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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 grandchildrens 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 with out 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 provided 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 effect 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 Klyne". The signature is written in black ink on a white background.

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.

Public Hearing – April 15, 1999

Legislative Initiatives Proposed by the Council for the Deaf and Hard of Hearing

I am in support of the initiatives proposed by the Council; the statute for sign language interpreters, the increase in GPR dollars for the Service Fund, and the funding of the Community Service Associates through the Office for Deaf and Hard of Hearing.

However, I have several concerns regarding the draft administrative rules on the Interpreter qualifications.

QUESTIONS REGARDING THE PROPOSED ADMINISTRATIVE RULES ON THE STATUTE FOR INTERPRETER LICENSURE

Thank you for sharing this draft copy of the administrative rules with people around the state. It is an important piece of legislation that can support quality assurance for people who are Deaf, Deafblind or Hard of Hearing when receiving interpreting services in serious medical, mental health or legal settings. The Registry of Interpreter for the Deaf (RID Inc.) is a professional organization that has established guidelines for interpreter ethics, and assessment of interpreting competency as well as support on-going professional development. In recent years, RID has been working with the National Association of the Deaf (NAD) to combine assessment tools. I do support the work and efforts of RID to establish and maintain quality interpreting services to people who are Deaf, Deafblind, or Hard of Hearing. However regarding this proposal, I do have some questions and concerns about specifics.

1. Who was on this committee? Since this proposed statute represents Wisconsin, were there people from throughout Wisconsin? Or was this a group primarily from Milwaukee where services are more plentiful? Were there representatives from the facilities and agencies who will be affected by this statute?
2. The statute addresses the need for professional development. Were representatives from interpreter preparation programs in Wisconsin a part of this committee? They are not mentioned within the body of the proposed statute and are conspicuously missing on the review board that is claiming power to determine what professional development will be required of those who violate this statute.
3. Will dollars be set aside for this professional development? Will there be guidelines that protect conflict of interest i.e. so that members of the review board will not only propose the professional development but also be the agency providing it? Where will the training occur? Will it be consciously provided in the areas of the state where the need is greatest i.e. the western and northern sections of the state?
4. For (6) there is the statement "... is currently certified **and who provides true and accurate communication...**" (emphasis added). This statement creates a policing nightmare. If RID certification is valid, but only for some, who will make the judgement calls regarding "and who provides true and accurate communication? This statement

implies that RID certification does not meet the need. Does this imply that Wisconsin will establish its own assessment in addition to the national assessment that will be more valid than the one nationally recognized? Who will do this? Is this a double standard? Does this make the requirement more stringent than national requirements?

5. Under the Legal Situations, there is the requirement that interpreters working in legal setting "... must possess current legal certification through the national RID and must have successfully completed the legal interpreter training through the Wisconsin Legal Institute or another accepted legal sign language interpreter training program defined by the department." A member of the committee that drafted this statute runs the Wisconsin Legal Institute. There is a conflict of interest in this statement as well as a statement that discredits the training that is provided on a national level by qualified trainers and recognized by the RID. I do have concerns about this language promoting a particular person / agency over others.
6. Under Sanctions, I have several concerns.
 - a) What is an "education letter"?
 - b) What are the guidelines for determining 1st, 2nd, 3rd ... offenses? Could someone be found to have 4 offenses in one week, before they are aware of the process in place? Or does one offense include an overall situation where a "complaint" was filed?
 - c) Under (2)(a)(2) Interpreters shall be fined \$500.00 *and* a requirement to participate in professional development as defined by the review board. (emphasis added)
 - 1) the \$500.00 fine for a second offense is steep
 - 2) ...*AND professional development as defined by the review board.* The review board does not have a member who is involved in interpreter preparation. Again, the agency in Milwaukee that was involved in drafting this proposal, wishes to become the agency for professional development statewide. I see a conflict of interest in the review board being the agency that designs the required professional development.
 - 3) The jumps between the penalties are steep and severe. Regarding "the loss of ability to practice in Wisconsin for a period of five years ...", does this mean to interpret in serious medical, mental health, and legal settings? Or does this mean that the interpreter cannot interpret at all?
 - d) I am puzzled as to why interpreters *must participate* in professional development activities and individuals *may participate*? In addition, "individuals" are not barred from practicing for the 5 year time period that is placed on interpreters? Does this say that "individuals" may continue to interpret? Who are the "individuals", family members?
 - e) Agencies and Facilities are fined and *may be subject to corrective action*? Why is it that interpreters "*must*" and facilities "*may*"? What will constitute a violation? Will this be different for facilities in more rural Wisconsin where RID certified interpreters are not available? How many phone calls must be made and how far before the police dept or hospital is found out of compliance? What is the corrective action? This is a clear imbalance of penalties.

