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

CHOICES FOR INDEPENDENT LIVING, INC.
941 W. Fountain Street
Mineral Point, Wisconsin 53565
Telephone (608) 987-3775
Fax (608) 987-3082

April 15, 1999

Senator Brian Burke
Senator Russell Decker
Senator Robert Jauch
Senator Kevin Shibilski
Senator Gwendolynn S. Moore
Senator Kimberly M. Plache
Senator Robert L. Cowles
Senator Mary E. Panzer
Rep. John Gard
Rep. Cloyd A. Porter
Rep. Sheryl K. Albers
Rep. Dean R. Kaufert
Rep. Mark C. Duff
Rep. David W. Ward
Rep. Gregory B. Huber
Rep. Antonio Riley
Joint Finance Committee
State Capitol
Madison, WI 53707

Dear Senator Burke, Senator Decker, Senator Jauch, Senator Shibilski, Senator Moore, Senator Plache, Senator Cowles, Senator Panzer, Rep. Gard, Rep. Porter, Rep. Albers, Rep. Kaufert, Rep. Duff, Rep. Ward, Rep. Huber, and Rep. Riley:

Thank you for this opportunity to submit requests and comments regarding the Wisconsin State Budget.

On behalf of the Board of Directors of CHOICES for Independent Living, Inc, I ask that your committee consider our request for $80,000 for locally-controlled and locally-accessible independent living services in rural southwestern Wisconsin.

Independent Living (IL) services are aimed at all persons with disabilities regardless of age. The four core services provided by independent living centers are: (1) information and referral; (2) individual and systems advocacy; (3) peer counseling; and (4) independent living skills training. Based on local consumer/client needs, other services provided may include housing, legal/paralegal, financial/benefit counseling, vocational, education, assessment, case management, communications, transportation, social/recreational, and personal growth/self-help.

Unlike many states, Wisconsin independent living centers have been concentrated in metropolitan areas. Certainly, there is a great need for independent living services in high population areas, and it is often difficult to extend the services to surrounding rural counties. However, the geographic isolation experienced in rural areas is particularly felt by people with disabilities and necessitates different solutions for problems experienced by rural citizens.

CHOICES for Independent Living, Inc. has been formed by people with disabilities who live in southwestern Wisconsin. It is ready to provide independent living services to people living in Grant, Iowa, and Lafayette Counties. However, come July 1, there will be no independent living center funds designated to go to small, rural agencies. Ultimately, rural people all over Wisconsin will be affected by the outcome of this request.

Thank you for listening to our concerns and for considering our proposal.

Sincerely,

Jan Walker
Chair, Board of Directors
CHOICES for Independent Living, Inc.

Enclosure

cc: Sen. Dale W. Schultz
Representative David Brandenmuehl
Representative Stephen J. Freese

BUDGET REQUEST

$80,000 for a small, rural Independent Living Center (ILC) in southwestern Wisconsin.

BACKGROUND

1994 - 1997

There were many conflicting ideas about who should provide independent living services in the thirteen western and southwestern counties of Wisconsin. In an attempt to resolve these differences, the State awarded Independent Living Center (ILC) funds to Great Rivers Independent Living Services (GRILS) in LaCrosse with the requirement that they subcontract the funds for Grant, Iowa, and Lafayette Counties to the Hodan Center in Mineral Point.

From the beginning, Great Rivers Independent Living Services (GRILS) and Hodan Center had an uneasy partnership. Great Rivers did not like being required to provide services through a subcontract with an agency which provided any centrally-based rehabilitation services to people with disabilities. However, the Hodan Center believed that, without this requirement, southwestern Wisconsin would have received few, if any, independent living services. Local consumers/clients were concerned that people in LaCrosse did not understand and were not listening to their rural concerns. Often, southwestern Wisconsin is not included in the same service area as LaCrosse which, unfortunately, meant that there was no base of trust to build on or work through these disagreements.

1997 - 1998

According to the 1997 Satisfaction Survey, the independent living services the Hodan Center provided under its subcontract with Great Rivers Independent Living Services (GRILS) were rated higher by both consumers/clients and service providers in their three-county area than the independent living services GRILS provided in the other counties.

