Institute for Research on Poverty Special Report no. 80

## Early Evidence from Wisconsin's Family Care Long-Term Care Pilot Program: Continuity and Change in the Provision of Formal Services

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July 2001

This study is partly supported by the John A. Hartford Foundation (Hartford Geriatric Social Work Faculty Scholars Program), the Institute for Research on Poverty, and the University of Wisconsin–Madison School of Social Work. We are particularly indebted to the care managers who participated in this study, providing both their insights and their most precious resource—their time. I also thank the county directors, CMO directors, and supervisors for recognizing the benefits of care manager participation in the study. Sarah Benedict, Cornelia Gordon-Hempe, and Anne Sweeney worked diligently to schedule and conduct the phone interviews. Content of the survey was developed through various interactions with county CMO care managers and administrators and with state workers in the Wisconsin Department of Health and Family Services. Specific feedback on survey design and/or content was provided by Marsha Seltzer, Rosalie Kane, Ann Pooler, Alice Mirk, Sarah Esmond, Peter Tropman, Sarah Benedict, Anne Sweeney, Howard Degenholtz, Steve Lutzky, Christina Neill, Jenny Synnes, Rachel Haberman, Jessica Holt, and Mary Fiore. Project assistance was provided by Sarah Benedict, Anne Sweeney, and Rita Chou, and administrative assistance was provided by Deb Komro. Opinions expressed in this report are solely those of the author and do not necessarily represent the views of sponsoring institutions or of those who provided helpful feedback.

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#### **Executive Summary**

This report examines early evidence regarding service changes brought about during the first year of implementation of Family Care, Wisconsin's pilot program for long-term care. Phone surveys were conducted with 64 care managers working in Family Care in four counties (Family Care CMs) and with 62 care managers working in the long-term support system across Wisconsin (Statewide CMs). The first goal of this report was to begin examining whether and how Family Care is changing the services provided to people with long-term support needs. Most care managers report that Family Care participants are accessing as many or more services than participants in the previous long-term support programs. Care managers suggest that the elimination of waiting lists and increased flexibility of both funds and program rules have, overall, led to more use of services and to more appropriate use of services under Family Care. However, both Family Care and Statewide care managers report many remaining challenges to meeting the service needs of program participants. The second goal of this report was to describe some of the specific service issues that will need attention to improve Family Care and the longterm support system in Wisconsin as a whole. Both Family Care and Statewide CMs listed their top three service concerns as (1) personal care/supportive home care services, (2) transportation services, and (3) residential options. In particular, unless more personal care/supportive home care workers become available, it will be difficult for any public program to meet the long-term support needs of Wisconsin residents. The third goal of this report was to describe some of the hopes and concerns that care managers have regarding the future of services under Family Care. Family Care CMs were, overall, very optimistic about the future of services under Family Care, believing that more people will be served, that more of their needs will be met, and that the greater flexibility of Family Care will allow needs to be met more appropriately. Research must continue in monitoring Family Care as it develops over time in order to learn how best to meet the increasing long-term support needs of residents of Wisconsin and other states.

## Early Evidence from Wisconsin's Family Care Long-Term Care Pilot Program: Continuity and Change in the Provision of Formal Services

## 1. INTRODUCTION

Wisconsin recently began a pilot long-term care initiative called Family Care in nine Wisconsin counties. One of the primary goals of Family Care is to increase access to long-term support services for frail older adults and people with physical or developmental disabilities. The Family Care initiative creates two new types of organizations. The nine Family Care counties have developed *Aging and Disability Resource Centers*, designed to provide "one-stop shopping" for information about and access to long-term support resources. Five of the Family Care counties have also created *Care Management Organizations* (CMOs) that will implement a new Family Care long-term support benefit.

Under Family Care, the county CMOs will coordinate all the long-term care services—home- and community-based services as well as institutional services—for those eligible for and desiring publicly funded long-term care services in Family Care CMO counties. What is most new about Family Care is that a county, through its CMO, will now bear the financial risk for coordinating and providing for all the long-term care (LTC) needs of county residents eligible for and requesting publicly funded LTC services. The state will combine the current multiple funding streams from a number of programs such as the Home and Community-Based Waiver programs, the Community Options Program, and some Medicaid card services. The state will then pay county CMOs a capitated rate for each Family Care enrollee. The current LTC system in Wisconsin is not only a fee-for-service system rather than a capitated system, but it separates nursing home care from home- and community-based LTC both financially and organizationally. Waiting lists to access home- and community-based services have been long in many Wisconsin counties, and Family Care aims to eliminate these waiting lists by eventually making the Family Care benefit an entitlement to those who are eligible (currently, people are only *entitled* to nursing home care under Medicaid). By combining funds from multiple programs, and by loosening complicated

rules about the provision of services, it is hoped that Family Care will provide a more flexible benefit to better meet the individual needs of participants in the long-term support system.<sup>1</sup>

As Family Care is implemented, it needs to be examined to determine whether the initiative as a whole, or some of its components, is successful at improving the long-term support delivery system. This report is part of an ongoing study of the Family Care initiative and of the long-term support system in Wisconsin more generally.

This is the first of a series of reports to examine Family Care and the long-term support system in Wisconsin. The report focuses on the early experiences of Family Care care managers (CMs) during the first year of Family Care CMO implementation, describing CMs' reports of continuity and change within the service environment in four counties. Some experiences of care managers who work in the long-term support system across the rest of the state in counties not participating in the Family Care pilot are also described. Future reports will examine issues such as CMs' recommendations for changes to both the Family Care system and the broader long-term support system in Wisconsin.

## 1.A. Purpose of the Report

The three main goals of this report are:

- 1) to begin examining whether and how Family Care is changing the services provided to people with long-term support needs (Section 3.A.);
- 2) to describe some of the specific service issues that will need attention to improve Family Care and the long-term support system in Wisconsin as a whole (Section 3.B.); and
- 3) to describe some of the hopes and concerns that care managers have regarding the future of services under Family Care (Section 3.C.).

### 1.B. Why Should Family Care Change the Types and Amount of Services Provided?

The long-term support system in Wisconsin has become increasingly complex. Multiple funding

streams each have different eligibility criteria for access to services and different rules about which

<sup>&</sup>lt;sup>1</sup>See a more thorough description of Family Care at <a href="http://www.dhfs.state.wi.us/LTCare/INDEX.HTM">http://www.dhfs.state.wi.us/LTCare/INDEX.HTM</a>.

services are covered, in what amounts, at what cost, and by whom. Such complexity can result in inadequate and inequitable provision of service. Services that might best meet a consumer's needs might not be allowable, resulting in a consumer's needs going unmet. Or services may be provided that are not most appropriate or efficient for meeting the need. For example, in some cases, expensive services might be provided because the more appropriate and less costly alternatives are not allowed. In other cases, services to meet a particular need may be denied entirely, potentially leading to poor consumer outcomes. Such outcomes are both socially undesirable and fiscally inefficient.

