

Committee Name:
Joint Committee on Finance – Budget Hearings (JCF_BH)

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Long Term Care

March-19-1999

Since I'm facing my most recent eviction and feel I have no strength to fight it, I have foreseen some of the places where I will end up. After 20 years I never thought I would have to choose since I had hope in the system.

I feel that I will either be homeless in a nursing home, or will be reduced to rely on primitive actions to survive (criminal activity).

A nursing home would be an option that could cost the taxpayers \$35,00 a day which is around \$4,000,00 a month. I'm receiving Medicare and medicaid but it would not cover it.

Why go this route when it could be less costly to keep me in my home and provide me with the in-home health care I need. All I have ever wanted was to be a full functioning citizen and member of the community but all the roadblocks I have faced in the last 20 years have made me more ill.

P.S. I would like to see if you would help me keep my present residence which I will lose in the next 7 days and this will worsen my already crisis (Pg. 1)

March-19-1999

Condition of health, please send me a
Response Letter.

Thank you

P.O. Box
260062

C. Noisler

Madison, WI 53726-0062

Thank you

P.O. Box

260062

Madison, Wisc. 53726-0062

C. Naylor



KATHLEEN FALK
DANE COUNTY EXECUTIVE

Area Agency on Aging of Dane County

Susan Crowley – Director, Department of Human Services
Rita Odegaard – Administrator, Area Agency on Aging

April 14, 1999

Good Afternoon: My name is Nell Mally and I am the Chair of the Area Agency on Aging of Dane County. One of our main tasks is to advocate for the 46,000 older adults who live here. I have also had 20 years' experience managing an agency which provides services for older adults, including adult daycare and senior center services along with case management, nutrition, transportation, and in home care. And I have taught Gerontology classes at MATC for a number of years. So, I speak with some real sincerity to you!

In the early 80's we courted small and large local communities to supplement the county and state dollars that we received. And that was good. Generally we operated with a 2 to 3 percent increase each year, even though we were seeing a hefty increase in the number of people that we served.

Today the picture is very different. We are working, not only with a greater number of older adults, but also with their family members who are challenged by the complexities of helping to care for a mom who seems to be growing confused, can't keep up with her medications, doesn't understand or retain what her physician says to her, isn't eating regularly and who wanders the halls of her apartment building looking for help from her frail neighbors. And not only are we trying to cope with increasing numbers of older adult needs, but we are being expected to do it with major cuts in state funding. It is highly possible that you will see agencies around the state fold when they can no longer maintain wages and services with dwindling dollars.

You know, with the inception of Social Security in 1935 and with the growing awareness of massive injustices lying beneath the gloss of prosperity in the 50's and the 60's, the government undertook a program and a philosophy of support of older persons that included Medicare and Medicaid and continues into today. We need to supplement our programs in proportion to the growing needs of the elderly...not cut them by even a penny.

In response to this, we are asking you (actually giving you an opportunity!) to restore some of the cuts made in the Governor's budget. And I like Kathleen Falk's suggestion of using some of the tobacco settlement money to make up for some of the human service losses that we have taken.

1. Long Term Care Redesign must be funded and moved ahead for the good of the older people in Wisconsin. By the way, we do not care for the term "Family Care" because it is a name with such limitations. Long Term Care certainly includes family care, but it also includes other services and arrangements in the community such as nutrition, adult daycare, supportive home care, transportation, and so on.

1955 W. Broadway, Madison, Wisconsin 53713 • (608) 224-3660 TTY (608) 224-3617 FAX (608)
224-3662

2. We need money NOW for the Community Options Program. This plan is actually just a shadow of itself in that there are 10,000 people on the waiting lists. Many elderly die while they are waiting for some kind of service.
3. We need an additional \$3 million put into the nutrition program. Sometimes the single service that keeps an older person in their home is a hot noon meal, whether delivered or eaten at their neighborhood meal site. In addition to an anticipated increase in the number of meals needed, we need funds to provide nutritional supplements or a second daily meal for especially vulnerable, and oftentimes isolated, older adults. And we need nutrition intervention services to help stave off premature nursing home admittance.
4. If you are an older person living in the Village of Brooklyn, the last time I checked there is one RSVP driver available on a limited basis to take you to a Madison physician appointment, and if you need groceries you could go to the closest store (which is in Oregon) only on Thursdays at 12:45 p.m. Heaven forbid that it conflicts with the physician appointment! Transportation systems are woefully inadequate in rural areas. Certainly dollars are needed to bolster the present system where it exists and to establish a system where there is none. Perhaps additional money could be put into shared ride systems.

Yesterday I received a memo from Dane County Human Services saying that the Director has prepared a statement for Dane County legislators describing "\$2.6 million in service reductions that might be needed in CY2000 given the stated and federal funding reductions and inflation. Roughly \$1.5 million would be within Adult Community Services."

We are most hopeful that we can influence you to authorize additional state funding so that these reductions will not come to be.

Thank you.

Sandra Klippel
1750 Fordem Ave. #601
Madison, WI 53704
(608) 249-1421

April 6, 1999

The Joint Committee on Finance:

Sen. Brian Burke, Sen. Russ Decker, Sen. Robert Jauch,
Sen. Gwen Moore, Sen. Kevin Schibilski, Sen. Kim Plache,
Sen. Robert Cowles, Sen. Mary Panzer.

P.O. Box 7882
Madison, WI 53707

Rep. Sheryl Albers, Rep. Mark Duff, Rep. John Gard,
Rep. Gregg Hube, Rep. Dean Kaufert.

P.O. Box 8952
Madison, WI 53708

Rep. Cooyd Porter, Rep. Antonio Riley, Rep. David Ward.

P.O. Box 8953
Madison, WI 53708

Dear Senators and Representatives of the Joint Committee on Finance;

I am writing to you because I may not be able to sit at the hearing on Family Care as long as it may take before my name is called. I am disabled in an electric wheel chair and want my voice heard. I have outlined my particular medical situation which requires a lot of housekeeping such as laundry, grocery shopping, lifting, bending, and medical care given by an attendant. I also mention some of the costs incurred that insurance does not cover that the COP and CIP programs help with.