On November 17, 1997, GRILS sent a letter to the Hodan Center stating that the Hodan Center would have to end all rehabilitation services provided on-site or GRILS would not continue subcontracting with the Hodan Center after June 30, 1998. On February 19, 1998, the Independent Living Consumer Advisory Committee in southwestern Wisconsin overwhelmingly voted to recommend the Hodan Center received Independent Living Center (ILC) funding with the understanding that it would "spin-off" the ILC program to created an independent, free-standing, locally-controlled independent living center. The Consumer Advisory Committee members were excited about the potential for local control and local leadership development.

1998-1999

Hodan Center obtained funding through the Wisconsin Department of Health and Family Services' Bureau of Aging and Long Term Care Resources to continue independent living services while an independent agency was established. CHOICES for Independent Living was formed, became recognized as an independent non-profit corporation, and has applied for 501(c)(3) tax-exempt status.

1999-2000

In general, Wisconsin Independent Living Centers have been established in larger cities and include large unserved and under-served rural areas. Unfortunately, the new State Plan for Independent Living continues this trend. The Plan does not provide funding for rural Independent Living Centers. Instead, it designates only Milwaukee and the Fox River Valley as expansion areas. It strives for $500,000 and 500,000 people per Independent Living Center. This focus of independent living services in urban areas means that most rural Wisconsin residents with disabilities will live more than an hour drive from their Independent Living Center; it will be difficult to promote grass-roots advocacy for rural people with disabilities; few opportunities will be available for rural persons with disabilities to have a real voice in policies affecting their lives; and more people with disabilities will move from rural to urban areas because they believe they must do so to obtain need services.

CHOICES for Independent Living, Inc. has been formed by people with disabilities. It is ready to provide locally-controlled and locally-accessible independent living services to citizens of southwestern Wisconsin.

Dear Joint Finance Committee Members:

The Wisconsin Council of the Blind would like to bring to your attention several areas that we are concerned about in the upcoming budget. Our concerns are based on areas that significantly affect persons who are blind and or visually impaired.

1. We are concerned that funding for an inter-city transportation pilot project has been taken out of the budget by the Department of Administration. Our major concern is that inter-city transportation is lacking for persons who are blind or visually impaired, as well as for those who do not drive for other reasons. We urge your support in restoring funding that will study the need for such services. Our concerns do not simply relate to getting people from place to place, but more importantly, we are concerned about the negative impact that the lack of adequate transportation has on peoples' ability to participate in such things as employment, socialization, recreation and the general opportunity to participate in society.

2. The Business Enterprise Program is a program that provides blind or visually impaired persons with the opportunity to establish small businesses. The program began in the 1930s and under the federal Randolph Shepherd Act, states are mandated to carry out such a program.

Because of the retirement of two of the three persons holding supervisory positions in the program, and because the third position is currently held by a new person, we are concerned over the vacant positions. We urge your support to ensure that qualified persons be sought and considered for the position in a timely manner.

3. We urge your support in restoring 5 (five) positions that have been cut at the Wisconsin School for the Visually Handicapped in Janesville. As you know, a legislative study is currently underway, and any attempt to cut staffing at this time will not only seriously affect the ability to serve the children who are already there, but will also make it difficult to implement any recommendations that might come from the study.

4. We urge your support in restoring the sum of $100,000 to services for older blind. As a Council, we serve many older blind persons and work very closely with the Rehabilitation Teaching Program offered through the Office for the Blind. We recognize how important the services offered by Rehabilitation Teachers are to the lives of many citizens of this state. This program affords persons who are losing vision the opportunity to re-learn basic skills; allowing them to continue living in their own home, and as importantly, continue to be productive and involved with families and community.

As a Council, we work very closely with the rehabilitative teaching program, and in fact, the Wisconsin Council of the Blind provides $1000.00 for each Rehabilitation Teacher to meet the needs of persons who already fall between the cracks.

5. We ask your support in the increase of funding for the Library Services for the Blind and Physically Handicapped. It is our understanding that inflationary costs were added to the budget for consideration of inflationary contract costs. We urge you to support allocations in the following manner: the first year budget increase of $38,300, second year of $73,600, for a total of $111,900 for the two year period. Many of the persons we serve use the library's services to blind and physically handicapped. For most it provides a an opportunity not only to continue to read in an alternative format, but as importantly, affords the opportunity to stay in touch with their peers.

