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Helen Schwartz  
159 Apple Tree Ct.  
Green Bay, WI 54302

March 22, 1999

For the past three years I have been caring for an 85 year old widow who has no family and little financial means. She needed help. Sophie had multiple health problems that made her confused, anxious and unable to access all the systems necessary for her care needs. We worked with a very good case worker through the Aging Resource Center and with my legs and energy finally have her care system in place. It took three years. She is now with the COP Program. There are many other older people in Wisconsin who aren't as fortunate as Sophie and who don't have the help to network all the systems needed for their long term care.

So---I ask---please talk with Gov. Thompson and encourage him to set the Family Care - 1-Stop-Shop into action. There are too many of our citizens who need help now. They want to stay at home and can if they can get some assistance.

COMMISSION ON AGING, INC.

*Brown County*

*To Rude, Welch, Robson, Bresh*  
**Aging Resource Center of Brown County**  
*formerly Brown County Commission on Aging.*

300 SOUTH ADAMS STREET  
GREEN BAY, WISCONSIN 54301

**SUNNY ARCHAMBAULT**

PHONE: (920) 448-4300 FAX: (920) 448-4306  
TDD: (920) 448-4335

DIRECTOR

**TESTIMONY BEFORE THE JOINT COMMITTEE ON HEALTH,  
UTILITIES, VETERANS, & MILITARY AFFAIRS**

**MONDAY, MARCH 22**

**ON BEHALF OF THE BOARD OF DIRECTORS & DIRECTOR OF THE  
AGING RESOURCE CENTER OF BROWN COUNTY**

Thank you for this opportunity to present information on issues that are critical for older persons in our community. For the past six years, the Board of Directors of the Aging Resource Center of Brown County has been learning about, and talking about, and advocating for a long-term care system that makes sense for older persons and their families--in particular, the frail elderly living in our communities. This one topic--a comprehensive community care service system that allows persons to live in the setting they choose--has been on every one of our agendas for the last three years.

We have been encouraged by the Governor's rhetoric regarding his commitment to "Family Care", but are quite disillusioned by the Governor's budget for long term care issues. And the budget is the state governments real declaration of values. While we realize that the issues around long-term care reform are numerous, complex, and controversial, older persons have spoken clearly and consistently on this topic. They have repeatedly stated: We want real choices regarding how and where we receive help; We want access to comprehensive and unbiased information in order to make informed decisions; We need advocates to help us understand the system on which so many of us depend; We want public control and accountability if we will be required to have a managed care system.

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We have been encouraged by the Governor's rhetoric regarding his commitment to "Family Care", but are quite disillusioned by the Governor's budget for long term care issues. And the budget is the state governments real declaration of values. While we realize that the issues around long-term care reform are numerous, complex, and controversial, older persons have spoken clearly and consistently on this topic. They have repeatedly stated: We want real choices regarding how and where we receive help; We want access to comprehensive and unbiased information in order to make informed decisions; We need advocates to help us understand the system on which so many of us depend; We want public control and accountability if we will be required to have a managed care system.

COMMISSION ON AGING

The Governor's budget provides dollars for nine pilot counties. Hopefully, the experience gained through these pilots will provide the information needed to implement an effective long-term care system statewide. However, this budget also provides *little to no* increases in any of the other state funded community services that older persons depend on *now* to remain independent. The promise of a comprehensive reformed system is empty for seniors in the remaining 63 counties of our state. ***This budget is not adequate.*** There are 371 persons on Brown County's COP waiting list, 94 of these individuals are over age 65. They have neither the time nor the capacity to wait for the next biennial budget to receive the help that is needed today. They need and deserve your support in *this* budget if they are to remain in their own homes or in other living situations of their own choice.

We ask for your support, but more importantly, we ask for your leadership. Please develop a budget that more realistically addresses the needs of the most vulnerable of our aging population. A statewide entitlement to community care that includes the opportunity for public management and accountability is a vision worth pursuing. Please don't let up the pressure on this critical issue. But equally important is the need to also adequately fund existing community programs such as transportation, COP, Nutrition, and increases for Personal Care Workers.

Thank you for your attention, your interest and your commitment to aging issues.

March 24, 1999

To: Senator Rod Moen, Chair  
Members, Senate Committee on Health, Utilities, Veterans and Military Affairs

From: Lynn Breedlove, Executive Director

Subject: Issues affecting Wisconsin citizens with disabilities in the 1999-2001 biennial budget bill

I am out of town today, but I am submitting written testimony on behalf of the Wisconsin Coalition for Advocacy. As the designated protection and advocacy agency for people with disabilities in Wisconsin as defined in Chapter 51, this testimony is also presented on behalf of the citizens with disabilities of Wisconsin.

I will focus on two major areas:

- The overall discouraging picture of this budget as it relates to community services for people with disabilities
- The current position of disability groups in response to the Governor's proposal for Family Care

**A. The overall discouraging picture of this budget as it relates to community services for people with disabilities**

The general consensus among disability groups in Wisconsin is that this budget, taken in its entirety, is a major setback to the efforts of the last several years to strengthen the community service system which supports people with disabilities to live in their own homes and their own communities. In contrast to an increase in rates for the State Centers for the Developmentally Disabled, for nursing homes, and for Corrections, there are no community services for people with disabilities which are proposed for an increase in either rates or in the number of people to be served. This includes the Community Options Program, both the Community Integration Programs 1A and 1B, the Brain Injury Waiver Program (which provides an alternative to hospitalization for individuals with a traumatic brain injury), the Family Support Program, and the Medicaid Personal Care Program. There is no provision for dealing with increased waiting lists for any of these programs, nor the increase in demographic growth which adds new demands for these programs.

On top of this bad news, Community Aids, which is a crucial funding source for many community services which people with disabilities rely on, has actually experienced a major cut. We are already beginning to receive specific reports from Milwaukee County, Racine County, Kenosha County, Dane County, Waukesha County, and other counties regarding the extent of the reduction in community services which will take place in their counties as a result of the loss of Community Aids. As you may know, there will be a disproportionately large effect of this cut in Milwaukee County, as a result of the particular method of calculating how the cuts would be applied in Milwaukee.

As advocates for people with disabilities, it is difficult for us to know where to start in attempting to make this budget more disability-friendly. Frankly, we would appreciate the help of the Senate Health Committee on any of these fronts. We believe a restoration of the lost Community Aids dollars is absolutely crucial. But we also are confounded by the possibility that this biennial budget would be the first one in the history of the Community Options Program in which there is no growth in that program. Ignoring the Community Integration Programs will have the predictable result of closing the door on any persons with disabilities in state, county, or private institutions who could live appropriately in the community at a lower cost to the taxpayer.

I've enclosed a chart which summarizes the overall devastating picture for people with disabilities if this budget is not changed.

## **B. The current position of disability groups in response to the Governor's proposal for Family Care**

The position of the Wisconsin Coalition for Advocacy is reflective of the broad position of disability groups which has been taken by the Survival Coalition. In short this position includes the following points:

1. We support the Governor's proposal to continue "pilot" projects in Redesign and to increase the number of pilots. However we believe that the pilots should really be pilots (and not the first stage of phase-in of a statewide model), which means that we would ask the Legislature to change proposed statutory language so that such language is limited in its impact to implement pilots and not set the stage for full statewide implementation.
2. We also believe, in the spirit of "piloting" different models, that the Legislature should specifically indicate that new pilot counties would have the opportunity of selecting the Alternative Model which has been developed by disability groups, counties, and aging groups (see attached summary description), in addition to the choice of the DHFS model.
3. We believe that the performance of all pilots should be evaluated by an independent third party to ensure an objective analysis.
4. We also believe that all long term care populations should be included in the planning for

Long Term Care Redesign, i.e., we are opposed to Secretary Leraan's position that people with developmental disabilities should be excluded from the reform of the long term care system.

The impetus for developing an alternative model grew out of the concern shared not only by disability groups but also aging groups and counties that the state appeared to be moving in the direction of privatizing the long term care system in Wisconsin, which historically has been the responsibility of county government. We do not believe that there is a strong consensus of the citizens of Wisconsin to exclude local government from long term care, and in fact we believe there are many people who like the idea that local elected officials would be accountable for overseeing the quality of a locally run long term care system. The Department cannot ensure that counties would be able to run the system that they propose; in fact they have specifically indicated their strong interest in opening up the competition for this role with the private sector. The alternative model would clearly continue the role of counties as the coordinating body for the provision of long term care in every county.



## THE DISCOURAGING BIG PICTURE FOR PEOPLE WITH DISABILITIES IN THE GOVERNOR'S BUDGET

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- |  |   |   |
|--|---|---|
| Community Aids Program                     | → | Governor's budget reflects an \$18 million overall cut in Community Aids  |
| Community Options Program                  | → | Governor proposes no new COP slots for demographic growth or waiting lists in the 1999-2001 biennium  |
| Community Integration Program 1A           | → | Governor proposes no increase in rates for the biennium – lowest projected # community placements from the State DD Centers in history of CIP1A   |
| Community Integration Program 1B           | → | Governor proposes no rate increase and no new slots in either year (unless ICF/MR's close existing beds)  |
| Brain Injury Waiver Program                | → | DHFS recently reduced the per diem rate from \$180 to \$151. No new slots and no rate increase proposed for Yr. 1 or Yr. 2  |
| Family Support Program                     | → | Governor proposes no rate increase and no services for families on waiting lists  |
| Medicaid Personal Care                     | → | After a combined total increase of 45 cents/hour during the last 9 years, and some personal care agencies going under during that time, Governor proposes no rate increase in Yr. 1 or in Yr. 2 |
| Mental Health/AODA Managed Care Initiative | → | DHFS & Blue Ribbon Commission on Mental Health propose 8 demonstration sites for the new model of mental health services; Governor cuts it to 2 sites.  |

March 12, 1999

## **LONG TERM CARE REDESIGN: AN ALTERNATIVE MODEL TO TRY IN THE PILOT PHASE**

The Wisconsin Department of Health & Family Services has begun the process of piloting one model of LTC Redesign: a risk-based managed care approach which will require special federal approval and will offer the private sector an opportunity to compete against county governments for the right to run the LTC System at the local level. Statewide disability and aging organizations have joined with the Wisconsin Counties Association to develop an Alternative Model, which we believe should also be piloted in multiple counties. Then there should be an independent evaluation of all the pilots, before the legislature makes a binding decision on which model to implement statewide.

The Alternative Model is simple – it's based on the premise that we can achieve the LTC reforms we all want by building on the current system, which would be preferable to blowing up the current system and starting over. The Alternative Model aims to achieve the same goals the Department has identified: simplify the system, pool the funding streams, include all the populations that need long term care, end waiting lists and the institutional bias of the current system, and provide consumers more choice.

The big difference between the two approaches is in how to achieve these goals. The Alternative Model would continue the 100 year tradition of county-based human services in Wisconsin, enabling consumers and families to continue their existing relations with county workers and with local elected officials who oversee the system. This model would also expand and consolidate the Community Options Program with other effective existing community programs, rather than eliminate good programs simply because they are underfunded.

### **Key Features of the Alternative Model:**

- Existing Medicaid waivers programs (e.g., COP and CIP) would be consolidated and expanded to serve people on waiting lists, with rates increased to cover actual costs. Statutory responsibility of counties (as in Chapter 51 for people with developmental disabilities) would be broadened to include elderly people and people with physical disabilities.
- As in Oregon's LTC Reform, a) Wisconsin would need no additional federal waivers beyond the standard Home and Community Based Waiver we already have, and b) Wisconsin would assure the same eligibility and entitlement for community-based long term care as for nursing home care.
- The Alternative Model will cost no more than the Department's model, and counties would continue to invest local tax dollars in the system. The core funding is the same federal-state matching funds for both models, eligibility is the same, and neither model proposes a more expensive package of individualized services than the other.
- The Alternative Model includes many of the features of the DHFS model: pre-admission screening for institutions; Resource Centers; a consumer-directed support option; outcome-based quality assurance; continuity of service; independent advocacy; and an opportunity for people currently in institutions to move out and receive community services.