7. Finally and of greatest concern is the design of the review board.
 - a) In this proposal, the review board is given a tremendous amount of authority to determine violations and the penalties imposed including the professional development and the corrective action. Yet, there are no agency or facilities representatives nor anyone from an interpreter preparation program on this board. In addition, what role is the parent to play on the board? This position does not make sense in light of the overall proposal.
 - b) "Upon receipt of the complaint, the review board may temporarily suspend an interpreters ability to practice." This statement is one of guilty until proven innocent. And does it mean that the interpreter can not interpret at all? Or just in the settings addressed in this statute?
 - c) The timeline of 10 days for the interpreter's right to appeal is unreasonable.

This statute will affect agencies statewide in a significant way. Have all Wisconsin police departments, courts, hospitals and mental health facilities, and interpreter referral agencies been given a copy of this proposal for their review? How are the agencies and facilities included in this process? The timeline for response (April 16, 1999 – less than 10 days) is a narrow window for comment.

Again, I want to reiterate that I do support quality assurance for interpreter services for Deaf, Deafblind and Hard of Hearing people in Wisconsin. The RID certification process is a valid measure of competency, and there is need for interpreters to continue their professional development in specific fields in order to be able to provide the level of service needed. While this draft statute is a good beginning, I hope that the state is willing to address and clarify specific areas. I also hope that this committee will view alternate proposals emphasizing participation from all areas of the state and with input from a wider range of people invested in this work in order to develop a fair and comprehensive statute that addresses the need while also addressing the potential for conflict of interest by a small group of people or one agency to design a statute that creates a business niche in development of the professional development etc.

Thank you,
Carol Schweitzer
4951 Midway Lane
Marshall, WI 53559

Position Statement in Opposition to License Fees for Ambulance Providers

The Wisconsin EMS Association opposes the implementation of license fees for Wisconsin ambulance service providers. Many of Wisconsin's ambulance services operate as non-profit, volunteer agencies. Many of these same services continually struggle financially in their operations. They look to community donations and hold fund raisers to purchase needed equipment and supplies, obtain continuing education, and upgrade the level of service that they provide to the community. It was for these reasons that the Funding Assistance Program (FAP) was created in 1990. In this program, the State of Wisconsin provides funding to ambulance services that provide primary emergency response. It is a complete contradiction for the State of Wisconsin to provide funding to an ambulance service and then mandate money be returned to the State of Wisconsin in the form of a provider license fee. This tactic is nothing less than moving money from an expense line of the state budget, to an income line of the state budget, in the form of a fee passed through the ambulance service.

During the past years, The Department of Health and Family Services (DHFS) and the State EMS Board have successfully demonstrated themselves to be friends and supporters of Wisconsin EMS and EMTs. The EMS Board has made it a priority to identify funding for EMS and has charged a committee with working toward this goal. Creating a new fee structure on ambulance providers directly contradicts the efforts of the EMS Board and the population they serve. It also sends a message to the Wisconsin EMS community that the ultimate goal of these two entities is truly not to support and aid Wisconsin's ambulance services.

The Wisconsin EMS Association urges that license fees for Wisconsin ambulance providers not be created. The implementation of an ambulance provider fee contradicts the efforts communities have instituted to generate volunteerism and to control costs associated with providing necessary services to local Wisconsin communities. The funds that might be raised for the State of Wisconsin through such a program are greatly outweighed by the negative impact that will be displayed on Wisconsin ambulance providers and EMTs. The Wisconsin EMS Association requests that this plan be removed immediately from the budget proposal of 1999-2000.