Under Family Care, changes in both *program goals* and *organizational rules and structures* should result in changing patterns of service use in the long-term support system. Some Family Care program goals include a renewed emphasis on consumer-directed care, consumer needs, and consumer outcomes. This emphasis should lead to improved identification of informal and formal supports that will best meet the particular needs of individual consumers. Family Care is also changing organizational rules to increase flexibility in funding of services so that services can be provided to best meet the needs of consumers. Improved identification of consumer needs and preferences combined with increased flexibility in how those needs can be met should lead to changes in the types and amounts of formal services provided.

Is there any demonstration of changes in the services being provided to participants during the first year of Family Care implementation? What are some of the challenges experienced by care managers regarding changes in services with Family Care? We expect that only modest changes will occur during the first year of implementation. The short-term goal of this study is to examine these preliminary changes, while the long-term goal is to use this information to help evaluate longer-term changes in Family Care over a number of years.

## 1.C. Why Focus on the Perspective of Care Managers?

This study is based on the perspective of care managers—social workers, nurses, and other human service workers who work with long-term support program participants to help them access the

resources they require. Care managers serve as the bridge between consumers and the long-term care service system. As such, they have a unique view of both the experiences of consumers and the perspective of the organization and service system. For example, although each program participant is most knowledgeable about how Family Care serves his/her own needs, care managers can identify trends or patterns in the quality of care expressed by multiple program participants. Simultaneously, care managers have to respond immediately to the changing organizational environment of Family Care. For example, they have to understand changes in system priorities and processes in order to implement the program. Being most familiar with the complex details of how the long-term support system is run, care managers are able to identify specific aspects of the system that provide opportunities and constraints in meeting program participants' needs.

Even before changes in trends in service utilization can be recognized in administrative data, care managers are likely to recognize these changes. Moreover, although changes in patterns may be described using administrative data, those data provide no information about *why* those changes have occurred. Care managers can provide insight about *why* such changes in service utilization have occurred.

#### 2. RESEARCH METHODS

Phone surveys were conducted with 126 care managers in Wisconsin. About half (n=64) were CMs working with Family Care (in four counties), and the other half (n=62) were CMs in the long-term support system in non-Family Care counties across the state.

## 2.A. The Family Care Sample and Survey

The study targeted all CMs who worked with Family Care participants in the four counties that began enrolling Family Care participants by fall 2000. These counties and the dates they began enrollment are Fond du Lac (February 2000), Portage and La Crosse (April 2000), and Milwaukee (July 2000). As of November 2000 (in the middle of data collection for this study), the four counties had the following CMO enrollments: Fond du Lac 496, Portage 293, La Crosse 494, and Milwaukee 502.

Lists of Family Care CMs were obtained from each of the four county CMOs. CMO administrators were informed about the study and were told that care managers would be asked to participate. In three counties, Family Care CMs work directly for the county in the CMO. However, in Milwaukee, most Family Care CMs work in agencies that contract with the county rather than working directly for the county. In Milwaukee, supervisors at each contract agency were informed that their CMs would be asked to participate in the study. All Family Care CMs received letters telling them about the study and notifying them that an interviewer would call them to see whether they were willing to participate, and if so, to set up a time to conduct a phone interview. In some instances, CMs who were contacted had no Family Care clients yet, had just started with Family Care, or had only one case. In these instances, the care managers were not considered eligible to participate in the study.

Of those CMs who were eligible, most were willing to participate, resulting in an overall response rate across the four Family Care counties of 85 percent. Fond du Lac had an 89 percent response rate (16 participants), La Crosse 84 percent (16 participants), Milwaukee 75 percent (18 participants), and Portage 100 percent (14 participants). We were unable to contact all of the Milwaukee care managers listed (phone calls were not answered or returned), and anyone not contacted was considered a refusal. Therefore, it is possible that the Milwaukee response rate might actually be higher than 75 percent if some of those we were unable to contact were not yet serving Family Care clients, were serving only one client, or had just begun with Family Care.

Despite the busy schedules of these CMs as they made the transition to Family Care, most took the time to participate in the study, many of them hoping that the results would further improve the longterm support system. We hope to re-interview these care managers at a later date to further examine the evolution of Family Care.

The phone survey was conducted after receiving oral consent from study participants. The survey contained both closed- and open-ended questions on a number of topics related to Family Care and to the broader long-term support system in Wisconsin. Surveys were conducted primarily in October and

November 2000, with a handful conducted in December 2000 and February 2001. The length of the survey ranged from 35 to 100 minutes, with a median of 57 minutes.

#### 2.B. <u>The Statewide Sample and Survey</u>

We drew a "statewide" sample of care managers (Statewide CMs) by selecting one CM from each Wisconsin county not currently implementing Family Care CMOs (all counties except La Crosse, Fond du Lac, Portage, and Richland). We also randomly sampled one Milwaukee care manager from the pool of Milwaukee care managers who do not work in the Family Care program (Milwaukee continues to run both Family Care and the previous long-term support system). We obtained a list of care managers for each county from The Management Group, with permission from the Department of Health and Family Services. We randomly selected one CM from each county and sent introductory letters to both the selected CM and their supervisors or directors. Care managers were then called to determine whether they were willing to participate. If the selected CM was no longer working in the position, was on maternity leave, etc., another care manager on the list for that county was selected. If a selected CM refused to participate, or if the supervisor/director would not allow the care manager to participate, that county was counted as a refusal.

We conducted 62 interviews and had six refusals, resulting in a response rate of 91 percent for the Statewide CM sample.

The Statewide CM survey was similar to the survey conducted with Family Care CMs, with both closed- and open-ended questions related to the long-term support system in Wisconsin. This survey was shorter because it excluded questions specific to Family Care. Most phone interviews with Statewide CMs took place in January and February 2001, with a handful conducted in November 2000 and in March and April 2001. The length of the interviews ranged from 30 to 75 minutes, with a median of 45 minutes.

## 2.C. Description of Family Care CM Survey Participants

The Family Care sample includes 64 care managers (see Table 1). The majority were women (91 percent). Looking at the educational background of the Family Care CMs, 25 percent had a social work

degree, 17 percent had a nursing degree, and 58 percent had a degree or training in another human service area. Some of the Family Care CMs were new to working in the long-term support system and some had been doing similar work for over 20 years; the median duration that Family Care CMs had worked in long-term support was 10 years. Because Family Care is a new program in each of these counties, most of these care managers had served Family Care participants for less than a year, with a median of 6 months. Most Family Care CMs had previously held positions in the long-term support system before working with Family Care (80 percent), with the remaining working previously in other human service capacities. Family Care serves frail older adults, nonelderly adults with physical disabilities, and adults with developmental disabilities (but Milwaukee currently serves only those aged 60+). Some Family Care CMs were serving only one target group whereas others were serving multiple target groups. Among Family Care CMs, 73 percent were serving older adults, 58 percent were serving nonelderly adults with physical disabilities, 48 percent were serving adults with developmental disabilities, and 3 percent were serving people in need of protective services.