Wednesday, March 24, 1999

Senator Rod Moen, Chair, and members of the Senate Health, Utilities, Veteran and Military Affairs Committee. Thank you for holding this public hearing giving the public an opportunity to share their views with you about "Family Care" and related issues.

My name is Dale Bruhn. I live in Madison and am appearing to share some feelings and concerns that I have about the Family Care program as proposed in the Governor's budget bill. First a little background. My wife was diagnosed with Alzheimer's in July, 1986, almost 13 years ago. She has been a resident of an assisted care facility since September 1, 1993. She requires total care, cannot stand or walk, holds her arms rigidly in front of her so she can do nothing for herself, does not recognize me or other family members and does not speak except for an occasionally uttered, irrelevant word. I served on one of the Long Term Care Redesign steering committees and still receive, review and comment on the materials distributed by the Department of Health and Family Services. I also have served for more than 4 years on the Dane County Long Term Support Committee, more than 4 years on the Public Policy Committee of the South Central Wisconsin Alzheimer's Chapter, and co-facilitate a Caregiver's Support Group that has more than 25 enrollees. And, very importantly, I am a recipient of financial assistance in paying for the care for my wife from the Community Options Program (COP).

I like the basic concepts of the Family Care program--the Resource Centers, development of a care plan, after an assessment of the individual's needs is made, providing options or choices for the individual and involving family and community members in the decision making process. I have long felt we need a long term care system that is either operated by the public so it is accountable to the citizens or at least managed by the public and one that offers CHOICE to the individual seeking assistance.

As I view the proposed Family Care program, several areas concern me. First, counties cannot be both Resource Centers and Care Management Organizations (CMOs). Counties that want to provide long-term care services to their residents will be required to create Family Care Districts, a public authority, to either be the Resource Center or the CMO. Second, counties will only be given two years after they enter into CMO contracts with DHFS to operate Family Care before they will have to compete to provide the services after that. I think many counties will not want to accept the risk of building the necessary capacity to run Family Care only to see DHFS award the contract to another organization after two years.

Of greater concern is what has not been addressed by Family Care. According to a Feb. 22, 1999, letter from Secretary Leean, only 25% of the state's population will have access to an Aging and Disability Resource Center, a Care Management Organization, and the Family Care benefit, by the end of the coming biennium. Furthermore the legislative language, according to Sec. Leean, does not commit the Department to implement the system statewide by a certain date. What about the remaining 75% of the population in the other 63 counties where pilots are not being run, who are in need? Must they be kept waiting for help? Must they die before help becomes available? Wisconsin can afford to help elderly needy stay in their own homes or in the community by reallocating more funds to the COP program and less for nursing home beds. The state should also support the "Wages for Personal Care and Certified Nurse Aides" initiative, the Elderly Nutrition program, one that has proven to be the most cost effective way of helping older persons remain in their own homes, and funding for additional ombudsmen to assure quality of care for patients and investigation of complaints promptly. And selfishly, on my part because I have keenly felt the need for it, make certain that the program now known as the "Alzheimer's Family Caregivers Support Program" (AFCSP) will be an integral part of the services offered through the Resource Centers and if that is not assured, then continue funding it as a separate budget item.

In conclusion, I support the basic concepts of Family Care but ask you to not neglect the other areas I identified above, as we try to redesign Long Term Care. Thank you.



# DANE COUNTY

**Kathleen M. Falk**  
County Executive

**Legislative Lobbyist**

**Charity Eleson**

March 24, 1999

**To: Members of the Senate Committee on Health, Utilities, Veterans and Military Affairs,  
Senator Rodney Moen, Chair**  
**From: Charity Eleson**  
**Re: 1999-2001 Budget Proposal to Redesign Wisconsin's Long-Term Care System**

Thank you for the opportunity to share information on the Governor's budget proposal to redesign Wisconsin's long-term care system. Dane County is on record as supporting pilots to test how Wisconsin can best redesign its system to serve older adults and people with disabilities, but the county is opposed to making statutory changes until pilots have operated for at least two years.

Wisconsin has a nationally recognized system of community-based care for people with disabilities and it is also well-known for the Community Options Program which provides community care options to consumers who would otherwise have to live in a nursing home. In my county, these services are high demand. In fact, they are so popular that there are almost 1,500 older adults and adults with disabilities on a waiting list for COP, 150 adults with developmental disabilities on a waiting list for residential services and 50 on a waiting list for vocational services.

This illustrates one of the primary things broken in our long-term care system: that we cannot offer services to people who are eligible for community-based services. As a consequence, many of them go into institutional care where they do not have to wait for services. That illustrates another problem with Wisconsin's system: we have one of the highest rates of nursing home use in the country, and in the 1997-98 fiscal year spent \$982.8 million on nursing home care. This contrasts with \$123.1 million spent on COP and COP-Waiver in the same year.

The Department of Health and Family Services, advocates, consumers, service providers and counties have all worked hard over the past year to determine how the long-term care system should be changed. There's agreement on eliminating waiting lists for long-term care services. There's agreement on ensuring that consumers can access community care with the same guarantee for services that currently exists for institutional care. There's also agreement that through diverting people from more expensive institutional placements it will be possible, over time, to save money, thereby finding the funds to serve people on the waiting lists and provide community care options for new consumers.

It's how we get there that there are divergent and opposing views. The department is proposing a model that is a managed care model under a pre-paid health plan. As such, it must

be "risk-based" and competitively bid. That model raises a variety of concerns, including the stability of the system, the continuity of care for consumers, and the adequacy of the funding to cover the individual cost of care, given the lack of data about the actual cost and profile of long-term care consumers in Wisconsin.


It is also possible to build on the current community-based system that enjoys such a high degree of popularity by expanding the Medical Assistance Waivers, including the Community Integration Program and the COP-Waiver. That model would build on the current system, increase federal funding coming into Wisconsin and offer community-based options to older adults and people with disabilities who do not currently receive services.

Wisconsin is at a crossroads in its long-term care system. Clearly, changes need to be made to address lengthy waiting lists for long-term care services, the institutional bias in the current system and the high rate of utilization of nursing home care. The state also has challenges ahead in planning for services to a larger aging population. However, how the state goes about making those changes is extremely important and will affect thousands of frail older adults and people with disabilities and their families for years to come.

That is why my county is recommending that you do real pilots before you make statutory changes. As state policy-makers you can direct the department to test different models and ask for an evaluation of the effectiveness of those models in the areas of cost-effectiveness, consumer satisfaction and the impact on institutional use. If the only "pilot" model that is tested is the one included in the Governor's budget, complete with the statutory changes putting it into law, you as state policy-makers will have no comparison data on which to make good policy decisions about how the system should be restructured once the pilot period is over.

Thank you for your serious consideration of these recommendations.

cc. Dane County Legislative Delegation

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SENATE HEALTH, UTILITIES, VETERANS AND MILITARY AFFAIRS COMMITTEE  
PUBLIC HEARING MARCH 24, 1999

Senator Moen, Chair, and Members of the Committee:

Members of the Autism Society of Wisconsin have been following the long process to develop a new program to provide long term care in Wisconsin. Many of the concepts show promise, but we oppose Family Care in its present form. We strongly support local control of the system and oppose any plan that proposes the use of for-profit corporations to provide care management. We support the county role as the care management agency. In addition, it is clear that the Department of Health and Family Services has grossly underestimated the funding needed to serve the population. The proposed risk sharing plan would lose over \$50,000,000 in overmatch funding, and other current direct services funding would be diverted to pay for Resource Centers and protective services. The proposed funding is not adequate to provide the level of care needed by the projected population.

An Alternative Plan for reform of long term care has been developed by disability advocates and representatives from counties and advocates for aging people in need of long term care.

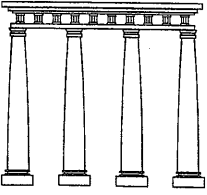
This plan builds on many of the positive ideas of redesign, namely: the same access to community care which currently exists for institutional care: simplifying and combining long term care funding; creating individual choice of how to receive support and services, and allowing "the money to follow the person"; and increased access to independent advocacy.

The alternative plan reforms, rather than replaces, the current successful long term care system in Wisconsin. The cornerstone of the proposal is to treat the Home and Community Based Services Waivers (CIP and COP-W) just like nursing home services. People who meet the same eligibility criteria would have equal access to funding for community services or nursing home services (Current the nursing home is the only entitlement for an eligible person. A person who wishes to live in the community is often entitled to a place on a waiting list!).

The proposed reform of the long term care system does not discourage county administration and thus does not encourage the loss of generous county funding. Our plan does not introduce profit motive into the management of long term care and does not require additional administrative costs for separate Resource Centers. It would maximize use of federal funding and minimize the need for additional state and county tax dollars.

Thank you.

Frances Bicknell .  
Legislative Chair.



# Center for Public Representation, Inc.

P.O. Box 260049

Madison, WI 53726-0049

608/251-4008

FAX: 608/251-1263

CPR@vms2.macc.wisc.edu

## Testimony

Senate Committee on Health, Utilities, Veteran and Military Affairs

March 24, 1999

Presented by AARP and Center for Public Representation

We would like to comment on the budget proposal for a "Managed Care Ombudsman" as described in the "Budget in Brief" on page 11. We note that there is no descriptive language outlining the functions of that position. It appears, however, to be a permanent new position created in the Office of the Insurance Commissioner.

Consumers need assistance in dealing with the complex new health care system. They require detailed information on rights and protections from knowledgeable people. They require individualized help in pursuing their claim through available systems of redress such as grievance procedures. Finally, there must be programs that possess "watch dog" capabilities to monitor and reveal problems and abuses in the provision of health care.

The position designated "Managed Care Ombudsman" appears create an additional person in the Insurance Commissioner's office who will specialize in managed care complaints. We are hopeful that the person will provide expert information and acquaint consumers with various avenues for redress. We therefore support the funding of the position.

We are committed however, to continue pursuing creation of additional positions and programs to assist consumers and to monitor quality and access. One position in the OIC consumer service office is only a hesitant beginning.

## TESTIMONY

**Bob Deist**

**3/24/99**

### Senate Health, Utilities, Veterans and Military Affairs Committee

My name is Bob Deist. As Director of Medical Assistance Personal Care Services at Community Living Alliance and as a past president of Wisconsin Personal Services Alternatives (WPSA), I am speaking in favor of a \$4.00 per hour increase in the Medical Assistance Personal Care reimbursement rate. WPSA represents the MA personal care only providers throughout Wisconsin. Currently 65 counties and 2 independent living centers are certified as MA Personal Care providers. I'm sure all of you know that currently thousands of adults and children are on waiting lists for COP or waiver funding. The reason so many counties have become providers is that the MA Personal Care benefit is the only community funding readily available to serve adults and children with disabilities. To present, admissions to nursing homes or other institutions, MA Personal Care is the only immediate alternative. In addition to waiting lists, counties have had to replace home health agencies that did provide personal care but terminated their programs due to the low reimbursement rate.



The current reimbursement rate of \$11.50/hour prohibits personal care providers from competing with the private sector for wages. Throughout Wisconsin, the industrial, retail and fast food private sectors are offering higher wages than MA Personal Care. As of today, CLA's Medical Assistance Personal Care Program that serves 95 consumers with significant disabilities has 53 vacant shifts. Since the program began in July 1988, the MA reimbursement rate has only increased by \$2.50/hour. From 1990 to 1997, there were no rate increases at all.

With the low unemployment rate MA Personal Care providers are struggling to recruit for and retain their personal care workers. WPSA in conjunction with an initiative by counties, are asking for a \$4.00/hour pass through wage rate increase that will elevate wages to a "living wage" and the ability of providers to offer health insurance and other benefits. It is only with such an increase, that we will be able to successfully compete in the labor market.

WPSA recognizes that tax relief is a priority for this budget, but we believe that this wage increase will reduce the need for higher institutional costs and therefore reduce the MA budget overall. In keeping with Governor Thompson's Family

Care goals to divert thousands of adults from nursing homes, the ability to recruit and retain community workers is essential. This wage increase will continue this diversion and build the workforce while the legislature debates the implantation of Family Care.