W-2 POLICY GROUP: 1999 LEGISLATIVE ISSUES (3/17/99 Draft)

After about a year of operation, it has become apparent that W-2 must be changed if we are to succeed as a state in moving people out of poverty and into the work force. The Policy Group on Welfare Reform, a coalition of statewide service, religious and non-profit organizations, recommends the following:

1. **Expand education and training opportunities and support to enable families to escape poverty and become self-sufficient.**
 - a. Allow those who lack basic skills, English language skills, and high school degrees, to concentrate on mastering those skills and obtaining degrees by being assigned up to 30 hours per week for education and training. Stipulate that any work assignments may not be allowed to interfere with their progress toward achieving these goals.
 - b. Provide that W-2 participants may pursue post-secondary training likely to lead to improved employment opportunities as long as they participate in up to 20 hours of subsidized or unsubsidized work activities, remain in good standing, and make reasonable progress.
 - c. Provide for child care eligibility for non-W-2 parents in education and training programs without a work requirement if they meet financial requirements, are in good standing, and are in a program likely to lead to employment.
2. **Provide better income support for families of marginal workers to prevent destitution of children.**
 - a. Pay benefits to all applicants who meet eligibility requirements, whether deemed "job ready" or not, within 30 days. Those required to do an up front job search should be placed in a W-2 work activity after 30 days, if they remain unemployed, and receive W-2 benefit payments for the month of job search.
 - b. Require agencies to place low-income, part-time workers in W-2 work or training positions and provide pro-rated W-2 benefits.
3. **Provide accountability and fairness in the system by restoring fair hearings and continuing benefits and providing a mechanism for participants to evaluate the program.**
4. **Improve access to W-2 and assessment of participants to make sure that low-income families are provided help when they most need it and are provided the kind of support they need to become self-sufficient.**
 - a. Provide mandatory training for all W-2 agency employees in dealing with special populations, including those with issues of domestic violence, homelessness, language and cultural barriers to employment and self-sufficiency, learning disabilities, AODA or other mental health problems.
 - b. Require DWD to promulgate rules setting standards for individualized assessments and improved services for the above populations, including counseling, legal services, transitional and subsidized housing, child care, and instructions for using available public transportation.
 - c. Require DWD to promulgate rules setting standards for intake and review procedures, access to emergency assistance and expedited food stamps, telephone access to agency workers, the right to be accompanied at interviews.
 - d. Provide rules that also cover timely access to county workers for those applying for food stamps, child care or medical assistance without applying for W-2 benefits.
 - e. Require the DWD to develop a Rights and Responsibilities statement and informational brochures for distribution at a potential applicant's first contact with the W-2 agency.

5. **Improve the quality of child care, and make it more affordable and accessible in order to ensure healthy children and more successful workers.**
 - a. Remove the requirement for co-payments for families with incomes below the federal poverty level, for foster parents and for those providing kinship care and reduce maximum copayments to 10% of income.
 - b. Increase eligibility limits for child care to 225% of the federal poverty level.
 - c. Restore the training requirement for all certified providers and increase the minimum training in child development.
 - d. Expand eligibility for in-home child care for second and third shift workers and sick children, regardless of the availability of out-of-home care.
6. **Improve transportation support to all low-wage workers, including public transportation, voucher systems and help with buying cars, reinstating licenses and obtaining occupational licenses.**
7. **Ensure adequate support for families with adults or children with disabilities or other significant barriers to work so that the basic needs of children are provided for while parents who are able to do so are helped to become self-sufficient.**
 - a. Increase the C-Supp benefit to \$250 for the first child and \$150 for each additional child of SSI parents.
 - b. Extend eligibility for C-Supp benefits to children of minor children of SSI parents.
 - c. Define as a W-2 work activity the care of a child with special needs or the care of a disabled member of the participant's immediate family.
 - d. Extend eligibility for child care services to 13 to 18 year old children with special needs.
 - e. Increase the benefit level for W-2T placements to equal the CSJ benefit.
 - f. Provide for eligibility for W-2 services (except for cash benefits) for SSI parents.
 - g. Eliminate the 2-year time limit for W-2 T placements.
8. **Support healthier babies by providing cash assistance to pregnant women and reducing work requirements for mothers of infants.**
 - a. Exempt parents of infants from work activities, except on a volunteer basis, for the first 12 months and provide voluntary parenting and mentoring support services.
 - b. Extend eligibility for W-2 work program placements to women in their last trimester of pregnancy, even if they have no other children.
9. **Expand eligibility for W-2 work programs to non-custodial parents.**
10. **Provide special attention to teen parents to set them on the road to self-sufficiency at the earliest possible time.**
 - a. Allow parents who are still eligible to attend high school to do so without any additional work requirement.
 - b. Exempt parents attending high school from child care co-payments while they are attending school.
 - c. Allow minor parents to apply for child care assistance on their own when a parent or guardian is unable or unwilling to do so.
11. **Expand eligibility for emergency assistance to those facing evictions, and make such assistance available to this new group as well as those who are homeless once every 12 months.**