## 2.D. Description of Statewide CM Survey Participants

The Statewide CM sample includes 62 care managers (see Table 1). As with the Family Care CMs, the majority were women (90 percent). The Statewide CMs had worked in the long-term support system for 1–33 years, with a median of 11 years. Regarding educational background, 44 percent had a social work degree, 2 percent had a nursing degree, and 55 percent had a degree or experience in another human service area. There is a greater proportion of nurses in the Family Care sample because Family Care has been hiring nurses to implement interdisciplinary teams. Among Statewide CMs, 84 percent were serving older adults, 58 percent were serving nonelderly with physical disabilities, 34 percent were serving people with developmental disabilities, and 13 percent were serving people in need of protective services.

Characteristics	Family Care CMs (n=64)	Statewide CMs (n=62)
Women	91%	90%
Median years in long-term support system	10	11
Educational background*		
Social work degree	25%	44%
Nursing degree	17%	2%
Other human service degree	58%	55%
Populations served		
Older adults	73%	84%
Nonelderly with physical disabilities	58%	58%
People with developmental disabilities	48%	34%
People in need of protective services	3%	13%

 TABLE 1

 Summary of care manager characteristics in both samples

\*Percentages may not add to 100 percent due to rounding.

#### 2.E. <u>Analyses</u>

This report uses primarily descriptive statistics to characterize care managers' experiences and opinions regarding services provided in their long-term support program. In some sections, chi-square tests are performed to compare responses between Family Care and Statewide CMs. Some tables in this report summarize CMs' responses to closed-ended questions (where we provided both the question and a choice of responses). Some tables summarize responses to open-ended questions (where we provided the question, but the care manager could answer in any way s/he wanted). To summarize the open-ended responses, we first read all responses looking for common themes. In many cases, common responses or themes were clear, but in some cases we created a generic category of responses to which we assigned some responses. For example, some care managers described a variety of problems accessing formal living arrangements, such as community-based residential facilities (CBRFs) or adult family homes. We put these responses into a more generic category called "residential options" for the purposes of some of the summaries, rather than separating responses about CBRFs from responses about adult family homes.

## 3. RESULTS

#### 3.A. Stability and Change in Services with the Introduction of Family Care

The first goal of this report is to begin examining whether and how Family Care is changing the services provided to people with long-term support needs. Family Care is supposed to improve identification of the needs of long-term support program participants and to increase flexibility in how those needs can be met. Are service patterns changing with Family Care?

To begin answering this question, we identified the subset of 44 Family Care CMs who had also worked in the previous long-term support system—we call them "transition care managers." Transition care managers were similar to the general Family Care CM sample, except that fewer transition care managers had nursing backgrounds, and transition care managers had worked longer in the long-term support system. We asked transition care managers to compare Family Care to the old long-term support system on a number of dimensions.

### 3.A(1). Perceived Changes in Specific Services

Transition care managers were provided a list of specific services and were asked to indicate whether Family Care participants receive fewer, equal, or more of these services than participants in the previous long-term support system. Table 2 demonstrates that the greatest proportion of transition care managers report that Family Care participants receive *equal* services to participants in the previous long-term support system (with the exception of one service—consumer-directed supports). There is more continuity than change in service use under Family Care during early implementation. However, there are also notable changes in service use, with about a third of transition care managers reporting increases in particular services under Family Care.

Type of Service	Fewer	Equal	More	(item n)*
Personal care	9%	59%	32%	(44)
Respite care	2%	61%	37%	(41)
Home modifications	21%	55%	24%	(42)
Skilled nursing services	7%	50%	43%	(44)
Transportation services	9%	70%	20%	(44)
Durable medical equipment	16%	47%	37%	(43)
Adaptive aids	9%	63%	28%	(43)
Daily living skills training	3%	65%	33%	(40)
Employment services	0%	63%	37%	(27)
Consumer-directed supports	0%	32%	68%	(41)

 TABLE 2

 Transition CMs' perceptions of changes in service use with Family Care

\*n represents the count of responses to each item, excluding missing responses (largely those reporting "don't know"); total n=44.

Transition care managers who reported changes in use of a particular service under Family Care (reporting either "fewer" or "more") were asked *why* they thought service use had changed. We summarize below the main themes in their explanations.

<u>Personal care</u>. About one-third of transition care managers reported that Family Care participants receive more personal care services than participants in the previous long-term support system. These transition care managers reported that personal care services are easier to authorize now and that there is more flexibility in who can be hired to provide care. The few transition care managers reporting fewer personal care services (9 percent) were from one county. They reported that personal care hours now receive greater scrutiny and cited a rule limiting the amount of personal care to 8 hours per day; one respondent said that family members were encouraged to do more in place of formal personal care workers.

<u>Respite care</u>. Over one-third of the transition care managers reported increases in the use of respite care. Reasons given for the increases were similar to those for increases in personal care—an easier authorization process and/or more flexibility in who can be hired. In fact, respite care is hard to distinguish entirely from short-term personal care services, although respite care can also involve a temporary out-of-home placement, such as in a nursing home.

Home modification. Changes in the use of home modifications had the most variability in response. Fewer than a quarter of transition care managers reported that there are fewer home modifications with Family Care. All but two of these care managers believed that the previous long-term support system had been inappropriately excessive in providing home modifications in their county, and that declines in utilization with Family Care were due to *appropriate* reductions. Some reported that using the new Resource Allocation Decision (RAD) method as part of Family Care helped them better evaluate whether home modifications provide the most appropriate way to achieve consumer outcomes. Among the 24 percent of transition care managers reporting increases in home modifications, some explained that this was due to an easier authorization process and perceived increases in funding for this service. Others suggested that there has been an increased need for home modification because Family Care is taking more people out of nursing homes and because more individuals are choosing home care over nursing home care. Increased levels of need among these community residents result in greater demand for home modifications to accommodate community living.

Skilled nursing. Increases in skilled nursing services were reported by 43 percent of transition care managers. Most of these care managers reported that adding nurses to the care management teams was largely responsible for this increase.

An increase in skilled nursing services can be either positive or negative. It can be positive if it reflects an increase in appropriate recognition of and attention to participants' medical needs. It can be negative if it reflects overmedicalization in dealing with participants' needs—that is, using medical services when social services are more appropriate. In general, the reported increase was described as appropriate by the care managers. Many of the transition care managers without nursing backgrounds reported that they had little nursing support in the old system, so the addition of nurses to the team was improving their ability to provide appropriate recognition of and attention to participants' medical needs. Among the few transition care managers who reported *decreases* in skilled nursing services (7 percent), a couple reported that these were appropriate decreases—having a nurse on the care management team led to more appropriate and consistent use of skilled nursing services rather than overuse or only crisis use.

