care / FC Partnership (100%) planners.

Figure 13. Percentage of Stakeholders Willing to Participate in Planning Process Again



4. Stakeholder Motivation/ Barrier to Involvement

Stakeholders were motivated to become involved in the planning process for many reasons. However, four factors emerged from the stakeholder survey as the primary motivators for involvement: two individual level factors and two system level factors. Primary motivators were defined as those factors that were selected as “very important” in response to the survey question. Evidence collected during stakeholder interviews supported the stakeholder survey findings.

On an individual level, 90% of stakeholders reported “quality of care for consumers” as a “very important” motivator. “Continuity of care in transition to managed care” was the second most frequently reported “very important” motivator (70%). Stakeholder interviewees consistently reported being motivated by the desire to improve members’ lives.

In addition to the individual level factors, systems level motivators were also identified. Eighty-two percent (82%) of stakeholder respondents reported “amount of funding available for LTC” was a “very important” motivator for involvement. Sixty-eight percent (68%) were motivated by “ending waiting

lists in Wisconsin". One stakeholder summarized the idea of ending waiting lists as "very enticing". Another described an "unending dedication from the people involved to get Family Care right." A third stated that "the ultimate motivator is to appeal to the best in people – that they really desire to better the lives of the consumers."

In addition to the themes cited above, another common theme that emerged during stakeholder interviews as a motivator was the idea that they had to become involved or be left behind. Some stakeholders acknowledged that they thought long-term care system reform was going to happen whether they liked it or not, and by becoming proactively involved in the planning process they would have more control over the changes that occurred in their regions. For example, one Wisconsin county was initially very resistant to the impending reform. However, after realizing the change was really going to happen, decided to get involved and became one of the first counties to "roll out" Family Care.

While there was more emphasis and discussion on motivation for involvement, the most frequently mentioned barrier to involvement was the large amount of information stakeholders needed to learn for effective involvement.

5. Case Manager and Provider Involvement in Planning

Case managers are a stakeholder group dramatically affected by the changes in the Wisconsin long-term care system. However, despite their pivotal role in the provision of long-term care services, few case managers reported being involved in its planning. This created a gap between those most directly involved with the consumers and those facilitating and directing the planning process.

According to interviews with case managers, the norm was that case managers were rarely at the planning table. It may be that their interests were represented by ADRC and MCO supervisors. As one supervisor reported, "I was always at meetings, and I always went back to my staff and shared any new information." Another supervisor said that, in her county, she felt that she "had a voice, was kept informed, and was heard at every level. This allowed my department to be very comfortable with the transition." Nevertheless, many case managers themselves reported being short on information about what was happening with the planning process. According to several case managers, some county directors/ managers were diligent about sharing

information with their staff, while others shared very little. As one case manager stated, “Human Service Directors communicated very differently. The transition went much more smoothly in the counties that made an effort to communicate information.”

The degree and tone of education and information was a strong factor in case managers’ buy-in. Case managers noted that receiving little information about the changes fed fears of the unknown, of changing or losing jobs, and of the system changes in general, while the opposite was also true. As reported by one case manager, “Our department head held regular meetings with the entire department to address fears and rumors. This was helpful in mitigating staff fears.”

Like many case managers, providers did not feel well-represented in the planning process. Consortia reports showed that provider forums were held, especially initially, and as with consumer involvement in planning, provider involvement saw varying degrees of success across consortia. One consortium report noted limited involvement by providers early in the planning process, but with targeted outreach providers did become more involved. One provider made the distinction between provider organizations at the planning table in lieu of field providers, i.e., “the people who do the work.” She pointed out that it was important that planners “be cognizant of not assuming that a representative from an association understands how issues play out in the field. Finding the appropriate people to get involved is not simple, but it is vital.” Another provider commented, “Providers are still figuring out what Family Care means for them and the impact that Family Care is going to have on their business.” Providers pointed out how managed care impacts every area of a business, and few understand many of the specifics at this stage of the game. For example, previously, no one had to know how people were funded. With Family Care, it is very important to know the funding source because it changes the care options. In a provider interview, one provider noted that, in the assisted living arena, there is lack of clarity about what constitutes room and board and that, in general, “there is lack of clarity among providers as to what is covered and not covered.” One consortium reported that smaller businesses had an easier time adapting to the new system than larger businesses.

H. Conclusion – Consumer and Stakeholder Involvement

In summary, the consumer survey and stakeholder interviews elucidated a variety of themes related to the role of stakeholders in long-term care planning. Specific themes that emerged included that:

- There were a range of perceptions concerning what constituted meaningful consumer and stakeholder involvement. To some, it meant knowing they were well represented at the table; to others it meant having a singular vote on decisions.
- Level of consumer involvement was highly dependent on county history and the priority it was given by county project managers and decision-makers.
- Obstacles to consumer involvement could be identified and addressed throughout the process, and obstacles could be entirely prevented with early and thorough planning.
- Early and continuing education was a must in order to ensure knowledgeable and consistent participation from consumers.
- Designing meeting formats to address pragmatic questions like “What does this mean for me and how will it affect my benefits” was critical to building a consumer constituency that supported the project.
- Having well-versed, knowledgeable consumer representation could be as important as having multiple consumers present.
- Going directly to consumers was one of the most effective ways to garner meaningful consumer involvement.
- Many case managers and providers were not as involved in planning as they would have liked, or as would have been helpful to them and the reform effort.

VI. Improving Consumer Access to Information

Goal 2 of the comprehensive systems change grant was to improve systems for consumer access to information on long-term care. The goal had four objectives:

1. Create an internet-based virtual resource center;
2. Provide information statewide to assist consumers in understanding their LTC choices;
3. Plan and implement a statewide network of Aging and Disability Resource Centers; and
4. Implement successful evidence-based prevention and early intervention strategies.

This chapter reports on each of the aforementioned grant objectives, with special focus on the ADRC expansion process. Key outcomes and issues associated with each topic are addressed. (Quality outcomes and issues are addressed in Chapter IX, Quality and Cost.)

A. Virtual Resource Center and Information Campaign

Per objectives laid out in the grant proposal, Wisconsin planned to implement an internet-based information source called the virtual resource center (VRC) for aging and disability issues and services. DHS completed initial activities for launching the virtual resource center during the first year of the grant, including needs assessment interviews and preparation of the technical requirements documentation. During the second year of the grant, a prototype was developed and tested. However, after that point, public rollout was deferred indefinitely¹. State staff interviewed hinted that the project may be revived after statewide “roll-out” of managed long-term care, while others held out little hope for its completion.

A number of formidable factors led to the stall in progress. A primary factor mentioned by State staff was that implementation of the “real” resource centers became a driving priority. This led to the loss of urgency for further work on the virtual resource center. State staff also pointed out the difficulty of accomplishing a truly user-friendly design, let alone establishing and maintaining the virtual center. An additional difficulty was hiring staff skilled in translating health program and policy language in a manner that matched the level of consumer health literacy. This was coupled with the challenge of regularly updating and linking external content to tightly controlled DHS web resources.

Although the virtual resource center project was not completed during the grant period, the experience and groundwork provided an opportunity to pursue a virtual resource center for the newly created Wisconsin Department of Children and Family Services. In the meantime, DHS learned many lessons about the complexity of gathering resources, whether they be staffing, fiscal, or information-based, needed to create and maintain a large information base in language accessible to consumers.

The State also developed many tools to communicate with stakeholders about the planning and expansion process. These tools included interactive webcasts, listserv communications, press releases, training programs on DVD and CD-ROM, and a website dedicated to LTC systems change. DHS also engaged consultants (for example, The Management Group) to gather planning and implementation tools produced by the 10 planning consortia. These tools were then posted to a website where they could be accessed by stakeholders across the state.¹

B. Aging and Disability Resource Centers

1. Background

Purpose. As introduced earlier in this report, Aging and Disability Resource Centers (“resource centers”) are visible and trusted county-based “one-stop shops” that consumers and their families can contact or visit in person for information and assistance regarding all of their long-term care needs. According to the Resource Center Expansion Committee of the Wisconsin Long-Term Care Council, one of the primary goals for ADRCs is “to keep people healthy for as long as possible to decrease their need for publicly funded long-term care”².

ADRCs provide information and assistance, early intervention and prevention, options counseling, and information on community resources^{2,3}. ADRCs also administer the long-term care functional screen and begin the enrollment process into publicly-funded LTC. ADRCs are required to offer a full array of services by the end of their first year of operation. These core services are defined in the contract between the State and each ADRC⁴.

History. The history of the ADRCs is described in terms of generations. The first generation of ADRCs were opened in nine counties in the years 1999 and 2000. Five of these counties began enrolling consumers in pilot Managed Care Organizations in 2000 and 2001⁵. The second generation of ADRCs began planning prior to the grant period, and opened during the grant period.

These second generation resource centers were open for a substantial amount of time before managed care expansion came to their respective counties. The third generation of ADRCs was planned during the grant period and managed care expansion. Generally speaking, the third generation ADRCs are opening on a timeline that is tightly linked to enrollment into a managed care organization^{6, 7}.

Funding. DHS was awarded two federal grants in 2004 that were used to fund county planning of ADRCs, one from CMS, the other from the U.S. Administration on Aging (AoA)^{8,9,10}. State staff indicated that additional funding for some ADRCs was secured for prevention and early intervention studies. The comprehensive systems change grant provided funds for county Family Care expansion planning grants. Planning consortia that received planning grants were required to plan for the development of ADRCs in areas within their region where there was no ADRC coverage. CSC grant funds were also used to contract with an ADRC consultant who was available to assist counties planning ADRC expansion. State staff confirmed that CSC grant funds were not used for ADRC start-up or operational costs.

State level planning. ADRC planning initially revolved around state-level efforts to shape the developing network of resource centers. The first accomplishment in this area was the establishment and subsequent work of the Resource Center Expansion Committee of the Wisconsin Long-Term Care Council. This committee was charged with developing ADRC standards. The committee researched core policy and procedural questions such as “What should the ADRC governance model be?” and “What services should an ADRC offer?” The committee met from January 2004 through February 2005 and produced a vision for ADRCs based on the system reform goals of access, choice, quality and economy. A document outlined and defined services that should be offered by Wisconsin ADRCs, and was approved by the Long-Term Care Council. The defined services became a fundamental part of the State ADRC contract.

2. Primary Outcomes

The expansion of ADRCs is a Wisconsin success story. The planning that occurred as a result of the expansion process resulted in three key outcomes: extensive policy development, the ADRC contract, and ADRC implementation.

a) Policy Development

One of the major accomplishments of the ADRC planning process was the development of statewide ADRC policies and procedures. The development of these policies took considerable time and effort, and shaped the role of both existing and new ADRCs. Although the ADRC vision and core services was contained in the Long-Term Care Council Resource Center Expansion Committee Final Report, DHS responded to a number of ADRC planning and implementation issues as the expansion process progressed. These issues were addressed through a series of eighteen information memos that were posted on the ADRC website between April 2006 and February 2008. The information memos clarified ADRC functions, proposed governance structures, advised the formation of multi-county ADRCs, discussed funding and budgeting, and clarified operational policies. Timely and clear policies on these matters were necessary to achieve standardized services across the State.

b) ADRC Contract

The development of the ADRC contract was another major deliverable of the planning process. The contract defined State and county responsibilities. It also addressed the purpose of the ADRC, defined its target groups, and gave directions for the physical requirements of the ADRC. The contract detailed each service that the ADRC was to provide. These core services were presented in Chapter IV, Strategic Planning for Statewide Implementation. The contract addressed many organizational and procedural requirements that the ADRC must follow, and served as the basis for further ADRC policy development. Most importantly, it provided the parameters for continued ADRC expansion during the grant period.

c) ADRC Planning and Implementation

The planning and implementation of a statewide network of county-based “brick and mortar” Aging and Disability Resource Centers became the focus of Goal 2. In this area, the State achieved dramatic results. As of November 2008, 28 ADRCs were serving 38 of Wisconsin’s 72 counties. This was an increase of 19 ADRCs over the original nine that were piloted beginning in 1999 and 2000. Wisconsin ADRCs currently serve nearly 70 percent of the state population, and additional ADRCs are scheduled to open in 2009¹¹.

3. ADRC Planning Issues

a) Prioritization of Managed Care Planning

Contacting an ADRC is the first step in the managed care enrollment process. Therefore, State policy required that ADRCs be in operation prior to managed care organizations. As a result, the ADRC planning agenda was driven by managed care planning. As mentioned earlier, the State built the ADRC planning agenda into the managed care expansion planning grants which required planning consortia to coordinate with the ADRCs in their geographic locations. To address ADRC planning, managed care planning consortia convened ADRC committees to plan for implementation of ADRCs in counties where they did not yet exist¹².

The APS evaluation team convened group interviews of directors and supervisors at the November 2008 ADRC Directors' Meeting in Madison. A number of interviewees expressed that planning for managed care was the total focus of their consortia. They also stated that "ADRC planners were not welcome at the table."

Clearly, not all accounts of the role of resource centers in the planning process were negative. One example of positive collaboration was in Waukesha, where one of the ADRC supervisors said joint public meetings were held, allowing ADRC planners and MCO planners to address concerns that were relevant to each organization. Interviewees who worked in established ADRCs said that their counties were able to have stronger leadership in Family Care expansion consortia and they were able to meet with managed care planners early in the planning process to develop more comprehensive plans.

b) Effects of Managed Care Planning Prioritization

A clear example of how the prioritization of managed care held ADRC planning back was seen in the Dane and Rock counties planning consortium. According to the final grant report of the Dane and Rock counties consortium, "Currently, the Rock County ADRC planning efforts are put on hold until the fiscal issues with regard to Long Term Care Reform are resolved with Dane and Rock Counties." However, ADRC planning continued in the subcommittee tasked with development for these two counties. Much progress was made in the planning of two separate county-based ADRCs. The consortium final report, issued in September 2008, stated that the ADRC Subcommittee had completed its

tasks as of June 21, 2007 and suspended meetings¹³. But, according to Dane and Rock county Departments of Human Services leadership interviews, ADRC planning had been halted because managed care planning was not progressing. “The ADRC Subcommittee felt that it had gotten as far as it could go in its planning without knowing what the managed care organization structure would be.” Dane, the second largest county in the state, has no planned ADRC start-up date.

Some stakeholders felt that the planning and implementation of ADRCs could have been faster had they not been tied to MCO planning. As expressed by one advocate:

ADRCs should have been developed ahead of the MCOs. Wisconsin had working models of ADRCs, we knew what they looked like. All 72 counties should have ADRCs in place, developed at the local grassroots. They could blend into whatever came in terms of the managed care organization.

c) Planning Time Frame

The change in focus from planning to implementation directed by the Governor prompted many to feel that the ADRC planning process was occurring too quickly. Some ADRC supervisors felt otherwise, though. One said, “It wasn’t really about the amount of time available. Operations always require adjustment to unforeseen factors.” In a meeting with ADRC supervisors, a common theme was that no amount of planning time would be sufficient to address all factors. Rather, many members of this group felt that continuous planning efforts were required for ADRC implementation. Others stated that once the ADRCs came online, they had to jump immediately into work and planning and optimization of services were left behind.

d) Local Planning Resources

Local ADRC planners told APS interviewers that they felt they did not have sufficient funding and support for planning and implementation. Some ADRC Supervisors said that the first and second generation ADRCs were well funded. However, they noted that the comprehensive systems change grant funds were dedicated to managed care development, making it a challenge to dedicate personnel to the task of ADRC planning.

e) Politics Stood in the Way of Creating Something New

The effort to create new ADRCs involved the consolidation of several public services into a single entity. A number of interviewees said that politics and internal power struggles within county government were a barrier to effective planning. Individuals were constrained by thinking in terms of the organizational arrangements with which they were comfortable. As one ADRC supervisor suggested, “the planning process wasn’t just about rearranging chairs. A facilitator, contracted by the county through DHS with grant funds, was helpful to more than one planning consortium in resolving difficulties working with the new concept of a consumer-focused, one-stop shop. As the ADRC supervisor said, the facilitator helped planners “put away [their] county hat and put on a regional hat.”

4. Policy Specific Issues

a) Policy Development

As mentioned earlier in this chapter, ADRC planning at the State level was a fluid process that resulted in the creation of an extensive DHS informational memo series that updated policy statements as time went by. The lack of clear direction from the State at the outset of the process led to frustration among some planners who felt that they were forced to make up policies and procedures as they went along. One respondent to the APS stakeholder survey advised the State to “develop consistent policies and procedures prior to the start up of ADRCs. Counties were flying by the seat of their pants on most of this stuff.” Others had a more collaborative view of the process, including one ADRC Directors’ meeting participant who said, “I’ve never been embarrassed to ask questions of State staff. They are big enough to admit ignorance.” This type of collaboration led to the policies and procedures that are in place today.

b) Governing Board Composition

Wisconsin statute and ADRC contracts specified that governing boards must give consumers voice in the governance of ADRCs, and that at least one-quarter of the board be consumers^{4,14}. The governing board is accountable for a number of specific functions of the ADRC, including hiring, budget, mission statement and grievance functions¹⁵. Several interviewees expressed concerns about ensuring the independence and effectiveness of governing boards. One advocate said that it was

unacceptable to have governing boards functioning merely as advisory boards that lack decision-making authority.

5. Implementation Issues

a) Start-up Time Frame

ADRC planners faced many challenges in the process of opening and optimizing new services. Similar to planning issues, much of the difficulty was aggravated by the tight timeline for MCO enrollment beginning shortly after ADRC opening. The ADRC application process and timeline stipulated that ADRCs must open two months prior to the associated MCO⁶. This was consistent with the DHS expansion cost model that allowed only for a two-month gap between ADRC opening and the MCO beginning enrollment. The State developed an ADRC readiness tool to help ADRCs determine when they were primed for implementation. For more detailed information, see the DHS document “Timeline for Transition to Managed Long-Term Care”¹⁶.

At the heart of the reformed long-term care system is the shift from thinking in terms of services to thinking in terms of outcomes. This was an easy shift for some, difficult for others. For successful implementation, it is a perspective that must be adopted by all who work in managed care. It presented a particular challenge for ADRC Options Counselors who, because of staggered Family Care enrollment, found themselves working with both Medicaid Fee-for-Service Waiver recipients at the same time as Family Care consumers. According to ADRC supervisors, this complicated the psychological transition out of the “waiver world” and development of a counseling style completely consistent with the goals of Family Care.

6. The Intersection of the Aging and Disability Resource Centers, the Economic Support unit, and the Managed Care Organizations.

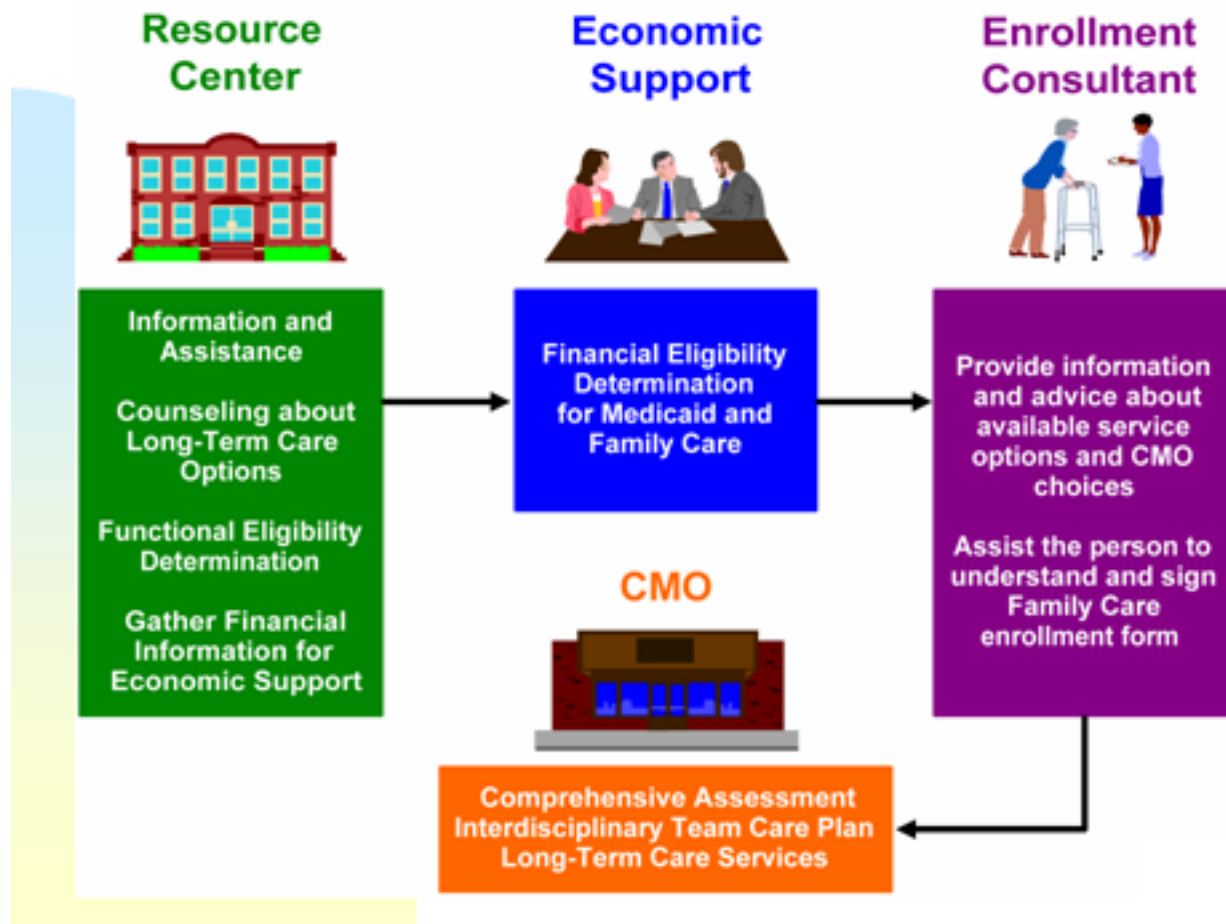
a) Finding Balance

Determining the best and most functional balance between the activities of the ADRCs, the Economic Support unit, and the managed care organizations (“CMO” in Figure 14 below¹⁷) was a consistent focus of policy development and staff discussion during the grant period. A core concern was that of maintaining the independence of each entity while at the same time recognizing and honoring their interdependence.

Interviewees frequently made reference to the image of a three-legged

stool, with each entity representing the unique function of each leg on the stool. Challenging this image in practice was the backlog of financial eligibility determinations of the Economic Support unit, and the dominance of processing initial transfers to the managed care organizations by ADRC staff at the expense of other ADRC functions.

Figure 14. Balance of ADRC Activities



Note: As indicated in the Figure 14 above, if a County operates both an ADRC and an MCO, enrollment counseling must be provided by an independent enrollment consultant, unless adequate structural separation between the ADRC and CMO is demonstrated to the State. In most cases, the enrollment consultation function is performed by the ADRCs, not by a separate enrollment consultant.

b) Organizational Separation between ADRC and MCO

Federal regulations require organizational separation between resource centers and MCOs to ensure independence and to avoid conflict of interest^{18,19}. According to the Resource Center Development Information Bulletin on organizational separation, “Any county agency that is a

managed care organization or is assuming full or partial risk for a managed care consortium cannot also serve as the Aging and Disability Resource Center.”