The help I require from a live in attendant in order to continue living independently is a large part household things. Grocery shopping, laundry, cleaning the bathroom, washing the floors etc. dusting (I have severe dust allergies), vacuuming, putting dishes away in the cupboards, assisting me with my wheel chair when needed. I understand that the way the CMO program is set up there will not be a lot of housekeeping attendant hours available and that it mostly focuses on only direct personal or medical care due to functional limits.

I would like you to look at those who fall through the cracks like me and consider how many lives would be in danger if the Department of Health and Family Services pass this bill and their proposal is accepted. I understand that many people's disability needs would not be met given the new system. I also believe that allowing corporate management with their monetary focus to oversee disabled and elderly people's care depersonalizes quality health care and is a trade off for their monetary quantitative gain. Quality of care must come before the appearance of saving money while taking away benefits. The elderly and disabled are one of the most oppressed groups of people in this country and have less money to care for themselves. Asking the poor to pay higher cost shares and co-payments on an already limited income is shameful. Remembering that they are not physically able to be employed and that it was not their choice does not make them second class citizens. It also does not make financial sense to staff and financially support entities that are costly by recreating the wheel on Long Term Health Care when there are alternative ways that are more cost effective and employ people who are already familiar with working with the elderly and disabled. Please see enclosed document Reforming Wisconsin's Long Term Care System.

Many disabled people do good things for their community as volunteers as their energy and life situations permits. At one time in my recent life when I had more energy and resources I was on the Board of Directors of the Wisconsin Association On Alcohol and Other Drug Abuse. This did not take much energy or time but it helped me feel worthwhile as a person and I did do some good work implementing change and shared good ideas for my community. Unfortunately my volunteerism is limited now because my health is deteriorating. I try to help my community by doing volunteer work in my home as much as I can. I want to give back to my community not just be a recipient of benefits. I hope I can make a difference. But again, I can only do this as my energy permits. Most of my time is taking care of myself.

I want you to remember this above anything else. Everyone is one step away from sitting in this wheel chair. Whether it happens in an unexpected accident or of medical problems or old age. I want you to remember that you are making a decision for your children's future, your parents future, and your grandchildren's future.

Please review the alternative long term care redesign and allow this alternative model a fair try in the pilot phase. Please do not pass the proposal from the DHFS. Please wait and do not pass this bill that is on the table today. It will affect many people like me who want to continue living a fairly normal life with those I love and with those who care about me.

I believe having a program like COP is necessary because there are so many out of pocket expenses that my small Social Security check does not cover. The co-payments for prescribed drugs and medications such as iron for my low red blood count are not covered. However my prescription iron is \$28.00 a month My multivitamins are \$58.00 a month. Vitamin E is \$9.00 a month. My Proanthanals are \$54.00 a month. My aspirin is \$2.00 a month. My acidophilus is \$64.00 a month. My capricin is \$52.00 a month. My calcium costs \$18.00 a month. My body therapies cost \$150 a month.

I see a doctor every month and get blood labs drawn monthly which is a \$6.00 co-pay. I also see

other specialists such as cardiologists, diabetologists, transplant physicians, pediatricians, dermatologists, ophthalmologists, peripheral vascular surgeons, neurologists etc. on a regular basis which makes my co-payments high. Co-payments on diabetic supplies are also \$28.00 out of pocket costs to me. My special extra depth shoes cost me about \$225 a year. I require special lenses that MA does not cover which is about \$185 a year.

Adding additional co-payments for attendants and other CMO. charges is asking us to squeeze blood out of a turnip. Our small checks and our 1% cost of living raises do not meet any realistic living standard.

I had to pay for a \$1700 lift in a donated van in order to get to my doctor appointments. I could not rely on attendants because I did not have anymore attendant hours left and their work schedules during doctor office hours did not line up. **Taking away any program that helps with medical needs or equipment is endangering disabled people's lives. My broken foot did not heal because I had to walk on it in a cast for over a year to doctor appointments at University Hospital before I got the lift. This continued to keep the fracture from healing given my severe osteoporosis.** My podiatrist told me to stay off my foot, but I couldn't without more attendant hours. I also have to pay \$35.00 a month for heated underground parking because if I attempted to walk on snowy or icy walks I could fall and land up in a nursing home from multiple fractures that would not heal due to my osteoporosis.

I could not use Madison Metro system because of my sensitivity to cold and heat. My heart surgeon said that I could not be chilled below 72 degrees nor could I tolerate summer heat and humidity and that I required air conditioning. I can not breathe in the summer time when it is hot or humid outside and require air conditioning because of my heart. I also could not be left unattended while waiting at the door for the ride due to my extreme fragile medical needs and need to be home to make sure I got my meal, insulin and medications on time because of the brittle diabetes. I could not risk a bus being late or my appointment running late and miss the ride..

I propose that the legislature give the Alternative Long Care Redesign Proposal a fair chance. An Alternative Model To Try In The Pilot Phase is a sound model and will more fairly meet the needs of disabled people. I have enclosed a brief paper outlining this model.

My concern with the way the State proposes to redesign the Long Term Health Care, is that it is very dangerous and doesn't provide for special needs. It probably won't provide enough because of one monthly rate and maybe too restrictive to cover all of the costs necessary. I am a perfect example of someone whose costs could fluctuate greatly from month to month. Examples include; insulin syringes, commodes, respiratory equipment and accessories, blood sugar monitoring equipment, suppositories, disposable gloves, alcohol swabs. Other examples that may affect me are, other diabetic supplies such as glucose tablets for low blood sugars, body therapies, equipment for severe allergies, eye glass lenses, and prescription medications for my survival not covered by Medical Assistance. The CMO is stuck with a monthly limit that endangers people's lives.

It is critical to my independence to have an attendant to help with my living needs. **I like the way**

the present program is set up, it empowers people to live fairly normal lives with the people they choose to hire and live with. Introduction of a corporately run program (It stands to reason that corporations can out bid smaller services and are more competitive), as written depersonalizes care and makes for inconsistent care. I believe it is our civil right to live with whom we want and select those people based on our own unique personalities, physical disabilities, and safety. I would not want my rights taken away from me and be forced to live with a stranger hired by a CMO, nor be forced into a nursing home. I am a private person and am very sensitive about who touches and takes care of my body.