It was also suggested that "maximizing Medicare" was partly responsible for the increase in skilled nursing services. "Maximizing Medicare" is a formal or informal organizational policy whereby services are reimbursed by Medicare, if possible, before using Family Care funds. If a particular Medicare-reimbursable service is most appropriate to meet a participant's needs, then "maximizing Medicare" has no impact on quality of care, only on fiscal management. Required nursing services are simply paid for by Medicare as the first payer. However, aggressive maximization of Medicare-reimbursable medical services instead of more appropriate social services that are not reimbursable by Medicare. Such aggressive maximization of Medicare), although it may increase national spending (nursing services are often more expensive than social services). It also may lead to an overprovision of nursing services, resulting in inappropriate medicalization of care. There is no evidence of inappropriate Medicare" came up numerous times during these interviews, attention should be paid to the issue of appropriate versus inappropriate Medicare was maximizing as family Care develops further.

<u>Transportation</u>. Of all the services listed, transportation seems to have changed the least, with 70 percent of transition care managers reporting no change. Those reporting changes in use of transportation provided a variety of reasons. Some transition care managers said that transportation services have decreased because of increased scrutiny of their use. In contrast, some said that transportation has increased because this benefit is now more flexible, particularly because transportation can now be provided for trips other than medical appointments. Others agreed that there is more flexibility in theory, but that the availability of transportation providers does not currently keep up with the demand. Others cite confusion over new rules and vendors that makes it hard for care managers to arrange appropriate transportation services.

<u>Durable medical equipment and adaptive aids</u>. There was great variation in whether transition care managers noted changes in the provision of durable medical equipment and adaptive aids, and in

reasons for any perceived changes. Increases in durable medical equipment and adaptive aids were noted by 37 percent and 28 percent, respectively, of transition care managers, and decreases were noted by 16 percent and 9 percent. Explanations for both increases and decreases were somewhat complicated. Some transition care managers reported increased flexibility in providing durable medical equipment and adaptive aids but, simultaneously, more scrutiny involved in making the decision to provide them. As a result, some Family Care participants receive less equipment than they would have in the old system while some receive more. Some transition care managers suggested that the previous system provided equipment too easily, even if people didn't really need it. In such cases, providing less equipment under Family Care was viewed as appropriate and positive. Others claimed that some participants in the old system were not able to access what they needed, so that perceived increases in providing equipment in Family Care was viewed as appropriate.

Issues regarding durable medical equipment (DME) were raised in many instances during the interviews. Before Family Care, most care managers did not have to directly arrange for DME. Medicaid card services paid for DME, Medicaid participants could arrange for this equipment themselves with a physician's order, and vendors billed Medicaid directly. Under Family Care, care managers are responsible for authorizing DME purchases, requiring an understanding of detailed billing codes. This change has not been smooth, with many care managers complaining that the authorization process for DME is unclear and overly burdensome. Such changes in procedures often are accompanied by stress during early implementation of the change. However, it appears that care managers in some counties experienced this transition as more seamless than those in other counties (data not shown). Therefore, more attention to both streamlining this process and improving training might enhance the experience of care managers, thereby potentially improving the quality and quantity of their time spent on other issues that benefit program participants.

<u>Daily living skills training</u>. One-third of transition care managers reported increases in daily living skills training. Transition care managers reporting increases suggested that these services receive

more emphasis now. They also report more flexibility in how the money can be spent to provide training that is most appropriate to meet individual participants' needs.

Employment services. Similarly, more flexibility was perceived by the 37 percent of transition care managers who reported increases in employment services in Family Care. For example, one transition care manager said, "Some people on my previous COP caseload were on the waiting list for employment services while now there is no wait list and they can access services immediately as needed." It is important to note that only 27 transition care managers responded to this item—some care managers, particularly those serving only older adults, do not have experience accessing employment services and therefore responded "don't know" to this question.

Consumer-directed supports. An increase in consumer-directed supports was reported by 68 percent of transition care managers. More transition care managers reported an increase in consumerdirected supports than in any other service, and no transition care manager reported a decrease. However, it is not clear how to interpret this information. It appears that there is no clear, shared definition of consumer-directed supports among the transition care managers, and we did not provide a definition in the survey. It is clear from the follow-up questions that some transition care managers saw consumerdirected supports as a general service approach that is consumer focused. Other care managers saw consumer-directed supports as something more specific, involving the practice of providing the consumer the opportunity to manage part or all of his/her own benefit (choosing desired services, hiring providers, managing providers, paying providers, etc., with little or no assistance). Most transition care managers reported that an emphasis on consumer preferences and outcomes has led to increased flexibility in how to meet the needs of participants. Others commented more on the promise of increased consumer-directed supports—reporting that they expected that consumers would increasingly direct their own care, rather than reporting that consumer-directed supports had already been firmly established. Of all those noting an increase, only one care manager noted feelings of caution about this trend. Future work needs to more explicitly provide a definition of consumer-directed supports and examine in more detail care managers' definitions of this service.

Other services. Transition care managers were asked whether other services had either increased or decreased with the initiation of Family Care. Interestingly, some reported that "care management services" had increased while some reported that they had decreased. This is consistent with reports during other parts of the interview in which some care managers reported that they get to do more with and for program participants, and reports from others that they have less time to work with participants or that consumer-directed care requires less care management services. Some transition care managers also reported increased use of durable medical supplies (DMS), citing similar flexibility in funds as was reported for DME. Some transition care managers also specifically mentioned increases in access to a variety of formal living situations for participants, such as CBRFs and adult family homes. Increases were also reported in day centers, in physical/occupational therapy services, and in nontraditional items or services.

In sum:

# • Most transition care managers report that Family Care participants receive equal services to participants in the previous long-term support system.

During the first year of Family Care implementation, lack of dramatic change in services is to be expected for a number of reasons. *First*, many Family Care participants "rolled into" the program from the old long-term support program. Maintaining these "rollover" participants with services similar to what they were receiving previously rather than changing their packages may make the transition to the Family Care system less disruptive for participants. Moreover, many of the rollover participants were receiving services perceived as appropriate by the care managers and program participants, thereby requiring no change. *Second*, keeping services the same for rollover participants makes the transition to Family Care easier for care managers during the initial phases while they learn the new Family Care system. It is easier for care managers to keep existing service packages in place for rollover participants than to change everyone's service package at once. *Third*, since Family Care is new, there has been little time for the service environments of communities to change to meet the changing needs and demands of Family Care participants. Even if Family Care CMs want to use increased program flexibility to provide services that are more tailored to the needs of individual participants, services and providers may not be available in

the community. For example, as we will discuss further, many counties have reported an insufficient pool of personal care workers to provide needed care.

• *Many transition care managers report that Family Care participants receive more services than participants in the previous long-term support system.* 

About one-third or more of transition care managers reported an increase in personal care, respite care, skilled nursing services, durable medical equipment, daily living skills training, employment services, and consumer-directed supports. Most reported increases in funding and/or more flexible rules as the reasons for increases in use of these services. Almost all of the increases were portrayed as appropriate and beneficial increases for program participants.