Some interviewees expressed concern that there was not enough separation between ADRCs and MCOs. To address this concern, the State designed a policy permitting the following organizational options:

- The county is an ADRC but not an MCO;
- The county is an MCO but not an ADRC;
- The ADRC and MCO are separate agencies within county government;
- In counties where there is more than one MCO and the county operates both the ADRC and one of the MCOs, the ADRC and county MCO must be separate agencies and there must be an independent enrollment consultant to ensure that prospective enrollees receive objective and unbiased information from the ADRC.

c) Strategies for ADRC/ MCO Interaction

Communication and collaboration between ADRC and MCO staff is essential to ensure the smooth functioning of the LTC system. Regular communication between the organizations to determine inter-agency policy and relay intra-agency policy information proved vital to successful implementation. The State requires an MOU between the ADRC and MCO which delineates each organization’s responsibilities in certain areas, for example, the handling of Adult Protective Services. A number of interviewees stated that there had been difficulties in this area, while providing solutions based on their experience. Specific strategies mentioned by ADRC supervisors and directors for working with MCOs included:

ADRC and MCO management policy retreat. One ADRC supervisor said that after start-up, the MCO and ADRC encountered policy issues that needed clarification. Finding it inefficient to work on these issues in normal work environments, a day was agreed upon for a policy retreat. Supervisors from the ADRC and MCO set aside other work and spent a day off-site drafting policies necessary for effective collaboration.

Written communication tool. Another ADRC developed a written communication platform with the local MCO. A supervisor from the ADRC said the tool provided up-to-date policy information in an efficient and clear manner.

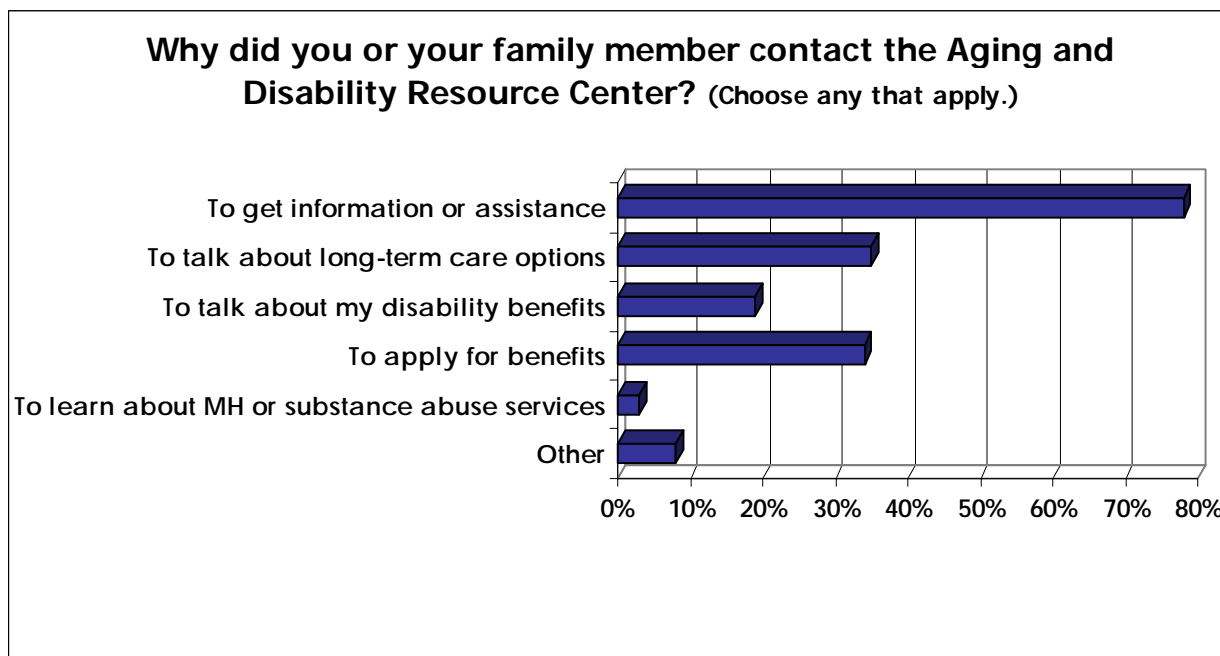
Request for state clarification or decision. A third ADRC supervisor mentioned that they worked with the MCO to develop procedures for maintaining functional screen quality. When they had disagreements, they consulted with State staff for interpretation.

d) ADRC Service Balance

ADRCs are responsible for providing a wide range of services. However, ADRC staff strongly communicated that ADRC functions involving the managed care enrollment process consumed far more resources than anticipated. One ADRC supervisor said, “During Family Care enrollment, you might get the impression that that is all that an ADRC does.” Another ADRC supervisor stated, “It felt like the piece of enrollment eligibility was the tail wagging the dog. It is supposed to be only 25% of your services.” Even some managed care stakeholders suggested that ADRCs needed the opportunity to provide a better balance of services. As one MCO Director stated, “The ADRCs should focus on options counseling and prevention. ADRCs should have started earlier, because their whole effort has become getting people into the MCO. This should ultimately only be 20% of their responsibility.”

Figure 15 shows that 78% of those who contacted ADRCs did so for information and assistance services, while 34% contacted the ADRC to apply for any one of the many services provided by the ADRC.

Figure 15. Reasons Given for Contacting ADRCs (by percentage)



e) Economic Support Issues

Several stakeholders brought up concerns with the current state of the Economic Support unit. One ADRC representative stated that “[Economic Support] is really bad. It is a 20 year old system that badly needs to be updated. It is like a horse-drawn carriage in the space age. Other processes have been redone from bottom to top, but IM has not been updated.” A common theme voiced by interviewees was that more Economic Support workers were needed. Some ADRC staff said in interviews that they occasionally complete paperwork that would otherwise be done by Economic Support staff because it was necessary to prevent these clients from losing services.

7. ADRC Core Service Issues

a) Importance of Information & Assistance

According to the ADRC Information Bulletin on Planning for Information and Assistance Service, the “core service of the Aging and Disability Resource Center (ADRC) is Information and Assistance (I &A). Approximately 80% of all contacts made to ADRCs do not result in a referral for government programs and services, and do not involve the traditional intake process²⁰.”

The Bulletin continues, “Information and assistance is a professional service provided by ADRCs to the public. I & A ranges from sharing information to responding to requests to in-depth conversations that take place over time regarding an individual's concerns and challenges. An ADRC professional can leverage emergency services and funds to help clients through difficult, one-time, situations. When appropriate, clients are internally referred for adult protective services, benefit specialists or long-term care options counseling.”

The 2007 ADRC report²¹ included success stories that provided a poignant example of the value of I & A services. The report includes the story of a senior receiving Medical Assistance who “spoke to information and assistance staff at the ADRC. He had been on a waiting list for over two years to be seen at a dental clinic. I & A staff were able to put him in touch with a dentist who was accepting Medicaid beneficiaries and would see him in a week. This client was fitted with dentures necessary for him to eat properly.” This story is a classic illustration of how information and assistance, offered through ADRCs, links clients to community resources and enables clients to access the services they need.

b) Marketing and Outreach

ADRCs were developed with public outreach as a priority. ADRCs aim to become effective community resources that consumers utilize in a manner consistent with prevention and early intervention. To achieve this, the ADRC must market itself to the public and to potential collaborators. ADRC marketing aims to educate individuals and organizations of the functions of the ADRC, and to convince them that the ADRC is competent and provides valuable services. There was concern among advocates that this core function is not meeting expectations.

There was the expectation of visibility and outreach from ADRCs. Some of the original ones did this, but recent ones are falling behind. The screening for MCOs is taking precedence over everything else. This is throw-back to the waiver program. At that time they were not doing assessments because there was not enough money. Currently there is more and more assessing, less and less outreach.

A number of ADRC supervisory staff spoke of the need for better internal outreach as well. Government agencies and offices not actively involved

in the development of ADRCs may not understand the function of ADRCs. One ADRC Supervisor highlighted the importance of familiarity of county employees with the ADRC in order to correctly refer constituents to the centers. As a result, this ADRC Supervisor stated that their “outreach included all county agencies, including the county clerk’s office.” Another said that outreach was needed because it was “commonplace for people who found out about the resource centers to refer people to the ADRCs from outside the target client groups or for services not provided by ADRCs, such as food services.” The interviewee found that this education was important to keep the ADRC from becoming a “dumping ground” for work or clients that other agencies didn’t wish to deal with.

c) Options Counseling

Description. Options counseling is a specific form of information and assistance that ADRCs provide to help clients navigate the options and benefits available in Wisconsin’s publicly funded long-term care system. It is a key component of the reformed LTC system. The important role played by options counseling was described by a disability advocate when he said:

When I first heard about options counseling, that is when I got excited. The options counselor could be someone to help the consumer start thinking differently about their services, familiarize them with SDS and get them excited about achieving their outcomes.

Options counselors work with consumers to help them understand each long-term care option and give them the information they need to make an informed choice. In managed care counties, there are three main long-term care benefit programs available to consumers: Family Care, Family Care Partnership, and IRIS. In counties with more than one MCO, choosing the correct benefit becomes even more challenging.

Preventing bias. An essential but difficult task for options counselors is to provide a non-biased view of each possible choice. Some stakeholders expressed concern over the ability of options counselors to provide impartial advice. One respondent to the stakeholder survey wrote:

“My only concern is that consumers really do receive the options counseling, and are not “encouraged” to do what is

easiest for the person they are working with. Everyone should be entitled to their own decision, and given the knowledge they need to be able to follow through and be successful in what they have chosen.”

To prevent bias, DHS advised options counselors to avoid discussing potential changes in consumer affiliation with MCO care managers because such a personal change could affect consumer program choices²². (The process for enrollment of Family Care or IRIS members is outlined in Volume 1, issue 1 of Resource Centered, a Wisconsin ADRC technical assistance bulletin^{2, 4}.

Provider networks. At the interview held at the ADRC Director’s Meeting, a number of interviewees said they were not able to provide complete options counseling due to incomplete provider networks in some MCO plans. These supervisors emphasized that in the area of options counseling, MCO problems quickly become ADRC problems. These interviewees held that their staff were unable to advise clients on Family Care enrollment when provider networks were incomplete. They said that it would reflect poorly on them if they advised clients to enroll in this situation. These comments indicate that regular updates of MCO policy and networks would be necessary for ADRCs to effectively counsel consumers.

Staggered enrollment. It is difficult to provide adequate options counseling when all existing waiver clients transition to managed care at the same time. To address this problem, DHS designed transition plans to spread enrollment of current waiver participants over the first six months and waiting list consumers over the first 24 months of managed care operation^{16, 23}. Staggered enrollment of this kind alleviates the impossibility of providing options counseling for the entire population all at once.

County case managers. Several stakeholders, including advocates, expressed concern that the State has allowed some counties to use current county case managers to provide options counseling, instead of ADRC options counselors, for individuals rolling over into managed care from waivers. This has become an issue because although county case managers were experienced in the fee-for-service waiver system, they were new to managed care. As stated by one advocate, “If you’re dealing with same-old same-old, you are going to get same-old same-old.” An

MCO Director shared this opinion and said, “The options counseling by county case managers has not been strong. ADRCs have done a better job, but they are not dealing with the numbers of people transitioning from the waivers county case managers must be strong – these are the critical link, and the system wasn’t very strong.” This interviewee went on to say that “county case managers have not received the necessary training to fully embrace the managed care system and provide adequate and unbiased information.”

Training. ADRC directors and supervisors indicated that options counselors received initial training from the State, but that the training was not consistent between ADRCs. Interviewees said that they were trained, but that once was not enough. They stated that on-going training was needed to deal with the increasing complexity of options counseling.

Self-Directed Supports. There is increased emphasis on self-directed supports in long-term care. Self-directed support is a key component to increase consumer independence and honor consumer choice. The particulars and issues associated with the Family Care self-directed support option and its complement in the fee-for-service system, IRIS, are discussed in Chapter VIII, Increasing Service Options within the Context of Long-Term Care Reform.

d) Disability Benefits Specialists (DBS)

As a result of the ADRC planning process, the services of Disability Benefits Specialists are now a core ADRC function. Disability Benefit Specialists provide advice on how to apply for services and assistance, including SSDI. According to State staff interviews, the demand for DBS services was underestimated. Several ADRCs employ DBS staff on a part-time basis, or share one person between two or more ADRCs.

8. ADRC Conclusion

Wisconsin made substantial progress in the area of planning and implementation of ADRCs over the course of the grant period. State policies and tools guided and assisted ADRC planning committees in their considerable work. The role of the ADRC, its core services, and its relationship to other government entities was clearly defined in the ADRC Contract. As a result of the planning efforts, 19 new ADRCs were implemented during the grant period.

Lessons can be learned from the ADRC expansion experience in Wisconsin. One clear lesson was that pressures to reform other components of the long-term care system compromised the growth of the ADRC network. ADRCs benefit both the government and the community by preventing reliance on public long-term care. An important role of the ADRCs is to assist consumers in accessing appropriate and cost-effective services. Effective use of the burgeoning network of resource centers will decrease reliance on more expensive forms of service provision, such as nursing homes, and can keep consumers in their communities. It is crucial that the ability of the ADRC to provide all the services within its purview is not compromised.

A second and related lesson is that ADRCs must be given the necessary latitude to become fully established as community resources to fulfill their mission. The two-month period between ADRC and MCO start did not seem to provide adequate time for ADRCs to become well-established. It is well understood that this is due to the ADRC Expansion Cost model, but other states may want to consider a longer ADRC lead time.

The importance of the ADRCs should not be underestimated. An advocate summed up well the importance of a robust ADRC system:

I remain a strong advocate of this managed care system. I really do believe that it moves us in the right direction that it should. But if those ADRCs fall down, we may not wind up with as strong a system as we could.

C. Evidence-based Prevention and Early Intervention Strategies

A final objective of Goal 2 of the comprehensive system change grant proposal was to promote the use of successful evidence-based prevention tools. Consistent with this objective, grant funds were utilized to implement a multi-county pilot of existing an Alzheimer's disease screening tool in collaboration with the Wisconsin Alzheimer's Institute. Originally planned to be piloted in Richland County, the program was twice expanded to include ten counties. The program consisted of a simple Animal Fluency Screen followed by a more comprehensive test. The program included training for ADRC and CMO staff to administer the tests, and training for physicians in patient referral based on screening results²⁴. According to one state interviewee, the ease of use and apparent effectiveness of this screening program helped make it successful in the pilot. State staff indicated in CMS grant updates and interviews with the APS

evaluation team that the Memory Screening Initiative was being integrated into Family Care as a pay-for-performance target of MCOs.

Although not funded by the comprehensive systems change grant, DHS pursued a number of related prevention and early-intervention programs funded through the Robert Wood Johnson Foundation during the grant period. These programs include “Sure Step,” a falls prevention study, done with collaboration from the Kenosha County ADRC. Wisconsin has the second-highest rate of falls among the elderly in the country, and this study was designed to address this issue²⁵. Also, a six-week chronic disease self-management course developed by Kaiser Permanente for consumers with chronic conditions was held by Milwaukee County and the Oneida Tribe. These initiatives added value to the ADRC and other long-term care reform initiatives funded through the comprehensive systems change grant by preventing or decreasing the need for publicly-funded long-term care.

VII. Long-Term Care System Access

A. Background

Goal 3 of the comprehensive systems change grant is “Managing Access to the Long-Term Care System.” The focus of this goal is the long-term care functional screen, its development, advancements, and application to children’s long-term care supports and mental health. This chapter lays out the development and uses of the long-term care functional screen, and explores its improvements and accomplishments (e.g., development of clinical logic for nursing home level of care determination, application to children’s long-term care supports and mental health, and incorporation into other service areas). This is followed by an exposition of screen issues, which include implications of standardization of functional eligibility, ensuring consistency and accuracy, and discrepancies between ADRC and MCO determinations.

The stellar accomplishment at the heart of system access is the end of wait lists in Wisconsin. Therefore, we begin with a look at the achievements of the Wisconsin long-term care reform effort in the elimination of waiting lists and a brief look at the range of perceptions of the rate of transition from waiting list to managed care.

B. Ending Wait Lists in Wisconsin

One of the primary factors that motivated stakeholders to plan and implement large-scale systems change was the desire to end wait lists. In interviews, stakeholders in any role, without exception, spoke of the elimination of waiting lists as a primary motivation of their involvement in the long-term care reform effort. As stated by one, “The impetus for change everywhere was that there were long wait lists, and the current system was broken and under-funded.”

This sentiment was reflected in stakeholder survey results. As mentioned in Chapter V in the discussion of stakeholder motivation/ barriers to involvement, stakeholders selected “ending wait lists in Wisconsin” as the second most important issue in redesigning the LTC system, trailing only behind “the amount of funding available for LTC.” Survey findings also showed the optimism of stakeholders that wait lists could indeed be eliminated. There was general agreement from people in each stakeholder group that the planning meetings would result in the elimination of wait lists.

Due to high demand, Wisconsin’s home and community-based waiver programs have been plagued by long wait lists since their inception. Under the waiver programs, it was

not rare for people to wait for years before receiving services. According to data from the Family Care website, the wait for services can be 1.5 years for seniors in some counties and nine years for people with disabilities in other counties, and 19% of seniors on the COP waiting list enter nursing homes because they can't wait anymore^{1,2}.

As of Oct 31st, 2008, 11,215 people aged 18 and over remained on Wisconsin's long-term support wait list³. The number of people on the wait list has been increasing each year during the grant period due to demographic trends. Another reason for the high number of people on wait lists is the legacy of what is referred to as "significant proportions." Under this policy, funding was allocated in disability categories based on the proportion that target category was funded in nursing homes. This did not lend itself to equitable distribution of funds across target groups in the past. In addition, the Department had received no significant new money from the legislature for the last ten years. All these factors combined to produce long wait lists and underlined the urgency of the LTC reform efforts.

As of December 2008, each of the five Family Care pilot counties (Milwaukee, La Crosse, Fond du Lac, Portage, and Richland) that had fully implemented Family Care, had also totally eliminated their waiting lists. Counties in early stages of implementation have also eliminated or are in the process of eliminating waiting lists. For example, Racine County (who implemented managed care in 2007) has eliminated its wait list. Other counties are in the throes of the transition, while many others will have reduced or eliminated their wait lists in 2009.

To facilitate the orderly enrollment of individuals into managed care from fee-for-service waiver programs, counties are required to submit transition plans which project the number of people that will be enrolled each month over a period of two years from MCO start-up. DHS expects "rollovers" from waiver programs to be competed within the first six months of MCO operation. For individuals on wait lists, DHS allows 1/24 of the wait list number to be enrolled each month during the first 24 months. This timeline is built into the budget model. Under State law, two years after MCO start-up, Family Care becomes an entitlement in that county, and the county wait list should be eliminated. As of November 2008, 23 counties submitted transition plans to the State which indicated start-up dates in 2008 and early 2009. Based on these plans, 3,737 people from these counties will be removed from the waiting list and enrolled in managed care by January 2011. (County transition plans are available upon a request to the State.)

As mentioned earlier, while the elimination of some waiting lists is a great step forward, the perception of the speed at which this is occurring is dependent on the point of view

of the observer. For consumers who are currently on a wait list, the transition to managed care can not occur quickly enough. On the other hand, for many involved in the operational aspects of implementation, the transition occurred too quickly, and did not leave time for proper options counseling or for care plans to be adequately reviewed with consumers. Nevertheless, within the larger context of the long-term care reform effort, the current number of people who have been eliminated from wait list status, combined with those who will be transitioned in the near future, is an achievement of major proportions and stands as one of the great accomplishments made possible in large part by the comprehensive systems change grant.

C. The Wisconsin Long-Term Care Functional Screen (LTC FS)

The Long-Term Care Functional Screen (i.e., the screen) is Wisconsin's answer to one of the primary goals of its redesign of the long-term care system, that is, to "ensure quality and statewide consistency in determining an individual's eligibility for Wisconsin's long-term care programs"⁴. To meet this goal, Wisconsin put considerable resources into improving the screen, developing clinical logic and IT applications, while at the same time creating policies and procedures, training materials, and quality measures to promote consistent use of the screen. Key results of these efforts were:

- Use of the long-term care functional screen to determine functional eligibility for Family Care, Family Care Partnership, and all home and community-based Medicaid waiver programs
- Development and implementation of the Children's Long-Term Care Support Functional Screen
- Development and implementation of the Mental Health/Alcohol and Drug Abuse Functional Screen
- Development of detailed screen policies and procedures
- Development of screen quality improvement and assurance measures, including the training and certification of screeners

1. LTC Functional Screen Development and Use

Prior to long-term care redesign, counties in Wisconsin used local policies to administer their wait list. This resulted in two primary approaches to providing services. The first approach provided intensive services to a small number of recipients. The second approach provided fewer services to a large number of

people. The differences inherent in these philosophies of access created disparities in access to long-term care support services across counties. It also created disparities within target groups, since people with the same functional levels could receive different types and amounts of services based on location. In order to provide context to the improvements made to the functional screen during the grant period, a few paragraphs are included below.

The Long-Term Care Functional Screen has been under development since 1997. It is a functional needs inventory that determines functional eligibility for Wisconsin's publicly funded long-term care programs and is used for all Family Care target groups. In addition to determining eligibility, the screen also serves as a foundation for the comprehensive assessment done by the MCO interdisciplinary team. It provides data for use in quality management, identifies whether an applicant is currently in need of Adult Protective Services, and indicates the need for referrals to other community resources; such as, mental health or substance abuse services. Current Family Care counties use screen results or screen information to provide a framework for information-gathering during options counseling, to set monthly payment rates based on people's functional needs, and to document factors to aid in prioritizing waiting lists.

There are three types of screens administered by certified screeners: Initial Screens, annual recertification screens, and Change in Condition Screens. The most common place for consumers to receive an Initial Screen is at an ADRC. Recertification and Change of Condition screens may be completed by either the ADRC or MCO. The screen's eligibility and nursing home level of care logics were extensively tested by the State, and approved by the Centers for Medicare and Medicaid Services to replace previous methods of home and community-based waiver eligibility in Wisconsin. This approval firmly established the place of the long-term care functional screen within the Wisconsin long-term care system as the determinant of functional eligibility for long-term care services.

For detailed information LTC FS history and policy, please refer to the *Wisconsin Long Term Care Functional Screen Clinical Instructions*⁵.

2. LTC Functional Screen Improvements and Accomplishments

a) Application to Determination of Nursing Home Level of Care

One of the tasks pursuant to functional screen improvement in the grant was to “develop clinical logic for nursing home level of care determination.” The State initially pursued this task by contracting with the Wisconsin External Quality Review Organization, Metastar, and Deloitte Consulting, to develop the programming logic necessary to use functional screen results to determine level for care for fee-for-service nursing home admissions⁶. However, by autumn 2006, investment in this project was postponed while DHS developed an acuity-based payment structure for nursing homes. (The acuity-based payment system is addressed in the next chapter.) State staff interviewees indicated that they plan to restart the process of streamlining the functional screen to determine level of care for nursing home residents as soon as possible. The long-term goal of DHS is to use the functional screen to determine eligibility and level of care for all state long-term care programs and level of care determinations for both community-based and institutional settings.

b) Application of Screen to Children’s Long-term Supports

During the comprehensive system change grant period, DHS developed clinical logic and IT applications for the functional screen in Children’s Long-Term Support services. The “children’s screen” has been implemented statewide, resulting in consistency across counties and programs in functional eligibility assessment for children.