Thank you for your time. I am available for questions. I would like to submit data to support the increase with my speech.

Bob Deist

MAPC Director of Personal Care Services

Community Living Alliance

1310 Mendota Street

Madison, WI 53714

(608) 242-8335 ext. 113

600 Williamson Street  
P.O. Box 7851  
Madison, WI 53707-7851



**Council on Developmental Disabilities**

VOICE (608) 266-7826  
TDD (608) 266-6660  
FAX (608) 267-3906

March 10, 1999

RE: The Caretaker Supplement Program for Parents with Severe Disabilities on SSI

Dear Senator:

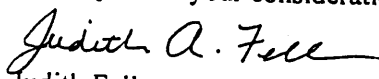
Since the beginning of the Caretaker Supplement Program, the Wisconsin Council on Developmental Disabilities (WCDD) has been highly concerned for the health and well being of the approximately 5,500 Wisconsin families with over 10,000 dependent children who have faced severe reductions in their monthly income.

Families have told the WCDD that they are in crisis and report that they are unable to pay their rent, feed their family or pay basic living expenses. Parents state that they are unable to provide the basic necessities for their children, that they feel they are being punished for their disabilities, and that the constant worry is affecting their health. The severe disability of the parent limits their ability to bring in extra earnings for their family.

The attached booklet entitled, *Families in Poverty*, provides you with the results of the WCDD survey and interviews with families headed by a parent on SSI. In addition, the attached publication, *Fragile Families*, provides a photoessay of sixteen families affected by the change to the Caretaker Supplement Program. Sadly, after the publication was sent to the printer, one of the parents, Tyonna Wilkerson, was killed in a house fire. Tyonna used a wheelchair due to severe arthritis. Her 18-month-old twins were not with her and are unharmed. We do not know the circumstances of the fire, nor if her lack of mobility may have contributed to her inability to escape the smoke and fire. We do know that in an August 1998 interview, she described her housing as unsafe and costly. She said of her housing, "It's kinda bad. I want to move into an apartment where it's a two bedroom and it's spacious where I can move around in. This is so small I can't move around and I can't do as much... I'm scared every day in here with my kids... The danger-people fight, break into your places, most of them are on drugs. I really don't talk to anybody. This entire apartment... is a messed up place. It's kinda sad that people have to live like this and live in here." Many parents who wrote the WCDD echoed her sentiments about unsafe housing.

The Wisconsin Council on Developmental Disabilities has worked with the other 49 member agencies of the SSI Parents Coalition to develop recommendations to improve the Caretaker Supplement Program. We hope that you will consider these recommendations as you prepare the 1999-2001 Biennial Budget. If you would like more information, please contact, Jennifer Ondrejka, the Executive Director of the Wisconsin Council on Developmental Disabilities.

Thank you for your consideration.

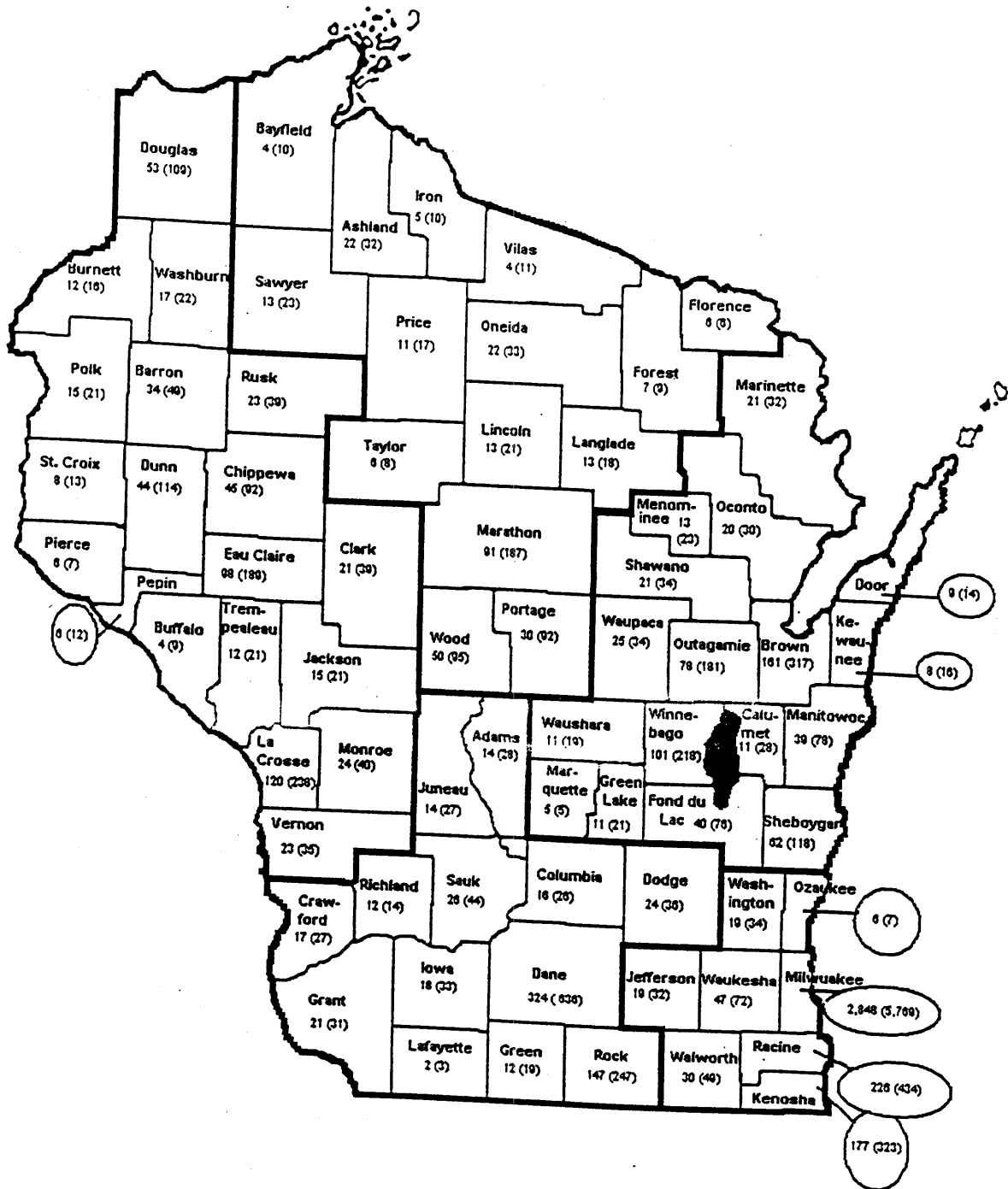
  
Judith Fell  
Chairperson

Attachments:

- SSI Parents Coalition recommendations on improving the Caretaker Supplement
- *Fragile Families: Personal Stories about the Impact of Welfare Reform in Wisconsin on Families headed by Parents with Severe Disabilities*
- *Families in Poverty: Parents with Disabilities and their Children*

# DISTRIBUTION BY COUNTY OF CARETAKER SUPPLEMENT FAMILIES AND CHILDREN

Map prepared by the Wisconsin Council on Developmental Disabilities  
with data provided by the Department of Health and Family Services  
January 1999



**TOTAL NUMBER OF CARETAKER SUPPLEMENT FAMILIES: 5,547**  
**(TOTAL NUMBER OF CHILDREN IN CARETAKER SUPPLEMENT FAMILIES: 10,820)**

# IMPROVING THE CARETAKER SUPPLEMENT PROGRAM FOR PARENTS WITH DISABILITIES AND THEIR CHILDREN

## Recommendations endorsed by the SSI Parents Coalition Steering Committee

March 4, 1999

**Background Information:** Over 10,800 children in 5,547 Wisconsin families headed by a parent with a severe disability have been harshly affected by the reduction in family income resulting from the Wisconsin Works (W-2) Program. Prior to W-2, low-income parents with severe disabilities received Supplemental Security Income (SSI) for themselves, and a child-only AFDC grant for their dependent children. Since January 1, 1998, they have had their income for their children significantly reduced. Families are in crisis and report that they are unable to pay their rent, feed their family or pay basic living expenses. Parents state that they are unable to do anything for their children, that they feel they are being punished for their disabilities, and that the constant worry is affecting their health. The severe disability of the parent limits their ability to bring in extra earnings for their family.

**Current Status:** The families headed by a parent with severe disabilities currently receive from the Caretaker Supplement program \$100/month per dependent child. The Governor's Budget includes an increase in the Caretaker Supplement to \$150/month per dependent child. The increase would occur on October 1, 1999 or later if the budget passage is delayed past that date.

### SSI Parent Coalition Steering Committee Recommendations:

#### 1. PROVIDING FAMILIES WITH A STABLE LIVABLE INCOME:

The Governor's budget recommendation to increase the Caretaker Supplement is a strong step towards providing families with a livable income. In trying to determine a reasonable supplement for the care of dependent children, the steering committee of the SSI Parent's Coalition endorses an allocation of \$250 for the first child and \$150 for each additional child. The cost of the additional \$100/month per family (\$1,200 per year) would be approximately \$6.65 million of federal TANF dollars. If the Caretaker Supplement were raised to \$250 for the first child, and \$150 for all additional children, the income of the families would be closer to the federal poverty level. Increase the Caretaker Supplement as of July 1, 1999.

#### Monthly Income for a Single Parent on SSI\*

Number Of Children	Income before 1/1/98: Parent's SSI & Maximum AFDC for the children	Current Income: Parent's SSI & \$100/month per child	Governor's Proposal: Parent's SSI & \$150/month per child	SSI Parent Coalition's Proposal: Parent's SSI & \$250/month for first child & \$150/month for additional children	Federal Poverty Level for a single parent family
One	\$ 823	\$ 684	\$ 734	\$ 834	\$ 904
Two	\$1,014	\$ 784	\$ 884	\$ 984	\$ 1,138
Three	\$1,091	\$ 884	\$ 1,034	\$1,134	\$ 1,371
Four	\$1,191	\$ 984	\$ 1,184	\$1,284	\$ 1,604
Five	\$1,283	\$ 1,084	\$ 1,334	\$1,434	\$ 1,838

\*This does not include food stamps or housing assistance. For every dollar increase in income, there is a reduction of \$0.30 in food stamps. Most SSI parents are not on housing assistance.

**Comparison of Family Income of SSI and Grants for Dependent Children  
to the Federal Poverty Level**

Federal Poverty Level	AFDC	\$ 100/child	\$ 150/child	\$ 250/first child \$ 150/additional children
\$ 904/month for a single parent household with one child	- 8.96%	- 24.34%	- 18.19%	- 7.74%
\$ 1,138/month for a single parent household with two children	- 10.87%	- 31.11%	- 22.32%	- 13.53%

**2. PROVIDING ALL W-2 SERVICES (EXCEPT A CASH GRANT) TO CARETAKER SUPPLEMENT FAMILIES:**

Interviews with 374 families conducted by the Wisconsin Council on Developmental Disabilities indicate that 80% of the parents on SSI would like to work if work disincentives were removed and if there was the opportunity for work that took into consideration their disability. This would include flexible and part-time work options.

Beside the grant at the CSJ and W-2 T levels, the W-2 agencies offer other services to help parents become employed. Life skills training helps provide the basic foundation to enable the parents to "understand and manage daily life and family stress in order to succeed in the workplace". Examples of life skills training from the W-2 work manual include: budgeting; problem solving/decision making skills; family nutrition/household management; time management; etc. Other W-2 services are childcare assistance, transportation assistance and job search assistance activities. Parents on SSI could benefit from these programs and from other opportunities for service coordination.

**3. EXPANDING ELIGIBILITY FOR W-2 CHILD CARE ASSISTANCE TO PARENTS ON SSI WHILE THEY ARE LOOKING FOR WORK OR PARTICIPATING IN EDUCATION OR TRAINING**

W-2 child care assistance is an economic necessity for low income parents wishing to work. However, SSI parents are ineligible for such assistance while they are looking for work. Only those participating in the W-2 program or in the food stamp employment and training program are currently eligible.