• *Few transition CMs report that Family Care participants receive* fewer *services than participants in the previous long-term support system.* 

Fewer than 10 percent of transition care managers reported that Family Care participants receive fewer services than participants in the previous long-term support system, for all services except two. Although 16 percent and 21 percent reported that Family Care participants receive less durable medical equipment and home modifications, respectively, these decreases were seen as *positive* by some. Some transition care managers felt that the previous long-term support system was providing expensive equipment and modifications when they were unnecessary, and that Family Care was decreasing these services in appropriate ways in some cases. Very few transition care managers reported that Family Care decreased services to participants who truly needed the services.

## 3.A(2). Further Explanations for Changes in Services under Family Care

Transition care managers were also asked open-ended questions about what is easier and harder to access under Family Care. The services they listed as easier and harder to access are well represented in the previous analysis of Table 2, so they are not presented here. However, care managers provided new information when they were asked *why* certain services are easier or harder to access under Family Care.

For those listing services that are *easier* to access, the two primary types of explanations for *why* access is easier were (1) increased flexibility in what can be provided and how it is authorized (reported

by 33 percent) and (2) elimination of the waiting lists to participate in the program as a whole or elimination of waiting lists to receive specific services (reported by 30 percent).

Although some transition care managers mentioned no specific service that was *harder* to access under Family Care, some reported that the *process* that care managers go through to help participants access services has become more difficult in general. Regarding why it is harder to access some services under Family Care, 44 percent of transition care managers described examples of increased complexity in the Family Care program. For example, some transition care managers described increased paperwork and/or difficulties understanding new processes. What is particularly interesting is that many transition care managers described decreases in their own ability to access services for participants, though in many cases it appears that transition care managers did not think that participants ultimately experienced an actual decrease in services.

Under early implementation of Family Care, removal of waiting lists and increased flexibility in program rules and service authorization processes have made it easier for many participants to receive services. However, although services are easier for the long-term support program participant to receive, they are often harder for the care manager to arrange.

# 3.A(3). Organizational and Structural Barriers to Formal Service Use—Comparisons between Family Care CMs and Statewide CMs

Another way to examine whether service access and use change under Family Care is to compare the experiences of care managers in Family Care counties to those in non-Family Care counties. We asked both Family Care and Statewide CMs about how often specific organizational or structural barriers impede the types or amount of formal services that can be provided to their program participants. Family Care is supposed to reduce some of the formal barriers to services, allowing more flexibility in what kinds of services are provided and where, when, how, and by whom they are provided. Do the Family Care CMs perceive fewer organizational or structural barriers to services than do the Statewide CMs? In beginning to address this question, we summarize responses to three survey questions.

How often does <u>availability of certain types of services or service providers</u> limit the types or amount of formal services that participants get?						
	Never	Sometimes	Frequently	Always	(n)	
Family Care CMs	9%	50%	39%	2%	(64)	

49%

2%

(61)

TABLE 3
How often does availability of certain types of services or service providers limit the types
or amount of formal services that participants get?

Statewide CMs cited availability of certain types of services or service providers as a more frequent barrier to formal services than did Family Care CMs. However, this difference is not large (chi-square=6.45, p=.09).

49%

0%

Statewide CMs

- According to 9 percent of Family Care CMs, availability of certain types of services or service providers *never* limits the types or amount of formal services that participants get. In contrast, all Statewide CMs reported this barrier at least sometimes.
- According to 41 percent of Family Care CMs and 51 percent of Statewide CMs, availability of • certain types of services or service providers *frequently* or *always* limits the types or amount of formal services that participants get.

TABLE 4
How often do restrictions on the types of services that are allowable or reimbursable limit
formal services that participants get?

	Never	Sometimes	Frequently	Always	(n)
Family Care CMs	35%	61%	3%	0%	(62)
Statewide CMs	18%	72%	10%	0%	(61)

- Statewide CMs cited restrictions on the types of services that are allowable or reimbursable as a more frequent barrier to formal services than did Family Care CMs (chi-square=6.10, p=.05).
- According to 35 percent of Family Care CMs, but only 18 percent of Statewide CMs, restrictions on the types of services that are allowable or reimbursable never limit formal services that participants get.
- Most care managers in both groups (61 percent of Family Care CMs and 72 percent of Statewide CMs) reported that restrictions on the types of services that are allowable or reimbursable sometimes limit formal services that participants get.

or amount of formal services that participants get?						
	Never	Sometimes	Frequently	Always	(n)	
Family Care CMs	32%	63%	5%	0%	(60)	
Statewide CMs	18%	48%	30%	3%	(60)	

 TABLE 5

 How often do limits or rules regarding residential options

 or amount of formal services that participants get?

• According to 33 percent of Statewide CMs, but just 5 percent of Family Care CMs, limits or rules regarding residential options *frequently* or *always* affect the types or amount of formal services that participants get.

In sum, there are many similarities and some differences between Family Care and Statewide CMs regarding specific perceived barriers to formal services in long-term support programs. Most care managers in both systems reported that the types or amount of formal services that participants receive are *at least sometimes* affected by (1) availability of certain types of services or service providers, (2) restrictions on the types of services that are allowable or reimbursable, and (3) limits or rules regarding residential options. According to almost half of all care managers, availability of certain types of services that participants receives or service providers appears to *frequently* limit the types or amount of formal services that participants receive.

In general, Family Care CMs perceive these three barriers as occurring less frequently than do Statewide CMs. In particular, Family Care CMs are less likely to report that limits or rules regarding residential options affect the types or amount of formal services that participants receive.

It is unclear whether the differences between these two groups of care managers represent *change* in the Family Care counties, or whether the Family Care counties were different from the non-Family Care counties even before Family Care was implemented. The clear difference between Family Care and Statewide CMs regarding perceived barriers in residential options, for example, may be due to differences between these counties that existed before Family Care. However, as discussed earlier, some transition

<sup>•</sup> Statewide CMs clearly cited limits or rules regarding residential options as a more frequent barrier to formal services than did Family Care CMs (chi square=16.06, p=.001).

<sup>•</sup> According to 32 percent of Family Care CMs, but only 18 percent of Statewide CMs, limits or rules regarding residential options *never* affect the types or amount of formal services that participants get.

care managers have reported that Family Care has loosened some of the rules regarding residential options, so it is likely that these results do represent change brought about with Family Care. Future research will need to examine whether trends in Family Care and non-Family Care counties remain the same or diverge even further.

## 3.B. Special Issues Regarding Services during Early Implementation of Family Care

The second goal of this report is to describe some of the specific service issues that will need attention to improve Family Care and the long-term support system in Wisconsin as a whole. All care managers were asked open-ended questions about the services that are most difficult to provide or access. Table 5 presents a summary of the primary responses provided by Family Care CMs and by Statewide CMs.

