



Family Care Expansion Envisioning a Positive Future

March, 2007

Disability Rights Wisconsin is the designated protection and advocacy agency for people with disabilities in Wisconsin.

CONTENTS

INTRODUCTION.....	1
1. FAMILY CARE EXPANSION SHOULD NOT RESULT IN THE EXPANSION OF SEGREGATED CONGREGATE SETTINGS.....	2
2. CONSUMERS, FAMILY MEMBERS AND ADVOCATES SHOULD BE WELL-REPRESENTED AND ACTIVE PARTICIPANTS ON ALL PLANNING GROUPS, DESIGN TEAMS, LONG TERM CARE ADVISORY COUNCILS, AND ADRC AND CMO GOVERNING BOARDS	3
3. THE TRANSITION TO FAMILY CARE SHOULD NOT RESULT IN REDUCTION OF SERVICE, ELIMINATION OF SERVICE OR ARBITRARY CHANGE OF SERVICES OR PROVIDERS TO CONSUMERS WHO ARE CURRENTLY RECEIVING SERVICES AND SUPPORTS	4
4. FAMILY CARE MUST IMPROVE THE QUALITY OF MENTAL HEALTH SERVICES	4
5. THE FAMILY CARE INDEPENDENT ADVOCACY PROGRAM SHOULD BE RE-ESTABLISHED AND ADEQUATELY FUNDED.....	5
6. THERE MUST BE FAIR RATE SETTING TO ENSURE ADEQUATE CONSUMER FUNDING	7
7. THERE MUST BE MECHANISMS AND SAFEGUARDS TO ENSURE THAT FAMILY CARE OFFERS EVERY CONSUMER THE OPTION OF CONSUMER DIRECTED SERVICES AND SELF DETERMINATION.....	8
8. THE STATE MUST ESTABLISH RIGOROUS OVERSIGHT OF THE COUNTIES AND/OR PRIVATE CORPORATIONS WHO OPERATE THE FAMILY CARE PROGRAM LOCALLY	9
9. THERE MUST BE SAFEGUARDS TO ENSURE THAT CURRENT PROVIDERS ARE NOT ARBITRARILY EXCLUDED FROM THE SERVICE SYSTEM.....	10
10. THE FUNCTIONAL SCREEN USED TO DETERMINE ELIGIBILITY FOR FAMILY CARE MUST NOT DENY PEOPLE WHO ARE TRULY ELIGIBLE.....	11
11. COUNTIES MUST CONTINUE TO HAVE MEANINGFUL ROLES IN GOVERNANCE, OVERSIGHT, QUALITY ASSURANCE AND LTC POLICY SETTING	12
12. STRONG DUE PROCESS PROTECTIONS ARE CRITICAL TO THE FAMILY CARE PROGRAM AND MUST BE EXTENDED TO ALL CONSUMERS IN THE FAMILY CARE EXPANSION COUNTIES AS REQUIRED BY LAW.....	13
APPENDIX: "DEFINING SELF-DETERMINATION IN WISCONSIN"	15

INTRODUCTION

Disability Rights Wisconsin (DRW) is the designated protection and advocacy agency for people with disabilities in Wisconsin, and one of only two statewide agencies that have provided individual and systems advocacy for Family Care enrollees (the Board on Aging and Long Term Care is the other agency). Consequently, we have an important perspective on what's working and not working in Family Care. As a disability rights agency, our views are primarily focused on Family Care enrollees with disabilities. However, we have assisted a number of Family Care enrollees over age 60 and we believe that many of the issues in this paper relate to the full age range of people receiving Family Care services.

Creating an entitlement and eliminating waiting lists for community-based long term care (LTC) services has been a long-standing priority for DRW. So we were glad to hear Governor Doyle's goal of ending long-term care waiting lists for adults by 2011. We also believe that Family Care has the potential to permanently reverse Wisconsin's institutional bias and finally ensure that every person who needs long term care services will have the option to receive those services at home or in their community. **We support the primary goals of Family Care: Choice, Access, Quality and Cost-Effectiveness.** However, our definitions of these terms may differ from the definitions of the Department of Health and Family Services (DHFS) in some important respects. Clarifying those definitions is one of the reasons to develop this paper.