6. We urge your support for an amendment to the statutes that will provide funding for the News Line program. It is our understanding that universal service funds were in the statutes for the last budget, and that an amendment to allow statutory language to again use universal service funds would be required to continue funding. We urge your support in this area because, while the program is relatively new, it meets an age old problem for persons who cannot read print. It affords the opportunity to access news and current events in a manner that is also timely.

SPECIAL COMMUNICATION

A Case for the Development of Family Practice Rural Training Tracks

James R. Damos, MD, Carrol Christman, MA, Craig L. Gjerde, PhD, John Beasley, MD, Maggie Schutz, RN, MS, and Mary Beth Plane, PhD

Enthusiasm for alternate training sites has been strong among practicing family physicians and students seeking family practice residency positions in Wisconsin. The number of rural training tracks in the state is increasing rapidly. The University of Wisconsin currently has 4 residents in two rural training tracks. If 1998 recruitment is successful, there will be 12 residents in seven rural training tracks operated by two sponsoring institutions in the state. The Wisconsin rural training tracks are 1-2 programs,[1] in which the family practice resident spends the first year in the urban medical center of the home program completing appropriate rotations, such as internal medicine, pediatrics, obstetrics-gynecology, emergency medicine, surgery, and critical care, and the last 2 years in a rural community and rural hospital as an apprentice with a family practice group. During the last 2 years, the resident can receive longitudinal training in specialty areas with visiting subspecialists and can spend time away from the rural medical practice for specialty rotations not available in the rural setting.

The development of the Wisconsin rural training tracks was based in part on the pioneering work of Rosenthal et al.[2] The process used to develop the first rural training track was adopted as a template for developing other rural training tracks in Wisconsin and in other states.[3] Not much has been published, however, assessing educational outcomes and documenting the effects of rural training tracks on communities. Despite this lack of documentation, we believe rural tracks have merit as a training model for family practice and they should continue to be developed and studied for the following reasons:

Submitted, revised, 12 November 1997.

From the Department of Family Medicine, University of Wisconsin Medical School, Madison. Address reprint requests to James R. Damos, MD, Department of Family Medicine, University of Wisconsin Medical School, 777 South Mills St, Madison, WI 53715.

Rationale for Rural Training Tracks

Family Physicians Are Urgently Needed to Provide Comprehensive Medical Services in Rural Areas

Compared with 9 percent of urban residents, 29 percent of rural residents of the United States live in areas with a shortage of health professionals.[4] Both the Council on Graduate Medical Education (COGME) and the American Academy of Family Physicians have recommended increasing the number of family physicians, in part, to meet the needs of rural and underserved areas. COGME also noted that while there are sufficient numbers of physicians, many generalists and specialists remain largely regionalized to urban and metropolitan centers.

An article in a recent American Family Physician newsletter[5] comments on maldistribution even within family medicine:

> Family medicine has provided thousands of physicians to underserved rural communities over the years. In recent years the number choosing rural practice have remained at about 600 per year, despite increases in residencies and resident positions. Family practice is now in danger of becoming much like the other medical specialties: as the supply increases, there is increasing maldistribution of the specialty. The only exception to this rule is urban poverty practice where family practice graduates have posted major increases. If family medicine fails to address this location issue, it will soon face more than threats to Title VII funding. Without special efforts to increase the numbers of family medicine residents choosing rural locations, much of the political power of the specialty will be lost. This could have impacts on graduate medical education funds at the federal and state levels.

We contend that family medicine must not only see as its mission the need to encourage graduates to select rural practice, but it must also be prepared to provide the needed comprehensive services. Maternity care, care of the elderly, and emergency care are essential services that are often inadequately available in rural areas.

In counties with populations of fewer than 10,000, less than 1 percent of the physicians are obstetricians.[6] With obstetricians largely regionalized near urban or teaching centers, the provision of maternity care in rural communities is essentially the responsibility of family physicians and certified nurse midwives. Two thirds of women giving birth in rural communities are attended by family physicians or general practitioners.[7] Nationally, however, the number of family physicians providing maternity care has been dropping for a variety of reasons (malpractice, lifestyle, struggles getting privileges in hospital maternity care units, lack of role models during residency training, and fear of emergencies that can develop even in low-risk deliveries).[8-11]

The declining role of the family physician in maternity care is having an impact on access to maternity care in rural communities. Larimore and Davis[12] have shown that declining access to maternity care in rural areas affected the ability of Florida to reduce its infant mortality rate. Allen and Kamradt[13] suggested that decreased access to maternity care in rural areas of Indiana resulted in an increase in infant mortality. Nesbitt et al[14] found that maternity patients who must travel from rural areas to regionalized perinatal centers for prenatal care and delivery have more complicated deliveries, higher rates of prematurity, and higher costs of neonatal care.