In addition, SSI parents are not eligible for child care assistance while in educational or training programs unless they have a 9-month work record and then continue to work while in training. Only W-2 participants are eligible for such care without a prior work period.

**4. INCLUDING IN THE CARETAKER SUPPLEMENT PROGRAM, THE CHILD OF A MINOR CHILD WHEN BOTH ARE LIVING WITH A GRANDPARENT ON SSI.**

The W-2 disability hotline and advocacy agencies in Milwaukee report special problems for families headed by a grandparent on SSI. If a minor parent and her child are living with the child's grandparent, and the grandparent is on SSI, the family is eligible for only a single Caretaker Supplement of \$100 per month. There is no additional money to help care for the infant. The family is not eligible for a kinship care payment nor is anyone eligible to participate in W-2. This family should at least be eligible for a Caretaker Supplement for the infant to help meet the many additional costs incurred for having a baby in the home.

## 5. ENSURING THAT FAMILIES LIVING AT THE SSI BENEFIT LEVEL RECEIVE MONTHLY CASH ASSISTANCE FOR THE CARE OF THEIR DEPENDENT CHILDREN

To receive a Caretaker Supplement, a parent must also receive an SSI cash payment. If a parent is temporarily removed from SSI, she or he will also not receive cash for their dependent children. The Wisconsin Council on Developmental Disabilities has heard from families who temporarily lost their SSI cash assistance due to an increase in income due to work or other reasons. For example, parents on SSI who are able to do limited work can lose their SSI in three-pay period months (compared to two-pay period months). One mother wrote that in December she lost both her SSI cash and her Caretaker Supplement because she was underpaid by \$5.00 a month for social security income from the death of her mother. By giving her a makeup check of \$55 in November, she became ineligible not only for the state portion of her SSI (\$83.78), but also her \$200 Caretaker Supplement payment.

The problem of parents temporarily losing their Caretaker Supplement highlights another problem. In 1996, Wisconsin SSI recipients lost eligibility for the state SSI supplement (\$83.78) if their income put them over the federal SSI limit (\$500 in 1999). They were made ineligible for a whole or partial state SSI payment that would have brought their income up to the 1999 state SSI income limit of \$583.78. When the Caretaker Supplement program was enacted, these parents were also ineligible for the Caretaker Supplement, greatly compounding the inequity.

The children in both these types of families need the financial assistance provided by the Caretaker Supplement program. This can be achieved by providing a Caretaker Supplement to all parents based upon their eligibility for SSI-related MA, rather than the receipt of SSI cash assistance. Parents would then not lose their eligibility for the Caretaker Supplement benefit if they were either ineligible for SSI because of the 1996 law, or were temporarily ineligible for SSI because of an extra income month.

## 6. USE 100% TANF (TEMPORARY AID TO NEEDY FAMILIES) DOLLARS TO PAY FOR THE CARETAKER SUPPLEMENT

The Caretaker Supplement is currently funded from a combination of TANF dollars and state GPR, the latter to meet the SSI maintenance of effort (MOE) requirement. But SSI funds are intended for people with disabilities and the elderly, not their non-disabled children. Furthermore, the state has a huge surplus of TANF funds, a portion of which could be used to fund the caretaker supplement.

SSI recipients have not received an increase in the state SSI benefit (\$83.78 for an individual) since 1996, while the federal SSI benefit has increased by a small cost of living adjustment (COLA) each year. That means that SSI recipients have seen their living standard sink further and further below the federal poverty level. (SSI for one adult is \$583.78 compared to a poverty level of \$670.83.)

Using TANF money to fund the Caretaker Supplement would mean that the state's MOE money would be available to increase support for the state's elderly and disabled population. It is our understanding that Wisconsin is the only state using state SSI dollars to provide for the children of SSI parents instead of TANF dollars.

For more information, contact Caroline Hoffman ([hoffmcp@dhfs.state.wi.us](mailto:hoffmcp@dhfs.state.wi.us)) or Jennifer Ondrejka ([ondrejkm@dhfs.state.wi.us](mailto:ondrejkm@dhfs.state.wi.us)) at the Wisconsin Council on Developmental Disabilities, (608) 266-7826, (608) 267-3906 FAX.

## Member agencies of the SSI Parents Coalition:

(Steering Committee Members are in bold type)

March 9, 1999

Access to Independence-Deaf and Hard of Hearing Services  
Alliance for Deaf, Deaf-Blind & Hard of Hearing  
American Lung Association  
Appleton Housing Authority, Homeowner Program  
**The ARC-Wisconsin**  
**Arthritis Foundation-Wisconsin Chapter**  
Association of Women's Health, Obstetric and Neonatal Nurses (AWHONN)  
Autism Society of Wisconsin  
Brain Injury Association of Wisconsin  
Children's Health Alliance of Wisconsin  
Client Assistance Program  
**Coalition of Wisconsin Aging Groups**  
**Community Action Coalition**  
Dane County Human Services  
Easter Seals-Milwaukee County  
Easter Seals-Wisconsin  
Family Resource Center, Prairie du Chien  
**Hunger Task Force of Milwaukee**  
Independence First  
Lakeshore CAP  
League of Women Voters of Wisconsin  
**Lutheran Office for Public Policy in Wisconsin**  
**Madison Urban Ministry**  
National Alliance for the Mentally Ill-Wisconsin (NAMI-WI)  
National Association of Social Workers-Wisconsin  
National Multiple Sclerosis Society-WI Chapter  
National Spinal Cord Injury Association-Madison Chapter  
Parent Education Project of Wisconsin  
Rehabilitation for Wisconsin  
**State Independent Living Council**  
State Rehabilitation Council  
Supported Parenting Projects-UW-Madison Extension  
United Cerebral Palsy of North Central Wisconsin  
**United Cerebral Palsy of Southeastern Wisconsin**  
United Cerebral Palsy of West Central Wisconsin  
**United Cerebral Palsy of Wisconsin**  
United Methodist Church, Wisconsin Conference, Board of Church and Society  
West Central Wisconsin Community Action Agency  
Wisconsin Coalition for Advocacy  
**Wisconsin Coalition of Independent Living Centers**  
**Wisconsin Committee to Prevent Child Abuse**  
Wisconsin Community Action Program Association  
**Wisconsin Council on Children and Families**  
**Wisconsin Council on Developmental Disabilities**  
Wisconsin Council for Persons with Physical Disabilities  
Wisconsin Facets, Inc  
Wisconsin Interfaith IMPACT  
Wisconsin Intergenerational Network  
Wisconsin Rehabilitation Association



Senators Briske  
Moyn.  
Drzewiecki  
Leg. Council Reps.

Glenn Copies

## SENATE COMMITTEE ON HEALTH

### BUDGET HEARING MARCH 9, 1999

### TESTIMONIAL

**Ladies and Gentleman, my name is Glenn Lamping. I'm the Executive Director for United Cerebral Palsy of North Central Wisconsin.**

**Our mission is to advance the independence, productivity, and full citizenship of children and adults with disabilities.**

**UCP of North Central Wisconsin directly serves over 220 children and adults with disabilities in a nine county area.**

***Marathon, Lincoln, Langlade, Oneida, Vilas, Taylor, Clark, Wood and Portage Counties.***

**For several years state officials, legislators and our Governor have been talking about:**

**CONSUMER CHOICE;  
REVERSING INSTITUTIONAL BIAS;  
LETTING THE MONEY FOLLOW THE PERSON;  
PEOPLE'S RIGHTS TO LIVE IN THEIR OWN HOMES;**

**WE WOULD LIKE TO SEE THIS STATE'S BUDGET FINALLY MAKE GOOD ON THESE PROMISES.**

**On behalf of our agency and people with disabilities, we have several concerns about the biennial budget request as we move into the new millennium:**

**IN GENERAL, we feel the budget MUST ADDRESS these principles**

- 1) Wisconsin must deal with waiting lists**
  - Funding for new placements in the Community Options Program**

**(COP) is FROZEN, causing the waiting list to GROW.**

- **Some of our families have been told they are on a 3-9 year waiting list for assistance. What are these families to do!! Their children need to be home and remain in the community.**
- **Several other states have recently invested several funds in “END WAITING LISTS” legislation.**

**2) We can't let anymore community provider agencies go under as a result of inadequate rates.**

- **MEDICAID PERSONAL CARE - After a combined total of 45 cents/hour during the last 9 years, and some personal care agencies going under during that time, the Governor proposes NO RATE INCREASE IN YEAR 1 OR IN YEAR 2.**
- **We support Marathon and Kenosha Counties efforts that brought forward to the state legislature a Resolution to support legislation to increase Medical Care Personal Care Rates by \$4/per hour. This legislation can be evaluated on the recruitment and retention of these Personal Care Workers.**

**3) All disability programs should feature CONTROL, CHOICE, AND FLEXIBILITY for consumers and families.**

**4) There should be NO SPECIAL TREATMENT for nursing homes or the continual support for institutional bias.**

- **No increases disproportional to what community services receive.**
- **Funding for individuals to move from the State Centers for the DD to community settings is FROZEN. This will result in few, if any, individuals leaving the State Centers during the next two years.**

**5) Funding for school districts to provide special education services to students is FROZEN, placing increased financial burden upon school districts to adequately serve students with disabilities.**

**6) ONE IMPORTANT AREA OVERLOOKED IN THE GOVERNOR'S BUDGET is appropriation of funds families for respite care.**

- **There will be legislation brought forward soon in both the ASSEMBLY AND THE SENATE known as the Lifespan Care Bill.**

**Representative Bonnie Ladwig ®  
State Senator Judy Robeson (D)**

- **SHARE STORY**
- **Respite care for all Wisconsin families regardless of age, disability, geographic location, or income is critical. This legislation will provide \$450,000 in funding giving families easy access to an array of flexible, affordable quality respite care service**

**WE RECENTLY CIRCULATED a petition to our families who all support Lifespan Respite Care which I'd like to present to you at this time.**

**In summary, all the funding sources FOR PEOPLE WITH DISABILITIES (CIP, COP, CIP 1A, FAMILY SUPPORT, SSI) Enable our families to keep their child or adult child in the community. For the past decade under the current Governor's Administration, Wisconsin has prided itself as a LEADER FOR THE NATION to follow. IT IS TIME FOR THIS STATE TO RECOGNIZE IT IS NOT A LEADER IN THE AREA OF ADDRESSING THE NEEDS OF PEOPLE WITH DISABILITIES.**

**TODAY, we have that opportunity to change all that. THANK YOU !**

Funding sources such as:  
COP, CIP, IA, Family Support, SSI, etc. -  
enable families to keep their children in the  
community to assist w/ supportive home care,  
respite care, adaptive equipment etc.

Without these funding sources - parents do not  
always have the finances to provide these  
services for their child(s). These services are  
critical for the <sup>child's</sup> well-being - development -  
& for the entire family. However - these services  
can be costly - financially draining.

Waiting lists - Some of our families have been  
told that they have/are on a 3-9 yr. waiting list  
for assistance. What are these families supposed  
to do?!! Their children still require care! &  
need to be home - a part (member) of the the  
communities. OVER  
→

# TRUE STORY

We had a ~~one~~ single mother who had 3 children. One of her children had Letts syndrome - she required total care.

Mom was an R.N. - but couldn't afford to work in order for her to pay for someone (qualified) to care for her daughter. Mom also was unable to keep her job because she was needed at home so much.

Mom got connected w/~~one~~ a respite provider & some funding to pay for the care. It wasn't enough. Mom could not afford to take care of her children (didn't qualify for W2). The county would pay for her daughter to live in a group home (approx. \$65,000.00 year).

But would not help pay for mom to stay at home w/ her daughter (or pay for enough childcare) respite costs approx. \$500. yr. (2 wknds per month) 1/3 of the \$65,000 would've been enough to live on! Mom felt that she had no other choice but to place her child in a group home. She had 2 other children to think about also.

It's unfortunate that this mother was forced to make this decision.