Services	Family Care CMs (n=60)	Statewide CMs (n=62)
Personal care/supportive home care services	43%	47%
Transportation	12%	16%
Respite	10%	5%
None	10%	0%
Residential options	8%	18%
Home health	8%	13%
Durable medical equipment/supplies (DME/S)	7%	3%
24-hour care	5%	6%
Home modifications	2%	5%
Therapies (OT/PT/speech)	2%	5%
Employment services (sheltered or supportive		
employment, or vocational education)	0%	8%

 TABLE 6

 Services care managers report as the most difficult to access or provide\*

\*Care managers could list more than one service, so percentages do not add to 100 percent.

Only responses mentioned by 5 percent or more of care managers within at least one of the two samples are listed above. Fewer than 5 percent of *Family Care CMs* cited the following services as *the most difficult* to access or provide: homemaker/chore, adult day care center services, socialization and recreational opportunities, major clean-up help, approving things previously acquired directly through Title XIX (Medicaid), bilingual personal care, natural supports, mental health services, expensive items, home modifications, and therapies (OT/PT/speech). Fewer than 5 percent of *Statewide CMs* cited the following services: homemaker/chore, adult day care center services, providers for high-need participants, home companion, snow removal, hospice, and DME/S.

Table 6 clearly demonstrates a shared sense among Wisconsin care managers that it is difficult to access personal care and/or supportive home care services. Although access to personal care services may have increased during early implementation of Family Care (increases reported earlier in Table 2 by 32 percent of transition care managers), it remains the most frequently cited service concern among Family Care and Statewide CMs alike.

Comparing the two columns in Table 6 demonstrates the similarities and differences between the challenges presented in Family Care during its early implementation stage and the challenges presented in the statewide long-term support system. What is most striking is the *similar* challenges reported by care managers in both systems.

• Virtually equal percentages of Family Care CMs (43 percent) and Statewide CMs (47 percent) reported that personal care/supportive home care services are the most difficult services to access or provide.

Care managers in both programs cite various reasons for poor access to personal care/supportive home care (PC/SHC) services. Many describe a *lack of availability* of PC/SHC workers. Care managers perceive poor pay as a primary reason for the scarcity of PC/SHC workers. Others claim that poor training contributes to high turnover of PC/SHC workers. One Statewide CM explained, "These service providers need to be prepared for the issues they'll encounter so they don't get scared and quit." Poor training also was cited as leading to lack of choice in high-quality workers who are willing and able to provide services to people with complicated needs.

- Similar percentages of care managers in both systems reported that transportation, respite, home health, DME/S, 24-hour care, and therapies were the most difficult services to access or provide.
   In terms of *differences* between Family Care and Statewide care managers:
- About 10 percent of Family Care CMs versus 0 percent of Statewide CMs said that there were *no* services that are difficult to access or provide.
- Employment services (sheltered, supportive, and vocational education) were cited as the most difficult services to access or provide by 8 percent of Statewide CMs, but by 0 percent of Family Care CMs.
- A greater percentage of Statewide CMs (18 percent) than Family Care CMs (8 percent) said that formal residential options were the most difficult to access or provide.

This corresponds to the results presented earlier demonstrating that Statewide CMs cited "limits

or rules regarding residential options" as a more frequent barrier to formal services than did Family Care

CMs.

We also asked care managers, "What services need to be developed or be more available to better meet the needs of [Family Care] participants?" Whereas the previous question focused on services viewed as *the most difficult* to access or provide, this question asks more globally for a list of services *that need to be more available in general*. Table 7 summarizes the responses provided by Family Care and Statewide CMs.

Services	Family Care CMs (n=62)	Statewide CMs (n=61)
Personal care/supportive home care services	45%	40%
Transportation	23%	26%
Respite	5%	5%
Residential options	24%	28%
Home health	5%	7%
Employment services	11%	8%
Adult day care centers	16%	5%
Care management (e.g., more time, smaller caseload)	8%	0%
Socialization options	3%	10%
Volunteers	3%	7%

 TABLE 7

 Services needing further development or greater availability\*

\*Care managers could list more than one service, so percentages do not add to 100 percent.

Only responses mentioned by 5 percent or more care managers within at least one of the two samples are listed above. Fewer than 5 percent of *Family Care CMs* listed the following services as needing further development/availability: improving the Family Care handbook, combining Key Link and Medicare cards, paying for spouse caregivers, multilingual personal care workers, preventive and wellness services, care manager training for medical issues, toenail clinics, marketing, dental coverage, services to meet socialization needs, therapies, developing natural/informal supports, education of providers about Family Care, increasing the allowable number of hours for providing supportive home care, administrative changes at the county level, socialization options, and volunteers. Fewer than 5 percent of *Statewide CMs* listed the following services as needing further development/availability: hospice, more flexibility in funds, therapies (OT/PT/speech), congregate meals, new building codes to expand rooms in houses so they can be accessible, mental health therapists who will go to participants' homes, funds for services to be provided while people are on waiting lists, home modification, natural community supports, gatekeepers for people with developmental disabilities to prevent exploitation, change in Medicaid eligibility criteria, daily skills training, mental health services for people with developmental disabilities in inpatient settings, and services to meet the medical needs of people with developmental disabilities.

Table 7 again demonstrates similarities between Family Care and Statewide CMs. According to both groups, the three services that most need to be developed or be more available are:

1) personal care and supportive home care services,

2) transportation, and

3) residential options.

Although Family Care CMs had not listed employment services among the most difficult services to access in the prior table, Table 7 indicates that 11 percent and 8 percent of Family Care and Statewide CMs consider these services as needing further development or availability. Although Family Care may have improved access to employment services through greater flexibility (as reported by transition care managers in Table 2), Family Care CMs report that still more needs to be done.

Also interesting in Table 7 is the emergence of different categories of services. Adult day care centers were cited by 16 percent of Family Care CMs and 5 percent of Statewide CMs as needing further development or availability. Although more Family Care CMs listed adult day care centers specifically, more Statewide CMs listed "socialization options" more generally, which might include adult day care centers. Some of the discussions about increasing transportation cited increased socialization as an important reason for increasing transportation.

Some Family Care CMs (8 percent) specifically mentioned care management services as those needing further development or availability, whereas no Statewide CM specifically listed this. These Family Care CMs reported that care managers needed more time with participants—that their own services needed to be more available. It is unclear whether there is a true difference between Family Care and the long-term support system in other counties in terms of the availability of care managers, or whether being in Family Care heightens care managers' awareness or concern about this issue.

## 3.C. Family Care CMs' Hopes and Concerns about the Future of Services under Family Care

The third goal of this report is to describe some of the hopes and concerns that Family Care CMs have regarding the future of services under Family Care. In the midst of their current struggles to adapt to

a changing organizational environment, did Family Care CMs expect the future of Family Care services to be positive or negative? We provided a number of statements and asked Family Care CMs to indicate whether they strongly disagree, somewhat disagree, somewhat agree, or strongly agree with each statement. Table 8 presents Family Care CMs' responses to statements related to service provision and utilization.