The change also improved consistency for families when transitioning into adult LTC services. Data from the screen allows DHS to monitor the quality of work performed locally and helps ensure consistency by targeting counties for training and quality improvement activities.

c) Application of the Screen to Mental Health and Alcohol and Other Drug Abuse Programs

Another application of the long-term care functional screen was in the area of mental health and alcohol and drug abuse. The capacity for the functional screen to determine service needs from these programs was developed during the grant period. The screen was used to determine eligibility for Wisconsin Comprehensive Community Services (CCS).

Staff has the option of using it for the Community Support Program (CSP).

The development of the mental health screen has led to greater recognition of the high level of mental health needs within the Family Care eligible population. DHS estimates that around 40% of Family Care enrollees have diagnosed mental health needs. Over time, it became apparent that few case managers had the skills to deal with these needs. MCOs have begun to address this with the addition of mental health practitioners to their interdisciplinary teams, or arranging for the availability of mental health consultations. The high level of mental health needs within the Family Care population is an area which requires further study and action.

d) Other Applications of the Long-Term Care Functional Screen

The change in focus from planning to implementation of LTC reform prompted by Governor Doyle's directive precipitated a shift from incorporating the developmental disability Preadmission Screen and Annual Resident Review (PASAAR) into the functional screen. According to Wisconsin DHS staff, this work was discontinued because it was cost prohibitive and most people targeted for PASAAR did not fall under the purview of Family Care.

During the grant period, the long-term care functional screen was used in Family Care counties to determine care needed and eligibility for the Supplemental Security Income-Exceptional (SSI-E) program⁷.

According to Wisconsin DHS, "It is critical that Wisconsin utilize the same standard for determining Levels of Care (LOC) for all individuals with Developmental Disabilities."⁸ To this end, during the grant period, DHS required the use of the long-term care functional screen to determine level of care for the Intermediate Care Facility for the Mentally Retarded (ICF-MR) restructuring initiative, a State program that transitions eligible individuals from institutional to community-based care. (More information on the ICF-MR restructuring initiative is included in Chapter VIII, Increasing Service Options within the Context of Long-Term Care Reform.)

e) Long-Term Care Functional Screen Policies and Procedures

DHS continued to develop functional screen policies and procedures during the CSC grant period. Several memos were issued to

communicate these changes to LTC FS users. One of the main resources for accurate and up-to-date policy information is the Wisconsin Long-Term Care Functional Screen Clinical Instructions, usually referred to as simply "the Clinical Instructions." The 92-page document was developed by DHS as a resource for screeners. It has been revised several times since its rollout in December 2005, and received a large update in October 2008. The recent update includes detailed information specific to each module of the screen. The instructions also present decision trees developed to ensure consistent target group definitions and designations, plus a frequently asked questions (FAQ) section. The Clinical Instructions represent a major effort by the State to ensure that information about the screen is accurate and available, and application of the screen is valid and reliable.

f) Quality Improvement and Assurance Measures

According to a DHS Info Memo, "A robust system of quality policies, procedures, and processes are needed to ensure [LTC] FS quality.⁴" To achieve this goal, the DHS updated its Functional Screen Quality Assurance Framework beginning in 2007. The update continued some previous practices and developed new elements that encompassed changes to the functional screen over time. (Please see DHS info Memo 2006-14 for detailed information on the quality framework.)

The State developed several quality assurance measures to maximize the consistency with which the screen was administered and to minimize some of the inherent limitations found in similar screening methods. The State built three levels of quality assurance into the screening process:

Screener. According to the Clinical Instructions, quality assurance begins with the screener. Each screener goes through a State certification process that requires that they meet education, training, and experience requirements. Additionally, "It is the screener's responsibility to be objective in screening, to be informed of the instructions, and to corroborate information gathered from the consumer.⁵" The State provides guidelines for screeners to follow to help ensure accuracy of information.

Screen Liaison. The next level of quality assurance is the Screen Liaison. The role of the Liaison is to oversee quality assurance measures like inter-rater reliability testing, training of new screeners, conducting random

sampling for accuracy and consistency, and consulting with State staff about specific consumer issues.

Annual Site Review. The third level of quality assurance is conducted by the DHS. Staff at the Department continuously review screens using various methods. These methods include automated queries of submitted screen data to identify any anomalies and suspicious patterns, care plan reviews that, among other things, identify discrepancies between completed screens and care plans, and examination of other exceptions or issues that come to State staff attention in other ways, such as complaints, questions, appeals, and anomalies noticed when analysts are working with screen data for other purposes.

An example of screen-quality issues that can be monitored through automated queries is identifying numerous and slightly different screens submitted during the course of one day for any single individual which indicates that a screener may be “fishing” for a desired result. One State interviewee described this type of monitoring when she said, “By monitoring the pattern of reported scores, the State can identify situations where an inquiry of the specifics of a case may be warranted.” Agencies receive feedback from State screen quality staff and following such reviews, correct and amend screen errors.

Thus, the quality process moves from the screener to the State and back, completing a quality improvement loop. The Clinical Instructions read, “All screening agencies should have experienced LTC FS Screeners to assist with questions. Refer all questions to your designated Screen Liaison Staff. The Screen Liaison in turn will refer unresolved questions to the Department as necessary. In this way, interpretations can be kept consistent and communicated to all programs utilizing the LTC FS, and revision can be made to the LTC FS if necessary⁵.”

3. Long-Term Care Functional Screen Issues

During the course of interviews, DHS State staff noted several issues surrounding the functional screen. These issues center around “the functional eligibility bubble,” and discrepancies between ADRC and MCO screens.

a) The Functional Eligibility Bubble

Prior to the implementation of Family Care, some counties were able to use funds from a variety of sources to pay for individuals who did not

meet the strict definition of functional eligibility for community long-term care but who were in need of some services. The standardization of functional eligibility through use of the long-term care functional screen which minimizes eligibility disparity across counties, reduces the ability of counties to provide Medicaid-funded services to people whose functional eligibility is “on the fringe.”

One stakeholder worried that the uniform implementation of the functional screen would create “lots of folks who fall through the cracks”. One advocate wondered what happens to people on the “functional eligibility bubble.” He asked, “What capacity will the county have to deal with those folks when they are no longer technically eligible for the Family Care benefit?” He continued, “One possible remedy to this issue is through ensuring that ADRC options counselors are well-educated in options outside of publicly funded long-term care. These options can then be discussed with individuals who are in this situation.”

b) Discrepancies between ADRC and MCO Screens

ADRCs and MCOs administer functional screens to the same individuals, but their screens are administered at different times and frequently under different circumstances. As indicated earlier, according to State policy, ADRCs are responsible for initial screens, while MCOs are responsible for rescreens⁵. ADRC screens are administered to individuals who are new to the system, often when an individual is seeking services during a period of crisis or transition. One ADRC supervisor saw the role of the ADRC as using the screen to “get a snapshot.”

In contrast, she continued, “The MCO does an entire assessment, and it is more like a movie than a snapshot.” ADRC supervisor also pointed out that the nursing staff of MCOs frequently have long-standing relationships with consumers and as such have a more accurate picture of those whose conditions and needs change over time.

Nevertheless, staff are sometimes concerned when screens administered with the same individual do not contain the same information. As stated by one interviewee, “it is a challenge to maintain consistent quality across the board.”

Interviewees confirmed that conflicts have arisen between ADRCs and MCOs when there are discrepancies between screen results. One Family Care planner described an MCO that had a policy of rescreening all

consumers on enrollment. Another county had its ADRC do both the initial screen and the rescreen.

Several ADRC supervisors discussed ways to explore discrepancies between ADRC and MCO screen results, primary among them was having screen review sessions with ADRC and MCO staff. Several supervisors pointed out that they customarily turn to the State for resolution if unexplained discrepancies are not resolved through discussions with one another.

Both ADRC and ADRC staff raised concerns about the relationship of the screen and its influence on the MCO capitated rate. Recognition of this relationship prompted one managed care director to state: “Having the MCO do the rescreen is an absolute conflict of interest.” On the other hand, Department staff pointed out counter-balancing incentives that reduce the motivation for MCOs to inflate screens. For example, fictitious information entered to make an enrollee look sicker for reimbursement purposes would call negative attention to the quality of the MCO’s care management during performance monitoring, since it would create a situation in which the provided services appear inadequate for the care need noted on the screen, or in which a member’s disability was worsening for no apparent reason.

Managed care workers highlighted in interviews that they thought training for screeners was insufficient in bringing awareness of the relationship between determination of care and the MCO capitated rate. State staff, on the other hand, questioned the relevance of knowledge about rate-setting methods to the task of entering accurate and timely information on the screen. One State Manager stated, “Screeners are trained to complete screens with nothing but the accuracy and completeness of the information about the member in mind. Awareness of the effect that the screen information could have on the capitated rate – or on anything but the member’s true level of care and eligibility – is irrelevant to the task of high-quality functional screening.

D. Conclusion

Impressive advances were made during the grant period to ensure equal access to LTC services throughout the state and across target groups. Headway was made in reducing waiting lists for LTC services with the promise of even more reductions in the near future. The long-term care functional screen was the key to successes in this

area. The LTC FS represents a standardized, objective method to determine eligibility for publicly-funded long-term care services in Wisconsin. Despite issues related to its application, a spirit of collaboration and innovation guided the development of the functional screen since its inception. Training for certified screeners includes a web-based training course, a website, and a highly detailed set of functional screen instructions. The State holds regular meetings with ADRC directors and supervisors and with MCO directors and managers and is receptive to concerns of both ADRC and MCO staff. DHS has proven itself open to revising and improving policies based on ADRC and MCO staff input. As stated by one interviewee “The State has been awesome in accommodating and adjusting the screen to be better. It makes for a good tool.” In addition to the above, the application of the screen in children’s long-term supports and mental health/AODA represents a major positive outcome. Plans for future adaptation of the screen to determination of level of care in nursing homes forecasts the time when the long-term care functional screen will provide consistency throughout all Wisconsin long-term support programs and options. Wisconsin DHS met and exceeded the grant objectives related to the improvement and expansion of functional screen capabilities.

VIII. Increasing Service Options within the Context of Long-Term Care Reform

A. Background

In the comprehensive systems change grant proposal narrative, DHS proposed to develop systems and processes that would enhance the availability of service options, continue to implement “money follows the person” strategies, reposition Wisconsin’s nursing home industry, ensure consistently available self-directed supports, and build on current workforce development efforts. This chapter summarizes the changes that occurred in these areas during the grant period, as well as the programs and initiatives that DHS implemented or sustained to encourage the trends. This section also provides an overview of advances in the areas of self-directed supports and the long-term care workforce.

B. Institutional Care in Wisconsin, Background and Trends

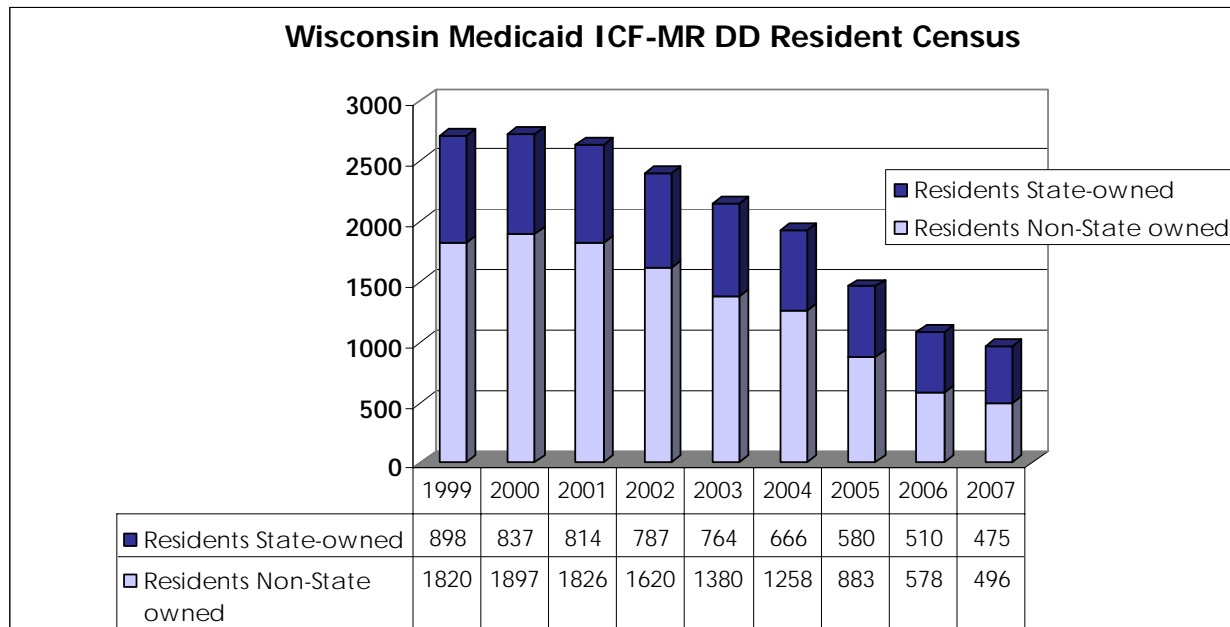
According to the DHS document “Family Care State-Wide,”¹ seniors and people with disabilities overwhelmingly prefer home and community care options to nursing homes when possible. The outcomes of the comprehensive systems change grant are testimony to the impressive changes in Wisconsin over the past 25-30 years to expand the availability of home and community-based care to all Wisconsin citizens in need of long-term care.

The project narrative of the grant proposal presented data on the balance between community-based and institutional care circa 2002². The following section presents updated information. These updated statistics are testimony to the accomplishments in this arena during the grant period.

- Nursing Facilities. The 2002 annual nursing home survey conducted by DHS reported that Wisconsin had 408 nursing facilities. The 2005 report, the most recent available, reported 401 nursing facilities³.
- Intermediate Care Facilities for the Mentally Retarded (ICF-MR). As of December 31, 2002, Wisconsin had 34 ICF-MRs, also known as facilities for the developmentally disabled (FDD). These facilities served 1,620 residents. As of 2007, Wisconsin had 15 ICF-MRs that served 496 residents. In 2002, Wisconsin operated three State Centers for persons with developmental disabilities. These

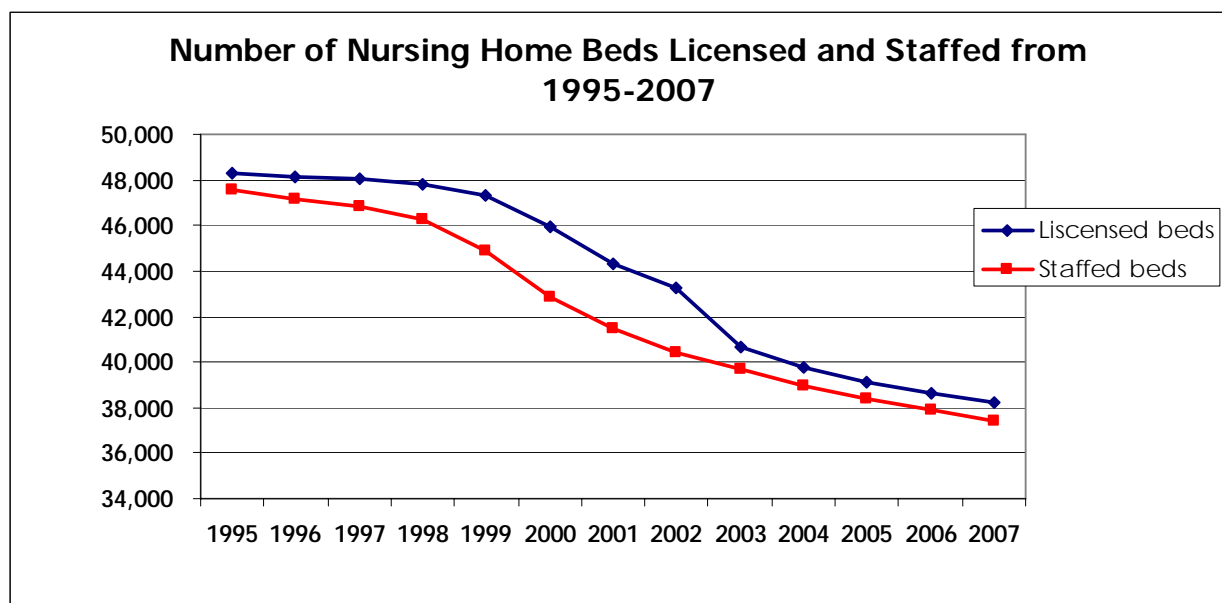
Centers served 787 people, excluding short-term Intensive Treatment Program residents. By 2007, the Northern Wisconsin Center ended its long-term care program leaving two State Centers serving 475 residents⁴ (Figure 16).

Figure 16. ICF/MR DD Residents– 1999-2007



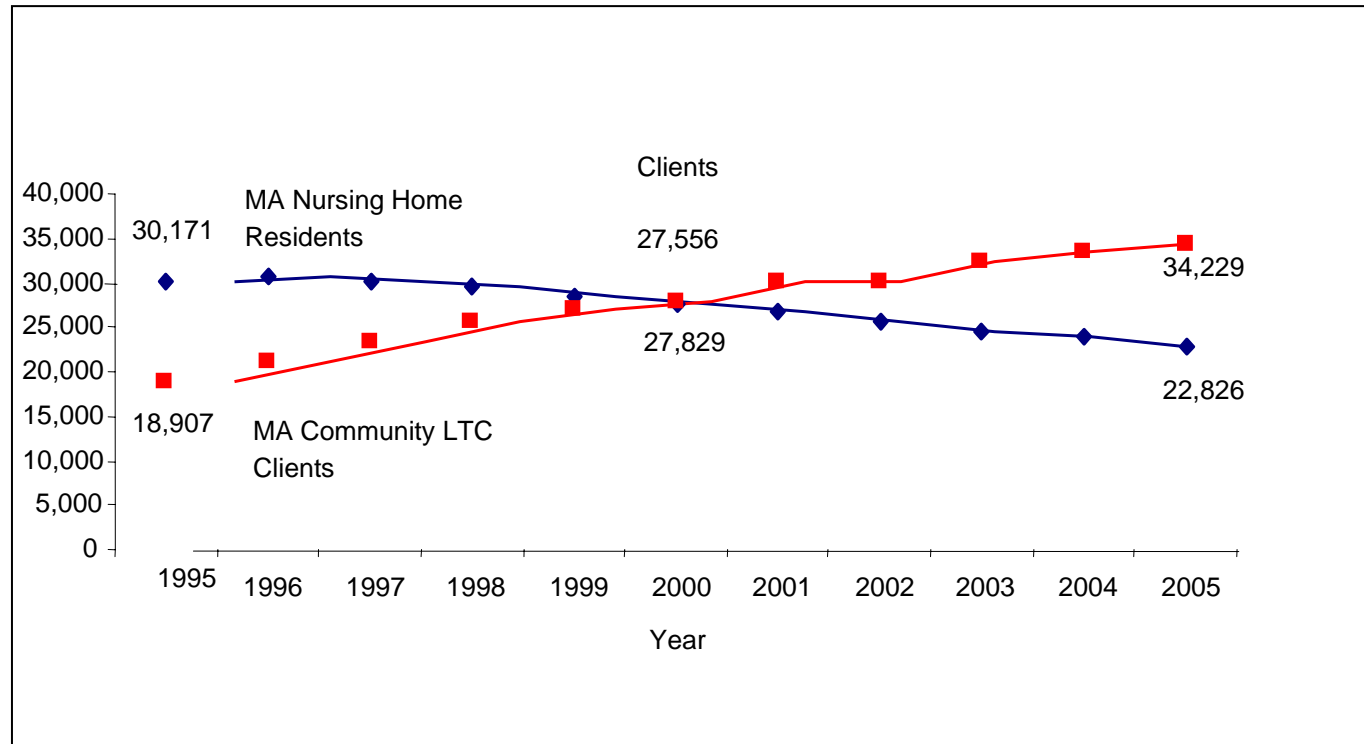
- Nursing Home Beds.** In the 2005 Wisconsin Nursing Homes and Residents Report, Wisconsin DHS reported that from 1995 to 2005, the number of licensed nursing home beds declined 19%, from 48,319 to 39,146. The number of staffed beds also decreased 19 percent during this decade, from 47,596 to 38,375. The number of staffed beds between 2005 and 2007 is projected³ (Figure 17).

Figure 17. Number of Wisconsin Nursing Home Beds – 1995-2007



- Nursing Home Beds vs. Assisted Living Beds. According to Sinikka Santala, Division of Long Term Care Administrator, “On November 19, 2008, the number of all types of licensed and certified assisted living beds became greater than the number of licensed nursing home beds in the state of Wisconsin. There are now 38,775 assisted living beds and 38,679 nursing home beds.”
- Community vs. Nursing Home Utilization. As mentioned earlier, more people are choosing home and community-based services for long-term care. Figure 18 shows that starting in 2000, more people chose to have their long-term care needs met in the community rather than in institutions⁴.

Figure 18. Community-Based LTC & Nursing Home Utilization – 1995-2005



C. Relocation Initiatives

Objective 1 under Goal 4 of the comprehensive systems change grant work plan was develop and implement “money follows the person” strategies and to use available funding to support a range of LTC options for consumers. Specific tasks included: 1) submitting a proposal for Wisconsin’s 2005-2007 Biennial Budget for a specific relocation initiative, 2) developing detailed plans to relocate individuals, and 3) implementing the relocation initiative.

To meet this objective, Wisconsin DHS coordinated funding from the comprehensive systems change grant with other federal funding. Specifically, Wisconsin was awarded a Money Follows the Person (MFP) Grant in FY 2003 (Wisconsin Money Follows the Person Grant #92010/5) to improve LTC systems by strengthening MFP initiatives. Federal funds from the three grants were coordinated to develop and sustain initiatives designed to provide people the option of living in the community.

Wisconsin DHS had three major initiatives designed to relocate individuals from institutions into community based settings:

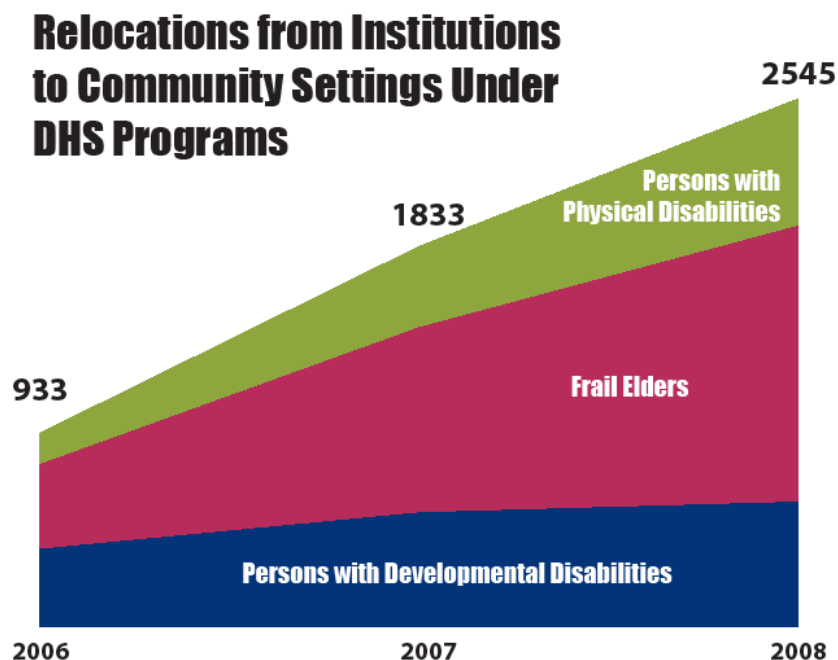
- ICF-MR Restructuring Initiative;

- Community Relocation Initiative; and
- Community Integration Program (CIP) 1A.