Given the following, I still find happiness in my life, and appreciate what little I have in the way of material things. My medical condition has helped me gain a better attitude about life and helped me see what is most important about existence in this life time. It helped me see and value people and their human needs and wants. I feel rich because I have someone who loves me and cares about me. It helped me get my values straight about building communities with care, empathy, and great thoughtfulness. I feel a great sense of integrity and responsibility to my community and I want the best for all people.

I also believe that the human spirit thrives when it is surrounded by loving and caring people who mean something to them. No longer having these people available to the elderly and disabled is the greatest disservice this bill will do to many people who have dedicated attendants who love and care for them in their homes. Depersonalizing care in favor of corporate management takes the spirit out of disabled people's lives. It takes the heart out of helping people. And it strips away their reason to live, to go on, to keep trying even when their health fails. It is the support of their spirit that prompts them to continue to keep going when there is genuine love, care and concern for their life Put yourself in their shoes and come sit in this chair for a day so you can feel what it is like before you make a decision on this bill. We don't want this bill. We want to live.

My situation requires a live-in attendant for a variety of reasons. I have end stage diabetes. Some of the challenges I face today are:

Diabetic retinopathy (vessels that grow inside the vitreous of the eye and hemorrhage leaving a person blind) which requires that I do not bend over or lift anything because it creates pressure in my head and puts pressure on the blood vessels growing inside my vitreous that will hemorrhage. My ophthalmologist said, **NO BENDING OR LIFTING**. I have had 8 laser surgeries in each eye which has left scar tissue making sight blurred and filled with black strings. It also prevents me from driving at night. Anything that one requires in their life to bend or lift, my attendant does for me.

Prior to having an attendant, when I was still on the waiting list, just taking out my garbage set off hemorrhages. In addition to my diabetic retinopathy, my cataracts make it impossible for me to read directions on food packages, pertinent medical information, pharmaceutical prescriptions, draw up insulin, etc and requires that my attendant do these things for me.

Prednisone related problems (an anti-rejection drug for my transplanted kidney):Muscle weakness and atrophy, cataracts, severe osteoporosis, loss of memory, yeast infections, fluctuations in blood sugar (poor blood sugar control) which increases my dehydration causing low blood pressure and elicits the effects of my stroke.

Cataracts (a cloud or screen like cover over the lens) cause an inability to draw up my insulin, make reading books and signs very difficult or impossible,

Severe Osteoporosis (I have greater than 50% of bone loss) disables me from walking even short distances sometimes and is worse with my circulation problems in my feet. I attempted to clean out my bathtub when I was moving because I did not have sufficient coverage for attendants and by bending down on my knees and resting on my feet, I broke my foot. It took 1 and ½ years to heal this break completely and today the foot becomes injured very easily by just walking. Needless to say I need assistance in cleaning my home. I also must take large doses of Calcium which is not covered by insurance. I can't take the required calcium building medications because it has caused kidney damage to me making my transplanted kidney only functioning 40%. The calcium costs \$18 a month.

Loss of memory. has caused me to burn every kettle and pan I have in my house because I forgot I had something on the stove. The only thing that has helped with this is an alternative medication not covered by insurance. My short term memory was so bad that when I listened to my answering machine I could not recall anyone who called just after hearing the messages. I need an attendant to be around during meal times when I am cooking because of this. I also have word find problems when I talk, making communication difficult sometimes.

Brittle Diabetes implies that I am sensitive to insulin and have extreme highs and lows. I have insulin reactions everyday which is when the blood sugar is low (below 70). I also can not feel my low blood sugar until it reaches dangerous levels which requires that an attendant intervene and get sugar immediately. If the blood sugars would drop too far and swallowing is impossible an injection must be given or unconsciousness will follow. At night it is imperative that an attendant be close to check for symptoms and administer proper glucose.

High blood sugars are common with brittle diabetes. Emotional upsets can make my blood sugar rise over 200 mg/dec. I could be having a normal blood sugar of 120 and within seconds have a 300 or higher blood sugar from just every day stress. These high blood sugars consequently dehydrate me and make my blood pressure fall. Falling down is the danger of low blood pressure for me with accompanying stroke symptoms. I can not stand up and must lay down part of the day when this occurs. An attendant must immediately bring me salt water to correct the fluid imbalances and raise the blood pressure. The other consequence is prompting stroke symptoms which make it impossible to feel my right foot, right hand, and makes speech difficult because the right side of my mouth and tongue become numb. Insulin reactions can have the same effects because the blood vessels in my brain constrict.

Stroke was caused from going off my anticoagulants prior to cataract surgery of my right eye. For

the most part it does not interfere with my life too much unless I have a fever, a cold, low blood pressure or low blood sugar, or are under emotional stress. Any stress to the brain will cause the symptoms from the damaged part of my brain where the stroke occurred. The electrical by-pass around the damaged part of my brain does not function when stress occurs which freezes my activity and requires laying down immediately. I can not take Coumadin the anti coagulant most prescribed because of my diabetic retinopathy and the risk of vessels in my eye hemorrhaging. So again, I take an alternative medication that insurance does not cover. Aspirin does not help without the alternative medication. This medicine costs over \$30 a month.

Heart Disease I had quadruple by-pass surgery in 1988 and have lost strength because of this. It is also dangerous for me to have insulin reactions because low blood sugars can harm my heart or possible close off vessels. It is important that my attendant give sugar immediately when I have a low blood sugar. I am on many heart medications and must take aspirin to thin my blood which is not covered by insurance. I must also take Vitamin E, Proanthanals, Multi vitamin supplements, and vitamin C in large doses for prevention purposes which are not covered by insurance. Low fat diet is required and costly. **My food bill exceeds a normal persons by \$300 per month** because fat free costs more and all meats must be lean and high quality **An example; egg beaters cost me \$20 a dozen where a dozen eggs cost the average person .69 cents. Another thing about my heart condition is that I can not stand or sit for long periods because I collect fluid in my legs and feet. My return vessel in my leg was used for the quadruple by-pass surgery so especially my right leg swells. This condition makes it hard for me and requires moving from sitting, standing and laying positions throughout the day. The heart can not pump up the excess fluids otherwise.**

Transplanted kidney was done in 1992. Fluctuation of fluids is one problem I have with this kidney. It takes fluids off of me especially at night so when I wake up in the morning I have a hard time standing up due to dehydration and must rehydrate with salt water before stroke symptoms occur. The other complications are medicines and side effect related. See Prednisone, Osteoporosis, Cataracts etc. When I have dehydration problems in the morning I can not do anything but sit and wait until my attendant runs to bring me salt water. High blood sugars contribute to this. Brittle diabetes swings blood sugar levels from dangerous low to dangerous high and when this dehydration occurs it contributes to stroke symptoms and light headedness so that I can't stand up and get the things I need to remedy it. This is pretty much an everyday occurrence.