AMERICAN COUNCIL OF THE BLIND 1999 LEGISLATIVE IMPERATIVES

INTRODUCTION

Our current legislative agenda focuses on four imperatives: Social Security reform, increased funding for Older Blind programs, proposed amendment of the Air Carriers Access Act, and proposed amendment of the copyright law to encourage increased production of books in specialized formats.

I. SOCIAL SECURITY REFORM

Two issues currently under consideration in Congress are of particular interest to persons who are blind or visually impaired.

Linkage

Issue: Until March of 1996, the exempt amount of earnings for blind persons receiving SSDI was linked by law to the exempt amount for seniors receiving Social Security. In 1996, that link was broken, resulting in a significant reduction in the earning capacity of many blind persons.

Proposed Legislative Action: ACB supports legislation that would amend Title II of the Social Security Act to restore the link between the maximum amount of earnings by blind persons permitted without demonstrating ability to engage in substantial gainful activity and the exempt amount permitted in determining excess earnings under the earnings test.

Improving Work Incentives

Issue: The President's Task Force on Employment of Adults with Disabilities has estimated that only about 22 percent of adults with visual impairments are currently employed. A large number of those adults who remain unemployed are dependent upon SSI and/or SSDI payments for subsistence. These programs are currently governed by regulations and policies which actually discourage people from seeking employment. For instance, people are frequently required to choose between a job and health insurance. Blind persons also face concerns about the cost of job-related transportation, assistive technology and reader assistance.

Proposed Legislative Action: ACB supports the Work Incentives Improvement Act of 1999 (S331) with or without the Ticket To Work And Self-Sufficiency provisions in Title II of the act, because this bill addresses important barriers to employment currently faced by blind persons seeking to leave the SSI and SSDI rolls and become self-supporting.

II. INCREASED FUNDING FOR SENIOR BLIND PROGRAMS

Issue: It is common knowledge that the fastest growing segment of the U.S. population is the group over age 65. One of the most common experiences of this population involves vision loss. As people live longer lives because of medical advances, an increasing number of them will be doing so while having to adjust to the impact of reduced or lost vision. Traditional rehabilitation programs have not

adequately addressed the needs of this population because the focus of these programs has been on assistance leading to employment. Individuals over age 65 may not be seeking to reenter the workforce, but they do need assistance in developing skills necessary to adjust to vision loss, avoid isolation, and maintain a quality, productive life. Current programs to serve this population are grossly underfunded.

Proposed Legislative Action: ACB supports legislation that would increase funding for programs serving the older blind, as authorized by Title VII, Chapter II of the Rehabilitation Act of 1973, as amended in 1998, to at least \$26 million beginning with fiscal year 2000 in order to ensure that funding for these programs is adequate to meet the needs of this rapidly growing population.

III. AIR CARRIERS ACCESS ACT AMENDMENTS

Issue: The Air Carriers Access Act has heightened the awareness of airline personnel to the needs of air travelers with disabilities and has provided recourse to persons with disabilities who have experienced discrimination by airlines. Unfortunately, airline practices remain inconsistent, incidents of discrimination in air travel against persons with disabilities continue, and of particular concern are those involving foreign airlines doing business in this country.