	Percentage of Family Care CMs Who			
Attitude/Belief Statement	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree
a. Family Care will increase services to some	0	0	8	0
participants who weren't getting enough services under the old system.	5%	9%	39%	47%
b. Family Care means that we will be able to reduce some of the unnecessary services being provided	201	21.67	510	2701
to some of our consumers.	2%	21%	51%	27%
c. Family Care will allow us to provide some types of services that weren't allowed before.	0%	3%	52%	45%
d. Family Care will provide a care manager more flexibility in the service plan that can be put				
together.	10%	13%	48%	30%
e. Family Care will offer more choices to				
consumers in the types of services they can get.	3%	9%	42%	45%
f. Family Care will offer more choices to				
consumers in who provides services to them.	5%	19%	41%	36%
g. Even if Family Care serves more people, the lack				
of care providers in my community means that				
people will not be served well.	2%	17%	48%	33%

 TABLE 8

 Family Care CMs' attitudes and beliefs about the future of Family Care services\*

\*Percentage may not add to 100 percent due to rounding.

Note: One CM was unable or unwilling to respond to statements b and d.

Table 8 shows that even during a difficult time of organizational transition, Family Care CMs are

overall very optimistic about the future of Family Care services. Most Family Care CMs believe that

Family Care will increase services to those with unmet needs and reduce some unnecessary services.

• Virtually all Family Care CMs (97 percent) agree (either strongly or somewhat) that Family Care will allow them to provide some types of services that were not allowed before; almost half of Family Care CMs (45 percent) *strongly agree* with the statement.

- 86 percent of Family Care CMs agree (either strongly or somewhat) that Family Care will increase services to some participants who were not getting enough services under the old system; almost half of Family Care CMs (47 percent) *strongly agree* with the statement.
- 78 percent of Family Care CMs either *strongly agree* or *somewhat agree* that Family Care will reduce some of the unnecessary services being provided to some of their consumers.

Most Family Care CMs also believe that Family Care will offer more flexibility to better meet the

needs of individual program participants.

- 87 percent of Family Care CMs agree (either strongly or somewhat) that Family Care will offer more choices to consumers in the types of services they can get; almost half of Family Care CMs (45 percent) *strongly agree* with the statement.
- 77 percent of Family Care CMs either *strongly agree* or *somewhat agree* that Family Care will offer more choices to consumers in who provides services to them.
- 78 percent of Family Care CMs agree that Family Care will provide a care manager more flexibility in the service plan that can be put together.

Although most Family Care CMs demonstrate an overall positive outlook on the future of Family

Care, there are some Family Care CMs who are less sure that Family Care will meet expectations. For

example, 14 percent disagree that Family Care will increase services to some participants who weren't

getting enough services under the old system, 23 percent disagree that Family Care will provide more

flexibility in the service plan, and 12 percent and 24 percent disagree that Family Care will offer more

choice to consumers in the types of services they can get and in who provides those services.

Moreover, despite overall perceptions that Family Care will increase service availability and

flexibility, most Family Care CMs also believe that the lack of care providers in their community will

mean that people will not be served well.

• 81 percent of Family Care CMs agree (either strongly or somewhat) that even if Family Care serves more people, the lack of care providers in their community means that people will not be served well.

Future research needs to evaluate whether full implementation of Family Care will justify the generally optimistic expectations of Family Care CMs. In particular, it will be important to examine the role that availability of care providers plays in the ability of Family Care and its care managers to fulfill their mission.

## 4. MAJOR CONCLUSIONS AND DISCUSSION

There were three main goals of this report:

- 1) To begin examining whether and how Family Care is changing the services provided to people with long-term support needs (Section 3.A.).
- 2) To describe some of the specific service issues that will need attention to improve Family Care and the long-term support system in Wisconsin as a whole (Section 3.B.).
- 3) To describe some of the hopes and concerns that care managers have regarding the future of services under Family Care (Section 3.C.).

This report examined these issues from the perspective of care managers-those who work in the

Family Care program (in four counties) and those who work in the long-term support system in non-

Family Care counties across Wisconsin.

A summary of the four major conclusions of this study is presented below.

## Conclusion #1: During early implementation of Family Care, care managers report both continuity and change in the service environment for program participants with long-term support needs.

Most transition care managers reported that Family Care participants receive *equal* services to participants in the previous long-term support system. However, many reported *increases* in some services as well. Few transition care managers reported that Family Care participants receive fewer services than participants in the previous long-term support system.

About one-third or more of transition care managers reported an increase in personal care, respite care, skilled nursing services, durable medical equipment, daily living skills training, employment services, and consumer-directed supports. Removing the waiting lists for services and increasing flexibility in program funds and rules were reported as primary reasons for increases in services under Family Care.

Future research needs to examine to what extent the cost of increases in some services is offset by reduced cost through decreases in other services. Future research also needs to examine whether the services that increase are being provided by paid professionals or by informal, unpaid supports and volunteers. This has implications for whether increases in services result in overall increased program

costs. If program costs are greatly increased, counties are unlikely to be able to sustain this level of service provision under the current capitated rate. If so, should paid service provisions be cut back, should informal/volunteer supports increase, or should the capitated rates paid to counties increase? Such decisions should be informed by close evaluation of how changes in services decrease or improve consumer outcomes.

Comparisons between Family Care and Statewide CMs indicate that there are many similarities and some differences between the two groups in their perceived barriers to formal services. Most care managers in both systems reported that the types or amount of formal services that participants get are *at least sometimes* affected by availability of certain types of services or service providers, restrictions on the types of services that are allowable or reimbursable, and limits or rules regarding residential options. According to almost half of all care managers, availability of certain types of services or service providers appears to *frequently* limit the types or amount of formal services that participants get.

In general, Family Care CMs perceive these three barriers as occurring less frequently than do Statewide CMs. In particular, Family Care CMs were less likely than Statewide CMs to report that limits or rules regarding residential options affect the types or amount of formal services that participants get. Although there seem to be fewer barriers to services in Family Care counties than in non-Family Care counties, it is unclear whether all of these differences were caused by Family Care or whether some of these differences between counties existed prior to Family Care. Moreover, similarities between the Family Care and non-Family Care counties are more striking than differences at this point. Most care managers in both systems report continued multiple barriers to accessing services in the long-term support system.

Conclusion #2: Despite care managers' perceptions of overall improvements in the service environment under Family Care, several issues need to be addressed both in Family Care counties and in non-Family Care counties across the state in order to improve services provided in Wisconsin's long-term support system.

Both Family Care and Statewide care managers reported the same major concerns about services. Care managers in both groups listed their top three service concerns as

- 1) personal care/supportive home care services,
- 2) transportation services, and
- 3) residential options.

Each of these three service concerns is discussed in more detail below.