Insulin Reactions occur everyday. The scariest time they occur is in the night. This is where an attendant is needed. When insulin reactions occur I'm too weak to get up and remedy this. My attendant must help me immediately when I call for her or when she notices that my body is shaking and sweating. These are dangerous because they cause vessel constriction and can activate a heart attack or stroke. My first three heart attacks were due to insulin reactions. My neurologist who over sees my stroke problems has warned me to be careful of insulin reactions. It is critical that my attendant be there immediately.

Peripheral Neuropathy is caused by a loss of circulation in the peripheral system of the body. This means that my feet are extremely sensitive as well as dumb. It requires special shoes that cost approximately \$125 a pair. Insurance does not cover this either. Frequent visits to the podiatrist are

common because diabetics need special attention to their feet such as getting nails clipped. It is particularly dangerous because there is numbness accompanied by hypersensitivity so soft comfortable shoes need to be worn because of breakdown. Amputation is common with diabetes. Massage to the feet and legs by my attendant helps with circulation. **Peripheral Neuropathy** numbs the feet and hands. I can not tell if I have an infection in my feet nor can I see well enough to tell by visual body check. I need an attendant to do daily body checks for breakdown on my skin, sores, infections, in grown nails etc. Peripheral Neuropathy disables me because I can not sit or stand for long periods of time. I also have muscle disease in my legs due to this problem where the calves of my legs are extremely inflamed, making walking very difficult. When I do attempt to walk even short distances my legs cramp and spasm because of poor circulation and the need for oxygenated blood flow to the muscle.

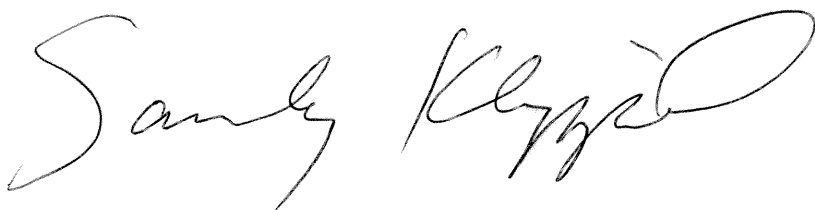
Arterial Sclerosis is what happens to diabetics as their blood vessels clog up with plaque and blood circulation decreases. I feel cold a lot and must keep my heat turned up to 75 which costs more money. I can not bend my neck back because it causes a crink in my artery and cuts blood flow off to my brain. In addition to this I can not raise my arms above my head because blood flow is reduced and I have stroke symptoms. Many household needs can not be met without my attendant.

Yeast infections because of being diabetic and because of my immune suppression I am prone to yeast. Yeast in my mouth, intestines etc need to be treated but transplants can not take the medications for treatment. There are however alternative medications that can be taken which again insurance does not cover. Just this medication alone costs \$120 a month.

Gastroparesis is a progressive diabetic condition causing a neuropathy in the stomach which makes emptying the stomach very slow. Gas build up, digestion is affected, insulin coverage is erratic and blood sugar regulation is difficult, constipation occurs, as does stomach distension, cramps etc. Over the counter aids like Mylanta, Gas-X, and suppositories of course are not covered by insurance and sometimes do not alleviate the pain or pressure.

I appreciate your taking the time to care enough to read this. This gives you a personalized look at one case where the new redesign would be life threatening. I hope you go into your heart and make a compassionate decision and give the Alternative Model a fair chance.

Sincerely,

A handwritten signature in cursive script that reads "Sandy Klyppel". The signature is written in dark ink on a white background.

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.

Reforming Wisconsin's Long Term Care System

For the past three years the many stakeholders in Wisconsin's long term care system have spent countless hours working with the Department of Health and Family Services (DHFS) to develop a plan to reform that system. There is overwhelming agreement and support for the goals of increasing the quality, individual choices, and cost-effectiveness within long term care, as stated by Governor Thompson in endorsing the concept of what he has termed Family Care. Despite the widespread and enthusiastic support for these goals, there has been from the start and remains today widespread concern over the Department's plan to implement these goals through a competitive, HMO model of managed long term care.

These concerns led DHFS to withdraw its original Long Term Care redesign plan in June, 1997. Now, more than a year and a half later, DHFS continues to pursue a model of managed long term care with uncertain risks to people in need of long term care today and in the future, high risk to the continued viability of local county programs which are the state's partners in administering the programs, and unclear assumptions about current and future long term care funding.

If the efforts of the past three years are not to be wasted in acrimonious debate within the Legislature in 1999, there must be greater consensus among the primary stakeholders than currently exists. This paper seeks that consensus. It has been developed by a coalition of Wisconsin Counties and the primary groups which represent Wisconsin's elders, people with physical disabilities and people with developmental disabilities. This coalition has worked closely together and with state government for the past three years. It is dedicated to continuing to work with the Governor, the Legislature and DHFS to reform Wisconsin's long term care system in a manner which Wisconsin citizens can support with pride and confidence.

We believe the following points form the basis for proceeding with long term care reform despite deep differences with DHFS in terms of how the system is to be administered in the future:

1. Agreement to begin the reform of the long term care system in the 1999-2001 biennium for *all* long term care populations;
2. Agreement to maintain a public, county-administered long term care system;
3. Agreement to *pilot* different approaches to long term care reform, including the managed care organizations proposed by DHFS and approaches based upon the attached alternative proposal;
4. Agreement on an independent evaluation of the outcomes of the pilots;
5. Sufficient funding of the pilots and of the system which evolves from them;
6. Adequately funded independent advocacy, beginning with the current pilots;
7. Continuity of services for people now receiving long term support; and
8. Limiting statutory language changes to only those changes required to implement the pilots.