Proposed Legislative Action: ACB supports amendment of the Air Carriers Access Act, as proposed in S82, which would strengthen the enforcement provisions of the act, particularly as it applies to foreign airlines doing business in the United States.

IV. COPYRIGHT LAW AMENDMENT

Issue: Currently, fewer than 4 percent of the books and periodicals published in the United States each year are available in audio, large print, or braille formats which can be read by people who are blind or visually impaired. Recent changes in the copyright law allowing reproduction of books in alternative formats by authorized entities without prior permission from publishers and copyright holders have not led to increased access to these published materials for this country's blind and visually impaired population.

Proposed Legislative Action: ACB supports legislation that would amend the copyright law to require that publishers submit an electronic copy of each publication they register with the copyright office of the Library of Congress and that these electronic copies be submitted in a manner that conforms to the standards used by the National Library Service for the Blind and Physically Handicapped for the production of books in alternative formats. These electronic copies would then be available to the National Library Service for more timely production of books in braille, audio and large print formats.

For further information on the above issues, please contact the American Council of the Blind at 1155 15th St. NW, Ste. 720, Washington, DC 20005; telephone (202) 467-5081, website www.acb.org.

Facts: Copyright Law Amendment, 1996

National Library Service
for the Blind and Physically Handicapped
Library of Congress
Washington, DC 20542

Copyright Law Amendment, 1996:
PL 104-197

December 1996

Background

The free national library program of reading materials for visually handicapped adults administered by the National Library Service for the Blind and Physically Handicapped (NLS), Library of Congress, was established by an act of Congress in 1931. The program was expanded in 1952 to include blind children, in 1962 to include music materials, and in 1966 to include individuals with physical impairments that prevent the reading of standard print.

From the beginning, this program was dependent upon the cooperation of authors and publishers who granted NLS permission to select and reproduce in special formats copyrighted works without royalty. Although many factors influence the length of time it takes to make a print book accessible in a specialized format, the period required to obtain permission from the copyright holder has sometimes been significant.

Public Law 104-197

Under the Legislative Branch Appropriations Bill, H.R. 3754, Congress approved a measure, introduced by Senator John H. Chafee (R-R.I.) on July 29, 1996, that provides for an exemption affecting the NLS program. On September 16, 1996, the bill was signed into law by President Clinton.

The Chafee amendment to chapter 1 of title 17, United States Code, adds section 121, establishing a limitation on the exclusive rights in copyrighted works. The amendment allows authorized entities to reproduce or distribute copies or phonorecords of previously published nondramatic literary works in specialized formats exclusively for use by blind or other persons with disabilities.

The act making appropriations for the Legislative Branch for the fiscal year ending September 30, 1997, sets forth the Chafee amendment as follows:

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, that . . . and for other purposes, namely:

(a) IN GENERAL--Chapter 1 of title 17, United States Code, is amended by adding after section 120 the following new section:

"SEC. 121. Limitations on exclusive rights: reproduction for blind or other people with disabilities

"(a) Notwithstanding the provisions of sections 106 and 710, it is not an infringement of copyright for an authorized entity to reproduce or to distribute copies or phonorecords of a previously published, nondramatic literary work if such copies or phonorecords are reproduced or distributed in specialized formats exclusively for use by blind or other persons with disabilities.

"(b)(1) Copies or phonorecords to which this section applies shall--

"(A) not be reproduced or distributed in a format other than a specialized format exclusively for use by blind or other persons with disabilities;

"(B) bear a notice that any further reproduction or distribution in a format other than a specialized format is an infringement; and

"(C) include a copyright notice identifying the copyright owner and the date of the original publication.

"(2) The provisions of this subsection shall not apply to standardized, secure, or norm-referenced tests and related testing material, or to computer programs, except the portions thereof that are in conventional human language (including descriptions of pictorial works) and displayed to users in the ordinary course of using the computer programs.