Our individual advocacy experience with Family Care enrollees has demonstrated to us that current Family Care counties have sometimes fallen short of the goals cited above. **This is not an indictment of Family Care, nor a statement of opposition to its expansion.** Rather, it is a realistic assessment that any new, complex undertaking on the scale of overhauling Wisconsin's entire LTC system (in a relatively short time frame in each county) will inevitably have shortcomings and difficulties. In our view, facing these difficulties head on and dealing with each of them in the planning phase is the best way to maximize the likelihood that Family Care will be a success for the people it is designed to serve. **That is the spirit in which this paper is offered: an effort by advocates "on the ground" to offer constructive insights which will help Family Care to achieve its laudable goals.**

Our second reason to develop this paper is out of concern that the current Family Care expansion planning around the state is not adequately addressing all of the factors which will determine whether a) Family Care will maintain the level of services for people currently receiving high quality services in non-Family Care counties, b) the new system will be an improvement over the status quo for people who are dissatisfied with their current services, and c) new consumers entering the LTC system for the first time will have a superior experience to that which they would have had in the old COP/CIP/Medicaid card system.

In other words, this paper is intended to present DRW's vision of a positive future under Family Care, and to point out the concerns we believe must be addressed in the current planning process.

1. FAMILY CARE EXPANSION SHOULD NOT RESULT IN THE EXPANSION OF SEGREGATED CONGREGATE SETTINGS.

In the 2003-2005 Budget Act the legislature added several revisions to Chapter 55 and related statutes. The "most integrated setting" was added as a requirement when considering community services for people with developmental disabilities. Wis. Stat. section 55.06 (9)(a)

"Most integrated setting" is defined as a "setting that enables an individual to interact with persons without developmental disabilities to the fullest extent possible." Wis. Stat. section 46.279(1)(bm). Although this statutory definition applies only to people with developmental disabilities, the "most integrated setting" requirement of the ADA (from which the state definition derives) applies to all people with disabilities, including many elderly people who meet the functional criteria for Family Care. **It is essential that the implementation of managed care in Wisconsin assure all consumers the right to "the most integrated setting":**

- People who currently are supported in individualized settings and new enrollees to any managed care program should not be presented with an array of choices which only includes living or working in congregate settings such as adult family homes, CBRF's and sheltered workshops. Doing so would violate not only their right to the "most integrated setting," but also their right to choice of provider and the principle of self-determination.
- When people transition from COP or CIP to Family Care, CMO staff should not automatically assume that people who are living or spending the day in congregate settings want to continue to receive those services. People should be informed of other service models available and given ample opportunity to explore their alternatives.
- Large congregate residential, vocational or day services settings should not be proliferated as a result of inadequate capitation rates or an over-emphasis on "cost-effectiveness" over quality of life for people. In particular we are concerned that the combined reliance on three congregate models (sheltered workshops, "skills training," and "day programs") appears to be a more appealing option for some Family Care counties than expanded supported employment. In contrast, we had hoped that supported employment would be viewed as the "first option" in Family Care, especially for people with developmental disabilities.
- Service planning should be tailored to each individual's needs. People should not be assigned to 4, 6, or 8 bed homes merely for the convenience of providers.
- The DHFS Office of Quality Assurance should not create variances enabling the development of congregate residential settings such as duplexes with several people with disabilities living on each side with interior connecting doors. These duplexes would in effect be operating as large CBRF's.

- Finally, if Family Care is really going to reverse Wisconsin's historical institutional bias, then Aging and Disability Resource Centers (ADRCs) and Care Management Organizations (CMOs) should be aggressively reaching out to people already living in institutions and people heading toward one, to ensure that they are fully aware of their Family Care eligibility and that all realistic alternatives to institutional placement have been explored. Just as the state has set a timeline for each new CMO to serve all the people on the waiting list, there should also be a timeline for the ADRC to complete outreach to all institutionalized persons from the county.

2. CONSUMERS, FAMILY MEMBERS AND ADVOCATES SHOULD BE WELL-REPRESENTED AND ACTIVE PARTICIPANTS ON ALL PLANNING GROUPS, DESIGN TEAMS, LONG TERM CARE ADVISORY COUNCILS, AND ADRC AND CMO GOVERNING BOARDS.

HFS 10.45(1) requires that each Family Care CMO have a CMO governing board. The same Administrative Code requires that at least 25% of the board members be older persons or persons with physical or developmental disabilities or their immediate family members, guardians or advocates.

Wis. Stat. sections 46.282(2)(b)1 and 46.282(2)(b)2 dictate that local long-term care councils consist of at least 53% representation of older persons or persons with physical or developmental disabilities or their immediate family members or other representatives.

- The State must provide rigorous oversight to ensure that counties or private providers who operate the Family Care program comply with the above requirements, and that all consumers and family members are provided adequate orientation, ongoing training and support in order to effectively carry out their roles. (Orientation, training and support of consumers and family members should be required in the contract between DHFS and the CMO.)
- DRW believes strongly that consumers, family members and advocates must be included as active participants in the planning and design of the expansion of Family Care. Vigorous outreach should be conducted to identify and engage consumers and family members. Training should be provided to allow consumers, family members and advocates to be full participants. In those areas where "stakeholder groups" are formed to include consumers it is important that these groups have input to all major decisions regarding Family Care expansion before formal decisions are made.