Given agreement on these basic principles, we believe the reform of Wisconsin's long term care system can proceed in the coming biennium, with opportunities to learn from both the DHFS proposal to administer the system through managed care organizations, and the alternatives to that proposal suggested in the attached paper.

Reforming Long Term Care: Key Features

This is an outline of a proposal to implement the long term care reform ideals that Governor Thompson originally expressed in his 1998 State of the State address. It is a proposal to create a holistic long term care system which would be a national model for quality, for responsiveness to individuals and families, and for effective use of public funding. It would do so without replacing the current human service system with HMO styled managed long term care organizations.

Key Objectives for Reforming Long Term Care

Over the past three years of discussion, DHFS has agreed with the input from the many stakeholders in the system who have suggested that Wisconsin:

- create the same access to community care and support which currently exists for institutional care;
- simplify and combine long term care funding;
- make better use of available funding in order to serve more people;
- create a resource center where people can gain easy access to the long term care system, support to know how to receive the support they need from the system, and stronger connections to a variety of community resources;
- respond to the needs of people on waiting lists and to the demographics which indicate a growing need for services, particularly for our aging population;
- create individual choice of how to receive support and services, and allow "the money to follow the person;"
- create an effective system of helping each individual manage their care, services, and support within the funding available to them;
- increase consumer involvement in program planning, oversight and policy making; and
- increase independent advocacy.

The following proposal incorporates these agreed upon objectives, but does so by reforming rather than replacing the current human services/long term care system. The cornerstone of the proposal is to treat the Home and Community-Based Services Waivers (CIP and COP-W) just like nursing home services. The key advantages of this proposal are:

- The home and community-based services waivers and nursing homes would have the same eligibility criteria and equal access to funding; thus people who are eligible would have the same access to community services and nursing home services;
- The proposal does not discourage county administration of local long term care programs, and thus does not encourage the loss of current county funding;
- It does not increase current risk nor introduce privatization into the management of the long term care system; instead, it reinvests savings from cost-efficiencies into reducing waiting lists rather than taking profits;
- It does not require separate administrative structures and costs for resource centers and agencies

- responsible for services;
- It does not require competition among managed care organizations to manage the system within an unproven and untested HMO model of managed long term care; and
 - It increases the amount and percentage of long term care funding from federal rather than state and county taxes without requiring approval of the federal Health Care Financing Administration of complex managed care waivers.

Key Components of Long Term Care Reform

This proposal builds upon the best of what is currently working in Wisconsin's long term care system. Our county administered Community Options Programs and Community Integration Programs and state administered Medicaid Program have been recognized throughout the state and the nation for their excellence. Our nursing home and other institutional programs have been noted for the overall quality of care they provide within their facilities.

The quality of these parts of our system has been compromised by the system's overall fragmentation and complexity, and by our overinvestment in institutional services. The following proposal would integrate and simplify the long term care system, and allow people who choose to do so to remain in and return to their own homes and other community settings.

Funding

1. Funding is based upon the concept of pooling *state* long term care funds. This pool of funding is used to access Federal funds through either an expanded Home and Community-Based Services (HCBS) Waiver, or through a nursing home/ICF-MR facility. Funding saved by reducing current and projected utilization of nursing homes and ICF-MRs (including the State Centers for People with Developmental Disabilities) is retained in the system for long term care expenditures.
2. For people who are Medicaid eligible, eligibility criteria *and access to funding are identical for HCBS and nursing home/ICF-MR services*. Functional eligibility criteria for both types of services will be expanded to allow Federal funding of services to many people with long term care needs who are now receiving services funded entirely by state and county taxes.
3. For people who meet current Wisconsin long term care eligibility criteria and are not eligible for services funded through HCBS Waivers or nursing homes/ICF-MR services, the long term care funding currently available for their service needs from revenue sources other than HCBS Waiver or nursing home/ICF-MR funds will continue to be available and allocated as it is currently done.
4. Pre-admission screening will be required for all individuals referred to or seeking admission to nursing homes/ICF-MRs, CBRFs, and Residential Care Apartment Complexes.
5. People currently residing in nursing homes/ICF-MRs will be offered the option of receiving community services.
6. The current complexity of several HCBS waivers with multiple rates based upon different historic circumstances are consolidated into a single, simplified waiver for older people and people with

- physical disabilities (COP-W) and a single, simplified waiver for people with developmental disabilities (CIP). Each waiver will include the full range of long term care services available through the federal HCBS waiver program, including personal care and home health care. Individuals who use only limited Medicaid long term care services may choose to remain in the fee-for services system.
7. Funding from the state pool and Federal matching funds will be provided based upon levels of individual need. If people receiving HCBS or nursing home/ICF-MR services wish to move to another setting or county, their funding will go with them.
 8. Resource center functions will be expanded to improve outreach and access to long term care services. As would be required in the DHFS LTC redesign proposal, enhanced resource center responsibilities would require additional state General Purpose Revenue (GPR) funding. Because many of these functions are now provided by county agencies, resource center costs under this proposal would be significantly less than the cost of the separately administered resource center proposed by DHFS.
 9. Planning, budgeting and funding will be flexibly provided across calendar years. Funding not spent in a particular calendar year will be retained by local government for the express purpose of spending on long term care services in subsequent years.
 10. Some individuals who have long term care needs but do not have needs which meet HCBS waiver and nursing home eligibility criteria are now on waiting lists and may initially be on waiting lists during a period of transition. Funding accrued through reducing utilization of nursing homes/ICF-MRs will be applied towards eliminating waiting lists. Information about the number of people on waiting lists and their projected costs must be maintained and reported periodically to both the county and the state.
 11. As is true of the DHFS proposal, the primary source of additional funding will be the result of decreased utilization of nursing home/ICF-MR services. This funding is available over time, as the new system is phased in. As is also true of the DHFS proposal, projections must be developed for additional state GPR funding needed during the phase-in period and in response to demographic pressures.