" (c) For purposes of this section, the term--

"(1) 'authorized entity' means a nonprofit organization or a governmental agency that has a primary mission to provide specialized services relating to training, education, or adaptive reading or information access needs of blind or other persons with disabilities;

"(2) 'blind or other persons with disabilities' means individuals who are eligible or who may qualify in accordance with the Act entitled 'An Act to provide books for the adult blind', approved March 3, 1931 (2 U.S.C. 35a; 46 Stat. 1487) to receive books and other publications produced in specialized formats; and

"(3) 'specialized formats' means braille, audio, or digital text which is exclusively for use by blind or other persons with disabilities."

(b) TECHNICAL AND CONFORMING AMENDMENT--The table of sections for chapter 1 of title 17, United States Code, is amended by adding after the item relating to section 120 the following:

"121. Limitations on exclusive rights: reproduction for blind or other people with disabilities."

Questions and Comments Raised by the Chafee Amendment

Q. What is the effective date of the amendment?

A. H.R. 3754 does not specify an effective date. Therefore, the effective date is September 16, 1996, the date on which the president signed the bill.

Q. Are the provisions of the amendment retroactive?

A. The exemption covers all nondramatic literary works protected by copyright regardless of when they were first published, but reproduction and distribution under the exemption must take place on or after September 16, 1996, the effective date of the amendment.

Q. Does the amendment cover periodicals?

A. The new exemption covers "nondramatic literary works"; section 101 of title 17 includes "periodicals" within the definition of "literary works." Therefore, the amendment covers periodicals.

Q. If a book is involved in litigation, will the exemption apply?

A. Nothing in the Chafee amendment withdraws the exemption in case of litigation. However, in the event that NLS is notified that a federal court has issued a final decision, holding that the work is an unauthorized publication and recall of copies is required, NLS will withdraw all copies of the infringing work.

Q. Is a published script of a play considered a "nondramatic literary work?"

A. A published script of a play would be considered a "dramatic work" or alternatively a "dramatic literary work" and would be outside the amendment, which covers only "nondramatic literary works." Therefore, NLS will continue to seek permission from the copyright holders to reproduce and distribute plays.

Q. What does "authorized entity" include?

A. The amendment defines and limits "authorized entity" to "a nonprofit organization or a governmental agency that has a primary mission to provide specialized services relating to training, education, or adaptive reading or information access needs of blind or other persons with disabilities." A "nonprofit organization" is understood to mean an organization that has been granted nonprofit tax exemption under section 501(c)(3) of the Internal Revenue Code.

To the extent that authorized agencies and organizations use or delegate authority to volunteers, special education teachers, and commercial producers under government contract to produce and distribute works under the exemption, those activities appear to be fully covered by the exemption. Such individuals can be said to be agents of authorized entities and are, therefore,

acting under implied authority. The activities of individuals not connected to those specialized agencies and organizations fall outside the exemption.

Q. Is copyright permission required for works published simultaneously in the United States and elsewhere?

A. All works protected by U.S. copyright law, including those first published abroad or in multiple editions published in several countries, are subject to the exemption for activities undertaken by authorized entities within the United States. Section 104 of title 17 sets out the eligibility requirements for U.S. copyright law protection. For further information, obtain Circular 38a from the Copyright Office.

Q. NLS produces braille and recorded versions of books published and copyrighted abroad. Under the Chafee amendment, will permission from foreign copyright holders be required?

A. All works protected by U.S. copyright law, including those first published abroad, are subject to the exemption. Thus, permission from foreign copyright holders for reproduction and distribution in the United States under the exemption is not required. If the braille or recorded versions of the books were distributed outside the United States, however, such act of distribution would not be covered by the exemption since U.S. copyright law has no extraterritorial effect. Since NLS loans material to eligible foreign agencies, NLS will continue to request permission for all books and periodicals published outside the U.S.

Q. Must foreign agencies who purchase NLS books continue to obtain copyright clearance?

A. Foreign agencies who purchase NLS books must continue to obtain copyright clearance. The principle with respect to this is the same as described above. The exemption applies only to activities within the United States.

Q. Will foreign countries still be able to purchase magazines that NLS produced in special formats?

A. As the previous answer indicates, the exemption will not apply to activities conducted abroad. Therefore, foreign agencies will have to seek their own individual written copyright permissions from the copyright holders before NLS will permit the purchase of copies of master recordings of audio magazines reproduced by NLS under the new exemption.