**LIFESPAN RESPITE CARE IS.....**

Respite care for all Wisconsin Families regardless of age, disability, geographic location, or income. Families will have easy access to any array of flexible, affordable, quality respite care services that are culturally competent, and individualized according to their needs, strengths and preferences.

**We the undersigned, support the Lifespan Respite Care Bill**

Name/ Address	Phone	Signature
Kirsten Lehman 2315 Gowen Street WAUSAU, WISC. 54403	842-8700	Kirsten Lehman
RICH LEHMAN JR 2315 GOWEN ST WAUSAU WI 54403	848-0809	Richard Lehman
Emily Lawrence 2120 Hwy 4, Wausau, Wis - 54401	675-3931	Emily Lawrence
Don Hoefs, 3850 Weston Pines TERRI KOCH 617 S. 3rd Ave. Wausau WI 54401	7101 355-5300 54476	Don. Hoefs
Phyllis Fay Campbell Collins 6411 Volkmann Weston, WI 54476	1100 Grand Ave, Schofield WI 54476	Phyllis Campbell Collins
Glenn Lampy 6411 Volkmann Weston, WI 54476	715-887-2966	Glenn Lampy
Susan Warren (715) 355-6818	715-241-4682	Susan Warren
Kathleen Buehler 5507 Country Ln Wausau WI 54403		Kathleen Buehler
Laura Williams 1231 W 1st AVE WAUSAU WI 54403	875-1386	Laura Williams
LISA Ammon 1812 N. 3rd ST / Wausau, WI 54403	849-8166	Lisa Ammon
Penny Mallett 1209 Pinecrest Ave Mesinee	693-0745	Penny Mallett







715 848 3511

UCP WAUSAU

002

**LIFESPAN RESPITE CARE IS.....**

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**We the undersigned, support the Lifespan Respite Care Bill**

Name/ Address	Phone	Signature
Ram T. Conside 6211 North Park Rd Wis. Rapids WI 5611 W. P. 2nd St	715-423-1782	Pamela Johnson
Betty Chipman Wi Rapids Wi 5611 Wagoner	715-423-1168	Betty Chipman
Gerald Chipman Wi Rapids 140 N 12th	715-423-1168	Gerald Chipman
Paul Chipman Clintonville WI 140 W 12th	715-823-344	Paul Chipman
Ben Chipman Clintonville WI	715-823-3441	Benjamin Chipman
Carolyn R. Saylor 610 Witten St. Wis. Rapids WI 54494	715-423-2084	Carolyn Saylor
Jeggy Lobue 340 20th Ave S. WIS RAPIDS WI 54495	715-423-8553	Jeggy Lobue
Lisa Sanger 3311 88th St S Wis. Rapids WI 54494	715-423-1729	Lisa Sanger
Carla Kniech Wi Rapids, WI 54494	715-423-9279	Carla Kniech

715 848 3511

UCP WAUSAU

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**We the undersigned, support the Lifespan Respite Care Bill**

Name/ Address	Phone	Signature
Mark Conroy	424-5517	Mark Conroy
Sherry J. Engelke	424-5517	Sherry J. Engelke
Kand A. Storer	421-0620	Kand A. Storer
RICHARD O ARNDT 2751 8TH ST. 50	423-1664	Richard O. Arndt
Kelli Krieger 5631 Wmzecha Ave	421-0620	Kelli Krieger
HELED BRAHMSTEAD 541 W. RUBY AVE	421-4083	Helen Brahmstead
Donna Mattero 2210 Lake Ave Wis. Rep. Jc W.		Donna Mattero
Ira M. Stala 521-2nd St. Apt. 109		Ira M. Stala
Raymond R. Anderson 550 Via. St.		Raymond Anderson
Judy Fawcett 6121 Norway Cir WRW	54495	Judy Fawcett
Lorraine Doster 4805 Ramsey, W.P.U.		Lorraine Doster
Donna Hanneman 3121 Wildewood Dr. W.R.		Donna Hanneman
Tori Hanneman 3121 Wildewood Dr.	424-2304	Tori Hanneman
Gracie Habeck 1440 Wisconsin St		Gracie Habeck
Carla Hill 620 13th Ave. N		Carla Hill

Joanie Mueller 1311 Airport one near Rapids Wis  
 Gillian Warner 136 Crestview Nelson, WI. 886-3979  
 Lela Warner

715 848 3511

UCP WAUSAU

002

**LIFESPAN RESPITE CARE IS.....**

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**We the undersigned, support the Lifespan Respite Care Bill**

Name/ Address	Phone	Signature
Judy Warnke 321 Cranmour Rd. N.E.K. WI.	886-5578	Judy Warnke
Ruth Porter 2550 Linn St.	471-0991	Ruth Porter
Vanetta Krueger 350 10th Ave W. Rapids	424-3377	Vanetta Krueger
Paula Kautonen 2511 Two Mile Ave. W. Rapids		Paula Kautonen
Andelle Osterbank 341 Grand Ave. W. Rapids		Andelle Osterbank
Dolores Simonds 111 Gardner SE W. Rapids, WI		Dolores Simonds
Ursian LaBuer 240-16th Ave N. W. Rapids	715 54495	Ursian LaBuer
Angelina Paraguly 331-15th Ave N. W. Wisconsin	54495	Angelina Paraguly
Konnie Schmidt 300 12th Ave S. W. Rapids WI	54495	Konnie Schmidt
LORRAINE-SCHULTZ - 1011-AIRPORT-AVE		Lorraine Schultz
Lucille Chapman 1231 South River Dr		Lucille Chapman
Linda Hancock 1241 Airport Ave W.R.	424-2175	Linda Hancock
Kathy Weesley 7121 Wazeeck Ave. W. Rapids		Kathy Weesley
Melvin Morzeval 4610 82nd St S. W. Rapids		Melvin Morzeval
Edna Morrison 8040 S. 1st Ave W. Rapids		Edna Morrison
Midge Bauer 325-5831 W.R.		Midge Bauer
Mary Hetzliff 2831 64th St S. W.R.		Mary Hetzliff
Herbert L. Seiny 1690-3rd Ave S. W. Rapids	102	Herbert L. Seiny

**LIFESPAN RESPITE CARE IS.....**

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**We the undersigned, support the Lifespan Respite Care Bill**

Name/ Address	Phone	Signature
Keith Drabheim 920 W. Campus Dr. Wausau	715-675-9699	Keith Drabheim
Greg Van Slyke 2156 Kowalski Rd. Mosinee	715-359-8171	Greg Van Slyke
Amanda Beese 205 Chicago Ave	715-849-4144	Amanda Beese
Jodi Krauser 613 S. 4th Ave. Wausau	715-849-4177	Jodi Krauser
Bridget Neumann 106 1/2 Everest Ave. Brookaw	715-678-2577	Bridget Neumann
Susan Eckes W19089 St. Hwy. 153 Wittenberg	(715) 253-3025	Susan Eckes
GEORGE H BLENKER 119 FREEMAN RICE LAKE	N4781 City Hwy W.	George H Blenker
Sue Beckett P.O. Box 1114, Brunauville	N4781 City Hwy W.	Sue Beckett
DOUGLAS HOSLER 1717 N. 13th St. Wausau		Doug Hosler
JEFF SCHILLINGER 3314 CARTER AVE. SCHOFIELD, WI	359-7451	Jeff Schillinger
Jill Lloyd 1864 Plantation Ln Mosinee, WI	355-3067	Jill Lloyd
Tony Hix 311 Quaker Ave., Edgar, WI	54426	Tony Hix

**TESTIMONY FOR THE SENATE COMMITTEE ON  
HEALTH, UTILITIES, VETERANS AND MILITARY AFFAIRS  
NORTH CENTRAL TECHNICAL COLLEGE, WAUSAU, WI  
MARCH 9, 1999**

My name is Harry Pokorny. I am the President of the Portage County Coalition of Aging Groups; a member of the District 7 Coalition of Wisconsin Aging Groups Executive Board; and an Alternate to the Governing Board of the Coalition of Wisconsin Aging Groups.

I should like to bring to the attention of this Committee a number of concerns that the elderly and disabled of Portage County and other counties have concerning the Governor's proposed 2000-2001 State Budget in the area of long-term health care.

The major Department of Health and Family Services initiative is "Family Care", a proposed redesign of Wisconsin's long-term care programs. The Governor proposes funding for 13 counties and 1 tribe to pilot long-term care redesign. This biennium, Portage County has been a pilot, providing an Aging and Disability Resource Center (that is, a single entry point or one-stop shopping), and a Care Management Organization. Our concern is that this pilot program will not be refunded as a part of the overall Budget Bill, but will be pulled out to be taken up separately. If this happens, it is entirely possible that the present funding will stop on June 30<sup>th</sup> of this year. The program would be put into limbo until a special bill is passed to resume the funding. It would be tragic if this were to happen. We need this funding to be continuous and to increase in the next biennium. We need a redesign because the present system of long-term care does not work for older people and the disabled because it is biased against helping people stay in their own homes.

The elderly and disabled also are very concerned about the Community Options Program. The Governor, in his proposed budget, did not increase the number of people to be served in this program. In Portage county, we have over 40 people on a waiting list, waiting for help so that they can stay in their own homes, instead of being institutionalized. It means a two year wait. There are over 9,000 elderly and disabled people in Wisconsin who are on a waiting list. In 63 counties, there is almost no hope because the wait is 3 or more years. My sister, who has cerebral palsy, lives in Milwaukee County. She waited over 5 years to get into the COP program. She, like the others on a waiting list, could have gone into a nursing home or a group home at any time, but she wanted to live alone in her own apartment. Therefore, she struggled for over 5 years to cope, while waiting for the help she needed.

The elderly and disabled who need some help to live alone, have three choices: wait up to 5 years or more years for the care they need; be institutionalized; or die. There is a need for institutional care, but someone with a little help to live alone, should not be forced into that setting. Not every one wants to go into a nursing

home. The State of Wisconsin spends over \$100 million a year in various programs designed to keep people in their homes, but then denies them the care to keep them there.

The whole waiting list of the elderly and disabled could be eliminated for \$45 million over the biennium. This amount would be matched by over \$65 million in federal funds under the COP waiver programs. This money, while a significant investment, is only 13% of the tobacco settlement money. Other states are proposing to do this with some of the tobacco money they are receiving. For instance, the Governor of Florida is proposing to create an endowment to support programs for children and elderly, including \$16.4 million "to eliminate a waiting list of people seeking care at home instead of nursing homes".

With Badger Care and other initiatives in the budget for children, Wisconsin could rival Florida in intergenerational caring if long-term care programs were fully funded.

Thank you.

**Testimony of Community Health Care, Inc.**

**Before The Wisconsin State Senate  
Committee on Health, Utilities, Veterans and Military Affairs**

**Wausau Wisconsin  
Tuesday March 9, 1999**

My name is Ann Bolz. I am the Director of Government and Community Relations for Community Health Care, Inc, an integrated health care delivery system based in Wausau. Our system serves communities and patients throughout a 14 county region of Northern and Central Wisconsin by providing in patient hospital services, home health, nursing home, primary and specialty physician services and durable medical equipment. Through our network of clinics, home health agencies, hospitals and nursing home, our 2200 employees meet the health-related needs of the residents of the area.

The Governor's biennial budget proposal has many elements that will effect how we provide health services to our constituents, and the ability of the people in our area to access health care. While some of the proposals enable a broadening of access, such as the proposed Badger Care expansion and additional funding for MA rates for Dental access, other elements in the budget will serve to restrict our ability to respond to our communities health needs in a fiscally responsible manner. I'd like to highlight a few of these issues today.

**Graduate Medical Education Funding**

The proposed budget will reduce the funding needed to support medical residency programs by \$3.6 million in Federal funds and \$2.5 million in state funds. In Wausau we are fortunate to have a University of Wisconsin Family Practice residency training site. This residency site graduates 6 family practice physicians per year, which over half remain in practice within over 100 miles of Wausau. These residents typically establish practices in smaller communities of northern and central Wisconsin. Without the residency to attract them we doubt we would be able to attract them to the area as practicing physicians, and thus would dramatically diminish the ability of patients to access family practice medicine within their local communities.