If proposals are submitted to DHFS for Family Care expansion in a cluster of counties without clear documentation of input from consumers, family members and advocates on all the major decisions included in the proposal, DHFS should send the proposal back to the planning body to obtain such input before DHFS takes final action on the proposal. (This documentation should include minutes of meetings and public hearings, showing the names of consumers, family members, and advocates who participated.)

3. THE TRANSITION TO FAMILY CARE SHOULD NOT RESULT IN REDUCTION OF SERVICE, ELIMINATION OF SERVICE OR ARBITRARY CHANGE OF SERVICES OR PROVIDERS TO CONSUMERS WHO ARE CURRENTLY RECEIVING SERVICES AND SUPPORTS.

The Family Care Program identifies 14 personal outcomes that the program is intended to help consumers achieve. Among these outcomes are: "1. People choose their services" and "2. People experience continuity and security." In some of the current Family Care counties, there have been some instances of individuals having to give up trusted caregivers, being forced to move and experiencing reductions in much needed services. These interruptions and losses mostly occurred when individuals were transferred from COP or CIP-W to Family Care. Enrolling in Family Care should not require a person to forfeit her right to choose where she lives and who provides her care. In many instances, the individuals who experienced these losses were not informed of their right to appeal.

- Family Care should afford individuals the full array of choices available under COP and the Medicaid Waiver plans. Safeguards must be in place to prevent individuals from experiencing interruption or reduction in services or a more limited choice in providers and services when they move into Family Care. These safeguards should include notification to DHFS for every consumer who experiences a termination or reduction of service. Also, in addition to ensuring that service levels to a consumer are maintained pending an appeal, there should also be assurances to providers that their payment levels will be maintained. The State should play an active role in ensuring that the CMOs provide clear notice of appeal and hearing rights to consumers faced with denial or reduction in services. HFS 10.55 (1)(f)
- Future external evaluations of Family Care should include a priority focus on people whose services were reduced when Family Care was implemented, e.g., was the reason for the reduction clearly documented? Was it justified? Was the person notified of his/her appeal rights?

4. FAMILY CARE MUST IMPROVE THE QUALITY OF MENTAL HEALTH SERVICES

We agree with the description of the current situation which was developed by the Wisconsin Council on Mental Health, in its recent statement of "Mental Health Budget and Policy Priorities":

"Long-Term Care Reform and Related Issues

Evaluations of the various long-term care programs, including Family Care, Partnership and the waiver programs have all identified that over 40% of their enrollees have identified mental health concerns. Similarly high numbers are found among individuals accessing services through the Aging and Disability Resource Centers. However, the long-term care system has not been oriented to identifying and addressing these needs. Many providers think first of finding some other placement for

these individuals rather than conceptualizing mental illness as one of a variety of health conditions that can be expected in this population, just as one would expect to encounter diabetes. If these programs are to be successful in meeting the mental health needs of their enrollees we need to support better access to mental health services.”

DRW’s recommendations for addressing these concerns (some of which are similar to those of the Council) are as follows:

- Family Care should be modified to include persons over 65 who meet an institutional level of care due to a mental health diagnosis only.
- The State should pay the full Medicaid amount for all mental health services for all individuals served in Family Care. This will allow these programs to adequately meet the mental health needs of enrollees.
- Ensure that COP funds now utilized to serve persons with mental illness (i.e., as part of significant proportions) remain available to serve persons with mental illness when a county begins Family Care operations. It is understood that these funds would continue to be available for each person currently using the funds, but if these persons move out of county, become eligible for a managed care program, or are no longer eligible for these COP funds, then the funds will be absorbed into the State funds for the Family Care capitation rates. These funds should remain available to serve persons who have a mental illness and have not previously utilized COP funds rather than being incorporated into the Family Care capitation rates.
- The State should develop mental health consultation and training capability for CMO and provider staff. Consultants would be available to consult on situations that challenge the expertise of Family Care staff.
- ADRC and CMO staff should be required to attend recovery-based training on mental health service delivery.
- DHFS should monitor the development of all CMOs’ provider networks to ensure that community support programs (CSPs) and other essential mental health services are available to Family Care participants.

5. THE FAMILY CARE INDEPENDENT ADVOCACY PROGRAM SHOULD BE RE-ESTABLISHED AND ADEQUATELY FUNDED.

When Family Care began, the State’s promise of an independent advocacy component in the original Family Care pilot counties was a critical factor in garnering the support of consumer and advocacy groups for using a managed care model for long term care in Wisconsin. During the first two years of Family Care operations, the state funded a minimum of one independent advocate position in each of the original 5 counties. These advocates assisted Family Care enrollees on a wide variety of matters.