Q. Must producers continue to add "all rights reserved" to the standard copyright notice that is currently placed at the beginning of books reproduced in special formats?

A. No, this is not required. The "all rights reserved" copyright notice originated in the Buenos Aires Convention of 1910. The effect of this Convention in the United States has always been

unclear. Since the United States joined the Berne Convention in 1989, there clearly is no need to include this statement.

Q. Does "bear a notice" refer only to announcements or does it include the print label affixed to all copies and phonorecords?

A. Section 121 of title 17 has two notice requirements; it provides that the copies or phonorecords produced under the exemption shall (1) "bear a notice that any further reproduction or distribution in a format other than a specialized format is an infringement," and (2) "include a copyright notice identifying the copyright owner and date of the original publication."

The copyright law has contained notice requirements for many years; those requirements have always been understood to mean a written notice. The previous copyright law contained a provision that said "copies of the work shall bear the symbol (c) accompanied by ..." Thus, the use of the word "bear" has been understood to mean that the copies have affixed to them a written copyright notice. In the 1976 copyright act, sections 401 and 402 of title 17 provided for the placement of a notice of copyright on visually perceptible copies and on the surface, label, or container of phonorecords of sound recordings.

Consequently, NLS will (1) include both of the required notices, in print, on all braille copies and on all phonorecords of sound recordings, and (2) include both notices in audible form on all sound recordings.

Q. Does "specialized format" include the NLS-produced instructional music cassettes recorded at the standard commercial speed of 1-7/8 ips rather than NLS's customary 15/16 ips speed?

A. The exemption does not include music, nor does it cover recorded material that is not in a "specialized format."

Q. NLS compiles a music magazine containing articles reprinted from national periodicals. Are magazines that are produced in large print, braille, and recorded formats covered by the exemption?

A. The exemption defines "specialized format" as "braille, audio, or digital text which is exclusively for use by blind or other persons with disabilities." Works reproduced in large print are, therefore, not included under the exemption.

Q. Where should questions concerning the Chafee amendment be directed?

A. Questions originating from the media should be directed to the Library of Congress Public Affairs Office at (202) 707-2905. Contact the Library of Congress Copyright Office Public Information Office at (202) 707-3000 for other general questions.

Q. NLS currently lends books through interlibrary loan (ILL) to foreign agencies serving blind and physically handicapped individuals. Will this practice continue, or will ILL be limited to books for which NLS has received copyright permission?

A. NLS will continue to lend to eligible foreign agencies through interlibrary loan. Such distribution is permissible under U.S. law and is unlikely to infringe the laws of other countries.

However, foreign agencies must look to the law of the country where the use takes place to determine whether they might be liable for acts of unauthorized importation or distribution of lawfully made copies without permission of the copyright owner.



**THE LEAGUE
OF WOMEN VOTERS OF WISCONSIN, INC.**

122 State Street, Madison, Wisconsin 53703-2500 608-256-0827 FAX 608-256-2853

**Statement to the Joint Committee on Finance on the Human Services Provisions
in AB 133/SB 45**

April 1999

Over the years the League of Women Voters has developed through its study and member agreement process many positions concerning human services. On the basis of those positions, we have a number of comments and suggestions to make concerning the provisions in AB 133/SB 45.

We commend the Governor for working toward a performance-based determination of W-2 agencies' profits. We believe this change will help to make the agencies' performance better and more accountable by requiring them to show that their clients are getting all the services they need to really be able to get and keep jobs.

We also commend the governor for realizing that the 16% per cent of income limit for child care is too high but we believe that lowering it to 12% not enough. We believe that there should be no co-pay if a family is at less than poverty level and that the limit should be 10% for those above it. We also believe that eligibility should be extended to 225% of the poverty level. Families within this limit are close to the edge of making it when such demands are made on their limited means. Child care providers often must eat the loss when families cannot make the co-payment, putting their own businesses and the availability of child care at risk.

We are also concerned about the lack of child care support for in-home care for second and third shift workers. Children who must have their sleep interrupted to be taken out and picked up are under a severe burden. A parent should be able to get reimbursement for someone who will care for the children at home. We also believe that all certified child care workers need training, including training in child development.