The State of Wisconsin has taken a leadership position in the training and placement of physicians in underserved areas of the State through specialized loan programs and placement activities. Reduction in training dollars for these physicians diminishes the strides Wisconsin has made in improving access to physician care for all areas of the State. We urge you to restore this vital funding.

## **Medicaid Rate Freezes**

The Governor proposes a two year freeze in the Medicaid rate for inpatient hospital services and a 1% increase in the outpatient rate over the two year period. While we are experiencing a shift in treatment from inpatient hospital stays to out patient treatments throughout the State, and nationally, what we are not experiencing at the same time is a freeze from the effects of health care inflation on the same services. The reality of such a freeze and not recognizing health care inflation is for providers to shift the cost of unreimbursed services to the private sector, and those who are privately insured.

With the reduction of those receiving services from Medicaid as a result of the W -2 program, we find many of the individuals who are still eligible and receiving Medicaid to be frail elderly, and disabled individuals. These individuals often present with complicated and/or multiple conditions and are, in fact, more costly to treat than the Medicaid population of ten years ago. Thus, to freeze the Medicaid rate at a time that inflation is low and the cost per treatment reflects a higher acuity, results in a larger cost shift to the private sector. At a minimum, we ask you to restore funding which reflects an increase comparable to inflation.

## **Background Checks**

The Governor's budget creates an opportunity for the legislature to revisit the Background Check statute passed last year. As you know, the emergency rule proposed has been revised and is still under development and consideration by the department and the legislature. We ask you to review both the rule and the original legislation thoroughly and determine the best course change to assure that patients are protected, and that individuals are allowed to seek employment in the health care sector. We firmly believe every patient has a right to expect to be treated with dignity, respect and in a safe manner when in our care. We also see as our responsibility, as an employer to assure our employees meet this standard. We look forward to meaningful amendments to both the law and the subsequent regulations that provide responsible application of the law to meet the law objective.

## **Conclusion**

We appreciate this opportunity to present our initial statement on the biennial budget. While there are many other areas concerning the provision of health services contained in the budget, we have focused on these issues for this time. We share the state's commitment to assuring the health of the population we serve in a fiscally sound and efficient manner. We are concerned that as both the Federal and State government continue to meet budget objectives by shifting dollars spent on health care to meet other government priorities, the result is increasing cost pressure on providers and the private sector. We are committed to working with the State to assure the State health policy objective of access to quality health care is met maximizing available Federal matching dollars with State dollars.



**My name is Mary Ellen Schreiber. My office is at 1010 East Wausau Avenue, Wausau, Wisconsin 54401. I have worked in Health Care my entire professional career. I have been a staff nurse as well as a Staff Development Coordinator and for the past 13 years; I have been the Director of Nursing of Colonial Manor Medical & Rehab Center, Wausau, Wisconsin. I thank you for the opportunity to testify today. I would offer testimony regarding two areas.**

### **Family Care**

**For as much as many people want to find an alternative to inpatient nursing home care, it is necessary that the Family Care pilots are allowed to function for a significant period of time and a thorough analysis is completed before we forge ahead. Cost is always a factor in health care, but accurate cost facts are not available for analysis. This must be completed before we proceed statewide. We have in place a system that provides exceptional care to the frail elderly. It is unacceptable to legislate its replacement until an analysis is completed. With analysis, modifications are always seen. This too supports the necessity for a minimum trial period of at least 24 months and then the thorough analysis. Now is not the time to vote this plan into effect without even considering the pilot information.**

### **Wage Pass-through for Nursing Home Employees**

**It is known that the State of Wisconsin has very low unemployment. I am here today to offer my support for the Coalition for Quality Nursing Home Care by asking for the legislature support for a 7% nursing home employee wage pass-through. What has been proposed by a 1% increase falls far short of what is needed. By the State's own forecasting a 3.3% inflation is expected in health care costs. This 3.3% should be made available for Medicaid rate increases in every year of this biennium as well. The greater Wisconsin Community expects perfection in health care. In addition, perfection should be delivered. Perfection will come when we employ the best and are able to pay them a fair wage. It is not possible to continue to expect the best care when employees in many jobs that do not require the ability and endurance of a nursing home employee are paid much more. The elderly rely on the Medicaid system for health care funding. This program must be able to fund what it expects.**

**Thank you .**



COMMUNITY HEALTH CARE

# VNA Home Health

*Keeping Local Health Care Strong*

Dear Senator;

Thank you for allowing me to address this Committee today. I am here to express a serious concern regarding the crisis situation with Personal Care Worker services. Personal Care Workers (PCW) provide basic assistance with activities of daily living. Basic PCW services include bathing, dressing, eating and toileting activities. Without these services, frail elderly and disabled clients face quality of life concerns, severe safety risks and possible need for institutionalization.

PCW service is in need of help from the state to remain an option for people who need this basic level of care. In light of the "Family Care" initiative, we must act today to strengthen this important supportive service. Presently, Medical Assistance reimburses PCW at a rate of \$11.50 per hour. This is simply not enough to provide competitive wages and benefits in order to maintain a reliable staff. Record low unemployment in Wisconsin and throughout the U.S. has made compensation a key issue in attracting an entry-level workforce. The VNA currently experiences the following costs per hour of Personal Care Worker Services:

	<u>Average Cost Per Hour</u>	
Average wage per hour	8.67	
Vacation, Sick, etc.	0.87	
Health, LTD, Life Insurance	3.27	(Family coverage, non-smoking)
Retirement	0.17	
Taxes	0.66	
Unemployment/WC	0.26	
Transportation @ .315/mile	<u>0.96</u>	
	<b>\$14.86</b>	Reimbursement \$11.50 Shortfall (\$3.36)

With the MA reimbursement rate of \$11.50, VNA subsidizes \$3.36 per hour for every hour of services provided. In many of the 15 counties we serve, the VNA is the only remaining provider of PCW services. In light of recent dramatic Federal Reimbursement cuts, we have been forced to limit access to PCW service for new clients and substantially manage down the number of hours being offered to our clients.

Among Wisconsin home health agencies surveyed by the Wisconsin Homecare Organization in 1997, the average cost of providing PCW services was \$16.40 per hour. Data gathered by the Wisconsin Bureau of Health Care Finance demonstrates that Wisconsin has the lowest payment rate for these services among neighboring states.

**Also sponsored by:**

Good Samaritan Health Center, Merrill • Langlade Memorial Hospital, Antigo • Memorial Hospital of Taylor County, Medford  
520 North 32nd Avenue • Wausau, WI 54401 • 1-800-600-8296 • 715/847-2600 • FAX: 715/847-2606

Personal Care Worker Services  
March 8, 1999  
Page 2

The VNA has also found that the work force has shifted over the past five years. In the past, many part time workers, with another family member bringing home the core income, would work as a personal care worker in order to gain extra spending money. We find an increasing number of applicants are single parents who must have a living wage and a basic benefits provided. Without the benefits, and on low wages, the Medical Assistance current PCW reimbursement in fact contributes to the creation to Medicaid recipients in the workplace.

A further contribution to wage costs is the lack of PCW trained people. When the program first began in the late 1980's, individuals would sign up for the 40 hour required training course. Today, we find that people are not selecting PCW training and unless you have inhouse training, the Technical College courses are no longer offered.

Instead, individuals are opting to be trained as Certified Nursing Assistants (CNA's). After receiving 120 hours of training, this certification allows individuals to work in a variety of settings (hospitals, nursing homes, assisted living facilities) at a higher rate of pay (\$8.00 to \$10.00 per hour). PCW care is only recognized in the home care setting, offers little job mobility and is much lower paying. As a result, we now find that we must staff PCW care with CNA's. This staff has a higher wage.

As you research this issue, you may wish to speak with the adult supervisors at the County Department of Social Services. Area heads of Commissions On Aging will also share with you their frustration and concern in finding certified caring people to care for needy frail elderly and disabled clients. Attached you will find a list of individuals you may wish to speak with (see Attachment II).

In light of the State of Wisconsin's commitment to maintaining frail elderly and disabled individuals in their homes and the need for the State of Wisconsin to adequately and fairly reimburse services which it requires to be offered, I respectfully request consideration of a minimum of a \$4.00 to \$6.50 increase per hour in the Personal Care Worker services reimbursement rate.

Thank you for your time in allowing these concerns to be heard. Your support on this issue is appreciated and we look forward to continuing to make this service successful and available to long term care recipients throughout North and Central Wisconsin.

Sincerely,



Cathleen M. Rohling  
VNA Executive Director

**State of Wisconsin lowest PCW payment of surrounding states**

State 1997	Illinois (limited)	Indiana (waiver only)	Michigan	Minnesota	Ohio	Wisconsin
PC rate	\$41.45/visit	\$14.70/hr	\$12 –13/hr	\$12.36/hr	\$12.68/hr	\$11.05/hr

Source: WI Bureau Health Care Finance  
Shelia Chaffee (608) 267-9697

**PCW Reimbursement Rate Paid By the Wisconsin  
MA PCW Program To Providers Since It's Inception**

July 1, 1998	\$9.00 Per Hr. PCW	\$38.72/Supervisory Visit
July 1, 1989	\$9.33 Per Hr. PCW (4% increase from 1988)	\$38.72/ Supervisory Visit
July 1, 1990	\$11.05 Per Hr. PCW (18% increase from 1989)	\$38.72/ Supervisory Visit
July 1, 1997	\$11.27 Per Hr. PCW (2% increase from 1990)	\$39.49/ Supervisory Visit
July 1, 1998	\$11.50 Per Hr. PCW (2% increase from 1997)	\$40.28/ Supervisory Visit