In spite of clear evidence of positive results of the individual and systemic advocacy efforts of the original Family Care Independent Advocacy program and bipartisan support in the state legislature for continuation of the program, Governor McCallum vetoed this component of Family Care after only two years of operation. DRW, along with other disability and aging advocacy groups, considers it a high priority to re-activate this program. This is especially important in light of the imminent start-up of new Family Care counties, since many consumers experienced confusion and transition difficulties when the original five Family Care pilot counties began operations.

During the time that Family Care Independent Advocacy was operational, there were a variety of problems for which Family Care enrollees sought assistance from independent advocates (often after unsuccessful attempts to resolve the problem inside the ADRC or CMO):

- Inadequate participation of enrollees in individual care planning
- Failure of the CMO regarding people transitioning from COP/CIP to Family Care to a) ask if they were satisfied with their current services, b) explain the other choices available, and c) provide a real opportunity for people to change their service plans
- Arbitrary termination of long-standing provider relationships
- Inadequately addressing enrollees' vocational needs
- Inadequately meeting enrollees' mental health needs
- Misunderstandings regarding whether family members can be paid caregivers in Family Care
- Delays in eligibility determinations and enrollment
- Lack of (or limited) choice of services for enrollees and over-reliance on congregate models of service (e.g., sheltered workshops, traditional group homes)
- Communication problems and confusion with the CMO for enrollees and families
- Reduction in service (without adequate process and justification)
- Enrollees and families not informed of the "consumer-directed" option for services
- Difficulties experienced by some enrollees in using the county's grievance process

We are pleased that the Long-Term Care Reform Council strongly endorsed an allocation of funding for this purpose, and that the Council reaffirmed the importance of the advocacy system being independent of state and county government, and separate from long-term care service

provision.

Unfortunately, Governor Doyle has only proposed a very modest amount of funding for this activity in his 2007 - 2009 budget. This proposal would add 1 full-time position to the Board on Aging and Long Term Care (BOALTC) for Family Care enrollees age 60 and over, and an amount of funding sufficient for 1 - 1.5 advocates statewide for persons under age 60. In the case of BOALTC, this new position would augment an established regional network of staff handling some Family Care cases already. For people under age 60, 1 - 1.5 staff statewide could not be considered an "independent advocacy system". Clearly this staffing level could not handle anything close to the volume of requests that were made in the first two years of Family Care (and there are many more Family Care enrollees now), nor would there be any meaningful "local advocacy presence".

At the very minimum, we believe there must be at least a 1.0 FTE advocate in each region of the state where there will be FC counties during the 2007 - 2009 biennium (and there should probably be a higher staffing level in SE Wisconsin).

6. THERE MUST BE FAIR RATE SETTING TO ENSURE ADEQUATE CONSUMER FUNDING.

To provide an appropriate level of high-quality support for consumers under any program of long-term care, sufficient funding must be provided to purchase the variety and quantity of services and supports required to meet the needs of each consumer in the program.

In a managed care system like Family Care the amount of funding that will be available from the state to provide services to consumers in any geographical area is a direct result of the "capitated rate" that is established for that area. This rate is the amount of money the state will pay for each participant in Family Care in that area. The total state payment to a locale equals the number of participants times the per capita rate. The major concern is whether or not the capitated rate will be sufficient to create a pool of money large enough to purchase adequate services for each individual in a Family Care region. From this follows the more fundamental question: How is the capitated rate to be determined?

The actuarial calculations that produce a "capitated rate" involve the application of statistical techniques to historical data along with a variety of assumptions regarding economic, demographic and other factors. The results of the calculation depend on the data provided.

When Family Care was first implemented, capitated rates for each of the initial pilot counties were calculated on the basis of each of those counties' historical costs for the services to be provided under the new Family Care (managed care) program. This resulted in different capitated rates for each Family Care county. With several years of experience doing managed care/Family Care in the pilot counties, capitated rates for FY 2007 have been developed using consolidated FY 2005 data from all Family Care pilot counties. (County-specific adjustments are still made that reflect specific differences among counties.)

As Family Care expands statewide the initial rates for new regions/MCOs --- as well as for counties continuing in Family Care --- will be based on data from areas already under Family Care. This is certainly an improvement over the original method (basing rates primarily on the historical costs of a single county), but it still raises a question: What if a county's service delivery models or a county's higher-than-usual commitment to the principle of "most integrated setting" have resulted in a service system in that county which is substantially different than the existing Family Care counties on which the new county's rates are based? In our view, this circumstance would justify a special adjustment in the rate.