According to the DHS 2008 Report on Relocations and Diversions from Institutions⁵, these three programs “provide elders, people with physical and developmental disabilities, and people with co-occurring mental illness residing in nursing facilities and Intermediate Care Facilities for the Mentally Retarded (ICF-MR) the opportunity to relocate to community-based settings.” Under another program, the CIP II Nursing Home Diversion Program, DHS “provides support to a limited number of individuals who are at imminent risk of entering a nursing home to be diverted from nursing home admission and remain in community settings.”

Since SFY 2006, 2,545 elders and people with physical disabilities have relocated from institutional settings and an additional 492 were diverted from admission to a nursing home through DHS programs, for a total of 3,037 individuals not in institutional settings⁵. See Figure 19⁵.

Figure 19: Relocations from Institutions to Community Settings under DHS Programs



According to the 2008 Relocation Report, in January 2007, DHS was awarded another federal Money Follows the Person grant to support further relocations from institutions to the community. Funding from this grant will help sustain the momentum for Wisconsin's relocation initiatives into the next biennium⁵.

D. Relocation Stories

Data and graphs give us a great deal of information, but consumer stories really bring that information close to home. Several stories are included here as testament to the personal impact of the relocation efforts.

1. R.Z. injured at age 17; now 49 years old

R.Z. was in a diving accident when he was 17 years old and has quadriplegia requiring total care. He now is 49 years old and has been in a wheelchair since the accident. In April 2006 R.Z. relocated from a nursing home to a duplex with a live in care provider. He receives Supportive Home Care and Personal care services through Gemini Helping Hands.

R.Z. now has a beautiful home with all the supports he needs. He is very intelligent and is going back to school through an online program. His own handicap accessible van this provides his transportation to all of his community outings. R.Z. and his care provider are very involved with the local church and he has developed a large circle of friends and community connections. R.Z. reports to his county care manager that the relocation program has been one of the greatest things that has ever happened to him. The local newspaper did a wonderful story about his new life. This is definitely a success story.

2. Roommates become housemates

Delores, age 68, entered the nursing home in June 2005 and Eleanor, age 75, in April 2005. Upon admission to the nursing home, both women were encouraged to give up their homes and most of their furniture and belongings were sold or given away.

Delores and Eleanor became roommates in the nursing home and developed a very close friendship. Delores was approached by the county care manager regarding the CIPII Community Relocation Initiative and wanted to participate. When she spoke to Eleanor about the program, Eleanor also asked to be considered by the county. In 2005, Delores and Eleanor began living together

in their own mobile home and celebrated their first Christmas there with each other and their loved ones. Delores left the nursing home on November 12th and Eleanor on December 18th.

Because both of these women had no furnishings for their home, they were able to purchase items through the relocation initiative. In addition their community costs of \$33.14 per day and \$45.28 per day are far below their nursing home costs.

3. Wife returns home to live with husband

C.L., age 61, resided in a nursing home 16 months – from September 2005 – January 2007. Mrs. L. has numerous chronic health conditions: COPD, CHF, CAD, Hypertension and most critically, Peripheral Vascular Disease. She entered a nursing home primarily as a result of the poor circulation. The circulation was so bad in fact that both of her legs were amputated above the knee. While in the nursing home she developed a bladder infection that became septic and was placed on a respirator. She also had a colostomy surgery and now has both a colostomy and supra-pubic catheter.

While she was in the nursing home she became very depressed. She, and her husband of 7 years, said that when she was in the nursing home she was given so much medication that she could not carry on a conversation, or track her thoughts. She developed a large sacral ulcer that did not seem to heal. She was just miserable and wanted to go home. In fact, after her colostomy surgery in December 2006 she flat out refused to return to the nursing home after her discharge from the hospital. She left the nursing home in January 2007 and returned to live with her husband in their apartment.

Many people (staff at the nursing home, her doctors, even the county to a certain extent) were skeptical as to whether or not she would be able to remain home. However, her determination and the care that is provided by her husband, has not only enabled her to remain home since January 2007, but she has thrived! The sacral ulcer has healed; she is on only a few medications. She is thrilled to be home. She can eat what she wants -- when she wants. In fact, she has gained weight. She can smoke when she wants, have a drink. She and her husband like to go to the local tavern, drink, listen to music and entertain with friends. They have an accessible van that enables them to be part of the community. She actually receives little assistance from the waiver program. Her husband proves the majority of assistance.

Her life is her own. When asked about what makes her happy she replied, "Being home with my husband, doing my bead work, and my dog." Simple pleasures. These are a result of her being home and out of the nursing home.

E. Culture Change and Repositioning the Wisconsin Nursing Home Industry

1. Background

Objective 3 of Goal 4 of the comprehensive system change grant sought to enhance the availability of service options through developing and implementing strategies to reposition Wisconsin's nursing home industry. Many of these strategies were developed to incorporate what is frequently referred to as the "culture change model" with long-term care. The Brown University report for the National Commission for Quality for Long-Term Care⁶ states that the common thread within the culture change movement is ". . . a desire to revolutionize how chronically frail and disabled individuals live and are treated. Culture change enthusiasts believe that the key to improvement is restructuring the way care is delivered, implementing systems of care around individuals' lifestyles, needs, and preferences⁶." Culture change has been an overarching theme in Wisconsin's LTC nursing home reform, driven and supported by the comprehensive systems change grant.

A shift in the role of nursing homes coincided with the culture change movement. According to Wisconsin DHS State staff, Wisconsin nursing homes are increasingly focused on providing acute, intense skilled nursing care to residents, as opposed to long-term intermediate levels of care. In addition, average nursing home stays are becoming shorter with facilities experiencing more resident turnover³.

2. Achievements

The CSC grant work plan laid out a number of specific strategies to reposition Wisconsin's nursing home industry and encourage the adoption of the culture change model. Wisconsin DHS achievements can be grouped into five major areas: a) access data; b) acuity-based payment system; c) quality measures; d) private sector restructuring; and e) property allowance incentives⁷.

a) Nursing Home Bed Access Data

The State workgroup on nursing home access sought to provide the Comprehensive Systems Change committee with an estimate of the

future demand for Medicaid-funded nursing facility beds, and project where those beds might be needed. This information was requested to help the State make informed decisions about the nursing home industry. A report was presented to that committee on December 8th, 2006. The report indicated that despite the increasing population of elders, the need for Medicaid-funded nursing home beds was substantially lower than current capacity⁸. According to one State staff interviewee, the findings of this report were recently compared to a similar study conducted at the direction of the State of Minnesota, which reached similar conclusions. The full report is available upon request from Wisconsin DHS.

b) Acuity-Based Payment System

During the grant period, the State moved to an acuity-based payment system to reimburse nursing homes for Medicaid-funded patients. According to information from State-level interviews, an acuity-based payment system allowed for the determination of more precise levels of care. Nursing home industry advocates feel the approach brings nursing home reimbursements more in line with the actual needs of their residents. According to one interviewee, it is hoped that this payment system will be an incentive for nursing homes to accept more difficult cases. This is consistent with the overall trend of nursing homes acting as short-term stay rehabilitation centers which provide sub-acute levels of care³.

The acuity-based payment system achieved 100% implementation in July 2008. The acuity-based payments uses RUGs (Resource Utilization Groups), the federally administered system used to reimburse for Medicaid nursing home expenses. According to Wisconsin DHS State staff, the overall goal of the acuity-based payment system is to provide a reasonable payment at the facility level for one year. DHS uses a payment formula that has created a much stronger relationship between acuity and cost. DHS staff described that there are still issues being discussed between the State and nursing home industry representatives, but on the whole the acuity-based payment system is being viewed as a success.

c) Nursing Home Quality Measures and Data Collection

Ensuring quality in nursing homes is a major goal of the culture change movement, and Wisconsin is very engaged in developing nursing home quality measures. The centerpiece of these efforts was the development

of a pay-for-performance system. Under this system, institutions were financially rewarded for providing high quality services in specifically defined areas. In principle, this allowed the State to buy better quality and stop paying for poor quality. However, there were no standardized methods for collecting data to determine quality. A nursing home scorecard/ report card was under development during the comprehensive systems change grant period. The scorecard relied on existing data and satisfaction surveys. However, due to budget constraints, data collection ceased after 2005. In May 2007, the pay for performance project was officially put on hold⁹.

Despite this delay, the State continued to actively work toward developing new and more robust measures of quality. A proposal was placed in the 2009-2011 biennial budget that could restart the nursing home pay-for-performance program. Progress was made in the development of tools to capture both quantitative and qualitative data, possibly gathered through the PEONIES tool (to be described in Chapter IX, Quality and Cost). Finally, the State is actively pursuing federal funds through new CMS grants.

d) Private Sector Restructuring

One of the tasks specified by the CSC grant in repositioning the nursing home industry involved establishing a pilot program that would allow qualifying facilities to reduce institutional beds while developing affordable assisted living. This program was called the Nursing Home Conversion Demonstration project and continued a partnership between Wisconsin DHS and the Wisconsin Health Economic Development Authority (WHEDA). The Nursing Home Conversion Program developed from 2001-2004 and used funding provided by a Robert Wood Johnson Grant to address the lack of affordable apartment-style assisted living in Wisconsin. This program, ending in 2007, resulted in a reduction in nursing home beds and the opening of two new Residential Care Apartment Complexes (RCACs). The overall result of the project was increased community capacity. According to Wisconsin DHS State staff, the State plans to use the Nursing Home Conversion Demonstration experience project as a model for maximizing community-based housing as Family Care expands statewide.

e) Property Allowance Incentives

The physical structures of nursing home buildings themselves present an obstacle to culture change. According to Wisconsin DHS State staff, the average age of nursing facilities in Wisconsin is 31 years. Many of these buildings were built to accommodate an older care philosophy. With the property allowance incentive, facilities that replace existing nursing homes receive a different rate determination if the new facility meets state-of-the-art design standards. One state employee described how the very decision to build a new facility to replace an old one frequently generates interest and enthusiasm on the part of staff, residents, and family and increases the likelihood that the nursing home will embody the culture change model.

The State set aside \$1 million of nursing home budget dollars to help nursing homes renovate and/or replace existing facilities. By August 2008, five nursing home proposals were approved, totaling \$874,175. The Wisconsin Association of Homes and Services for the Aging (WAHSA), in its 2009-11 Nursing Home Funding Budget Request Policy Statement to the State, indicated its support for expansion of the property allowance incentive program¹⁰.

F. Self-Directed Supports

1. Background

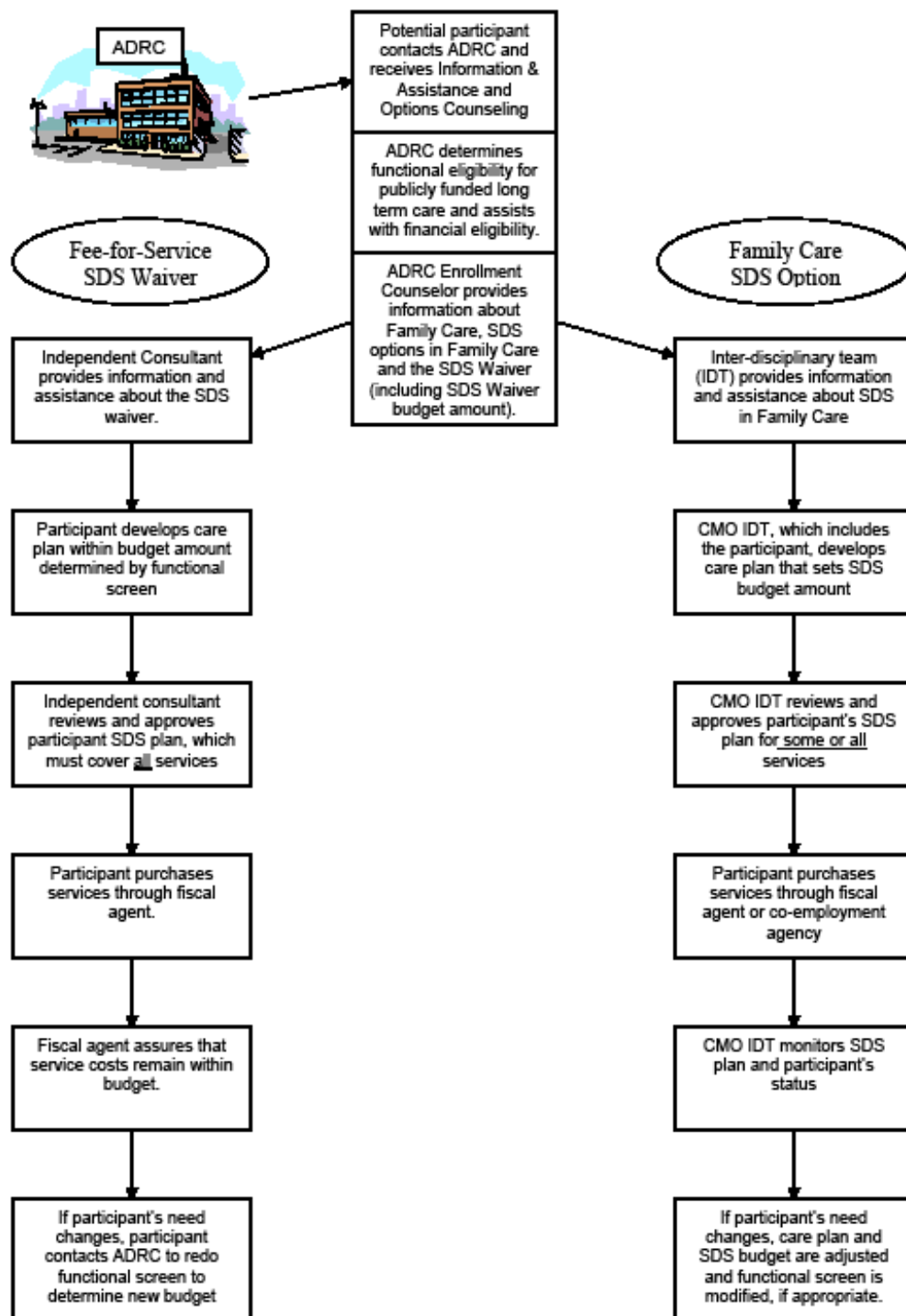
Objective 5 of Goal 4 of the comprehensive systems change grant was designed to ensure self-directed supports (SDS) were consistently available in LTC programs statewide. Self-directed supports make a range of options available to consumers to self-direct their care. This is part of a national trend towards the implementation of self-directed support models.

In Wisconsin, SDS options are provided to consumers through three programs: the legacy fee-for-service waivers, Family Care SDS, and the IRIS program (an acronym for Include, Respect, I Self-Direct). The Family Care SDS is a managed care model; IRIS is an SDS fee-for-service model. While the Family Care SDS option was available beginning in the pilot phase, IRIS was implemented during the grant period. This section presents the basic elements of these two programs, stakeholder perceptions of the programs, and implementation lessons learned.

2. The Family Care SDS Option

The Family Care SDS option was written into the Family Care contract of the five pilot counties. Several challenges arose during implementation, and according to Wisconsin DHS State staff, the initial learning curve was high. There were many philosophical, legal, operational and training issues that needed to be addressed. An in-depth study of these issues is presented in the 2005 report entitled “Consumer Directed Support: Lessons Learned from Wisconsin’s Family Care Program,” conducted by Pathways to Independence, DHS, and the Waisman Center¹¹. According to Wisconsin DHS policy, the Family Care SDS option can be chosen by the member at any time once they are enrolled in a managed care organization. The member works with their interdisciplinary team to determine the services they would like to self-direct, and those for which the MCO is responsible. The process of developing an SDS care plan within Family Care is fully described in the flow chart below (Figure 20¹²).

Figure 20. SDS Choices in Family Care Expansion



3. The IRIS Program

The IRIS program was developed to provide a fee-for-service alternative to managed care self-directed supports. According to a July 2008 Division of Long-Term Care (DLTC) memo, “CMS directed DHS to develop an option to provide more choice to consumers eligible for publicly funded long-term care. To comply with this federal directive, DHS developed and received federal approval for a new Self-Directed Supports Medicaid waiver program. This new program is called IRIS, an acronym for “Include, Respect, I Self-Direct.”¹³

IRIS was built on the core values of self-determination. The program is designed to ensure that clients make decisions about their lives, including determining how they spend their days and the type of assistance they need. IRIS covers only those services that are available under the current home and community-based waiver programs. Clients receive other services through the Medicaid “card” fee-for-service system. Like Family Care SDS, IRIS is only available in current Family Care or Family Care-Partnership counties. It was designed as a fee-for-service SDS option for individuals prepared to self-direct all of their services. IRIS participants receive a fixed budget based on the results of their functional screen. These funds come from the Family Care budget, and are based on the projected costs of individual service needs. Again, the flow chart titled “Self-Directed Supports Choices in Family Care Expansion” gives detailed information on the IRIS enrollment process.

While Family Care SDS participants work with their interdisciplinary teams to develop their care plans, IRIS participants do not have teams. Instead, they utilize a completely different support structure to ensure that their needs are met. The IRIS support structure is provided by two agencies: an Independent Consultant Agency (ICA) and a Financial Services Agency (FSA)¹⁴.

a) Independent Consultant Agency – The Management Group, Inc.

The Management Group, Inc. (TMG), a Madison-based consulting agency, directed a group of independent consultants to help participants plan their supports and services, keep the plan within budget, approve the final plan, and assist with required paper work. Independent consultants also helped clients find workers and service providers, develop an “emergency backup” plan, and with support brokers for additional support, if necessary. The independent consultants were available, and continue

to be available, to provide assistance at the direction of the clients, and provide support accordingly.

b) Financial Services Agency – Milwaukee Center for Independence

Financial Services for IRIS participants are provided by the Milwaukee Center for Independence, a Milwaukee-based independent living center. The financial services agency (or FSA) acts as a payroll agent and takes care of all money issues and other employer-related financial paperwork requirements. It sends checks to employees, pays providers, and provides a monthly budget report listing all payments made from the approved plan.

IRIS was implemented on July 1st, 2008. According to the October 2008 IRIS Enrollment Report, the cumulative total of IRIS referrals from all ADRCs and for all three target groups (frail elderly, developmentally disabled, physically disabled) was 133 individuals. Enrollment occurred after referral, and as of October 2008, there were 20 individuals enrolled in IRIS¹⁵.

4. Stakeholder Perceptions of SDS and IRIS Issues

Self-directed supports were discussed in several stakeholder interviews. Most comments focused on the IRIS program. Several themes emerged related to late implementation, distribution of program information, and the range of program support.

As mentioned earlier, the IRIS program was developed and implemented at the direction of CMS. This directive came late in the LTC planning process supported by the grant. It should be noted that Wisconsin DHS acted decisively to establish a fee-for-service SDS option as soon as it was notified by CMS that it would be required. Still, some stakeholders expressed discontent over this late time frame. One stakeholder said, “IRIS was a last-minute affair”. Another recounted that, “IRIS didn’t come out in the planning process as soon as it might have. I don’t fault anybody for this; I’m not sure where it got hung up. But, the effort that led to IRIS came out late in the game and IRIS has been a monkey wrench ever since.”

Because IRIS came out later in the planning process, there was a relatively quick turnaround time between planning the program and implementing it. This short turnaround time left some stakeholders wondering if everything could be done in time for program “rollout.” A comment on the stakeholder

survey expressed concern about the lack of a pilot test for IRIS. According to another survey comment, “IRIS was not up and running 7/1/08 and enrollment of our clients in IRIS had to be delayed due to that. During the planning process, the State should have been more honest in telling counties that IRIS would not be ready on time.”

The program timing caused problems with the distribution of information on IRIS. Some stakeholders complained about a lack of information regarding IRIS. One survey respondent wrote that consumers “complained about the lack of hard info on IRIS.” The State addressed this issue through the implementation of an IRIS website and several consumer-directed pamphlets that detail the program.

In addition to issues related initially to lack of information, ADRC supervisors said that at the beginning there was apprehension that they would not be prepared to offer effective options counseling on this option due to the condensed time frame. This concern was tied to training. According to ADRC supervisors, the IRIS program was initially not very well-known or understood by options counselors. However, this appears to have been quickly rectified by the State. The supervisors reported that they were generally “impressed” with the training they received from the State. The State prepared a webcast and a toolkit and also did some in-person training described as “very helpful.” After this, the supervisors said their staff quickly embraced IRIS, and the ADRCs and State collaborated well on its implementation. An ADRC supervisor referred to IRIS saying, “Now I think it is a terrific option. I’m really glad it’s there.”

Relative to the concerns expressed above, data from interviews indicated that support for both the Family Care SDS Option and IRIS was strong, especially in the developmental disability (DD) community. One advocate said “DD folks want SDS.” Another said there was “strong advocacy for SDS and consumer training” in her organization. A county staff person said “the DD population will push for IRIS. Overall, people in Family Care probably won’t leave, but younger people will more likely select IRIS.”

The amount of support for IRIS or managed self-directed supports appears to be influenced by the amount of involvement from the local DD community. An ADRC supervisor from a county that had referred over 25 people for the IRIS program said that “the DD population here was very savvy, and were very

involved in planning for IRIS.” Another ADRC supervisor reported that in her consortia “Family Care in general has been very successful. There is an SDS piece in Family Care that people can choose. I am from a more conservative community, which has been slower to adopt IRIS.” While another stakeholder expressed his concern about the difference between the programs in theory and in practice: “Definitely there is already a big discrepancy in what SDS is supposed to be and what it will really turn out to be. SDS could be one of the best parts of Family Care if it turns out the way it was originally intended.”

In conclusion, despite apprehensions expressed especially by DD advocates, support in general from stakeholders for SDS and IRIS is strong. Yet, while the concept of SDS is held in high regard, many considered the planning and operational aspects of IRIS to be lacking. Clearer information and training on SDS and IRIS could have been provided, especially initially, to ensure that procedures were properly followed during the enrollment process.