**Resource/Contact List**

**Attachment II**

**Marathon County**

Mr. Larry Hagar, Director Social Services – 715-261-7500

Ms. Deb Menacher, Director Commission on Aging – 715-261-6070

**Lincoln County**

Ms. Donna Simek, Director Adult Services – 715-536-6200

**Taylor County**

Mr. Russ Blennert, Director, Adult Services – 715-748-3332

**Portage County**

Mr. Jim Canales, Director Adult Services – 715-345-5800

**Langlade County**

Mr. Jim Meisinger, Director Social Services – 715-627-4750

**Wisconsin Home Care Organization**

Mr. Russ King, Executive Director 608-278-1115

**United Cerebral Palsy**

Mr. Glen Lamping – 715-842-8700 ext. 308

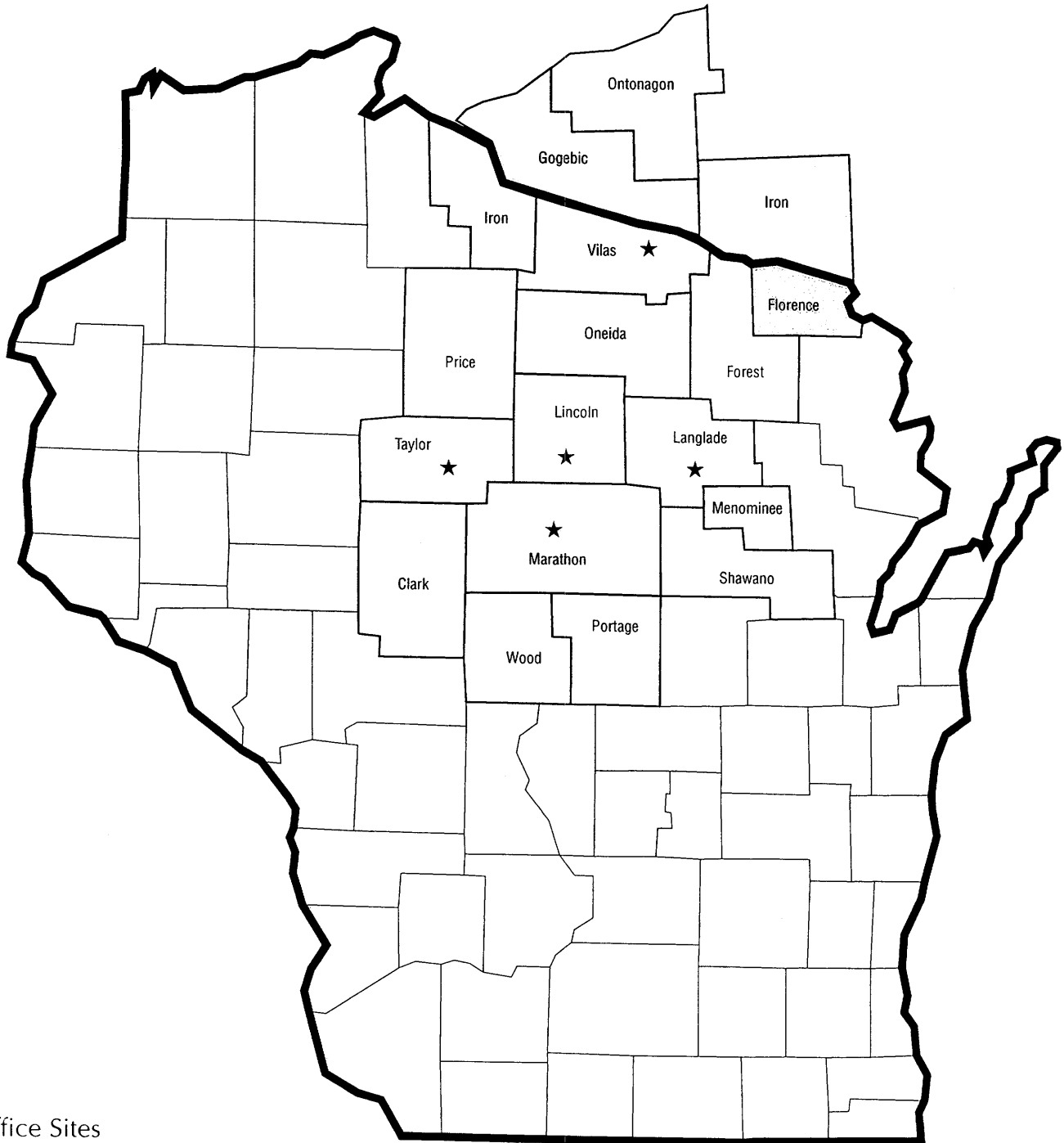
**Bureau Health Finance Administration**

Mr. Jim Johnston – 608-267-9474

**Bureau of Aging and Long Term Support**

Ms. Sharon Beall, Nurse Consultant – 608-267-9583

# VNA Home Health INC.



★ Office Sites

## VNA Home Health Service Area

- 1) You indicated in your January 11, 1999 letter to the Governor that it would "seem prudent to use the pilot approach to Family Care at this time." Yet this budget contains language which would permit the Family Care pilots to operate concurrently with statewide implementation of the program. Why place this proposal in statute if you don't even know if Family Care will work as intended? Why implement the program before the pilots have concluded and there has been an opportunity to analyze the data collected by the pilots? If you don't need to analyze that data, why pilot at all?
- 2) Would you oppose removing the Family Care proposal from statute and placing it in the budget as a nonstatutory provision, leaving the appropriation but applying the Family Care provisions only to the pilots?
- 3) How long do you believe the pilots should operate before they will have provided you with the data you need to confirm that the program works?
- 4) You were quoted as saying (1/12/99 Milwaukee Journal Sentinel) that there has to be some support for a statewide implementation with the folks that you deal with in Family Care in order for you to suggest that somehow the Legislature can pass something. In that same article, you stated that at that time, nobody was supporting statewide implementation. Has that changed? Is anyone now supporting statewide implementation of this proposal? \_\_\_\_\_ Providers \_\_\_\_\_ Advocates of the developmentally disabled \_\_\_\_\_ Elderly advocates \_\_\_\_\_ Counties. If the support of the stakeholders is not there for statewide implementation, why pursue it in statute? Why not use the pilots to prove the program works and then place it in statute for statewide implementation, with any modifications you might add or delete based on the findings from the pilots?
- 5) Do you truly believe that if the pilots prove that Family Care works and our constituents like it that the will of the Legislature upon the conclusion of the pilots will be to ignore those constituents? Do you truly believe the only way to go forward with Family Care is to put it in the statutes today, even if the pilots bear out your contention the program works and people like it?
- 6) What if the pilots prove Family Care doesn't work as intended, that your cost assumptions are significantly off the mark? By placing Family Care in the statutes with an implementation date of July 1, 2001, aren't you making a commitment to elderly and disabled people that this program will be available to them at that date? Is it responsible to make such a commitment without knowing if the program works?
- 7) If the proposal were to remain in the budget as statutory language but were amended to apply only to the pilots, with the statewide implementation date deleted, would you commit to recommending to the Governor that he not veto that language? If you did, do you think he'd follow your recommendation?
- 8) What constituencies support, or even prefer, the HMO risk-based model, utilizing state-set capitation rates, that is being proposed as Family Care? Do you think that those constituencies which support the concept of a care management organization might change that support if they became aware that the CMO is really a HMO?

- 9) This budget appropriates \$11.4 million to operate the pilots in this biennium. Yet by placing Family Care in statute and establishing a 7/1/01 implementation date, aren't you asking the next Legislature either to pay for a commitment they didn't make or to take the political heat for modifying or pulling the plug on a program they didn't adopt?
- 10) Are the current pilot counties conducting functional and financial screens on all prospective admissions to the long-term care system? If not, will they and by when? Has the DHFS established the capitation rates for the Family Care benefit? If not, when will those rates be set and be available for the CMOs to provide services? The Resource Center pilots began July 1, 1998; the CMO pilots began 1/1/99. What have you learned from those pilots to date?
- 11) What is the status of the federal waivers from the Health Care Financing Administration that will be necessary to implement Family Care? More specifically, has HCFA accepted the concept of the Family Care District, which is created in this budget, to allay its concerns with the potential conflict of interest with a county serving as both the capitated rate-setting Resource Center and the capitated rate-receiving CMO?
- 12) You stated in a 2/22/99 "Dear Colleague" letter to Family Care stakeholders that the budget bill "does not commit the Department to implement the system statewide by a certain date." However, the budget bill also states, under s.46.281(1)(e), the DHFS "shall contract" with one or more entities after 6/30/01 for services of the entity as a resource center and/or a CMO. Is your intent to begin statewide implementation 7/1/01? What information will you need before you finally decide whether to move forward? Should the Legislature be saddled with such uncertainty?
- 13) In that same 2/22/99 "Dear Colleague" letter, you provided the following rationale for why Family Care must be in statutory language:

"To test and perfect a truly reformed system, we must have statutory language in place to allow new ways of providing the supports that people need. One crucial part of the proposed new system is the flexible new Family Care benefit, which is an entitlement to those with the highest needs."

- A) The 9 Resource Center pilots and 5 CMO pilots which were established under 1997 Act 237 were in nonstatutory language. Why was that acceptable but an expansion of the pilots is not?
- B) You talk about "new ways" of providing supports and the "flexible new Family Care Benefit." But you are only proposing to pilot a HMO-risk-based-capitated-managed care model. Others have proposed a voucher system or an expansion of the Medicaid entitlement to the MA-waiver programs. Where is the "flexibility" in piloting only one model?

"People who join a Care Management Organization in the next two years must be assured of continuing to receive needed services if, for whatever reason, further implementation of Family Care does not go forward."

- A) Absolutely. But why place in statute the assurance that these needed services will continue to be provided through a program the Legislature decided didn't work? Assure the services but find a different vehicle than the untested Family Care program to provide that assurance.

"We must also have in place all components that will assure full federal financial participation for people who are Medicaid-eligible."



- A) Has the federal Health Care Financing Administration (HCFA) approved any of the waivers that will be needed to implement Family Care? By placing Family Care in statute before the waivers are approved, don't you run the risk of having just the opposite take place; namely, that full federal financial participation will be denied because some or all of the components of Family Care were unacceptable to HCFA?

“Finally, we need to test a system in which people get advice about their options at the point when critical decisions are being made about where to reside when services are needed, which means that requirements must be in place for facilities to refer people to Resource Centers. These kinds of provisions are not appropriate for non-statutory language.”

- A) As noted above, we currently are testing the Resource Center system in 9 pilot counties. The authority to do so is found in the non-statutory language contained in 1997 Act 237. Please explain this seeming inconsistency.



1805 Kensington Drive, Waukesha, Wisconsin 53188-5697 • Telephone (414) 548-5965 • Fax (414) 548-5981

March 19, 1999

MAR 22 1999

Senator Rodney Moen  
State Capitol Room 8-S  
P. O. Box 7882  
Madison, WI 53707-7882

Re: Family Care

Dear Senator Moen:

We are writing to you about an issue that is critically important to our company and the seniors we serve. The proposed Family Care Program included in the budget proposal contains sweeping and dangerous changes to the long-term care delivery system in Wisconsin.

Our Chairman, Larry Weiss, had the opportunity to testify before the Legislative Health Committee on Tuesday, March 18, 1998 concerning Family Care. There was remarkable agreement among those who spoke including providers, the Wisconsin Counties Association and a wide array of advocate groups. The consensus was that the Wisconsin's long-term care delivery and financing system need reform, but not the reform proposed in Family Care.

We have enclosed a copy of our position statement which recommends that Family Care be revised as follows:

- Remove Family Care from the budget and consider it in the appropriate legislative committee hearings where it can be subject to rigorous and focused debate.
- Pilot other options, including those suggested by the Wisconsin Counties Association.
- Reduce the Family Care pilots to a reasonable size and evaluate the results before creating sweeping new entitlements for vast numbers of seniors.
- Limit the Family Care entitlement to cost-effective options – if there is money left over after enrolling all eligible seniors, then more expensive options could be considered.
- Eliminate Family Care's bias against congregate living environments and the unrealistic provision that no senior will be required to live in a skilled nursing facility as a long-term residence.
- Eliminate the anti-competitive provisions relating to Case Management Organizations
  - Prohibit Case Management Organizations from owning or affiliating with providers.
  - Eliminate the power of private Case Management Organizations to unfairly and arbitrarily "limit profits."
  - Eliminate provisions allowing non-eligible seniors to buy-into case management services.

We would greatly appreciate the opportunity to discuss our concerns with you. Please contact me at (414) 548-5965. Thank you for your time and consideration.

Very truly yours,

Kevin R. Weiss  
CEO

The Arboretum • Brookfield Woods • Laurel Oaks • Layton Terrace • Library Square • Oak Hill Terrace  
Oak Hill Village • Omni Home Care • Omni Therapy • Park Point Manor • SevenOaks • Specialty Home Services  
Westmoreland Health Center • Wilkinson Woods

**THE LAUREATE GROUP**  
**POSITION STATEMENT ON**  
**FAMILY CARE**

The Laureate Group, Inc. is a family-owned, Wisconsin company with approximately 1,350 employees and 1,900 residents and clients. Since the 1960s, we have been developing and operating communities in Wisconsin providing the full range of long-term care services including skilled nursing, assisted living, independent living and home care. As a full continuum provider, we directly provide many of the services envisioned under Family Care. We have comprehensive experience with the current long-term care system and can offer unique insights into the issues raised by the proposed Family Care program.

Like DHFS, consumers, advocates and providers, we have been frustrated by the limitations of the current long-term care funding system in Wisconsin. We have supported DHFS efforts to consolidate state and federal funding streams and expand services available to seniors needing public assistance. We agree that the current funding system is inappropriately biased towards nursing home care. Unfortunately, Family Care is a misguided overreaction to these problems.

**THE FAMILY CARE “PILOTS” ARE FAR TOO LARGE - THE “PILOTS” CREATE AN EXPANDED AND PERMANENT ENTITLEMENT FOR 25% OF WISCONSIN SENIORS.**

We agree with the recommendations made by advocates and providers alike that the “pilots” are in reality just the first phase of statewide implementation and that the statutory language should be revised to prevent statewide implementation before a third-party review of the pilots. However, we believe that the “pilots” themselves need to be reviewed.