For counties entering Family Care whose historic *per capita* spending on long term care has been lower than that in existing Family Care counties, the change in the rate-setting method should result in an **increase** in funds for long-term care services. This increase should allow for an increase in levels of service in those areas where individuals have been chronically underserved. It should also allow for an increase in provider rates in those areas that have a history of paying rates inadequate to provide well-trained and motivated direct care staff. (This is independent of the increase in total funding for a county/MCO that will take place as individuals currently on the waiting list begin to be served.)

Family Care may well be a boon to individuals receiving long-term care services who reside in areas of the state that have historically spent less on these services --- and to individuals who have lingered for years on the waiting list for services. That is good news! It is unclear, however, that Family Care will benefit individuals currently receiving services in counties that have developed robust (higher than statewide average cost) systems for providing long-term care. In fact, there is real concern that Family Care will have a significant negative impact on many consumers in such counties.

Counties that have historically provided relatively higher levels of service to individuals and higher rates to providers will, upon entering Family Care, be offered capitated rates based on the experience of a group of counties (those currently in Family Care) whose benefit structure and historical cost experience is quite different. The key consideration at that point becomes the extent to which "local factors" will be allowed to increase the final capitated rate offered to a Family Care MCO. (The matter becomes even more complex when counties with divergent benefit structures and historical costs are "yoked" in a single Family Care organization. How will individuals in the "high benefit" county fare in the new organization?)

If rate-setting in Family Care begins with the assumption that all individual participants should receive appropriate levels of high-quality service, the result can be a system that can afford to provide such services. If rate-setting in Family Care is carried through with the commitment to preserve or enhance the supports provided to every participant in the program, the result can be a system that rewards rather than punishes those who join. However, if Family Care rate-setting begins with the assumption that the key concern is limitation of the financial exposure of the governmental and/or business entities paying for LTC services to current levels of expense, then consumers will be harmed and strong LTC systems in some counties will be undermined.

7. THERE MUST BE MECHANISMS AND SAFEGUARDS TO ENSURE THAT FAMILY CARE OFFERS EVERY CONSUMER THE OPTION OF CONSUMER DIRECTED SERVICES AND SELF DETERMINATION.

The Family Care statute contains language creating a “consumer-directed services” option for any Family Care enrollee who wants to use it. In DHFS’ own report on this option, it was acknowledged that this is generally used only as a basis for consumers to hire their own in-home workers. DRW endorses the Survival Coalition definition of Self Determination (attached), which goes beyond the common application of consumer-directed services in current Family Care counties.

Specifically, Self Determination enables consumers to:

- control the use of their own individual budgets
- choose individualized living arrangements such as apartments and single family homes over a CBRF or Adult Family Home
- choose supported employment instead of sheltered work or segregated day services
- utilize family members, neighbors and other alternative sources of support instead of traditional providers listed in the CMO provider network

On the positive side, DHFS officials have acknowledged at a recent meeting of the Long Term Care Reform Council that all of the above examples are allowable under current Family Care statutes, as is the use of a “broker” (selected by and accountable to the consumer) to assist the consumer in fulfilling his/her aspirations.

We believe that ADRCs and CMOs should do a better job of providing training, consumer-friendly materials, and other assistance to ensure that all Family Care enrollees actually know the full extent of what consumer-directed supports and services can include. We believe this training and assistance should be required in the DHFS contract with either the ADRC or the CMO or both. Only then will consumers be able to make an informed choice of whether and how to use this option. We also believe that DHFS should engage in active oversight efforts to confirm that this is happening. This should also be a key focus of external evaluations of Family Care.

8. THE STATE MUST ESTABLISH RIGOROUS OVERSIGHT OF THE COUNTIES AND/OR PRIVATE CORPORATIONS WHO OPERATE THE FAMILY CARE PROGRAM LOCALLY.

The State must establish contractual oversight of the Aging & Disability Resource Centers, the Care Management Organizations and its contracted agencies, as provided by state law and regulation. ss 46.281 Wis. Stats.; HFS 10ff

State law gives DHFS broad powers of oversight of the Family Care Program in general and the Aging & Disability Resource Centers (ADRCs) and Care Management Organizations (CMOs) in particular. With the expansion of Family Care statewide, and with the influx of private organizations into what has traditionally been the responsibility of county government, it is imperative that the state continues to carefully monitor the ADRCs and CMOs at the local level to ensure that enrollees' rights* are protected and that consumer-centered services are provided.