G. Workforce

1. Background

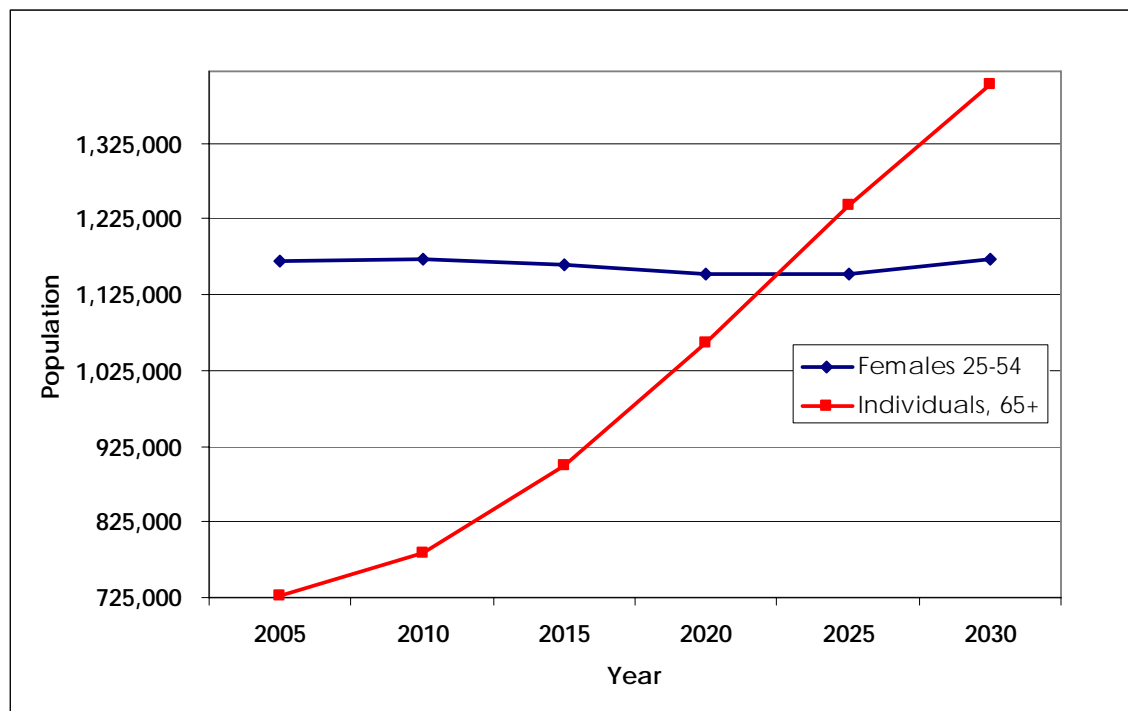
Paramount to ensuring access to long-term care services is a qualified and adequate workforce to provide those long-term care services. Wisconsin DHS State staff recognized this as a significant issue and included objectives focused on workforce retention and an improved LTC workforce in the comprehensive system change grant work plan. However, the objectives and tasks were short-circuited as staff and funding were redirected to plan expansion efforts. A sentiment frequently expressed, especially by providers, is captured well in the following statement: “Planning was all about getting the system up and running, but there was not enough effort put into developing the workforce needed to implement the system.” As stated by another stakeholder, “Without an adequate workforce, any long-term care reform will be unsuccessful.”

2. Wisconsin Workforce Trends

Demographic trends indicate a growing gap between the number of people likely to need care and the number of people who are most likely to provide that care. According to the Wisconsin LTC Workforce Alliance, between 2005 and 2030, the number of people in Wisconsin over the age of 85, those most likely to need care will increase by more than 60% to 173,600¹⁶. During the same period, the 65 years and older population will increase by 86%¹⁷.

Women aged 25-54 have traditionally, and currently, comprised approximately 90% of the long-term care direct care workforce¹⁸. Also, between 2005 and 2030, the number of women aged 25-54 in Wisconsin is expected to increase by about 4,000, or less than 1%¹⁶ (Figure 21).

Figure 21. Expected Increase in the Number of Persons Aged 65+ & Women Aged 25-54 in WI – 2005-2030



Wisconsin trends are consistent with national trends in that healthcare jobs are the fastest growing sector. This trend is projected to continue well into the future. Home health aides/ direct care workers are projected to have one of the largest percentages of projected growth. However, the need for other long-term care healthcare workers will continue to grow as well, with anticipated workers shortages for nurses, medical assistants, pharmacy technicians, and other healthcare support positions¹⁹. Focus on the direct care worker pool is necessary, as well as efforts to recruit and retain all types of healthcare workers to ensure a sufficient long-term workforce into the future.

Direct care worker shortages are attributable to a variety of reasons. Causes include high turnover up to 22%-100% annually²⁰, large numbers of vacancies, and difficulty attracting new employees due to low wages and benefits, poor

working conditions, stereotyping, economy, lack of education and training, and limited data on workforce supply/demand. The instability/shortages of the workforce contribute to service access problems for consumers, ranging from safety concerns, quality of care, quality of life, excessive provider and taxpayer costs, extreme workloads, and high accident/injury rates²¹.

3. Workforce Accomplishments and Opportunities for the Future

Prior to the diversion of staff and funding to LTC reform implementation, Wisconsin DHS delivered on the initial activities of its full slate of proposed workforce grant deliverables to CMS. Primary among those was initiation of a committee on direct care workforce issues of the Wisconsin Council on Long Term Care. This committee developed 17 direct care workforce quality indicators, completed a report with specific recommendations for addressing workforce shortages, and evaluated training requirements for licensed and certified providers in community-based settings where it was determined that FC mitigates against perceived barriers. After the report was completed in 2005, the LTC Council Workforce Committee was dismantled.

Grant funding supported one workforce staff person for a portion of the funded period. The focus of the work of this staff person for 18 months was to develop an understanding of home-care worker cooperatives in Wisconsin and then collaborate with the Department of Workforce Development (DWD), USDA, and UW Extension to promote worker cooperatives. A second staff person had been designated to explore the possibility of factoring CNA retention into nursing home payment rates. However, this work came to a halt when the responsibilities of staff were transitioned to other implementation and relocation efforts. The decision to make this change was made with the agreement of Susan Hill, then CMS project official for the CSC grant.

4. Action Areas

Based on the continued need to develop the direct-care workforce, it is clear that workforce issues will be a constant area of need and central to the success of the long-term care reform process. The areas identified in Wisconsin's Council on LTC Reform, Direct-Care workforce committee report, "Strengthening Wisconsin's Long-Term Care Workforce," Final Report June, 2005²² remain pertinent to future planners. Many of the issues are in line with those addressed in the Institutes for the Future of Aging Services report "The Long-Term Care Workforce: Can the Crisis be Fixed?"²¹. The report theme is

that opportunities exist to take meaningful steps to retain and expand the supply of personnel coming into the LTC field while developing more comprehensive plans. Areas noted in the reports include:

- Improving working conditions and the quality of LTC jobs, including worker respect, recognition, teamwork, and worker support and safety;
- Creating a demand for more competitive LTC direct care worker jobs through wages and benefits increases;
- Making investments in the development and continuing education of the LTC workforce;
- Improving data collection and information about the workforce; and
- Developing sound reimbursement policies.

H. Conclusion

The State of Wisconsin made great progress over the course of the comprehensive systems change grant period in the areas of managing access, rebalancing the long-term care system, and repositioning the nursing home industry. As the Family Care program expands across the state, more and more people will be removed from wait lists. According to current system trends, the majority of these new enrollees will receive care at home or in the community. This transition will be accompanied by advances in the manner in which consumers are engaged in the implementation of their care plans, whether they remain in fee-for-service (IRIS program) or managed care (self-directed supports).

Workforce, on the other hand, remains the elephant in the room, acknowledged but largely unaddressed due to budgetary and staffing shortfalls at Wisconsin DHS. Workforce-related grant deliverables proposed in the CMS grant proposal were curtailed and diverted by intense planning and implementation efforts. Nevertheless, initial grant efforts for workforce development live on through the Wisconsin Long-Term Care Workforce Alliance and collaboration between the Wisconsin Department of Workforce Development and Department of Health Services. Ensuring a continued stream of direct long-term care workers will require reenergized diligence from the State. Without this dedication, the continued quality of and access of consumers to the Wisconsin LTC system will be seriously jeopardized.

IX. QUALITY AND COST

A. Background

Goal 5 of the CMS comprehensive systems change grant called for strategies to improve the quality, consistency, and cost-effectiveness of LTC services in Wisconsin. Objectives of this goal addressed measuring ADRC quality, support and training for local advisory groups, implementation of performance monitoring of consumer outcomes in all LTC settings, and improvement in the capacity to collect and use information. This chapter will discuss consumer perceptions of the quality of ADRCs and MCOs, and the quality management and IT systems developed to maintain a quality system.

Wisconsin made substantive progress in its development of a statewide quality management system in 2003 through 2006 as part of its CMS Quality Close to Home Grant¹. At the heart of this quality management system were expanded roles for the counties and care management organizations in creating and maintaining local quality management systems. This system continued the Wisconsin tradition of consumer-centered, outcome-driven care. The relationship between local and state systems was examined, responsibilities were clarified, and a framework that outlined the continuous quality loop between the two systems was developed (Appendix L).

Wisconsin built on this foundation with the comprehensive systems change grant. The challenge was to better define quality in managed care, and to develop effective methods to collect data, analyze trends, and follow through on findings².

B. Quality and the ADRCs

1. Consumer Perceptions of ADRC Quality

The number of people who say they would contact the ADRC if they had a question or issue, whether they felt they were listened to, and whether they would recommend the ADRC to others are all indicators of whether the ADRC is considered by consumers as a helpful resource. The APS Healthcare team asked these and other related questions in their survey of publicly-funded long-term care consumers. In terms of the percentage of consumers who would contact the ADRC with a disability-related or long-lasting health problem, over 30 percent of all respondents selected the ADRC as the primary source they would contact. Elderly consumers selected their care manager or

social worker 52% of the time, while non-elderly consumers selected their care manager or social worker 73% of the time (Figure 22).

Figure 22. Percentage of Consumers Who Would Contact the Following with Disability-Related or Long-Lasting Health Problem Question

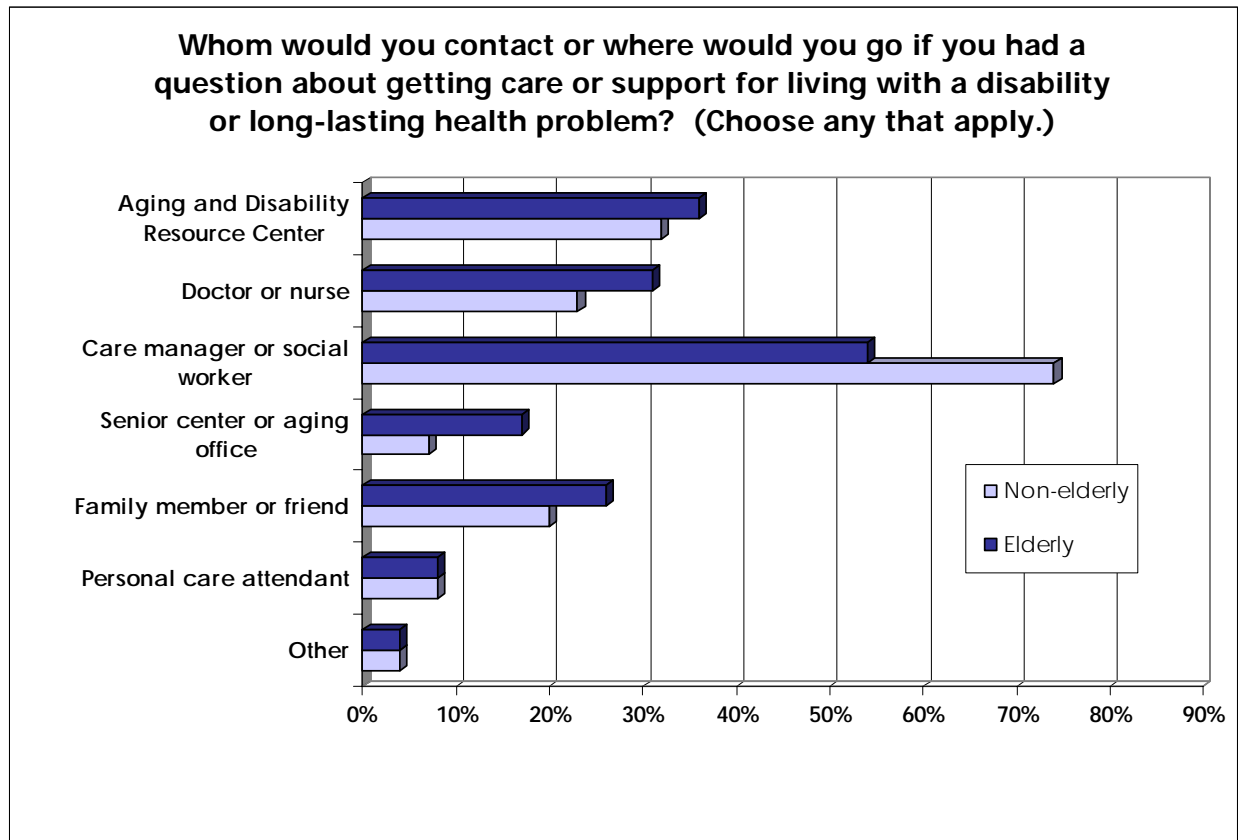


Figure 23 below shows that more than half of all survey respondents indicated they had heard of ADRCs prior to receiving the consumer survey. The following Figure 24 shows that of those who had heard of ADRCs, a higher percentage of elderly (76%) consumers compared to non-elderly consumers (54%) had contacted an ADRC.

Figure 23. Percentage of Consumers in Each Consumer Group Who Had Previously Heard of ADRCs

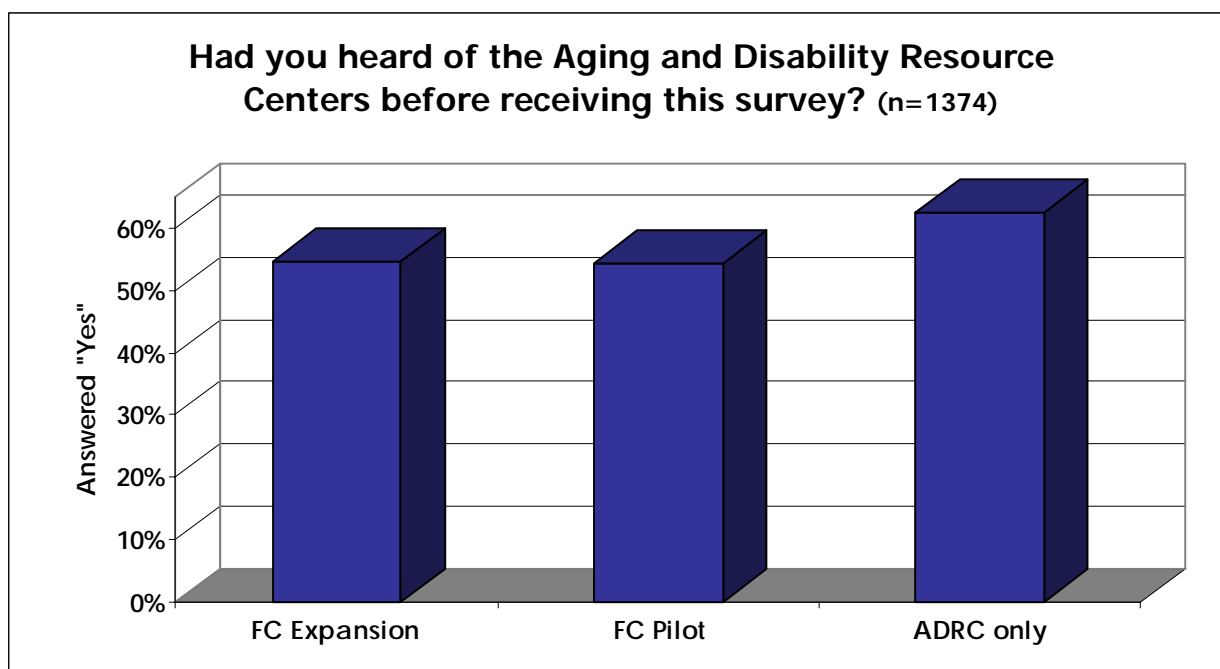
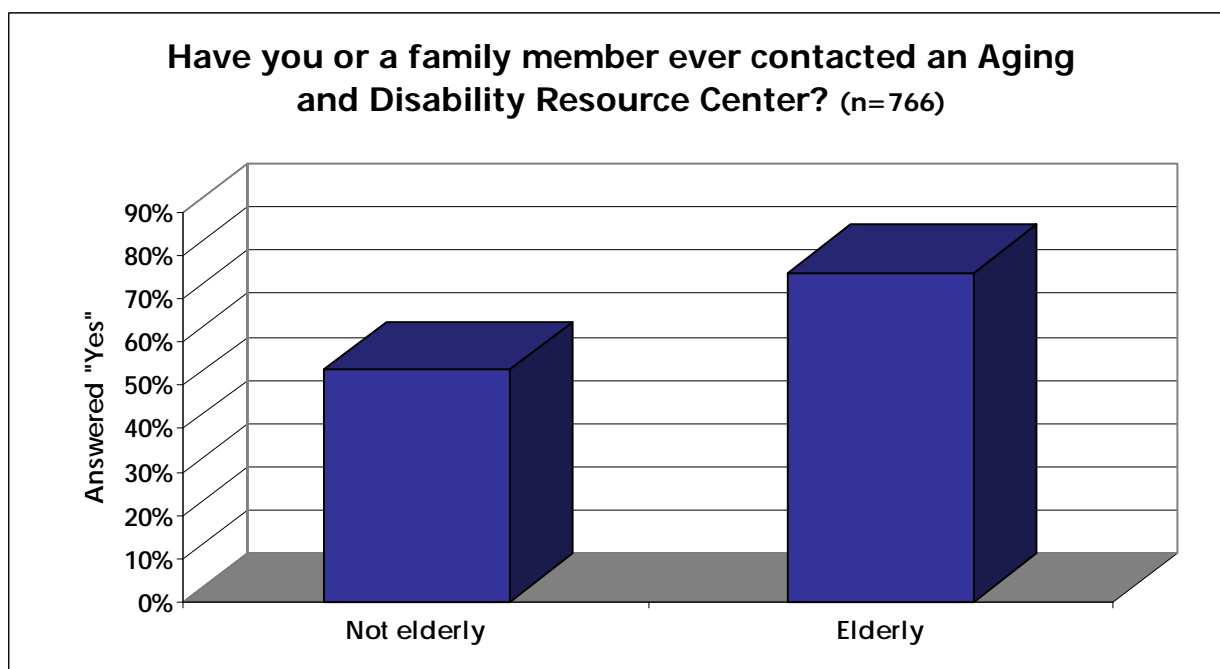


Figure 24. Percentage of Consumers Who Heard of ADRCs and Contacted One



Two measures of consumer satisfaction - whether staff listened carefully and whether information provided by staff was helpful - showed high levels of satisfaction among respondents to the consumer survey (Figures 25 and 26).

Figure 25. Extent to Which ADRC Staff Were Perceived to be Listening Carefully by Consumers

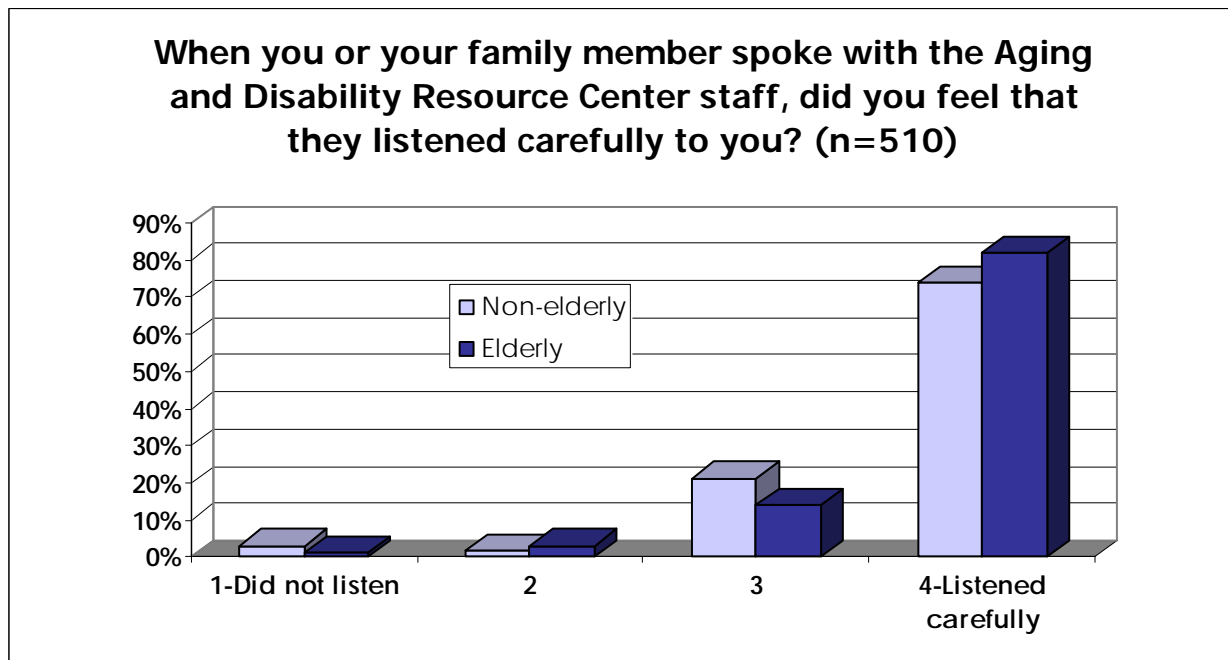
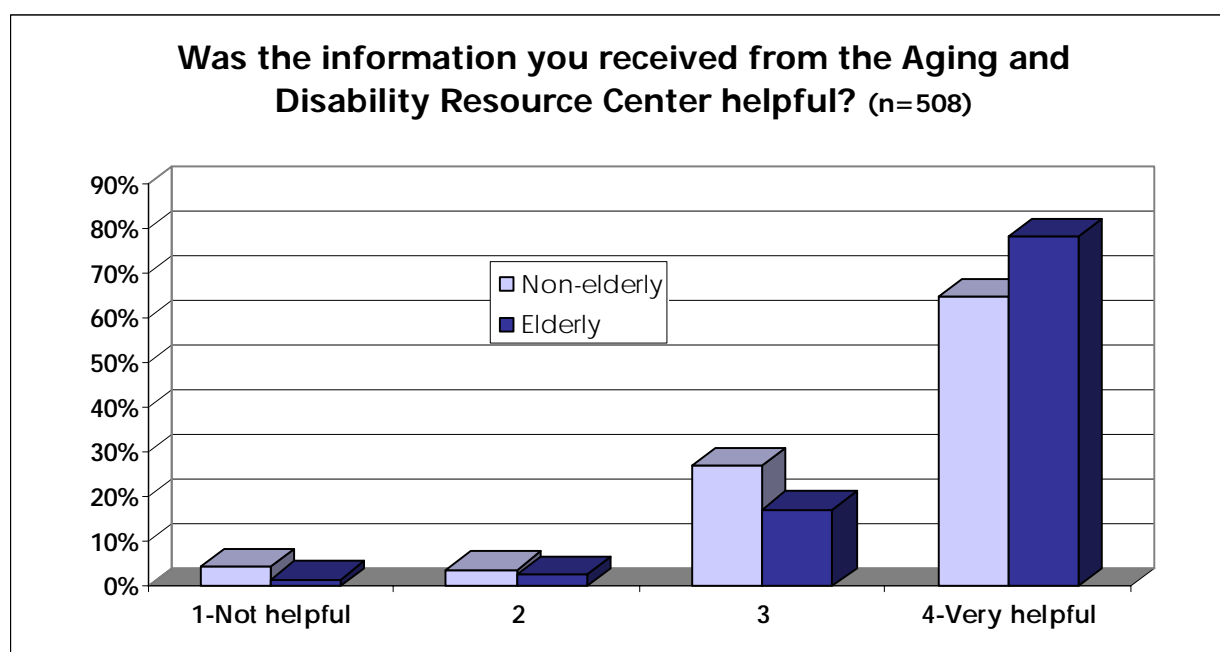


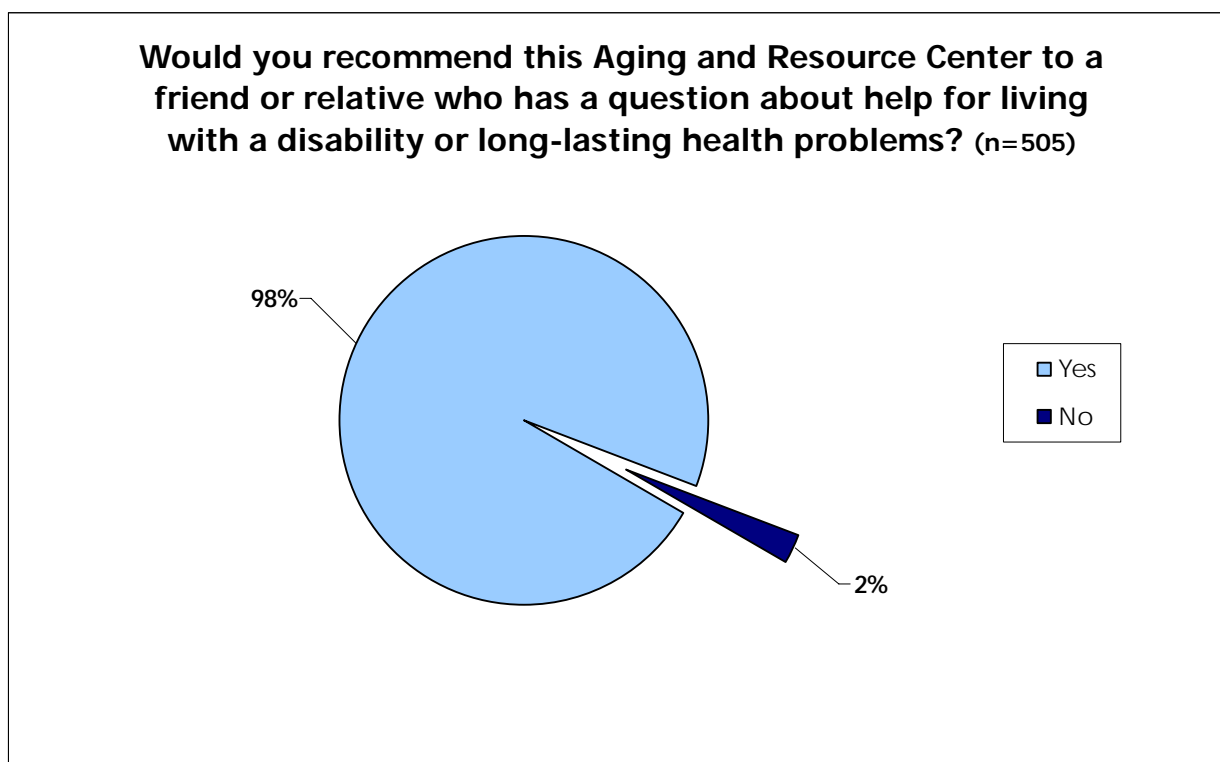
Figure 26. Extent to Which Information from ADRCs was Perceived as Helpful by Consumers



Statistical significance (chi-square tests) between non-elderly and elderly respondents suggest that non-elderly consumers are less likely to contact ADRCs (figure X, $p < 0.0001$) and are less likely to find the services helpful (figure X, $p < 0.01$) if they do contact an ADRC.