Systems Governance and Management

12. A State Long Term Care policy board will be established, with at least 51% of the board composed of elderly people, and of people with disabilities who receive long term care services and their family members. The board will have broad oversight and planning responsibilities.
13. Local government remains responsible for long term care fiscal administration through its county executive and board structure. A local Long Term Care policy board will be formed in each county (or multi-county catchment area), with at least 51% of the board composed of elderly people, and of people with disabilities, who receive long term care services and their family members. Some appointees to the board must come from local/regional aging and disability groups. Within each county or multi-county system the board will be responsible for long term care program planning, oversight and policy making; assuring needed resource development;

oversight of quality improvement and assurance; and hearing grievances and appeals.

14. The outreach and access, extensive information and referral, and emergency and protective service functions described in the DHFS proposal will be provided by each county directly or through contract. All persons will be able to gain access to the system in a simple, straightforward and timely way.
15. State specified and monitored performance criteria will be established for the provision and management of both resource center and long term care services. DHFS and local boards will share responsibility for the continual improvement of the long term care system. In addition to health and safety requirements, county agencies will be required to meet specific performance and outcome requirements based upon the needs of the individuals being served. A range of state monitoring options will be developed, including the power to replace agencies which do not meet requirements.
16. At the option of the county and local Long Term Care policy board (or if the local agency is replaced as noted above) a local long term care authority may be created to manage long term care funding and services.
17. Primary responsibility for the long term care system will be administered at the state level within an organizational unit which has primary responsibility for development and oversight of community programs.

Choice and Self-Directed Services

18. Persons eligible for long term care services will have a maximum range of choices available within adequate funding available to meet their identified needs. Every person will have the opportunity to develop her/his own plan, and choose the manner and location in which services will be delivered.
19. Self-directed services are an option for all persons receiving long term care. For some individuals, this option will be shared with or delegated to families or others who share decision-making authority with the person.

Advocacy and Rights Protection

20. Beginning with the implementation of pilots, an independent entity (or entities) with no conflict of interest (i.e. no direct service provision) must be designated and adequately funded by the state to provide advocacy services to individuals within the long term care system. The independent entity will be controlled by persons who receive long term care services and will have the capacity to pursue all appropriate remedies.

Transition to a Reformed System

The transition to a reformed long term care system can only occur with the consent and cooperation of the many stakeholders involved. Despite the hard work of DHFS staff and the many agencies and

individuals outside of the Department who poured their efforts and energies into three years of planning, the DHFS proposal has key features which are troubling, threatening and simply unacceptable to large numbers of people who currently rely upon long term care services. We believe the elements outlined in this proposal would garner the support of the many stakeholders involved in our system, would allow us to meet the original intent of the Department, and would accomplish the Family Care goals proposed by our Governor.

Budget Implications

We believe this approach will be more effective than the DHFS proposal. Both approaches will reduce Wisconsin's high rate of nursing home/ICF-MR utilization through pre-admission screening and through offering people the opportunity to remain in their homes and communities. However, this proposal has the fiscal advantage of retaining current funds in the long term care system, and it does not require a separate and costly administrative structure to provide resource center and managed care rate setting functions.

JOINT FINANCE TESTIMONY 4/15/99

Hello, my name is Walter Dillingham and I live in Madison. I have been receiving Medical Assistance Personal Care services since November 1991. I am here to support a \$4 dollar an hour increase in MA personal care, to be used as a wage increase for workers all over this state.

Everyday personal care workers assist me to get up, to go to bed, to make meals and do laundry. They can make more money at dozens of other jobs in Dane County and not have to work evenings, weekends or holidays at my home. Private businesses can raise their prices to pay higher wages. I need you to help my workers get a raise and keep getting yearly raises to keep them with me. If I can't find workers who will work for this pay, I would end up in a nursing home. I would rather die on the streets than be in a nursing home.

I can't do my volunteer work or my private business from a nursing home. I give back to my community every way I can. For all the seniors and people with disabilities in Wisconsin who need personal care please understand our problem here. We need to be able to compete with private businesses for

workers. The unemployment situation is desperate, with fewer and fewer people even looking for work. I need to compete on an even basis for my help.

Thank you for this opportunity to speak.

Walter Dillingham
124 Proudfit #1
Madison, WI 53715
608-255-8481

**MEDICAL ASSISTANCE PERSONAL CARE
REIMBURSEMENT INCREASE
TESTIMONY**

**By
Bob Deist
4/15/99**

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 with disabilities 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

**WISCONSIN MEDICAL ASSISTANCE PERSONAL CARE (MAPC) SERVICES
FACT SHEET**

WHAT REIMBURSEMENT RATE HAS BEEN PAID BY THE WISCONSIN MAPC PROGRAM TO PROVIDERS SINCE THE INCEPTION OF THIS PROGRAM?

JULY 1, 1988	\$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

WHAT ARE OTHER STATES CURRENTLY PAYING FOR MAPC SERVICES?

- ILLINOIS \$41.45 PER VISIT
- INDIANA \$14.70 PER HOUR
- MICHIGAN \$12 - 13.00 PER HOUR
- MINNESOTA \$12.36 PER HOUR
- MISSOURI \$15.50 PER HOUR (in 1996)

WHAT ARE THE REASONS WHY THE NUMBER OF INDIVIDUALS RECEIVING MAPC SERVICES HAS NOT SUBSTANTIALLY INCREASED BUT THE UNITS OF SERVICES ARE INCREASING?

If this is indeed true as the State of Wisconsin reports, although we have not seen statistics to support this theory, the following are all reasons for the increase in MAPC units of service:

- The population of MAPC consumers is aging and needing more service. The MAPC population of recipients is chronically ill, getting older and sicker as the disability progresses.
- Consumers are referring themselves directly to MAPC agencies. They have already been in the system.
- The Balanced Budget Act of 1997 will see more consumers utilizing MAPC

- services/cost shifting as Medicare pays for less and less.
- The changes in the MA PC regulations from 1992 at which time more and more home health aide hours were "bumped" down into the MAPC category.
- Natural support systems are aging, gone, dying.
- Some counties have such high waiting lists for county services, MAPC services have been maximized.
- Counties have expanded MAPC services and to Group Homes and CBRF's the last couple of years. Most of these individuals have already been in the Medical Assistance system.
- Most counties have always encouraged full utilization of MAPC services involvement to maximize MA card usage.
- The move towards cost containment by counties have cost shifted waiver costs to MA card costs.
- Agencies and counties have attempted to maximize the use of family members to provide increased services needed to existing cases. Agencies have difficulty opening new cases due to serious staff shortages in all parts of the state.