Among the oversight responsibilities prescribed by ss465.281 Wis. Stats. are:

- Quality assurance and quality improvement measures, including standards for operation, outcome-based performance expectations, ongoing evaluations and reviews by independent, external organizations, which are available to the public
- Ensuring that the ADRCs and CMOs establish adequate and effective complaint and grievance procedures

The administrative rules promulgated by the state pursuant to ss46.281 are found in HFS 10. HFS 10 prescribes in great detail the conditions that the ADRCs and CMOs must meet in order to be certified; how eligibility is to be determined; and what and how services are to be provided. The rules emphasize consumer choice and respect and informal and formal complaint resolution.

Oversight of Resource Centers

HFS 10.24 requires the state to monitor the performance and operations of the ADRC with respect to all of its duties, including providing information about LTC options and linking eligible persons to needed services; respecting individuals' rights and dignity and giving consumers a strong role in program and policy development; and providing early intervention and prevention services. The rules require the department to develop and use indicators to measure and assess the performance of the ADRCs.

Oversight of Care Management organizations

HFS 10.43 requires that all CMOs who want to participate in Family Care must meet certain conditions for certification and enter into a contract with the state. The rules give the state the power to conduct any necessary investigations to verify that the certification information provided to the state by the CMOs is accurate. The rules specify that the state's contracts with the CMOs shall specify a range of remedies that may be imposed if the CMOs fail to comply with contract requirements.

Currently DHFS staff involved in Family Care have expressed a genuine intention to carry out an active oversight role. However, as Family Care expands it is not at all clear how DHFS will meet the person-power demands associated with this role. We propose that CIP

*The rights include the right to choice, to consumer directed services, continuity of provider, participation in the individual service planning process, etc.

follow-along workers be re-deployed to Family Care oversight. Other current DHFS staff and new staff as needed should also be reassigned to this role. If not, it is hard to see how the state will fulfill its statutory and regulatory responsibilities.

In deciding on the focus of external evaluations of Family Care, DHFS should solicit input from both the Long Term Care Reform Council and the agencies providing Family Care Independent Advocacy.

9. THERE MUST BE SAFEGUARDS TO ENSURE THAT CURRENT PROVIDERS ARE NOT ARBITRARILY EXCLUDED FROM THE SERVICE SYSTEM.

The implementation of Family Care would do a huge disservice to people with disabilities if it were to result in the arbitrary elimination of agencies that currently provide services. Over the years that Wisconsin counties have administered long term care services, a network of highly skilled service providers has evolved. Many of these providers employ staff who have devoted their professional lives to serving people with disabilities in a safe, respectful, cost effective and inclusive way. The learning curve for the provision of safe, respectful, cost effective and inclusive services is steep and to lose our most successful and wise providers would be difficult to recover from.

Consumers and their family members have developed trusting relationships with provider agencies based on years of working together toward a common goal. The disruption of this continuity could mean a huge setback for consumers who trust that their provider agency knows exactly how to provide for their intimate and often quite complicated needs.

In order to best ensure continuity of services and to retain highly skilled staff, CMOs should be:

- Required to seek out and negotiate with current providers for new and existing recipients of service
- Prohibited from using rate setting to arbitrarily eliminate providers (e.g., by setting rates for a category of service so low that it makes it impossible for a provider to do business in that county)
- Required to offer providers similar rates to what they are now being paid to provide services (unless there is clear evidence that a particular provider's rates are "out of line")
- Required to negotiate individual consumer rates that will be sufficient for current providers to be able to continue services and to continue to provide staff adequate wages and benefits
- Required to include every current county-contracted provider at the beginning of Family Care unless there is proof of malfeasance by the provider or the provider opts out voluntarily

Also, in those counties where more than one CMO is operational (or there is a CMO and a Partnership Program) there should be safeguards to ensure that a successful enrollee-provider relationship in one of the county's long term care systems can be continued when a person transitions to another long term care system in the county.

There is one scenario in which we believe a CMO would be appropriately using its discretion to exclude a provider from the provider network. That is the situation when a provider has been cited for numerous regulatory violations and/or has been the subject of a substantial number of consumer complaints.

10. THE FUNCTIONAL SCREEN USED TO DETERMINE ELIGIBILITY FOR FAMILY CARE MUST NOT DENY PEOPLE WHO ARE TRULY ELIGIBLE.

By rule, eligibility for the Family Care benefit is based on findings that the applicant has service needs in a certain number of activities of daily living and/or instrumental activities of daily living. In recent years a computerized "Long Term Care Functional Screen" (LTCFS) has been used by staff to determine eligibility for the benefit. Staff input information into a laptop computer and a finding, either of functional eligibility or ineligibility, is made by operation of the computer program.