Ninety-eight percent of those who contacted their local ADRC said that they would recommend the ADRC to others (Figure 27).

Figure 27. Percentage of Consumers Who Would Recommend their ADRC to a Friend or Relative



Results from the consumer survey suggested that consumers were increasingly aware of the existence of ADRCs and the information and assistance they provide, and that ADRCs are quickly becoming established as organizations trusted by long-term care consumers. The consumers sampled in this survey represent those who are enrolled in Family Care or another Medicaid Waiver program and, as such, represent a limited view of ADRC services. Nevertheless, they provide a starting point for quality improvement recommendations for the State and ADRCs.

2. ADRC Quality Indicators Study

Amy Flowers of Analytic Insight was contracted by Wisconsin DHS through an Administration on Aging grant to conduct an in-depth study of ADRC quality³ (Results available at: www.adrc-tae.org/tiki-download_file.php?fileId=27545). In this study, staff interviews and focus groups from a subset of ADRCs were used to assess perceptions of quality

The goal of the Analytic Insight study was the identification of a set of indicators that could be used prospectively to assess quality in a number of service domains (e.g., information availability, informed decision-making, accessibility, guidance and customization of services) by ADRC staff in their quality improvement efforts. The results of this study, including a format for a web-based reporting system, were presented in a number of settings from September - November 2008^{3, 4}. The interactive reporting system that Dr. Flowers outlined would allow each ADRC to view its performance on a number of measures relative to others throughout the State.

Dr. Flowers used linear regression techniques to determine which factors had the greatest impact on consumer satisfaction and consumer impression of service effectiveness and usefulness³. This work elucidated the most important areas on which to focus quality improvement efforts. Regular implementation of consumer surveys, as suggested by the Council on Long Term Care, will continue to ascertain ADRC performance⁵.

3. ADRC Quality and IT Issues

The new ADRC data requirements are outlined in the ADRC Activity Reporting for 2008 memo and accompanying documents⁶.

Beacon is the recommended software platform for data collection. The majority of Wisconsin ADRCs use the program, and it has been configured to meet the needs of both Wisconsin DHS and the ADRCs. The data elements were chosen “to strike a balance between obtaining descriptive information with information burden⁶.” The Beacon platform is also modifiable to allow DHS to collect additional elements once a quality tracking and improvement system has been established⁶.

Encounter data has been collected since January of 2008 by the county-based ADRCs. However, as of December 2008, DHS had not yet begun compiling encounter-level data from all ADRCs using the Beacon system due to changes implemented by the Beacon software owner.

ADRC supervisors expressed concern that standardization was lacking in the encounter data that has been gathered by counties to this point. They also indicated finding no value in the data being collected for the State. Instead, many viewed it as “merely a requirement to fulfill.” Several supervisors said their ADRC did not use Beacon. While these supervisors felt the indicators

should be standardized, they did not want to give up the systems they had developed and now trusted. Local investment was clearly duplicated in the development of multiple data systems for Wisconsin ADRCs. However, as indicated by Wisconsin DHS staff, the ADRC IT requirements and encounter-level data reporting currently being developed is an important step in the development of an ADRC data collection system.

Another critical step noted by Wisconsin DHS staff is to determine how exactly the encounter data and other elements will be used to measure quality. This development has been proceeding out of order and the establishment of quality measures for ADRCs is long overdue. In a May 2008 meeting of the Wisconsin Council on Long Term Care, members decided on priorities for quality assurance and quality improvement. The Council determined that complaints and grievances were limited in number and not a robust tool for measuring quality. The Council felt that consumer surveys, tests of information and assistance responsiveness, and peer evaluations were better ways to assess performance. The Council also recommended evaluation of ADRC progress on addressing specific goals including a focus on groups which have historically been “alienated from ‘the system’”, youth-to-adult transition, and individuals with multiple ADRC contacts⁵.

The ultimate role of a quality assurance and quality improvement system is to determine whether the goals of the ADRC are being met. Though tardy in implementation, it appears that the core elements of an effective system are being put in place.

C. Regional Advisory Committees

Regional advisory committees are being developed to fulfill Objective 3 of Goal 5 of the CSC Grant which is “to provide support for local advisory groups to participate in local QA.QI and in peer review.” According to a DHS Information Bulletin, “The 2007-2009 biennial budget added statutory language creating regional long term care advisory committees. The charge to these committees is to evaluate the performance of the long term care system in their area and make recommendations for changes as appropriate.”⁷

Wisconsin DHS and the Council on Long-Term Care have begun defining the scope and responsibilities of these regional advisory committees^{5, 8, 9}. The committees are being planned to consist of representatives chosen by ADRC governing boards and would be responsible for evaluating the entire long-term care system in each region.

Due to the potential scope of such committees, it is premature to make a judgment on the success of Wisconsin in developing this function for system quality oversight.

D. PEONIES

1. Definition

At the core of developing a reliable process to identify and assess personal experience outcomes of consumers is the project known as PEONIES. PEONIES stands for **P**ersonal **E**xperience **O**utcomes **i**ntegrated Interview and **E**valuation **S**ystem. It is a project funded by Wisconsin DHS and developed by the University of Wisconsin Center for Health Systems Research and Analysis (CHSRA). Partially funded by CSC grant dollars, the PEONIES outcomes-measurement tool was developed during the grant period and represents significant progress made by the State during this time.

According to the PEONIES website:

- *Personal Experience* means that each person judges the quality of his or her own life.
- *Outcomes* are conditions or circumstances that have value all on their own. There are 12 personal experience outcomes.
- *iNtegrated* means that this project combines *interview* and *evaluation* into a system. All the pieces work together.
- *Interview* means that we learn about each person's Personal Experience Outcomes by talking with him/her.
- *Evaluation* means that the Personal Experience Outcomes can be used to help learn how successfully each person is achieving the things they want. It also means the Personal Experience Outcomes can be used to help learn whether people are receiving the kinds of supports and services that help them reach their outcomes.
- *System* means the information about the Personal Experience Outcomes is collected, presented, and used in clearly defined ways.

PEONIES is intended to help care managers and consumers work together to make sure services are supporting the consumer's outcomes. A major outcome of the project was defining the 12 Personal Experience Outcomes

(PEO)s. Definition of the Personal Experience Outcomes represent an intense collaborative effort across state units and programs. The Personal Experience Outcomes are:

- I decide where & with whom I live. One of the most important and personally meaningful choices I can make is deciding where and with whom to live. This decision must acknowledge and support my individual needs and preferred lifestyle. My home environment has a significant effect on how I feel about myself and my sense of comfort and security.
- I make decisions regarding my support and services. Services and supports are provided to assist me in my daily life. Addressing my needs and preferences in regard to who is providing the services or supports and how and when they are delivered allows me to maintain dignity and control. To the extent that I desire and am able, I am informed and involved in the decision-making process about the services and supports I receive. I am aware that I have options and can make informed choices.
- I decide how I spend my day. Making choices about activities of daily life, such as sleeping, eating, bathing, and recreation enhances my sense of personal control, regardless of where I live. Within the boundaries of the other choices I have made (such as employment or living with other people), I am able to decide when and who to do these daily activities. It gives me a sense of comfort and stability knowing what to expect in my daily routine. It is important to me that my preferences for when certain activities occur are respected and honored to the extent possible.
- I have relationships with family and friends I care about. People for whom I feel love, friendship, and intimacy are involved in my life. These relationships allow me to share my life with others in meaningful ways and helps affirm my identity. To the extent that I desire, people who care about me and my well-being provide on-going support and watch out for my best interests.
- I do things that are important to me. My days include activities such as employment or volunteer opportunities, education, religious activities,

involvement with my friends and family, hobbies, or other personal interests. I find these activities enjoyable, rewarding, and they give me a sense of purpose.

- I am involved in my community. Engaging in the community in ways that I enjoy provides me with a sense of belonging and connection to others. Having a presence in my community enhances my reputation as a contributing member. Being able to participate in community activities gives me opportunities for socialization and recreation.
- My life is stable. My life is not disrupted by unexpected change for which I am not prepared. The amount of turnover among the people who help me (paid and unpaid) is not too much for me. My home life is stable, and I am able to live within my means. I do not worry about changes that may occur in the future because I think I am reasonably well prepared.
- I am respected and treated fairly. I feel that those who play a continuing role in my life respect me. I am treated fairly as a person, program participant, and citizen. This is important to me because it can affect how I view myself in relation to others and my sense of self-worth.
- I have privacy. Privacy means that I have time and space to be by myself or with others I choose. I am able to communicate with others in private as needed. Personal information about me is shared to the extent that I am comfortable. Privacy allows me to be free from intrusion by others and gives me a sense of dignity.
- I have the best possible health. I am comfortable with (or accepting of) my current physical, mental, and emotional health situation. My health concerns are addressed to the extent I desire. I feel I have enough information available to me to make informed decisions about my health.
- I feel safe. I feel comfortable with the level of safety and security that I experience where I live, work, and in my community. I am informed and have the opportunity to judge for myself what is safe. People understand what I consider to be an acceptable level of risk and respect

my decisions. If I am unable to judge risk for myself, I have access to those who can support me in making those determinations.

- I am free from abuse and neglect. I am not experiencing abuse or neglect of my person, property, or finances. I do not feel threatened or mistreated. Any past occurrences have been adequately dealt with or are being addressed.

2. Implementation Status

PEONIES uses a semi-structured interview approach to identify the individualized, specific outcomes desired by individuals in each of the 12 outcome areas and to determine the current status of each desired outcome, identify the types of help needed to maintain or achieve each desired outcome, and identify the current status of the help needed¹⁰. Defining these outcomes is central to the development of a consumer's care plan.

According to the developers of the tool, there was initially some resistance to the PEONIES project from MCOs because they considered themselves too busy with expansion to implement any new tools. Some care managers expressed hesitation at the thought of incorporating any new tools into their already busy routine. However, the developers indicated that the resistance has eased as more people are trained and the value of the tool is recognized.

As of December 2008, PEONIES staff were testing the validity of the measures that are created when external quality reviewers do PEONIES interviews. To that end, PEONIES developers have conducted over 60 interview tool training sessions. There is still high demand for trainings, which is being met, in part, by the development of two training webcasts covering basic interviewing skills and the twelve outcomes themselves. So far, interviews have only been conducted for reliability purposes. Pending available funding, testing will continue through June 2010¹¹.

The Long-Term Care Council Committee on Family Care Quality discussed the development and use of the PEONIES tool at length in recent meetings and is on record for support of its continued development and application.

E. Consumer Perception of MCO Quality

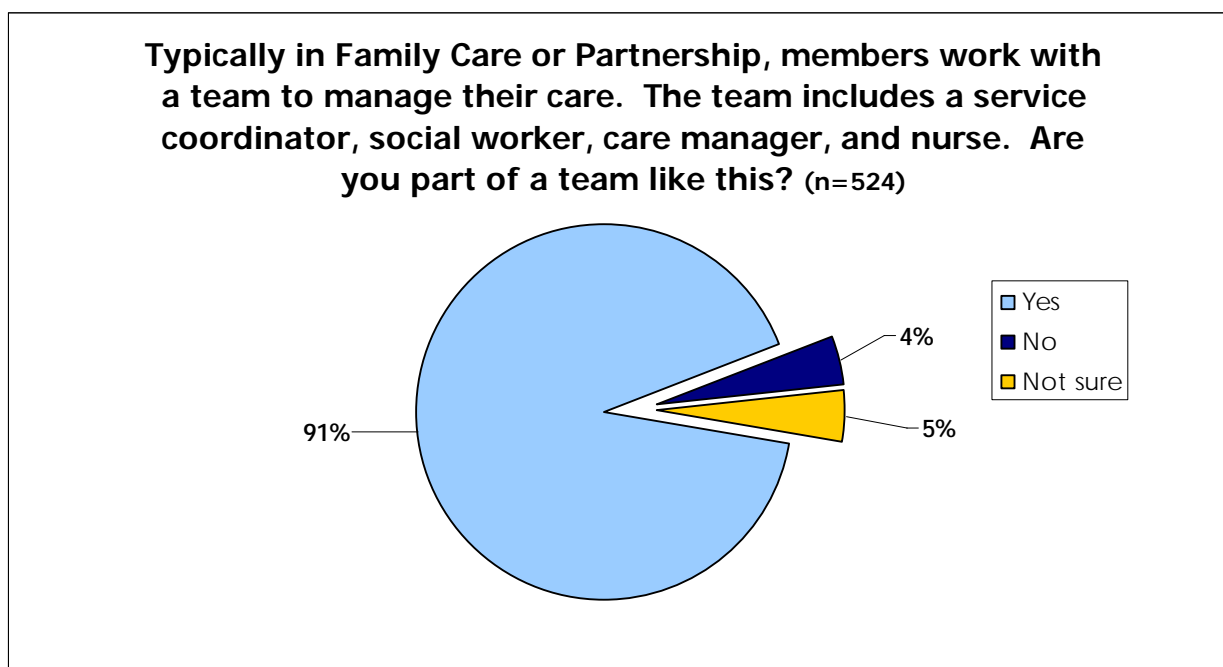
This section will report the findings of two consumer surveys. The first was conducted by APS Healthcare as part this CSC grant evaluation. Results from this survey have

already been cited in several chapters of this report. The second survey is a consumer satisfaction survey conducted in 2005 during the grant period by PACE/Partnership state staff. The findings of the PACE/Partnership survey¹² are included here as a complement and supplement to the findings of the 2008 APS Healthcare consumer survey.

Both the APS Healthcare survey and the PACE/Partnership consumer survey reported that consumers were overall very satisfied with their MCO experiences and their membership in Family Care or Partnership. Multiple measures speak to this satisfaction including input in creating their care/service plan, quality of care, overall experience, being treated with respect, and likelihood of recommending the program to others.

A significant change from the LTC waiver fee-for-service program to Family Care was the use of interdisciplinary teams (IDTs) and the consumer's role with IDT members, especially as it relates to creating their care plans. Findings of the APS consumer survey indicated that the vast majority of consumers knew they were part of an IDT (91.4%) (Figure 28).

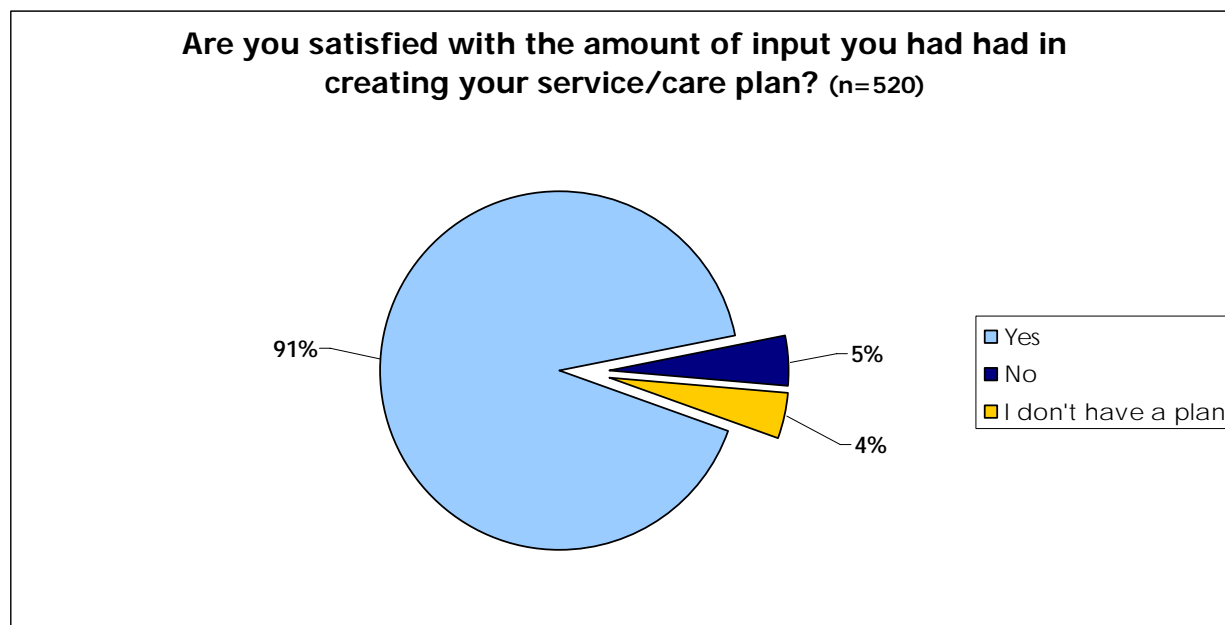
Figure 28. Percentage of Members Who Indicated Having an IDT



The vast majority (91.3%) of consumer respondents reported they were satisfied with the amount of input they had in creating their care/service plans (Figure 29). No

significant differences emerged between the three survey groups (i.e., consumers from ADRC-only, Family Care pilot, or Family Care expansion counties).

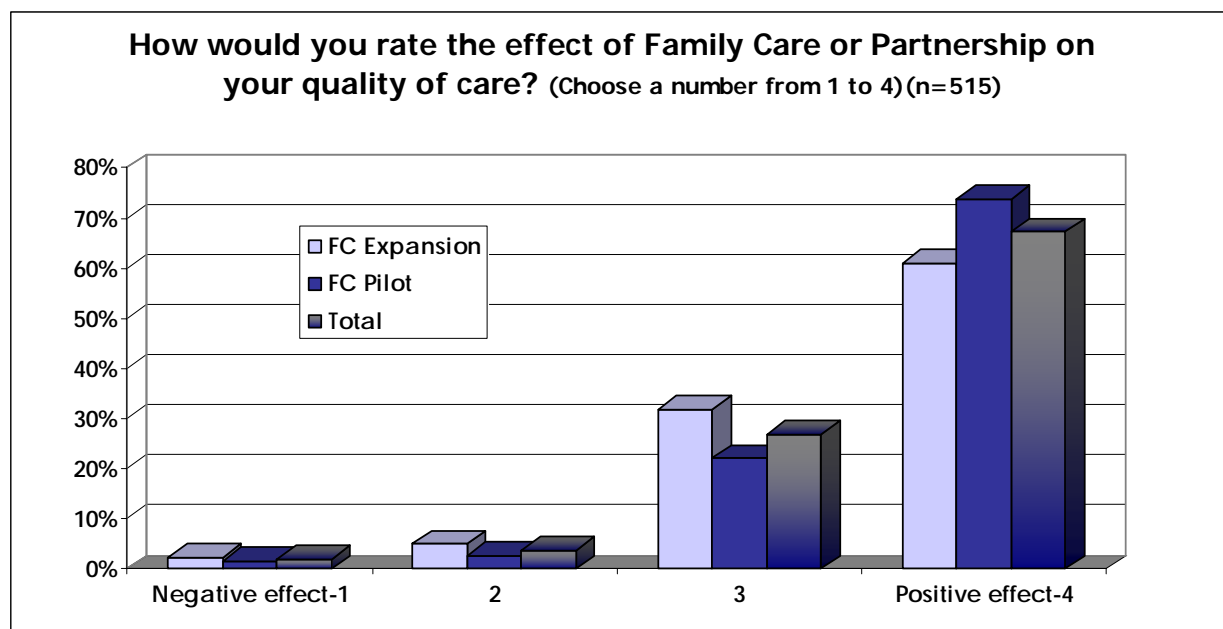
Figure 29. Percentage of Members Satisfied With Amount of Input



Consistent with APS consumer survey results, the PACE/Partnership survey found that the majority (69.9%) of members felt their team “always” involved them in decisions about care and another 25.3% “usually” felt involved in decisions about their care.