Family physicians and general internists provide the majority of primary care services to the home-dwelling elderly and nursing home residents in rural communities. Many rural elderly are unwilling or unable to travel to urban areas to see a variety of subspecialists for their multiple medical problems. The elderly population is growing at a pace greater than that of the general population.[15,16] Currently 1.5 million Americans live in nursing homes; by the year 2030, this number could increase to 5 million.[17-19] Rural elderly represent a large population that is particularly vulnerable to health care provider shortages.

To save lives, rural hospital emergency departments must be able to manage the first hour of trauma or critical care before transfer can be made to a higher level center. Many rural family physicians have completed emergency advanced life support courses (advanced cardiac life support, advanced trauma life support, pediatric advanced life support, advanced life support in obstetrics) and routinely provide emergency services when residency-trained emergency physicians are not available. In reality, even when board-certified emergency physicians are available at a rural hospital, family physicians are called in to assist with major trauma when many victims are involved.

Table 1. Relation Between the Length of Rural Training and Rural Practice Choice.

Number of Required Rural Months	Programs with Rural Months, No.	Graduates Choosing Rural Practice, %
0	212	24.4
1	82	36.5
2	29	45.6
3	15	52.3
4-6	4	51.0
22+	11	68.5

Length and Content of Training Appear to Be Related to Choice of Rural Practice

Many family practice residencies offer residents a brief exposure to a rural family practice career through rural rotations. A short exposure might not be enough. Bowman[20] found that the more time family practice residents were required to spend in rural communities with rural physicians, the higher the likelihood of the residents choosing rural practice (Table 1). Their national survey of rural family physicians found that 31.5 percent took a required rural rotation during residency and 48.5 percent took an elective rural residency month. The same study showed that the more maternity care training a family practice resident had, the more likely he or she was to choose rural practice (Table 2).

Residents Tend to Settle Where They Train

Magnus and Tollan[21] reported that the establishment of a new medical school in northern Norway had a beneficial effect with 56 percent of the graduates remaining in remote northern areas. Lebel and Hogg[22] showed that community-based residents in Ottawa were more likely to choose a

Table 2. Relation Between the Length of Obstetrics Training and Rural Practice Choice.

Number of Obstetric Rural Months	Number of Programs	Graduates Choosing Rural Practice, %
2	14	23.8
3	11	31.2
4	71	34.1
5+	30	42.1

small community practice, and LeFevre and Colwill[23] found that residency location had an effect on practice location.

The experience of the University of Wisconsin family practice residency programs indicates that residency location is a strong determinant for graduate practice location. Dots representing all program graduates in Wisconsin (Figure 1) show clusters of graduates around the residency training sites. We speculate that if more training is moved to rural tracks, the same factors that encourage residents to practice near their urban residency sites will lead them to practice near their rural residency sites as well as in other rural sites. Bowman[20,24] recommends rural tracks as one strategy for increasing rural practice selection based on evidence from the Society of Teachers of Family Medicine study.

Urban Residency Programs Where Graduates Locate Might Have Difficulty Providing Sufficient Patient Care Experience for Residents

The history of subspecialization offers a warning. Until the 1950s, most US physicians were general practitioners who had 1 year of postgraduate training (rotating internship). In the 1950s and 1960s, the National Institutes of Health began to offer research fellowships to attract young physicians into academic research.[25] By the 1970s, research fellowships became clinical fellowships and further evolved into subspecialty residency positions that were supported by Medicare or hospital funds. Hospitals found that subspecialty residents were essential because they could perform a wide variety of procedures and provide both care for hospitalized patients and service to the hospital.

The increased number of subspecialists graduating from university hospital fellowships prompted community hospitals to add subspecialists to their staffs. As these graduates began to care for patients in the same communities served by the university hospitals, the number of patients needing attention at the university hospitals declined, and many university hospitals began to struggle for patient referrals.