There is a significant problem with the reliability of the screening tool which could result in some people who should be found eligible being found ineligible. Whether a person's functional eligibility is determined properly is wholly dependent on the accuracy and completeness of the data the screener inputs into the computer program. Detailed instructions to screeners set the parameters of the data they are permitted to input. The instructions to screeners have been altered on many occasions. At least one relatively recent change to the instructions, the so called "one third of the time" rule results in the screener failing to capture significant functional deficits of people whose needs fluctuate. For example, a person with multiple sclerosis may have good and bad days, where care needs may vary quite widely. Under the "one third of the time" rule a person who has problems with mobility 9 days or less per month will not be found to have any functional need with the "mobility in the home" activity of daily living. We believe this is wrong. Before the "one third of the time rule", functional needs were assessed based on the person's "worst day" during the month. That standard is the appropriate one because a person who has a significant deficit in a number of ADLs even once per month is not likely to be able to maintain their independence in a community setting.

The instructions to the screen may contain other instances where they have the effect of restrictively evaluating people's functional deficits. When the Department makes major policy decisions—like the "one third of the time" rule (which is a significant change from past eligibility determinations)—we strongly believe the Department is obligated to go through formal, notice and comment, rulemaking procedures before it adopts them. It is improper under Chapter 227 of the Wisconsin Statutes to initiate major policy changes that have the effect of limiting eligibility in conflict with existing administrative code requirements in the form of "instructions" to line workers.

Before Family Care is extended to other counties the “one third of the time” rule must be eliminated; as must any other provisions of the instructions that have the effect of excluding from eligibility consideration actual functional deficits of consumers.

11. COUNTIES MUST CONTINUE TO HAVE MEANINGFUL ROLES IN GOVERNANCE, OVERSIGHT, QUALITY ASSURANCE AND LTC POLICY SETTING.

One of the most basic tenets of the delivery of services to vulnerable people in a way that is safe and thoughtful is the investment of local, fellow citizens. This comes about as a result of local taxpayers' involvement in the electoral, legislative and budgeting process via their County Board of Supervisors (and committees) and their County Executive (or County Administrator). The ability to impact change on a local level is a time honored feature of a democracy.

County officials and staff currently have a partnership role with consumers, families, advocates and service providers. This partnership provides for irreplaceable opportunities to ensure that there is good governance, oversight and quality assurance; and some local accountability to tax payers.

In order to best ensure that Counties continue to have a meaningful role in the delivery of services, disability advocates strongly encourage county governments to take on the CMO role as is the case in the first five Family Care Counties, or through a multi-county publicly - controlled structure.

- Counties should be afforded adequate latitude to develop multi-county configurations based on their unique situations (with the acknowledgment that a CMO must have a minimum number of enrollees to realistically handle the economics of managed care).
- Counties should be allowed to explore the development of separate CMOs for different populations if that best suits the unique aspects of their county.
- Where counties opt out of being the CMO the State should require some level of ongoing county involvement in oversight, quality assurance, and LTC policy setting. This could take the form of requiring CMOs to invite representatives of county government to sit on their Boards, joint CMO-county public hearings, and other mechanisms.

12. STRONG DUE PROCESS PROTECTIONS ARE CRITICAL TO THE FAMILY CARE PROGRAM AND MUST BE EXTENDED TO ALL CONSUMERS IN THE FAMILY CARE EXPANSION COUNTIES AS REQUIRED BY LAW.

Sub chapter V of HFS 10 deals with the Protection of Applicants, Eligible Person and Enrollee Rights.

HFS 10.51(1) lists the client rights which are to be embodied in the Family Care program. These provisions incorporate due process protections guaranteed by the U.S. Constitution and other federal and state laws.

The rules ensure protection of enrollees' rights to due process by mandating that:

"...resource centers, CMOs and county agencies under contract with the department shall assist clients to identify all rights to which they are entitled, and if multiple grievance review or fair hearing mechanisms are available, which mechanisms will best meet clients needs." HFS 10.51 (1)(g)

In addition, the rules also require support for Family Care enrollees who wish to exercise their due process rights under other statutes such as Wis. Stats. Ch. 51 and HFS 94 for persons with mental illness, for those with developmental disabilities, those residing in nursing homes, CBRFs, or adult family homes.

A critical component of due process is adequate and timely written notice of consumers' rights and responsibilities at time of application; of any intended action, such as a denial, termination or reduction of services; and of the availability of the right to file a grievance, departmental review or a fair hearing. **This means that a due process notice must be sent to the consumer whenever the Family Care program intends to take any action that would adversely affect a consumer's receipt of services under Family Care, including when a consumer is required by the Family Care program to move from one residence to another.** Currently notices are only required when there is a denial, reduction or termination of services specifically listed in the rules.