In our opinion, the Family Care “pilots” are far too large. Family Care provides for full implementation of the entire Family Care program in each of the “pilot” counties. These “pilots” will cover 25% of Wisconsin seniors including all seniors in Milwaukee County. Further, DHFS is authorized to create additional “pilots” without restriction. Family Care provides that those that qualify for Family Care are entitled to receive benefits. Anyone who receives benefits through the “pilot” programs will be entitled to retain those benefits even if the pilots are discontinued. Family Care also provides the “pilots” may be implemented even if DHFS is unable to obtain federal waivers to fund the program.

In short, Family Care creates an expanded and permanent entitlement covering 25% of Wisconsin Seniors. We believe that such a large-scale pilot program is ill advised. While DHFS no doubt believes Family Care will work -- what if it doesn't? How will Wisconsin fund senior services for the other 75% of the state if large cost-overruns occur in the pilot counties? Will Wisconsin be willing to cut the quality standards that have contributed to higher per capita nursing home costs? Will Wisconsin allow 3 and 4 residents per nursing home room like other states? Will Wisconsin be forced to adopt shared rooms in assisted living facilities? Family Care pilots should be limited to a reasonable number of seniors – just enough to prove whether or not it will work. Any larger than necessary and the pilots become high stakes gambling funded by Wisconsin taxpayers.

**DHFS HAS DRASTICALLY UNDERESTIMATED THE COST OF IMPLEMENTING THE NEW FAMILY CARE ENTITLEMENT.**

The comparatively broad functional screen in Family Care will entitle huge numbers of new seniors to aid (the so-called “woodwork effect”). Only a small fraction of the residents in our assisted and independent living communities receive public funding. Prior to moving into our

communities, however, most of our nearly 2,000 seniors received some type of financial or caregiver assistance. Many of our seniors continue to receive financial support from their families. Under Family Care, many of these seniors will be entitled to publicly funded support. Other seniors who are being cared for at home by family or friends will also be entitled to the benefit with family members entitled to compensation for caregiver assistance. There will be huge cost shifts from the private to the public sector, well above the minimal increases projected by DHFS.

Family Care also relies on the creation of “yet to be identified” alternatives to nursing home and congregate care. It further provides that no senior shall be required to live in a nursing home as a long term resident. While certainly a utopian goal, this goal ignores the reality of caring for extremely frail seniors, medically complex patients and those in the later stages of progressive diseases like Alzheimer’s. We operate a number of communities with specialized units for Alzheimer’s patients and extremely frail seniors. We have discovered that there are very real limits on the level of care that can be practically and cost-effectively provided in an assisted living setting. Family Care’s reliance on “yet to be identified” alternatives to congregate care is wishful thinking. Nursing homes and assisted living facilities are admittedly expensive, but they are also cost effective. The plain and simple fact is that congregate settings provide the most cost effective environment for the frail and compromised seniors who will be entitled to Family Care benefits. Home care and other alternative settings, in contrast, are only cost effective where seniors require relatively infrequent and scheduled assistance.

Family Care also creates a myriad of new or expanded consumer-dominated bureaucracies including Long Term Care Councils, Long Term Care Support Planning Committees, Family Care Districts, Resource Centers and Case Management Organizations. While operation of these new bureaucracies will be expensive, there is a far larger problem. Each of these new, untested bureaucracies is empowered and encouraged to informally “regulate” the provision of care through powerful tools including control over contractual requirements, required service levels and types, care planning requirements and a host of other non-legislative restrictions and mandates. The cost of complying with regulations promulgated by DHFS is substantial. The cost of complying with uncoordinated county-by-county regulations and service mandates will be much higher. This delegation of informal regulatory authority to unaccountable consumer-dominated bureaucracies is irresponsible and will lead to uncontrollable cost increases, haphazard regulation and operational inefficiencies.

The most crippling defect in Family Care, however, is the relegation of cost-effectiveness to a non-controlling factor in determining the appropriate service environment for aid recipients. Seniors who are ineligible for public assistance make difficult health care and residential decisions based on a careful cost/benefit analysis. Family Care aid recipients cannot be free of these financial considerations or all hope of containing program costs will be lost. Aid recipients should be allowed to chose less cost effective options if and only if all other eligible seniors have been adequately funded.

**FAMILY CARE IS BASED ON THE DANGEROUS ASSUMPTION THAT SENIORS WILL BE BETTER SERVED IN NON-CONGREGATE SETTINGS.**

Family Care has a consistent bias towards providing services to seniors in their own “homes.” In defining “home,” Family Care excludes CBRFs and RCACs even though many of these (including all Laureate Group facilities) are apartment-based communities. It targets these entities with unconditional referral obligations and potential forfeitures, while putting absolutely no restrictions on non-congregate providers. This bias arises from the belief that services can be more cost effectively provided in non-congregate settings. While true for seniors with modest

needs, this bias is utterly unsupportable for the frail compromised seniors who would be entitled to the Family Care benefit.

Congregate living solutions arose almost entirely in the private sector in response to consumer demand for cost effective alternatives to home care and skilled nursing facilities. The market's acceptance of these solutions is borne out by the explosion in assisted and congregate living industry, which stands in stark contrast to the recent contraction of the home care industry. Our communities are full of Wisconsin seniors who have made the difficult choice to leave their traditional "home" and move into our congregate care communities. They made their decisions with full knowledge of the services we provide, the cost of those services, and their alternatives including home care. It is not only patronizing, it is foolish to assume that the tens of thousands of Wisconsin seniors living in congregate environments have made the wrong choice.

Family Care ignores the tangible benefits of living in a congregate environment that our residents recognized when they left their homes. Among these benefits are the immediate availability of help in the event of an emergency, the availability of 24 hour staff to every single resident, nutrition monitoring, the ability to address unscheduled care needs, the frequent opportunities for social interactions, activities and outings, along with a host of other benefits. As our residents have recognized, many of these benefits cannot be matched in a non-congregate setting at any cost. In fact, living alone in a single family dwelling is often simply not appropriate for seniors with significant mobility issues or unscheduled care needs, those at high risks for falls or accidents, frail seniors or those suffering from dementia. Our residents and families have recognized this and chosen to pay, not with public money, but their own hard-earned funds, for the lifestyle, safety and security a congregate community offers. The simple fact is that the vast majority of seniors entitled to the Family Care benefit cannot be cost effectively served in non-congregate settings.

**FAMILY CARE'S GRANT OF NEAR MONOPOLY POWERS TO CASE MANAGEMENT ORGANIZATIONS, PARTICULARLY THOSE THAT ALSO PROVIDE SERVICES, IS UNNECESSARY AND CREATES IRRECONCILABLE CONFLICTS OF INTEREST.**

Family Care effectively discards the traditional county role in providing counseling and case management services to aid recipients. We have found that the counties we deal with, within the limits of available funding and the varying restrictions applicable to funding streams, have effectively administered aid programs. They have long-standing relationships with providers and are directly accountable to the community. We believe that an expansion of waiver funding and COP programs, without the existing anti-CBRF bias, could meet the goals of Family Care without destroying the existing infrastructure that has made these programs successful. We also believe that counties, with their direct accountability to voters and relative lack of ulterior motives, will not be subject to the conflicts of interest that will plague non-county managed care organizations. In our view creation of a host of new bureaucracies that effectively socialize the long term care system is unwarranted until we have established that existing, experienced entities cannot effectively administer the long-term care system with simplified, consolidated funding streams.

Private Case Management Organizations, in contrast, present far more troubling problems. Family Care allows private CMOs to provide services directly to beneficiaries. In allowing these entities to provide services, Family Care has created a powerful and inescapable conflict of interest. Provider CMOs have every incentive to engage in self-interested financial mischief at the expense of other providers. They have an incentive to steer less-costly clients into their own facilities. They have an incentive to pay their own providers more money than they pay non-

affiliated providers for comparable services. Those that operate acute care facilities will have incentives to self-refer patients for Medicare and Medicaid eligible services. In short, provider CMOs will have the incentives and power to discriminate against competing providers to their own benefit. If the CMO concept is to be successful, it must remain free from perverse incentives that are not aimed at minimizing taxpayer costs and meeting mandated service levels.

This conflict of interest is exacerbated by the statutory power granted to CMOs to arbitrarily "limit profits" of providers. Market-based managed care organizations do not have the power to unilaterally limit profits, only to negotiate prices. Similarly, non-state agencies should not be empowered to "limit profits," especially the profits of competitors. Moreover, as Medicaid and other cost-based reimbursement programs have demonstrated, artificial limits on profits dampen the innovation and cost control efforts of private tax paying entities. Family Care should focus on obtaining quality service at a reasonable cost, not on limiting profits.

Finally, Family Care provides that all seniors, even those who do not qualify for financial assistance, may purchase case management services. Based on DHFS cost estimates and program descriptions, it appears this will allow private-pay seniors to purchase services through a CMO rather than directly from providers. We believe that Wisconsin has a legitimate interest in assuring that its purchasing power is fully recognized on behalf of aid recipients. It has no legitimate interest, however, in applying its purchasing power on behalf of non-aid recipients. Allowing the state, counties or private case management organizations to negotiate with providers on behalf of private citizens is an unprecedented intrusion on the free market. While problematic in the case of counties and non-provider CMOs, in the case of provider CMOs this provision allows a provider CMO the unprecedented right to sell the services of competing providers. Wisconsin should not allow these perverse incentives to taint its long-term care reform effort.

### CONCLUSION

Family Care does meet the rigorous standards that must be applied to the creation of an entirely new entitlement. DHFS assumes care can be provided cost-effectively in unidentified "alternative settings" which have yet to be developed. DHFS assumes that Family Care will largely self-fund through reductions in payments to nursing homes and other phantom savings. DHFS assumes care in congregate settings is more expensive than care provided in again undefined "community-based" settings. DHFS underestimates the numbers of seniors who would qualify for benefits and utterly ignores increased incentives for divestment.

Two decades of experience providing all levels of senior care, including in-home care, tells us that DHFS is simply wrong. Any savings will be small in comparison to the added expenditures associated with the expanded entitlement and new bureaucracies. When funding deficits arise, taxes will increase or future seniors will face even more restricted access to senior care. With pilots that are far larger than necessary to evaluate the pilots, Family Care is high-stakes gambling of taxpayer funds exposing taxpayers and tomorrow's seniors to enormous long-term risk.

### RECOMMENDATIONS

We believe that, at the very least, Family Care should be revised as follows:

- Remove Family Care from the budget and consider it in the appropriate legislative committee hearings where it can be subject to rigorous and focused debate.
- Pilot other options, including those suggested by the Wisconsin Counties Association.
- Reduce the Family Care pilots to a reasonable size and evaluate the results before creating sweeping new entitlements for vast numbers of seniors.

- Limit the Family Care entitlement to cost-effective options – if there is money left over after enrolling all eligible seniors, then more expensive options could be considered.
- Eliminate Family Care’s bias against congregate living environments and the unrealistic provision that no senior will be required to live in a skilled nursing facility as a long-term residence.
- Eliminate the anti-competitive provisions relating to Case Management Organizations
  - Prohibit Case Management Organizations from owning or affiliating with providers.
  - Eliminate the power of private Case Management Organizations to unfairly and arbitrarily “limit profits.”
  - Eliminate provisions allowing non-eligible seniors to buy-into case management services.



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**FAX TRANSMISSION COVER SHEET**

DATE: 3-24-99

ATTN: Sen. Rod Moen

COMPANY: The Capitol - Legislative FAX# 267-2871

FROM: MC FARLAND OUTREACH & SPECIAL SERVICES DEPARTMENT

FAX #: 608 838-3619

SENDER: Ingrid Forgy

TOTAL # OF PAGES (Including this cover sheet): 3

COMMENTS: Please include this letter during your  
discussion of long term care at  
tomorrow's (March 24<sup>th</sup>) meeting of the  
Senate Health, Utilities, Veteran + Military Affairs  
Committee.  
Thank you.

5915 Milwaukee St. • P.O. Box 110 • McFarland, WI 53558-0110 • FAX: (608) 838-3619

Administration 838-3153	Community Development 838-3154	EMS 838-3152	Fire 838-3278	Outreach 838-7117	Police 838-3151
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