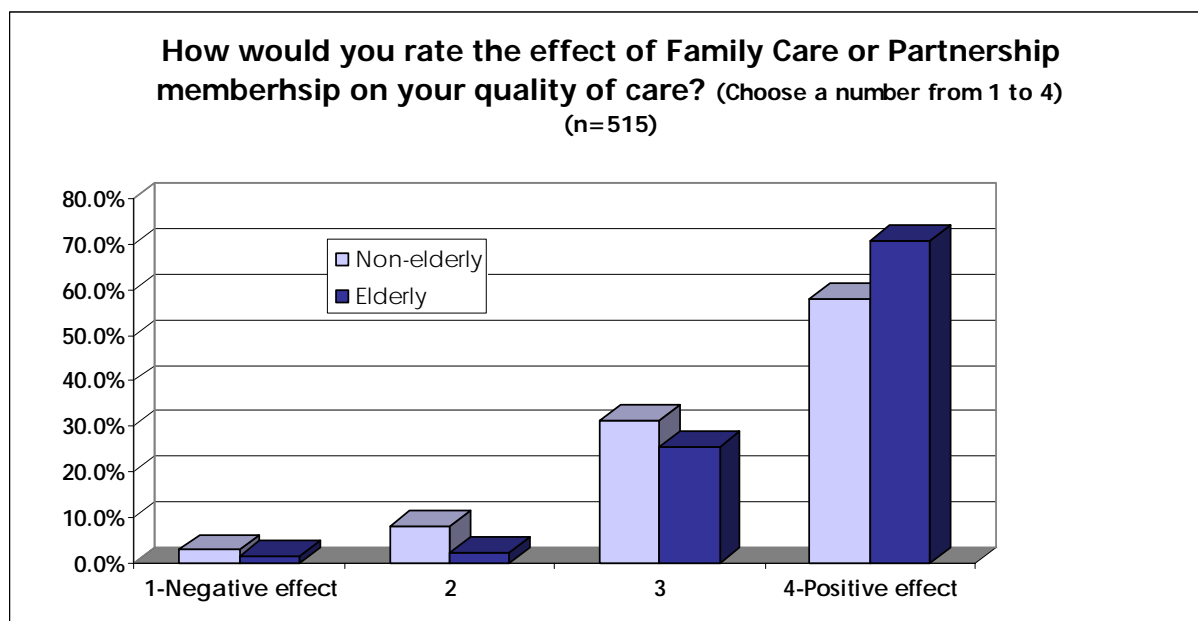
Respondents to the APS consumer survey reported membership in Family Care or Partnership had a positive effect on their quality of care. Members were asked to rate Family Care/Partnership effect on their quality of care on a scale from 1 to 4 with 1 anchored at “negative effect” and 4 anchored at “positive effect”. Sixty-seven per cent (67%) of all respondents answered this question with a 4, indicating a “positive effect”, while 2% reported that Family Care/Partnership had a “negative effect” on their care (Figure 30).

Figure 30. Effect of Family Care/Partnership on Consumer Perceived Quality of Care



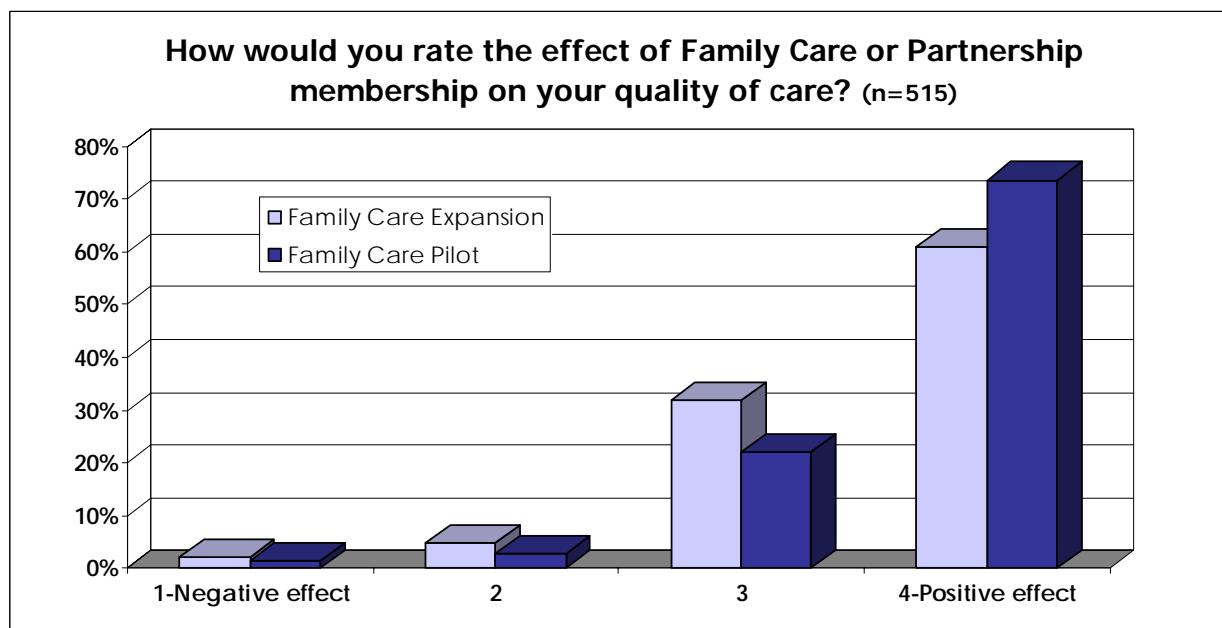
Significant differences emerged between age groups and geographic regions. Elderly respondents rated the effect of Family Care/Partnership on their quality of care significantly higher than non-elderly respondents (Figure 31).

Figure 31. Effect of Family Care/Partnership on Consumer Perceived Quality of Care by Elderly and Non-Elderly Respondents



Consumers from Family Care pilot counties rated the quality of care significantly higher than those in the Family Care expansion counties (Figure 32).

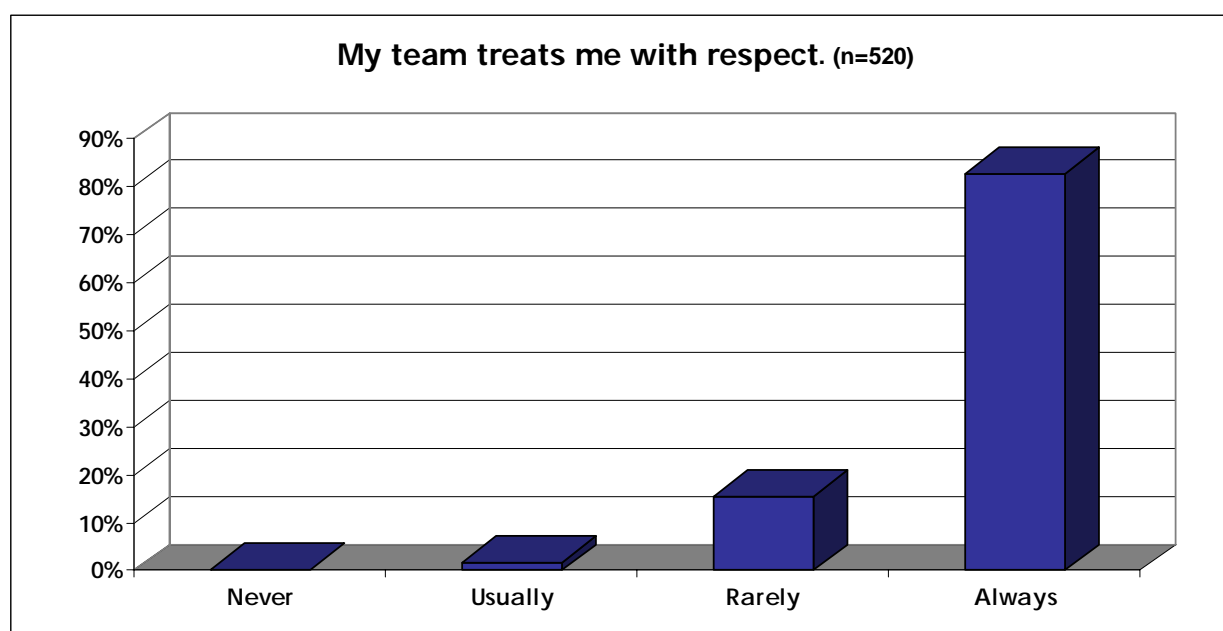
Figure 32. Effect of Family Care/Partnership on Consumer Perceived Quality of Care by Respondents from Family Care Expansion and Family Care Pilot Counties



The DHS PACE/Partnership survey asked members what had improved since being enrolled. The most frequent response was “better health, more active, less pain” followed by “help, nursing service & equipment in the home”.

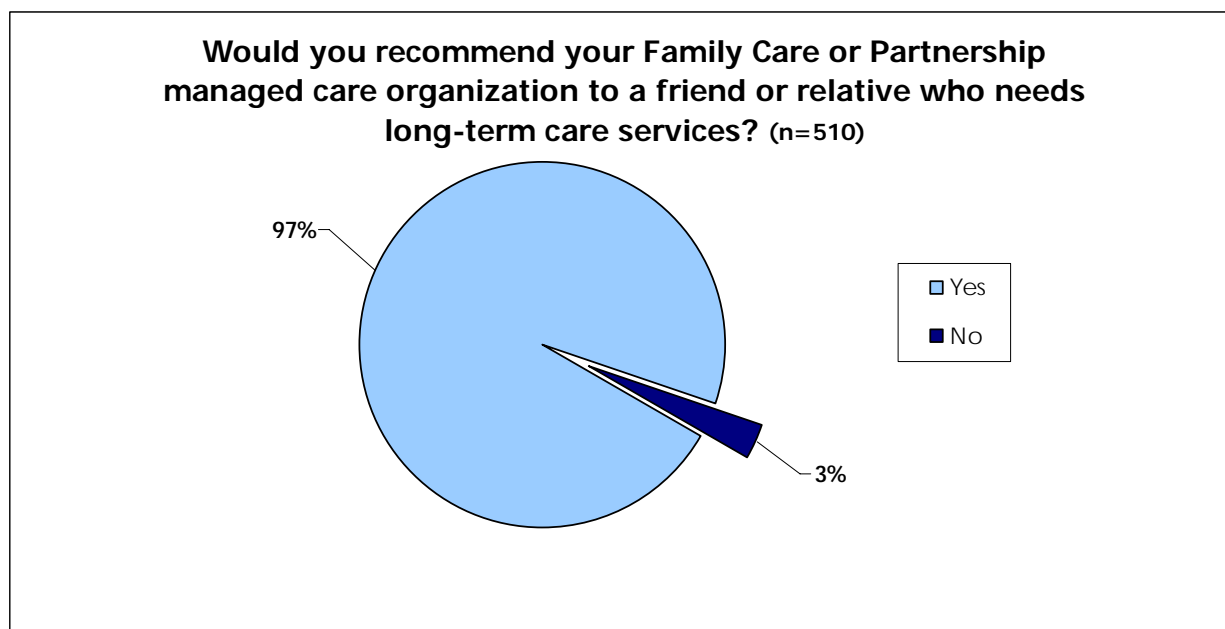
The DHS PACE/Partnership survey also reported how frequently consumers felt respected by their team. Over 82% of respondents reported they “always” felt treated with respect, whereas only 0.2% of members felt they were “never” treated with respect (Figure 33).

Figure 33. Frequency that Respondents to PACE/Partnership Survey Felt They Were Treated With Respect by Their Team



Another indicator of satisfaction is the likelihood that a consumer will recommend their LTC program to a friend or family member. Both the APS survey and DHS PACE/Partnership survey found that nearly all consumers would recommend their MCO or PACE/Partnership program. The APS survey asked specifically if respondents would recommend their MCO to a friend or relative who needs long-term care services. Ninety-seven percent of respondents answered “yes” (Figure 34).

Figure 34. Percentage of Consumer Survey Respondents Who Would Recommend Their MCO to a Friend or Relative in Need of LTC Services



The PACE/Partnership survey asked, “Would you recommend Partnership to your friends?” Again, this yielded a positive response, with 98% reporting they would recommend Partnership to their friends.

Conclusion. These overwhelmingly positive responses confirm the high level of satisfaction by consumers with their long-term care programs, their relationships with their interdisciplinary teams, and the amount of input they had in preparing their care plans. It is worthy to note that, in the spirit of quality improvement, consideration should be also given to the few reported instances of low satisfaction, perceived negative impact on care, not enough care/service plan input, and not feeling respected. Investigation into why these instances occurred and possible organizational or team changes needed is necessary. Nevertheless, the findings of these surveys clearly give the message that consumers are very satisfied with their managed care program, their team, and the process of creating their care plan.

Personal Story. Survey data revealed consumer perceptions about the MCOs in aggregate. However, aggregate findings, by their very nature, do not relate the unique experience of the individual consumer. This section tells the story of one particular consumer as related through a consumer interview. The interview captures well this individual’s experience as he transitioned from the LTC fee-for-service waiver program to managed care. As of 2008, this person had been a member of Family Care for 8

years. Previous to membership in Family Care, this person received Medicaid Community Options Program waiver services. He had an unusually high involvement in LTC planning, having been a participant in the LTC planning councils at the State and local levels.

This consumer was very clear about his satisfaction with the Family Care program, his managed care organization, and how he knew that his needs were met in the Family Care MCO. He used the example of purchasing a new wheelchair. He stated:

In the old system, I received a new wheel chair every 4-5 years, regardless of need. In the new system, I went about 8 years without a new chair. After about 8 years, I was having mechanical trouble with my chair and parts were hard to find. The MCO met with me and the durable medical goods company, and then decided it was more efficient to purchase a new chair. The durable medical goods wheelchair representative met with me to identify what I would like in the new chair. We went through the process of identifying what I needed and wanted. Once the decision was made, I had a new chair in a week.

From this consumer's perspective, the key to satisfaction with his Family Care services was distinguishing between his wants and needs. He continued:

Sometimes your wants are your needs, and sometimes your wants are not always what you need. You get what you need." There needs to be a change of perspective from wants to needs with the predominate question being: 'Are my needs, not my wants, being met?' All of my needs have been met. If I have a severe problem I don't just sit around, it gets taken care of.'

Previously, this consumer had received a new electric wheelchair every 4-5 years, regardless of the chair's condition. Under managed care, he received a new chair only when it became fiscally irresponsible to continue to repair the old one. The determination to purchase the new chair was made with his interdisciplinary team using the Resource Allocation Decision Method (RAD). After applying the RAD, the decision to purchase was prompt, and he obtained his new wheelchair within a week. This was a much quicker turnaround than through the previous system. The team called on the expertise of a representative from a durable medical equipment supplier to determine all necessary features on the new chair. In this way, the MCO right-sized the consumer's chair and used the most cost-effective method to meet his needs.

F. Cost Strategies

The planning and implementation of Family Care has been characterized both by excitement about its potential and concerns about its costs. The prospect of eliminating wait lists for publicly funded community-based long-term care services has been tempered by the realization that county consortia were accepting new levels of financial risk. This chapter discusses these cost concerns and the potential impact of the implementation of the “franchise model” currently under consideration to increase standardization, quality, and efficiency.

1. Cost Concerns

Respondents to the APS stakeholder survey ranked “the amount of funding for long-term care” as the second most important planning issue out of seventeen, the first being “quality of care for consumers.” Standing in contrast, and as indicative of their faith in the system, these same stakeholders ranked their belief that planning successfully resolved the issue of long-term care funding lower than all other items and they ranked resolution for quality of care as one of the top items. This implies that although there is great interest in creating a financially viable long-term care system, stakeholders did not feel that the planning process adequately addressed these concerns.

Despite the progress made in eliminating wait lists, exuberance was tempered by apprehension related to the capitated per-member per-month (PMPM) rate. One stakeholder expressed ambivalence in the following survey comment, “I definitely think there will be positive and negative changes for the consumer once Family Care is in place. Many will now receive services as the wait lists are eliminated, which is positive, but many will not get the services they had been receiving due to cost restraints. This will definitely be negative.” This sentiment was confirmed in a number of interviews.

Transitioning people off wait lists has caused fear among stakeholders about the amount of Family Care funding available as a whole. One concerned stakeholder said, “Eliminating wait lists is great, but it creates the need for more dollars. My concern is that the consortia will be expected to serve everyone who applies with the same amount of money the counties had with wait lists. How is that going to work?”

The concern about funding has been especially high among members of the developmentally disabled (DD) community. In general, DD members have

traditionally had more costly service plans than members of other target groups. There is fear that increased financial pressures will result in fewer services for members. The following themes emerged from interviews with disability advocates as sources of apprehension about the transition to managed care:

- Rigid control of functional eligibility through the Long-Term Care Functional Screen (LTC FS) will result in loss of eligibility
- The possibility of insufficient PMPM rates will result in service reductions
- Insufficient experience by MCO staff in making DD level of care determinations will result in inappropriate (and insufficient) functional screen determinations
- The rate-setting model is insensitive to greater outcome expectations of young consumers

2. Capitation Rate Issues

Per member per month rates were the biggest concern voiced by interviewees and stakeholder survey respondents. A number of interviewees said that they thought that the current rates set by the State would be insufficient to provide care to their members.

Interviewees also expressed concern that rates or eligibility would be altered in the future. There was a general feeling among a number of interviewees that the balance between serving more members and per-member savings in the program would not add up. “Some people think Family Care is about the money and not the people. There is fear that funding will be inadequate, and that Family Care will ‘get shorted’ down the road.”

Even if budget models on which the program has been operating are sufficient to meet the needs of the program, it is likely that budgetary constraints will affect Family Care services. As one stakeholder noted, “Stakeholders want to be assured that funding is guaranteed, which isn’t possible. I am hearing this from multiple levels and types of stakeholders.” With a tightening recession and November 2008 predictions of a shortfall in the State government budget of more than \$5 billion ¹³, budgetary pressures on Family Care spending can be anticipated even before it reaches full implementation.

In addition to the concerns mentioned above, several interviewees cautioned that the October 7, 2005 APS Healthcare independent Evaluation of Family Care as a widely disseminated work may have become a misleading resource. According to these interviewees, the findings of that evaluation “may not be applicable to the current structure of Family Care.” The 2005 evaluation was based on five pilot, county-based, managed care organizations. Family Care expansion includes many variations from the single county-based model. This has many implications for the way funds in county budgets can be proportioned. To some, this is an argument for placing less trust in the cost analysis of the independent evaluation.

DHS contracted actuaries, Price Waterhouse Coopers, set Family Care rates yearly for managed care and PACE/Partnership organizations. The rates are capitated and account for eligibility category and acuity levels as well as a number of other variables. The model has been consistently reevaluated and improved with the expansion of Family Care. Nevertheless, there remain concerns that year-to-year rate increases will not be sufficient for MCOs to continue to maintain the same quality of services. In addition, many stakeholders acknowledged the complexity of the rate setting process while wanting to have had the opportunity to understand it better. One interviewee likened the rate-setting process to “a black box, with the actuaries in the box. I’m sure I would have been able to understand it if given the opportunity.”

3. Application of the Franchise Model

The Wisconsin DHS is looking toward applying a franchise business model to Family Care and ADRCs in order to address both quality and cost-effectiveness concerns that have become more apparent as expansion has progressed. According to a presentation of the model in development to MCO Directors in September 2008, benefits of franchising include¹⁴:

- Program consistency
- Efficiency and cost management
- Better member outcomes
- Standardization and technical support
- Reduced risk

A report from The Management Group (TMG) outlines well the services which lend themselves to the franchising process and what shape these standardized services might take¹⁵. The franchise model suggests that many cost duplications, arising from each consortium developing IT systems, governance models and other systems from scratch could be avoided. Standardization of systems would also enable DHS to provide a greater capacity to assist in local system optimization and troubleshooting.

4. MCO IT Issues

The potential of addressing IT issues is a primary factor to those who support adaptation of the franchise model. MCO IT systems are a particular concern of both Wisconsin DHS and MCO staff and management. MCOs require systems which meet their utilization and quality goals without excess data entry. DHS requires consistent data across consortia to monitor utilization and quality. An efficient system would enable DHS to track data on quality measures and use that information to assist MCOs to meet performance and financial benchmarks. One MCO Director said that the consortia were wary of Wisconsin DHS efforts to “standardize IT” because of the tremendous effort consortia had already exerted to build their own systems. According to a number of MCO directors, a more acceptable solution than “the franchise model” would be for the State to sanction one or more of the consortia-developed IT systems rather than requiring the use of a single system.

G. Conclusion

The State accelerated statewide implementation of managed long-term care during a period originally intended for planning. While there may be tangible benefits to consumers by providing this program years before what might have otherwise been possible, quality and cost-efficiencies were somewhat side-barred in the wake of managed care expansion. However, issues raised in each of these areas are being addressed.

The State made progress in the initial identification of quality indicators for the ADRCs through its survey analysis. However, State data collection was hampered by tardy implementation of an IT system that will eventually enable encounter data collection by the State. Nevertheless, the core elements of an effective data collection system are being put in place at a pace that is logistically possible, and consumer perception of quality of ADRC services registered as consistently high.

The State made significant progress in the development of a reliable process to identify and assess personal experience outcomes of consumers through design of the PEONIES tool. CMO initial resistance to use of the tool eased as people were trained and the value of the tool was recognized. As with the ADRCs, overwhelmingly positive responses to consumer surveys confirmed the high level of satisfaction by consumers with their managed care program, their relationships with their interdisciplinary team members, and the amount of input they had in preparing their care plans.

Cost efficiency concerns were consistently high on the radar of both the State and counties from the inception of Family Care. Transitioning to a carefully-conceptualized franchise model is being designed to address these concerns. Cost concerns are currently being exacerbated by the nationwide economic downturn and State budget woes. There is little doubt the commitment by State and county planners to the operational and financial success of the program will be tested during the next few years, and expansion of the program may be slowed or diverted in some way based on budget constraints. Nevertheless, the successes of the effort thus far are testimony to the dedication, perseverance, and leadership of State and county staff. These characteristics will no doubt carry them through the highs and lows of further expansion.

In conclusion, this report confirms that, with few exceptions, Wisconsin DHS met and exceeded the goals and objectives of the CMS Comprehensive Systems Change Grant.

X. References

Reference numbering begins anew with each new chapter; Chapter 1 Introduction¹, Chapter 2 Background¹, etc.

Chapter I Introduction

1. Wisconsin Department of Health Services. (2008, November 1). *Family Care Partnership and PACE enrollment data: Monthly snapshot as of November 1, 2008 total MCO enrollment by target group*. Retrieved December 16, 2008 from State of Wisconsin Department of Health Services, Family Care General Information Web site: <http://dhs.wisconsin.gov/ltcare/Generalinfo/EnrollmentData.htm>
2. Luedtke, K. (n.d.). *Managed Long-Term Care in Wisconsin* [Power Point]. Presented at the November 2008 NASDDDS Annual Conference Constructing the New Paradigm: Responding to Demographic and Economic Realities. Retrieved December 16, 2008 from http://www.nasddds.org/Meetings/2008_Annual_Conference/2008_AC_Presentations/LUEDTKE.ppt
3. Wisconsin Department of Health and Family Services. (2008, April 2). *Transition Overview: Size and scope*. Madison, WI.