The notice must inform consumers of their right to receive continuation of services pending a fair hearing decision if a grievance, review of fair hearing is filed before the effective date of the action. In addition, the notice is required to inform consumers that if they receive continuation of services pending an appeal and lose the appeal, they will be liable to repay the cost of those services. Finally the rules require the department, resource center and CMO to cooperate with any advocate selected by a consumer to assist with a problem or articulating a need.

All Family Care grievances, reviews and fair hearings must comply with the time limits set by law or contract. Frequently, consumers who get unfavorable grievance decisions at the CMO level do not know to exercise their right to request a fair hearing. For this reason, DRW recommends that any consumer who loses a grievance have an automatic appeal to a fair hearing, without having to specifically request one.

Attachment: "Defining Self-Determination in Wisconsin" (Survival Coalition of Wisconsin Disability Organizations)

Defining Self-Determination in Wisconsin

Self-determination, sometimes referred to as self-direction or consumer-direction, is increasingly recognized as an essential element of long-term care. Self-determination is a necessary aspect of Wisconsin's publicly-funded systems of support for elders and people of all ages with developmental disabilities, physical disabilities, or mental illness. We offer the following definition and guiding principles for what self-determination means within those systems:

Self-Determination is the right of all people with disabilities (with their chosen allies) to make choices and direct all aspects of their lives, including how they are supported; and to control the funding to pay for that support.

In the words of a person with a disability "I, the people I care about, and those who care about me making a life that is good for me."

The following guiding principles apply to all people who may need support from our systems of long-term care, education and health care.

Guiding Principles of Self-Determination

Choice

All people have the right to choose what they will do with their lives, including where they live, who they live with, and what they do during the day. When people need help making choices, friends and family are typically the most effective allies in assisting them to broaden their experiences and to exercise the right to make their own choices.

Dreaming, Planning, and Creating

All people have hopes and dreams for the future as well as goals they want to achieve. A system based upon self-determination helps people identify these dreams, and create a plan to realize them. "No, we can't" is replaced by "How can we make this happen?"

Control of Funding

An essential element of self-determination is enabling people to have authority to direct how the public funding available to support them is allocated.

Responsible Use of Funding

With control by the person over how funds get spent there is also responsibility to live within a budget. To find the best quality for the most reasonable price, people are able to purchase in and out of a service provider network, and are encouraged to be innovative and creative. Public funds will not be used for activities that are illegal or harmful to the person or others, or that are unrelated to a person's needs for support.

Collaboration

Self-determination is based upon collaboration among the person; their allies (typically families and friends); their communities; and the systems and agencies that are designed to support them.

Community Connections and Contribution

Everyone has the ability to contribute to his or her community in a meaningful way.

When we give of ourselves, we feel a sense of belonging. That sense of belonging is strengthened when people are in control of their lives, have their own homes, have a job, are involved in community activities, and have opportunities to make a difference in the lives of others.

Importance of Relationships

Relationships provide everyone with strength, support and security. Maintaining and deepening old relationships and helping develop new ones is often one of the most effective ways of supporting self-determination. Paid services can sometimes unintentionally isolate people if there is not deliberate attention to maintaining and creating community connections.

Support from the System

Our publicly funded systems retain critical roles and responsibilities within a system built upon self-determination. Those roles and responsibilities are best designed and managed within a system in which people with disabilities, and their families and allies share in the design and governance of the system. Essential systems roles include:

- creating fair and equitable individual allocations of funding;
- setting boundaries on what supports and services are allowable;
- providing unbiased information and support to individuals and families on what is available and enlisting people's creativity about what might be possible (often this assistance is provided through a personal agent or a support broker);
- assuring effective care management, including attention to and support for well-being, quality, and cost-effectiveness;
- creating an efficient infrastructure that enables people to select, create and pay for needed goods or services, and to hire, manage and dismiss support staff.

Support from Providers and Professionals

Providers and professionals, including direct support professionals, are encouraged to become allies with the people they support. They provide day to day support to assist people in realizing their dreams.

Dignity of Risk and Attention to Vulnerability

All people have the right to be treated with dignity and to be respected as a whole person, the right to "the dignity of risk." A network of support makes risk possible by providing safety and supporting growth. However, self-determination is not an excuse for ignoring issues of potential vulnerability on the grounds that a person "chose it." There are limits to the level of risk society will allow people to take with their own lives and physical well-being. A system based upon self-determination supports people to learn decision-making and manage their actions to the greatest extent possible, rather than offering a "choice" of inadequate support or excessive restrictions.

Adopted by the Survival Coalition of Wisconsin Disability Organizations, September 2006