Likewise, family practice training programs might also see their clinic patient populations decline in urban areas as their graduates enter practice in nearby communities. Continuous patient care with a stable panel of patients is a basic requirement for family practice training and program accreditation. Although rural tracks are not the only option for providing residents with access to stable patient populations, such programs move residents into settings that can provide equivalent or better training while taking the pressure off urban programs.

Rural Family Physicians and Their Practices Are Well Suited to Prepare Residents for Rural Practice

Academic medical centers that require tenure pressure family practice faculty to develop a research focus, obtain grant support, and publish in peer-reviewed journals. Academic development, however, can come at the expense of maintaining the wide range of clinical skills essential to rural family practice; university-based family practice faculty might drop maternity care, critical care, or procedures common to rural family practice to focus on teaching and research in a limited area. These limitations can result in fewer comprehensive practice role models for residents interested in rural practice, where a broad set of clinical practice skills is needed (maternity care, emergency care, care of adults, care of the elderly, care of children and adolescents).

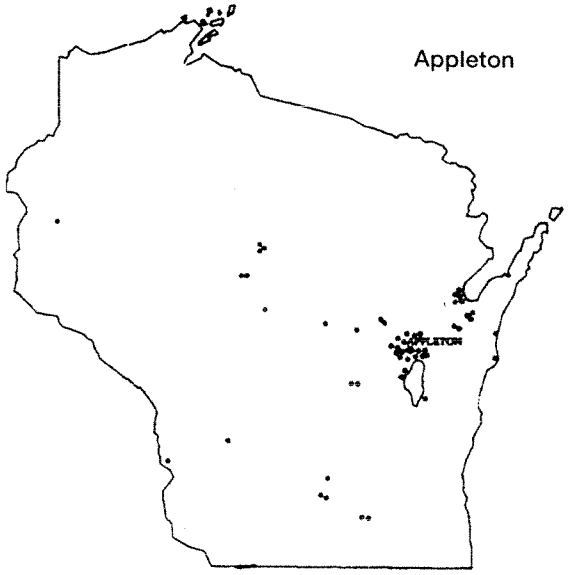
Observing rural physicians successfully provide maternity care can be a great encouragement to residents. In a 1991 survey, University of Wisconsin family practice graduates suggested that to keep maternity care a strong part of family practice, residents should be ensured the positive experience of working with skilled, confident family physician role models.[26] Graduates recommended avoiding training by nonsupportive obstetricians, even if it meant training in a community outside the program where family physicians routinely provide maternity care and work collaboratively with obstetricians.

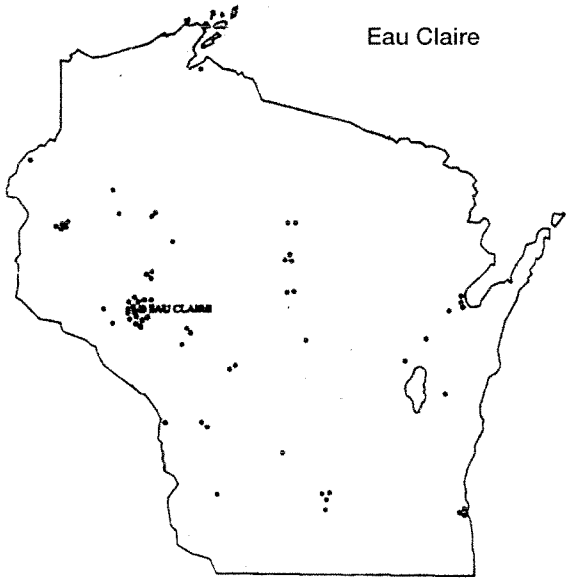
Smith and Howard[27] reported that factors positively associated with providing maternity care were (1) practicing in a rural community and (2)

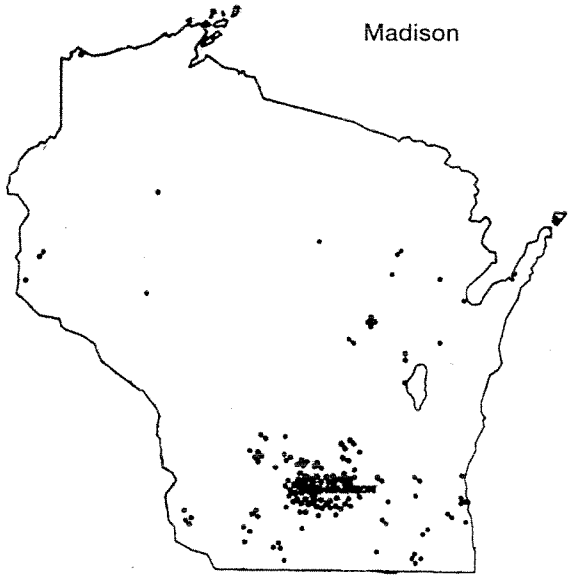
Figure 1. Locations of University of Wisconsin family practice residency graduates (1973-1996) practicing in Wisconsin.