WHY IS THERE A DESPARATE NEED FOR A RATE CHANGE IN THE MEDICAL ASSISTANCE PERSONAL CARE RATES?

1. Home Health agencies, Personal Care agencies, County agencies currently have costs on the average which are higher than the MAPC reimbursement rate of \$11.50/hr.(costs to provide services on average range from \$13.96 to \$16.40/hr).
2. There have been home health agencies who have discontinued their MAPC programs or will take no new MAPC referrals making it difficult for consumers to receive services.
3. Low unemployment rates throughout the state are causing serious personal care worker staff shortages and higher wages and more comprehensive benefits are needed in order for agencies providing personal care services to stay competitive in this labor market.

Prepared by: Jean Rumachik
 Legislative Chairperson
 Wisconsin Personal Services Alternatives, Inc. (WPSA)
 9/30/98

I'm sorry I was not able to give my statement. I was here at 9:30 but had to leave at 2:00.

Pacific Intention out of NeRooska Wis

My name is E H

Since I don't give speeches often I'd like to read my statement today.

I'm here on behalf of Pac Int, They work with the correction of the problem of nocturnal enuresis which is (bedwetting) Senator Kevin Shibilski is in favor of the cost of Pacific's correction being handled by State of Wis for those who cannot afford it.

We had this problem with our son. For 8 years we went to doctors and eroulogists, we tried everything. We tried pills, nasal sprays, bed alarms, Big Ben alarm clocks and waking him up at all hours of the night to use the restroom. Nothing worked-we were told he'll out grow it/he'lloutgrow it. We tried these same things over and over for years, but it never got better only worse. Our son missed out on so much of his earliest years. He missed years of camp outs and overnights stays. He was affraid of the embarrassment if he was found out. Our vacations were well prepared with extra supplies to bring along to protect the hotels bedding. (Our son was 12 years old and still wetting most every night.) We heard of Pac and of course we decided to try once again.

To our joy in just 3 1/2 months with Pac they helped us change our sons sleep patterns. We had a case worker assigned to us. We followed their detailed directions, and with hard work and determination on our son and my part he did it. He was declared dry and has been doing fine since. We were thrilled for him and for us. I only wish we had heard of Pac earlier. I feel sad for him and for all those years wasted.

There's no price we could put on our son's self esteem. He can now do what kids do all the time- stay over night, have a friend over, RELAX no more washing bedding every morning. We're thrilled we could afford to do this for him, but others cannot. HERE is where some money can do some real good.

Bedwetting is devastating for the child or adult who has this problem. It can totally disrupt everyone in the family. Please find a spot in the budget to help those who do not have the finances to pay for this program.

Thank you

Elaine Hellenbrand

he had sleep
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could
have
been
easier

TO: Joint Committee on Finance Members

FROM: Eugene Lehrmann
Ellen Rabenhorst
David Slautterback

Representing the Following Organizations:

AARP
Coalition of Wisconsin Aging Groups
Wisconsin Retired Educators Association
Wisconsin Council of Senior Citizens
Wisconsin Alzheimer's Chapter Network
Wisconsin Association of Area Agencies on Aging
Wisconsin Association of Aging Unit Directors
Wisconsin Council of Churches
Milwaukee Consortium of Service Providers
Dane County Elderly Services Network

DATE: April 15, 1999

SUBJECT: State Budget Priorities for the Elderly

On behalf of the organizations listed we urge your support for the following priority issues:

1. Family Care – We support the Family Care pilot projects in the proposed budget. Family Care is extremely important to older persons because it provides one-stop shopping (Resource Centers) for older persons and their families, and it creates equal access to home and community long-term care services as it does to nursing home care. Because there is no system serving older persons, Wisconsin still provides 77% of long-term care to the elderly in nursing homes. Family Care will give many more older persons the opportunity to remain in their own homes.
2. Community Options Program (COP) – While we pilot Family Care, we urge you to provide additional COP dollars to provide hope to people on waiting lists in the remaining 63 counties that are not Family Care pilots in this budget. Nursing home utilization has been going down in Wisconsin and is projected to continue to decrease in this budget. Additional funding for COP will help assure the projected decrease and Medicaid savings in nursing home costs.

3. Ombudsman – We urge your support for eight additional Ombudsman positions (four in each year of the budget) to serve the long-term care population in Wisconsin of over 90,000 people. This would put Wisconsin at approximately twice the national recommended standard of one Ombudsman for every 2,000 long-term care clients (i.e., 1:4,000).
4. Long-Term Care Workers – We support wage pass-through legislation that will provide increases to the lowest paid long-term care workers; i.e., Personal Care workers and Certified Nurse Aides.
5. Elderly and Disabled Transportation – From FY96 through FY 99 the DOT budget has increased by \$387.4 million while the Elderly and Disabled Transportation program has increased by only \$1.2 million or three-tenths of one percent (.003%) of the overall increase. We support an increase of \$8 million a year in the E&D Transportation program. Even with this increase the program would still be less than 1% of the total DOT budget.
6. Elderly Nutrition Program – State funding for the Elderly Nutrition Program has not increased since 1994 despite a shift toward more costly home delivered meals to accommodate the growing population of people age 85 and over. We urge an increase in this budget.
7. Alzheimer's Family and Caregiver Support Program (AFCS) – This program has not received an increase in funding since it was initiated in 1985. We support an increase of \$1.8 million to eliminate waiting lists (750 people) and to serve additional families.