<u>Personal care/supportive home care.</u> Concerns about this service arose throughout the interviews with both Family Care and Statewide CMs. The apparent lack of availability of people willing and able to provide quality personal care and supportive home care services inhibits care managers' ability to help consumers put acceptable services in place, challenges program participants' ability to make choices about who will provide their care, and most likely affects the ultimate quality of care and quality of life experienced by participants.

As one Family Care CM reported after being asked about challenges in accessing services for participants, "It's not the services, it's the providers. We can be creative in the services but still have to find people to provide them." To what extent can the flexibility of the Family Care benefit be expected to improve services and consumer outcomes if there aren't changes in the availability and quality of personal care and supportive home care workers? Will there be enough workers to meet basic needs? Will there be enough workers to provide program participants with choice in where, how, when, and from whom they get assistance?

In fact, without innovations that will improve the size and quality of the pool of PC/SHC workers, we might even expect that Family Care will experience worsening problems with PC/SHC shortages. With Family Care, there will be a *greater demand* for PC/SHC workers because eliminating waiting lists will produce an increase in numbers of program participants in the publicly funded long-term support system.

Addressing the shortage of PC/SHC workers may be necessary to improve both the Family Care program and the long-term support system across Wisconsin. This will most likely require a multipronged approach designed to both increase the size and quality of the pool of workers and improve the conditions under which individuals provide that care (e.g., increasing the work's financial value and societal value).

As one Statewide CM summarized, "We need workers who are paid better, trained better, and are more willing to serve difficult clients."

<u>Transportation services.</u> Transportation is another key issue raised throughout the interviews. Both Family Care and Statewide CMs described the need for transportation, particularly to access medical resources and to provide socialization options.

In Family Care, although there is a more flexible benefit, it appears that barriers to transportation remain, particularly transportation for socialization reasons. Some of the barriers include complicated authorization processes, lack of enough transportation services present in the community, and scrutiny over who can receive the services and for what purposes.

Statewide CMs reported similar barriers to accessing transportation services. However, they more frequently cited the complete lack of available transportation in their communities, particularly in rural areas, as a barrier to access. One Statewide CM explained, "We have no public transit other than one cab in this area."

Beyond attending to participants' most basic physical needs, both Family Care and Statewide CMs describe one of their roles as facilitating social integration for program participants. Social integration with family, friends, and the community is a value held by many people, so the quality of social integration can affect the quality of program participants' lives. Care managers report that problems accessing transportation can severely hinder social integration, particularly in more rural areas where there may be fewer options for organized socialization opportunities. Improving transportation options, as with increasing the pool of PC/SHC workers, appears to be an issue that could benefit from more statewide policy attention.

<u>Residential options.</u> Residential options were listed by both Family Care and Statewide CMs as the third most important type of service needing further development or availability. However, more problems accessing residential options were perceived by Statewide CMs than by Family Care CMs. In Family Care, transition care managers reported some increased flexibility in residential options. Improvements in residential options under Family Care may be partially due to a recent change in Family

Care rules regarding access to CBRFs. Under Medicaid waiver and Community Options Program (COP) rules in the long-term support system, funds cannot be spent for placements in CBRFs with more than eight beds. Statewide CMs frequently cite this rule as a barrier to accessing residential options. In Family Care, this eight-bed rule has been eliminated for two target groups—frail older adults and nonelderly adults with physical disabilities. Elimination of this rule has been cited by Family Care CMs as improving residential options.

However, even with fewer restrictions on the use of CBRFs, Family Care CMs report that residential options remain a particular problem. Both Family Care and Statewide CMs report that not enough CBRFs, adult family homes, or other residential options exist in their communities. Some of the residential options that do exist are perceived as being of low quality, and some care managers report that there are few residential options for specific types of program participants (such as people with both developmental disabilities and mental health problems). Even when residential options do exist, care managers report that vacancies are infrequent. There are also additional rules about the conditions under which public long-term support money can be spent on some of these residential options.

According to care managers, improving publicly funded residential options across Wisconsin requires two primary initiatives: (1) the development of additional residential options and (2) a loosening of rules about the use of public funding for some residential options (such as CBRFs).

One issue to be examined in the future is whether care managers' perceived need for more formal residential options will decline if more services become available to provide care in participants' own homes. There will always be program participants and their families who will truly prefer CBRFs, adult family homes, or other more formal residential options. However, to what degree are some program participants, family members, and care managers considering these more formal residential options because of lack of adequate supports to provide care in participants' own homes? Does the shortage of personal care workers, for example, create a greater perceived need for more formal residential options because in-home support options are currently inadequate? We have no information in this survey to

directly address this question, but this issue should be investigated and discussed further before making significant changes to loosen rules about residential options or to develop new options.

## Conclusion #3: Even during a difficult time of organizational transition, most Family Care CMs are overall very optimistic about the future of Family Care services.

Most Family Care CMs believe that Family Care will increase services to those with unmet needs and reduce some unnecessary services. Most Family Care CMs also believe that Family Care will offer more flexibility to better meet the needs of individual program participants.

However, most (81 percent) Family Care CMs agree that even if Family Care serves more people, the lack of care providers in their community means that people will not be served well. Consistent with the discussions above, increases in the pool of personal care and supportive home care workers, in particular, may be necessary to meet the long-term support needs of program participants in Family Care and across Wisconsin.

Finally, although Family Care CMs report that program participants have equal or greater access to services under Family Care, those services are often harder for the care manager to arrange. In the short term, increased barriers to access might not be experienced by program participants, with care managers buffering the effects of inevitable organizational change. However, if care managers continue to bear the brunt of organizational change, this may ultimately affect both the quantity and quality of their work with program participants. Family Care CMs' generally positive expectations for Family Care are no doubt helping them get through a challenging period of early organizational change, but those positive expectations may begin to dwindle if attention is not paid to addressing many of the issues faced by care managers. A future report will focus more specifically on some of the recommendations that care managers have about how to improve Family Care and the long-term support system as a whole.

Conclusion #4: Examination of early implementation of Family Care indicates that it is indeed a program worth studying. Lessons learned from careful examination of Family Care will inform long-term support program and policy efforts in both Wisconsin and other states.

This report represents a snapshot during early implementation of Family Care. Research needs to evaluate the progress of Family Care over time and to monitor similarities and differences across counties in the process and outcomes of the program. It will be some years before the program is mature enough to be fully evaluated for its strengths and weaknesses. Caution must be taken not to draw grand conclusions about either positive or negative aspects of program viability and quality from early process evaluations such as this one. However, ultimately, there is much to learn by properly evaluating Family Care. We may learn that the Family Care model as a whole proves successful, or we may learn that the model is not one we wish to replicate. But even if the latter is true, we will no doubt learn about successful pieces of the model that we may wish to replicate in other counties, such as how to conduct effective interdisciplinary teams, the appropriate uses of consumer-directed supports, or how to successfully develop natural supports. Lessons learned through Family Care will help us make decisions about how to better serve people with long-term support needs and their families.