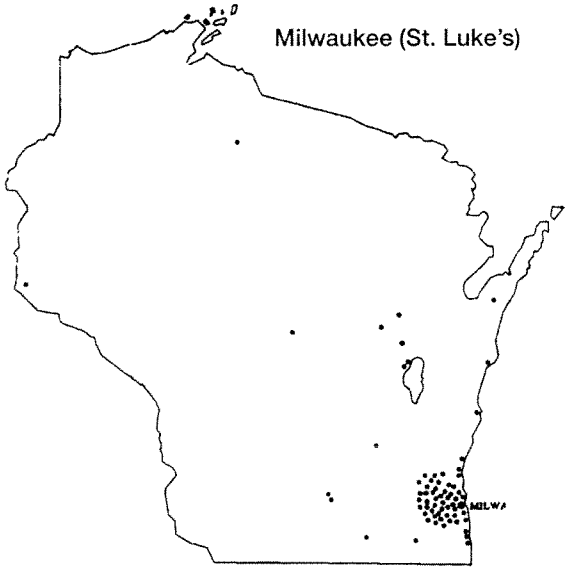
Program	Total Graduates No.	Graduates in Wisconsin* No.(%)
Appleton	87	53 (61)
Eau Claire	109	68 (62)
Madison	289	149 (52)
Milwaukee	129	73 (57)
Wausau	88	57 (65)

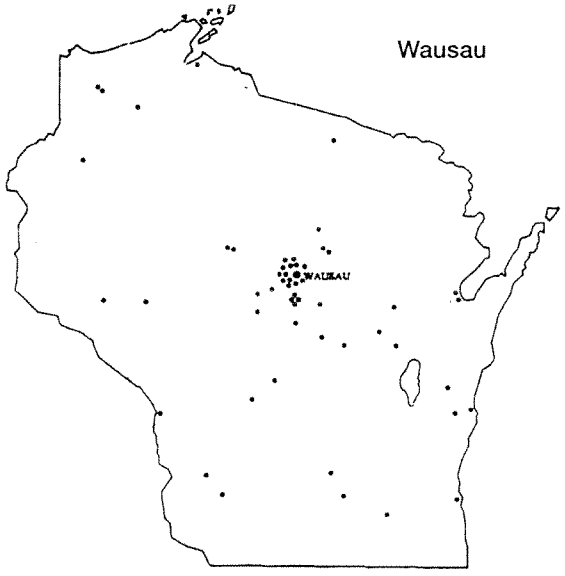
*Confirmed number, 10-15% might be lost to follow-up.
Note: each dot = 1 graduate.











being exposed to good family physician role models during training; they found that graduates who felt inadequately trained in maternity care chose not to provide maternity care and were more likely to go into urban practices. The nursing literature is replete with the value of mentors as role models in training.[28,29] A national survey by Sakornbut and Dickinson[30] illustrated that supervision of obstetric care by family practice faculty increased three- to four-fold the likelihood that family practice residents will choose to do obstetrics.

The lack of immediate on-site specialty backup in rural areas should be seen as a challenge rather than as a threat to the aspiring rural family physician. In larger urban teaching centers, an abundance of subspecialists are available for immediate consultation for neonatal resuscitation, delivery room emergencies, and trauma and cardiac emergencies. In some cities, family practice residents are told by subspecialists and even by some academic family physician teachers that they should not be performing certain procedures common to rural practice. Because referral is the accepted standard of care in university settings, family physician faculty might be more likely to refer patients who would normally be cared for by family physicians in rural settings. As a result, urban family practice residents can learn a sense of helplessness when encountering delivery room emergencies (retained placenta, postpartum hemorrhage, instrument delivery) and neonatal emergencies (resuscitation, sepsis evaluation, hypoglycemia, tachypnea) and miss the opportunity to acquire the breadth of skills needed in rural practice.