Testimony Before the Joint Committee on Finance

April 15, 1999


My name is Mary Pike and I reside in Middleton. I am a family care giver for my husband and am here to urge you to increase the appropriation for the Alzheimer's Family and Caregiver Support Program (AFCSP) in the Governor's Budget Bill. There has never been an increase since the program was initiated in 1985. This has resulted in waiting lists in several counties. In 1997 AFCSP served approximately 950 people and there were still 750 people on waiting lists. This is a serious problem since many people eligible for AFCSP are already on the COP waiting list. I support the Wisconsin Alzheimer's Association Chapter Network request for the appropriation to be doubled. It is presently at \$1.8 million and I urge you to increase this to \$3.6 million.

As I am sure you are aware, Alzheimer's disease is a progressive, degenerative disease that attacks the brain and results in impaired memory, thinking and behavior. My husband was diagnosed in 1993 having shown classic symptoms for the two previous years. From the onset of the symptoms I cared for him at home for 4 years, when due to falls it became necessary for him to be placed in a CBRF where he lived for 22 months. A year ago he fell and broke his hip which necessitated his going into an Alzheimer's Special Care Unit in a Nursing Home. Caregiving for a family member with Alzheimer's disease can be an emotionally and physically exhausting, 36-hour day, 7-day a week job. Through my experience the past seven to eight years I can testify to the need for making Respite Care available to family care givers who as the disease progresses are unable to leave their loved one alone and at times get very little rest thus the reference to the 36 hour day.

There are 498,000 informal caregivers across the state who provide some 463 million hours of unpaid care, saving 3.8 billion dollars each year in Wisconsin. Nearly one in five caregivers is taking care of someone with dementia. For many Alzheimer's families, respite is the basic service that enables them to keep their loved one at home. I was fortunate that I had the resources to be able to send my husband to Adult Day Care the final year I cared for him at home. But for those without the financial resources like the 750 on the waiting list (a number which will continue to grow as the population ages) the AFCSP program provides up to \$4,000 annually for services such as respite for the unpaid primary caregiver of an Alzheimer's patient, allowing a temporary break from caregiving. This break can be anything from a couple days a week in an Adult Dementia Specific Day Care to having someone come stay with the person for a few hours or days or placing them in a home offering 24 hour respite care for a week. Providing respite for the caregiver allows the Alzheimer's patient to stay in the familiar setting of their home where they feel safe and experience less agitation, confusion and behavior problems.

The AFCSP program not only saves taxpayers a tremendous amount of money and has proven itself to be a sound financial investment but also provides an essential service for Alzheimer's patients, families and caregivers. Without this support, the state would be left to shoulder the financial burdens of their care at a much earlier date.

Mary F. Pike
6258 Elmwood Ave.
Middleton, WI 53562

 ASW... ASW... ASW... ASW... ASW... ASW...

JOINT COMMITTEE ON FINANCE
PUBLIC HEARING APRIL 15, 1999

Senator Brian Burke and Representative John Gard, Co-chairs;
and Members of the Joint Finance 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.

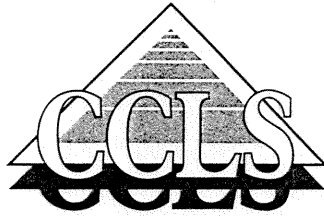
This plan builds on many of the positive ideas of redesign, namely: the same access to community care which currently exists for institutional care: simplifying and combining long term care funding; creating individual choice of how to receive support and services, and allowing "the money to follow the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

^{Our}
~~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.



**Creative Community
Living Services, Inc.**

TO: Senator Brian Burke, Co Chair; Representative John Gard, Co Chair;
Senators Decker, Jauch, Moore, Shibilski, Plache, Cowles, Panzer
Representatives Ward, Porter, Albers, Kaufert, Duff, Huber, Riley

RE: 1999-2001 State Biennial Budget

My name is Barbara Fox. I am the President of Creative Community Living Services, Inc. Our agency provides community services for nearly 500 people with developmental disabilities in 15 different Wisconsin counties. We employ over 500 people, most of them in direct care positions. I have some serious concerns about the allocations for people with disabilities in the proposed state budget.

Our agency is already experiencing a cut in allocations from Milwaukee County because of the 1999 cut in base community aids to Milwaukee County. We are seriously looking at closing at least one program in Milwaukee County because of that cut.

Over the past two years, the State of Wisconsin has approved increased licensing regulations in community-based residential facilities and increased regulations in criminal background checks and reporting requirements. All of these regulations have been expensive to implement, and yet we had to implement them with no increase in allocations. A cut in community aids and no increases in the waiver programs is adding insult to injury.

Our agency is currently hiring direct care staff at \$7.50 to \$8.00 per hour. It is the most we can afford. The fast food restaurants are paying better than that. With the labor shortage, we are having a very difficult time hiring and maintaining staff. For the past several months, 9% of our staff positions have been vacant. We have been using our current staff to fill the positions, and paying an enormous amount of overtime, and burning people out.

If there are cuts in funding to the counties, those cuts will be passed on to provider agencies. We cannot cut already low staff wages or we will lose all of our staff. The other alternative, which many providers will need to consider, is to close programs or simply go out of business. If agencies start closing their doors, the State of Wisconsin will have to find some way to provide services. Emergency placements are expensive and traumatic to the individuals involved.

Please restore the cuts to community aids and put in an inflationary increase of 3%. There also needs to be an increase in the waived dollars. CIP 1A is currently paying anywhere from \$125 to \$184 per day, compared with \$349 per day in the state centers. CIP 1B has not had a significant increase in 9 years. The current rate of \$48.33 per day is not enough to provide adequate services to an individual in the community. This amount needs to be increased to a minimum of \$70 per day.

I am also very concerned about the proposal to re-design the long-term care system. We need to pilot the Family Care proposal in a few counties, and then use an outside source to evaluate the data from the pilots. I would also like to suggest that one of the pilots be an alternative plan to the proposed Family Care, utilizing the current county-run system. Family Care will be expensive to implement. The current county-run system needs reforms, but I believe it can continue to work for Wisconsin for many more years.

In summary, Wisconsin is in an economic boom. It is a wonderful place to live and to work. Please make it be a wonderful environment for people with disabilities, as well.

Barbara Fox
Creative Community Living Services, Inc.
P.O. Box 260
Watertown, WI 53094-0260
920-261-1345, extension 32