There are a number of problems with W-2 that we urge the legislature to correct. The fair hearing process for dealing with complaints should be restored to what it was under AFDC. It cannot be considered a fair method of handling complaint appeals when the Department of Workforce Development sits in judgement, with no other recourse, on the program which it runs. Given that 2/3 of the complaints under AFDC were found to be justified by independent hearing officers, it is probable that a similar situation may exist under W-2. We do not think it is the intention of the legislature to have a program that is run capriciously.

We believe that W-2 would help people become truly self-sufficient if real educational opportunity were provided. We urge the legislature to allow those lacking basic skills, English language skills and high school diplomas be allowed to use up to 30 hours per week of education to meet their work requirements, and that no work requirements be allowed as long as they are in good standing and making progress toward their education goals. We also believe that W-2 participants should be allowed to pursue post-secondary education programs as long as they work up to 20 hours a week, remain in

good standing and make reasonable progress. Better educational opportunities would be a help to employers, too, by increasing the supply of more skilled workers.

The W-2 program set up four job categories. We are concerned that a fifth category has developed - that of "job ready." These people receive no benefits once they are so labeled. If for whatever reason they cannot find a job, they are left without any resources. We ask the legislature to provide benefits whether "job ready" or not, if employment is not found within 30 days. We also ask that those who are only paid for part-time work be provided with pro-rated benefits.

There is considerable evidence that W-2 has not been easily accessible and that, because of poor assessments, participants are not getting help when they most need it. W-2 agency employees are not adequately trained to deal with special populations, such as victims of domestic violence, those with cultural and language barriers to employment, the homeless, those with learning disabilities, AODA or mental health problems. The DWD should be required to establish standards for assessments and for the provision of services, such as counseling, legal services, etc. While we understand that agencies need flexibility in meeting the needs of participants, that is not inhibited by defining what constitutes those services. Participants also need to be informed what their rights and responsibilities are. Those applying for food stamps, medical assistance and child care without applying for W-2 benefits should be served promptly. The DWD would actually be assisting the agencies in performing better by clarifying these issues through a good rule-making process.

Families with either an adult or a child with disabilities face major problems. When the adult has a disability, we agree with the Governor that the allowance for the children should be increased. However, we ask that the allowance for the first child be increased to \$250, with \$150 per child for each additional child. This added supplement would help the family to meet the greater expenses caused by a first child. When a child has a disability, child care support should also be provided until the child is 18. Since care for severely disabled children may be very difficult to find, care of that child should be considered a work activity in meeting W-2 work requirements. The benefit level for W-2T should be raised to equal the grant for CSJ benefits and the two year limit should be eliminated for those with disabilities which are not covered by SSI.

We urge the legislature to exempt new mothers from work activities for the first 12 months. With the high cost and lack of availability of child care for infants and the research that shows the importance of the child's first years in determining its future, parents should be offered voluntary parenting and mentoring support services during that first year. In addition, pregnant women should be eligible for W-2 services in the last trimester, even if they have no children. This is not a time when they can easily find jobs and they need services to ensure healthy babies. Teens also need some special treatment. They should be allowed to complete high school with no additional work requirements and should be exempted from child care co-payments while doing so. This will allow them to give their full attention to completing school, better preparing them for achieving self-sufficiency.

Finally, we ask that emergency help be available once every 12 months to those facing evictions as well

as those who are homeless.

We recognize that all of these changes would require money. However, since there is a large excess of Temporary Assistance to Needy Families funding, we believe that those funds should first be used to meet the needs described above of W-2 participants who are trying to become self-sufficient. If then there is left-over money, it can be used for other human service needs.

Among those other needs is increased funding for Community Aids. This funding has not been increased in several years. W-2 is not a substitute for Community Aids; it provides services for all parts of the population, not just the poor, and is used to provide services for a variety of needs. Wisconsin has a proud history of providing assistance for all sorts of vulnerable people and it should not let that assistance deteriorate further. The burden for meeting these needs will increasingly fall on the local community or be abandoned to the detriment of these citizens. We urge the legislature to at least provide an increase to cover inflation.

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