Chapter II Background

1. Wisconsin Department of Health Services. (2008, October 30). *Family Care Partnership Program*. Retrieved December 22, 2008 from State of Wisconsin Department of Health Services Web site: <http://dhs.wisconsin.gov/wipartnership/>
2. Wisconsin Department of Health Services. (2008, November 3). *Family Care: Options for Long-Term Care*. Retrieved December 22, 2008 from State of Wisconsin Department of Health Services Web site: <http://dhs.wisconsin.gov/ltcare/>

Chapter IV Strategic Planning for Statewide Implementation

1. Wisconsin Department of Health Services (n.d.). *Managed Long-Term Care Expansion Planning Grants*. Posted January 7, 2009 by the State of Wisconsin Department of Health Services Division of Long-Term Care: <http://dhs.wisconsin.gov/managedltc/grants>.
1. Wisconsin Department of Health Services. (2008, December 1). *Family Care Implementation Information Map*. Retrieved December 16, 2008 from State of Wisconsin Department of Health Services General Information on Long-Term Care Reform and Expansion Web site: <http://dhs.wisconsin.gov/managedltc/generalinfo/pdf/implemntmap.pdf>

2. Wisconsin Department of Health Services. (2008, November 1). *Current and Proposed Aging and Disability Resource Centers*. Retrieved December 18, 2008 from State of Wisconsin Department of Health Services Aging and Disability Resource Centers Web site:
<http://dhs.wisconsin.gov/lrcare/Generalinfo/adrcmap.pdf>
3. Luedtke, K. (n.d.). *Managed Long-Term Care in Wisconsin* [Power Point]. Presented at the November 2008 NASDDDS Annual Conference Constructing the New Paradigm: Responding to Demographic and Economic Realities. Retrieved December 16, 2008 from
http://www.nasddds.org/Meetings/2008_Annual_Conference/2008_AC_Presentations/LUEDTKE.ppt

Chapter V The Role of Stakeholders in Long-Term Care Planning

1. Wisconsin Department of Health and Family Services. (2006, May 22). *Managed Long-Term Care Expansion Planning, Information #1: Framework for Stakeholder Involvement in Managed LTC Expansion*. Retrieved December 16, 2008 from State of Wisconsin Department of Health Services Managed Long-Term Care Expansion Planning Information Series Web site:
<http://dhs.wisconsin.gov/managedltc/grantees/pdf/info1stakeholder.pdf>

Chapter VI Improving Consumer Access to Information

1. Wisconsin Department of Health and Family Services. (n.d.). *Comprehensive Systems Change Grant DHFS Reports to CMS*. Madison, WI, State of Wisconsin, Department of Health Services, Division of Long-Term Care. Luedtke, K.
2. Wisconsin Council on Long Term Care Reform. (2005, April). *Resource Center Expansion Committee Wisconsin Council on Long-Term Care Reform Final Report*. Retrieved December 12, 2008 from Wisconsin Council on Long-Term Care former Wisconsin Council on Long Term Care Reform 2003-2007 Resource Center Expansion Committee Web site:
<http://www.wcltc.state.wi.us/former03-07/PDF/adrcrpt.pdf>
3. Wisconsin Department of Health and Family Services. (2006, May 23). *Aging and Disability Resource Center Development Information #3: Aging and disability Resource Center Vision*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, Aging and Disability Resource Center Web site:
<http://dhs.wisconsin.gov/lrcare/pdf/adrc3vision.pdf>
4. Wisconsin Department of Health and Family Services. (2008). *Exhibit 1 Scope of Services for the Contract between Department of Health and Family Services Division of Long-Term Care and the Aging and Disability Resource Center of <<County>> January 1, 2008 –December 31, 2008*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, State and Federal

Requirements Web site:

<http://dhs.wisconsin.gov/ltcare/StateFedReqs/2008ADRCContract1.pdf>

5. The Lewin Group. (2008, October 24). *An Annotated History of Wisconsin's Aging and Disability Resource Centers*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services Family Care Research and Reports Web site:
<http://dhs.wisconsin.gov/ltcare/pdf/AnnotatedHistoryofWIADRCs.pdf>
6. Wisconsin Department of Health and Family Services. (2007, June 1). *Application Instructions and Forms: To Contract as an ADRC*. Retrieved December 13, 2008 from State of Wisconsin Department of Health Services Aging and Disabilities Resource Center Web site:
<http://dhs.wisconsin.gov/ltcare/pdf/ADRCApplication.pdf>
7. Wisconsin Department of Health and Family Services. (2006, October 18). *Aging and Disability Resource Center Development Information #8: Informational Materials regarding Funding of Aging & Disability Resource Centers*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, Aging and Disability Resource Center Web site:
<http://dhs.wisconsin.gov/ltcare/pdf/adrc8funding.pdf>
8. Marquis, S. (2007, September 25). *Grant to Wisconsin aims to expand aging and disability resource centers*[Press Release]. Retrieved December 23, 2008 from State of Wisconsin Department of Health Services, 2007 DHFS News Releases Web site:
<http://dhs.wisconsin.gov/news/pressreleases/2007/092507ADRC.htm>
9. The Lewin Group. (2006, November). *The Aging and Disability Resource Center (ADRC) Demonstration Grant Initiative: Interim Outcomes Report*. Retrieved December 12, 2008 from U.S. Department of Health and Human Services Aging and Disability Resource Center Technical Assistance Exchange Web site:
<http://www.adrc-tae.org/documents/InterimReport.pdf>
10. U.S. Department of Health and Human Services Administration on Aging. (2008, October). *Aging and Disability Resource Centers: A Joint Program of Administration on Aging & Centers for Medicare & Medicaid Services*. Retrieved December 13, 2008 from U.S. Department of Health and Human Services Administration on Aging Web site:
http://www.aoa.gov/press/prodsmats/fact/pdf/fs_ADRC.doc
11. Luedtke, K. (n.d.). *Managed Long-Term Care in Wisconsin* [Power Point]. Presented at the November 2008 NASDDDS Annual Conference Constructing the New Paradigm: Responding to Demographic and Economic Realities. Retrieved December 16, 2008 from

http://www.nasddds.org/Meetings/2008_Annual_Conference/2008_AC_Presentations/LUEDTKE.ppt

12. Milwaukee County Department of Health and Human Services. (2008, September 11). *Milwaukee County Department of Health and Human Services, Disabilities Services Division Long-Term Care: Planning grant – Final Report*. Milwaukee, WI: Lyday, G. L.
13. Dane-Rock Region: Planning for Change in Long-Term Care. (n.d.). *Long-Term Care Planning Grants – Final Report*. Madison, WI: Kuehn, J.
14. Wisconsin Department of Health and Family Services. (2007, December 10). *Aging and Disability Resource Center Development Information #16: Aging and Disability Resource Center Governing Boards*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, Aging and Disability Resource Center Web site: <http://dhs.wisconsin.gov/ltcare/pdf/adrc16.pdf>
15. Social Services, Wisconsin Stat. 46-2825-283 (2005-06 & 2008). Retrieved December 13, 2008 from State of Wisconsin Legislative Documents Search Web site: <http://www.legis.state.wi.us/statutes/Stat0046.pdf>
16. Wisconsin Department of Health and Family Services. (2007, November 7). *Timeline for Transition to Managed LTC*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, Information for Agencies Transitioning to Managed Long-Term Care Web site: <http://dhs.wisconsin.gov/managedltc/transition/pdf/timeline.pdf>
17. *Family Care Consumer Corps Training* [PowerPoint]. (2007). Presented at 2007 Wisconsin Department of Health Services Family Care Consumer Corps Training. Retrieved December 16, 2008 from <http://dhs.wisconsin.gov/managedltc/generalinfo/pdf/consumercorpsppt.pdf>
18. Social Services, Wisconsin Stat. 46-285 (2005-06 & 2008). Retrieved December 13, 2008 from State of Wisconsin Legislative Documents Search Web site: <http://www.legis.state.wi.us/statutes/Stat0046.pdf>
19. Wisconsin Department of Health and Family Services. (2006, June 16). *Aging and Disability Resource Center Development Information #4: Organizational Separation between Aging and Disability Resource Centers and Managed Care Organizations to Avoid Conflicts of Interest*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, Aging and Disability Resource Center Web site: <http://dhs.wisconsin.gov/ltcare/pdf/adrc4separation.pdf>
20. Wisconsin Department of Health and Family Services. (2006, August 1). *Aging*

and Disability Resource Center Development Information #6: Planning for Information and Assistance (I&A) Service. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, Aging and Disability Resource Center Web site: <http://dhs.wisconsin.gov/lcicare/pdf/adrc6ina.pdf>

21. Wisconsin Department of Health and Family Services. (2007). *ADRC Success Stories*. Madison, WI: Smith J.
22. Santala, S. (2008, December 1). *DLTC Info Memo Series 2008-10: Family Care Transition Guidance to County Long-Term Support Agencies*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services Division of Long-term care information memo series-2008 Web site: http://dhs.wisconsin.gov/dsl_info/InfoMemos/DLTC/CY2008/200810im.pdf
23. Wisconsin Department of Health and Family Services. (2008, February 26). *Managed Long-Term Care Expansion Planning Information #5: Transitioning from Medicaid Waiver Programs to Managed Long-Term Care*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, Managed Long-Term Care Expansion Planning Information Series Web site: <http://dhs.wisconsin.gov/managedltc/transition/pdf/info5transition.pdf>
24. Wisconsin Alzheimer's Institute. (2007). *The Wisconsin Memory Screening Initiative: WAI Progress Report for Year Three (October 1, 2006 to September 30, 2007) & Summary for the Memory Screening Initiative in Family Care Counties*. Madison, Wisconsin: University of Wisconsin School of Medicine and Public Health.
25. Mahoney, J. & Hale, L. (n.d.). *Falls Prevention in Wisconsin* [PowerPoint]. Presentation presented for the January 2007 ASTHO injury prevention webcast. Retrieved December 12, 2008 from <http://www.astho.org/pubs/Falls-Mahoney.ppt>

Chapter VII Long-Term Care System Access

1. Wisconsin Department of Health Services. (n.d). *Family Care State-Wide*. Retrieved December 11, 2008 from State of Wisconsin Department of Health Services, Statewide expansion of managed long-term care Web site: <http://dhs.wisconsin.gov/managedltc/generalinfo/pdf/fcpolicypaper.pdf>
2. Wisconsin Department of Health Services. (2008, November 3). *Family Care: Options for Long-Term Care*. Retrieved December 22, 2008 from State of Wisconsin Department of Health Services Web site: <http://dhs.wisconsin.gov/lcicare/>
3. Wisconsin Department of Health Services. (2008, October 31). *2008 HSRS LTC Module: State / County Long-Term Support Waitlist CY2008: Applicants waiting by County, Age Group, Target Population Data as of: Oct 31, 2008*. Retrieved December 15, 2008 from State of Wisconsin Department of Health Services,

Community Options Program Web site:

http://dhs.wisconsin.gov/ltc_cop/LTSWaitlistByAgeCY2008.PDF

4. Santala, S. (2006, July 24). *DLTC Info Memo Series 2006-14: Assuring Wisconsin Functional Screen Quality and Requesting Feedback*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services DDES information memo series-2006 Web site:
http://dhs.wisconsin.gov/dsl_info/InfoMemos/DDES/CY2006/2006-14.pdf
5. Wisconsin Department of Health Services. (2008, October 29). *Wisconsin Long-Term Care Functional Screen Instructions*. Retrieved December 11, 2008 from Wisconsin Department of Health Services, Wisconsin's functional screen Web site: <http://dhs.wisconsin.gov/ltcare/FunctionalScreen/LTCFSinstrux-clean.pdf>
6. Wisconsin Department of Health and Family Services. (n.d.). *Comprehensive Systems Change Grant DHFS Reports to CMS*. Madison, WI, State of Wisconsin, Department of Health Services, Division of Long-Term Care. Luedtke, K.
7. Santala, S. (2008, September 24). *DLTC Info Memo Series 2008-11: SSI-E Certification*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services Division of Long-term care information memo series-2008 Web site:
http://dhs.wisconsin.gov/dsl_info/InfoMemos/DLTC/CY2008/200811im.pdf
8. Santala, S. (2006, August 25). *DDES info memo series 2006-18: Completion of the Long-Term Functional Screen for People Residing in ICF/MR and Nursing Homes, related to the ICF/MR Restructuring Initiative*. Retrieved December 11, 2008 from State Wisconsin Department of Health Services Division of Long-term care information memo series-2006 Web site:
http://dhs.wisconsin.gov/dsl_info/NumberedMemos/DDES/CY2006/2006-18_numb_ICF_MR.pdf

Chapter VIII Increasing Service Options within the Context of Long-Term Care Reform

1. Wisconsin Department of Health Services. (n.d.). *Family Care State-Wide*. Retrieved December 11, 2008 from State of Wisconsin Department of Health Services, Statewide expansion of managed long-term care Web site:
<http://dhs.wisconsin.gov/managedltc/generalinfo/pdf/fcpolicypaper.pdf>
2. Wisconsin Department of Health and Family Services. (2004, July 19). *Real Choice Systems Change Grant Application 2004 Wisconsin Department of Health and Family Services Comprehensive Systems Reform Effort: Project Narrative*. Retrieved December 12, 2008 from Wisconsin Council on Long-Term Care, Centers for Medicare and Medicaid Systems (CMS) Real Choice Systems

Change Grant: Comprehensive Systems Reform Effort - Summary Web site:
<http://www.wcltc.state.wi.us/former03-07/PDF/CSCgrantNarr.pdf>

3. Wisconsin Department of Health and Family Services. (2006, November). *Wisconsin Nursing Homes and Residents 2005*. Retrieved December 11, 2008 from State of Wisconsin Department of Health Services, Nursing homes and facilities serving people with developmental disabilities Web site:
<http://dhs.wisconsin.gov/provider/pdf/05nh&r.pdf>
4. Wisconsin Department of Health Services, Division of Long-Term Care. (n.d.). *Number of Nursing Home Beds Licensed and Staffed*. Madison, WI. Bove, F.E.
5. Wisconsin Department of Health Services. (2008). *SFY 2008 Report on Relocations and Diversions from Institutions, as required by s. 51.06 (8): Executive Summary*. Madison, WI. State of Wisconsin, Department of Health Services, Division of Long-Term Care.
6. Miller, E. A., & Mor, V. (2006). *Out of the Shadows: Envisioning a Brighter Future for Long-Term Care in America*. Brown University report Retrieved December 22, 2008 from the National Commission for Quality Long-Term Care Web site:
http://www.qualitylongtermcarecommission.org/pdf/brown_report_out_of_the_shadow.pdf
7. Wisconsin Department of Health and Family Services. (n.d.). *Comprehensive Systems Change Grant DHFS Reports to CMS*. Madison, WI, State of Wisconsin, Department of Health Services, Division of Long-Term Care. Luedtke, K.
8. Wisconsin Department of Health Services, Division of Long-Term Care. (2006, December 8). *Estimating the Future Demand for MA-Funded Nursing Facility Beds*. Madison, WI: Frye, J. & Sharon, N.
9. Santala, S. (2007, May 4). *DLTC Info Memo Series 2007-06: Update-Nursing Home Recognition for Performance (R4P) Quality Initiative*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services DLTC info memo series-2007 Web site:
http://dhs.wisconsin.gov/dsl_info/InfoMemos/DDES/CY2007/2007-06.pdf
10. Sauer, J. (2008, August 7). *WAHSA 2009-11 Nursing Home Funding Budget Requests*. Retrieved December 11, 2008 from the Wisconsin Association of Homes and Services for the Aging, Inc. Web site:
<http://www.wahsa.org/medreq.pdf>
11. Rosenberg, L., Williams, E.M., & Sievert, A.L. (2005, Fall). *Consumer-Directed*

Supports: Lessons Learned from Wisconsin's Family Care Program. Retrieved December 22, 2008 from University of Wisconsin Madison, Waisman Center Community Outreach Wisconsin, Program and Projects Web site:
http://cow.waisman.wisc.edu/Documents/SDS_WI%20stuff/SDS%20Lessons%20Learned.pdf

12. Wisconsin Department of Health and Family Services. (2007, October 10). *Self-Directed Supports Choices in Family Care Expansion.* Retrieved December 16, 2008 from State of Wisconsin, Department of Health Services Web site:
<http://dhs.wisconsin.gov/em/imac/minutes/2007/10Oct/SDSparticipantflowchart.pdf>
13. Wisconsin Department of Health Services. (2008, July 3). *DLTC Info Memo Series 2008-06: Implementation of IRIS Program.* Retrieved December 22, 2008 from State of Wisconsin, Department of Health Services. DLTC information memo series-2008 Web site:
http://dhs.wisconsin.gov/dsl_info/InfoMemos/DLTC/CY2008/200806im.pdf
14. Wisconsin Bureau of Long Term Support. (n.d.). *IRIS Wisconsin's Self-Directed Waiver Program: Participant Handbook.* Retrieved December 22, 2008 from IRIS independent consultant agency, Participant Resources Web site:
http://www.wisconsin-iris.com/images/iris_handbook_C.pdf
15. Wisconsin Department of Health Services. (2008, October). *IRIS Enrollment Report-October 2008.* Madison, WI. State of Wisconsin Department of Health Services, Division of Long-Term Care.
16. *Wisconsin Population Projection Tables: 2000-2030- Population & Household Projections: 2000-2035- State and County Age-Sex Population Projections, 2000-2035* [Data file]. Retrieved December 15, 2008 from State of Wisconsin, Department of Administration, Demographic Services Web site:
<http://www.doa.state.wi.us/docview.asp?locid=9&docid=2107>
17. Wisconsin Long-Term Care Workforce Alliance, (n.d.). *Wisconsin Long-Term Care Workforce Alliance 2008-09: Critical issues* (Position Paper). Brookfield, WI.
18. National Clearinghouse on Direct Care Workforce. (2006, November). *Fact Sheet: Who are Direct Care Workers?* Retrieved December 15, 2008 from
<http://www.directcareclearinghouse.org/download/NCDWCW%20Fact%20Sheet-1.pdf>
19. Wisconsin Department of Workforce Development. (2007, April). *Wisconsin Health Care Workforce Annual Report 2007: Grow Wisconsin Initiative.* Retrieved December 15, 2008 from State of Wisconsin, Department of Workforce Development, Select Committee Web site:
http://dwd.wisconsin.gov/healthcare/pdf/healthcare_annual_report2007.pdf

20. Wisconsin Long Term Care Workforce Alliance.(n.d.). *Long-Term Care Workforce Fact Sheet*. Retrieved December 15, 2008 from <http://www.wiworkforcealliance.com/advocacy/factsheet.pdf>
21. Institute for the Future of Aging Services (2007, January). *The Long-Term Care Workforce: Can the Crisis be Fixed? Problems, Causes and Options*. Retrieved December 15, 2008 from American Associations of Homes and Services for the Aging Web site: http://www.aahsa.org/uploadedFiles/IFAS/Publications_amp_Products/LTCCommissionReport2007.pdf
22. Wisconsin Council of Long-Term Care. (2005, June). *Strengthening Wisconsin's Long-Term Care Workforce: Final Report*. Retrieved December 15, 2008 Wisconsin Council of Long-Term Care, Former Wisconsin Council on Long Term Care Reform 2003-2007, Committee on Direct Care Workforce Issues Web site: <http://www.wcltc.state.wi.us/former03-07/PDF/cdcrpt.pdf>

Chapter IX Quality and Cost

1. APS Healthcare, & The Management Group, Inc. (2006, September). *Quality Close to Home: A Preliminary Design for an Integrated Quality Management System*. Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, Research and Reports Web site: <http://dhs.wisconsin.gov/ltcare/ResearchReports/PDF/qcthrpt-full.pdf>
2. Wisconsin Council on Long Term Care. (2008, June 12). *Committee on Family Care Quality Wisconsin Council on Long-Term Care meeting of June 12, 2008: Approved minutes*. Retrieved December 15, 2008 from Wisconsin Council on Long-Term Care, Committee on Family Care quality, Web site: <http://www.wcltc.state.wi.us/pdf/fcqcmin061208.pdf>
3. Flowers, A. (2008, October 14). *Evaluating Customer Satisfaction: A Guided Tour of Wisconsin's Comprehensive ADRC Customer Services Evaluation* [PowerPoint]. Presentation presented at the 2008 Wisconsin ADRC Conference. Retrieved December 15, 2008 from U.S. Department of Health and Human Services, Aging and Disability Resource Center Technical Assistance Exchange Web site: http://www.adrc-tae.org/tiki-download_file.php?fileId=27545
4. Flowers, A. (2008, September 2). *ADRC Customer Satisfaction: Evaluation Results* [PowerPoint]. Presentation presented at the September 2008 Wisconsin Long Term Care Council Meeting. Madison, WI.
5. Wisconsin Council on Long Term Care. (2008, May 6). *Wisconsin Council on*

Long-Term Care meeting of May 6, 2008 approved minutes. Retrieved December 15, 2008 from Wisconsin Council on Long-Term Care, Meetings, Web site: <http://www.wcltc.state.wi.us/pdf/min050608.pdf>

6. Smith, J. (2007, October 30). *ADRC Activity Reporting for 2008.* Retrieved December 15, 2008 from State of Wisconsin, Department of Health Services, Aging and Disability Resource Centers Web site: <http://dhs.wisconsin.gov/ltcare/pdf/ADRCMemoActivityReporting2008.pdf>
7. Wisconsin Department of Health and Family Services. (2007, December 10). *Aging and Disability Resource Center Development Information #17: Regional Long-Term Care Advisory Committees.* Retrieved December 12, 2008 from State of Wisconsin Department of Health Services, Aging and Disability Resource Center Web site: <http://dhs.wisconsin.gov/ltcare/pdf/adrc17.pdf>
8. Wisconsin Council on Long Term Care. (2008, July 1). *Wisconsin Council on Long-Term Care meeting of July 1, 2008 approved minutes.* Retrieved December 15, 2008 from Wisconsin Council on Long-Term Care, Meetings, Web site: <http://www.wcltc.state.wi.us/pdf/min070108.pdf>
9. Wisconsin Council on Long Term Care. (2008, March 14). *Wisconsin Council on Long-Term Care meeting of March 14, 2008 approved minutes.* Retrieved December 15, 2008 from Wisconsin Council on Long-Term Care, Meetings, Web site: <http://www.wcltc.state.wi.us/pdf/min031408.pdf>
10. Wisconsin Council on Long Term Care. (2008, July 25). *Committee on Family Care Quality Wisconsin Council on Long-Term Care meeting of July 25, 2008: Approved minutes.* Retrieved December 15, 2008 from Wisconsin Council on Long-Term Care, Committee on Family Care quality, Web site: <http://www.wcltc.state.wi.us/pdf/fcqcmin072508.pdf>
11. University of Wisconsin-Madison Center for Health Systems Research and Analysis. (2008, August 18). *PEONIES: Personal Experience Outcomes-Integrated Interview and Evaluation System.* Retrieved December 15, 2008 from http://www.chsra.wisc.edu/peonies/PEONIES_Index.html
12. Wisconsin Department of Health Services. (2008, March 5). *2007 Member Satisfaction Survey Wisconsin Partnership Program and PACE Program.* Retrieved December 15, 2008 from State of Wisconsin, Department of Health Services, Family Care Partnership Program Information & Publications Geared Toward Professionals Web site: <http://dhs.wisconsin.gov/wipartnership/pdf-wpp/2007membresatsurvey.pdf>
13. Marley, P. (2008, November 11). *State deficit will exceed \$5 billion, Doyle says. Milwaukee Journal Sentinel.* Retrieved December 15, 2008 from <http://www.jsonline.com/news/statepolitics/34288794.html>

14. The Management Group, Inc. (2008, September). *A Public Franchise Model for the Family Care Enterprise Development and Management: Rationale, Model Components, Implementation Options and Resource Requirements*[PowerPoint]. Presentation presented at the September 2008 State of Wisconsin, Department of Health Services, Division of Long-Term Care MCO Directors meeting, Madison, WI.
15. The Management Group, Inc. (2008, September 17). *A Public Franchise Model for the Family Care Enterprise Development and Management: Rationale, Model Components, Implementation Options and Resource Requirements*. Retrieved December 15, 2008 from State of Wisconsin, Department of Health Services, General Information on Long-Term Care Reform and Expansion Web site: <http://dhs.wisconsin.gov/ManagedLTC/generalinfo/pdf/franchiserpt.pdf>

XI. Sources Consulted-Bibliography

XII. Appendices

The Bibliography and Appendices are located in separate electronic files.