Other rapidly evolving changes in urban health care systems further highlight differences in urban and rural practice. In some large university programs, the combination of managed care, numerous clinical sites, heavy reliance on Medicare funds passed through hospitals, and multiple duties of academic faculty require complex, multiclinic after-hours call systems quite different from systems encountered in rural practice. The evolution of a hospitalist model, in which family physicians care for outpatients and subspecialists care for inpatients, is also gaining momentum in some larger urban areas. How will family physicians receive training relevant to rural family practice if changes such as these become the norm?

Our rural family physician colleagues and the environment in which they practice can be much better positioned to serve the family practice resident interested in a rural career.

Rural Training Tracks Offer Advantages for Residents, Academic Faculty, and Rural Physicians

Family practice residents are exposed to many advantages when they receive training in a rural community. Fewer primary care residents and very likely no subspecialty residents compete for patient care experience. Faculty role models perform procedures common to rural practice. Residents can experience being part of a community where all members of a family seek care from the family physician for most of their health care needs. For residents considering rural practice, this type of preparation is vital. For those who ultimately choose urban practice, the experience will be no less valuable because it exposes the resident to the essence of family practice.

The nonclinical aspects of training in a rural community can also be enlightening. Residents can participate in community activities and experience the effects of their medical practice as they interact with patients as neighbors and citizens. A resident's spouse and family members can experience rural life first hand.

Students applying to the University of Wisconsin family practice rural training tracks say they look forward to a great deal of experiential learning, believe they will receive more personalized teaching, and sense they will be welcomed and needed by the rural practice. Students realize that to achieve these benefits, they must be committed to living in the rural area for the last 2 years of their training.

Rural physicians gain the following benefits from rural training tracks: (1) clinical assistance in their practice, (2) increased career satisfaction, (3) improved image both locally and at the academic medical center, (4) increased collaborative linkages to academic medical centers, and (5) increased attractiveness of the practice to physicians being recruited.

Rural training builds relations between academic and rural physicians that can benefit all parties. Rural physicians can learn teaching skills from experienced academic family physician teachers through faculty development programs. Academic family physicians can broaden their horizons by observing clinicians skilled in rural medicine practice case management. Town-gown

rivalries that might exist can be bridged by having urban and rural physicians work together on educational ventures to improve access to health care in rural communities.

Rural Training Track Weaknesses

Despite many good arguments for developing rural training tracks, there are drawbacks. Administrative and teaching time, program cost, practice volatility, distance, isolation, quality, and accreditation requirements are serious concerns. Many programs (and rural clinics) interested in developing a rural track have neither the time nor the staff for the enormous amount of preplanning required to prepare the site, write the accreditation documents, negotiate affiliation agreements, facilitate site visits by the American College of Graduate Medical Education (ACGME), write recruitment materials, and train the rural faculty. It could be difficult to recruit and maintain the number of residents required by the ACGME—at least 2 residents per site, 1 second-year resident and 1 third-year resident—to increase collegial support.

Smaller training sites are also more vulnerable to staff changes. Should one or more physicians leave the practice suddenly, inadequate teaching time could result as the remaining physicians struggle to care for the patients who visit the clinic. What should be a positive experience could turn out to be negative for residents if they work with exhausted, stressed role models. Distances that need to be traveled by residents pose driving dangers and weather hazards. Residents can feel isolated from the colleagues they trained with during their first year. The quality of education residents receive in rural tracks might be questioned until sufficient learning outcomes research shows the effectiveness of this educational model. Such problems are not unique to rural tracks, but they might have to be addressed differently than they are in the larger urban programs.

Rural Tracks Alone Will Not Solve Rural Physician Shortages

Many additional changes in the health care system are necessary to enhance rural health. Typically, Medicare pays health maintenance organizations 18 percent more to care for urban enrollees compared with rural enrollees.[31] Medicare must recognize the contributions of rural providers and compensate them equally. The American College of Physicians has recommended remote access telecommunication and innovative delivery systems to improve access to and delivery of primary care in rural areas.[32]

Finally, it is up to the rural medical communities that remain underserved at the end of the 20th century to persuade graduates to consider staying in rural areas, find satisfying practices, and provide the services needed. Rural physicians must contribute to collegial partnerships with academic physicians, teach clinical skills, and share their enthusiasm for rural practice. Community members must help residents integrate into the social community.

Conclusions

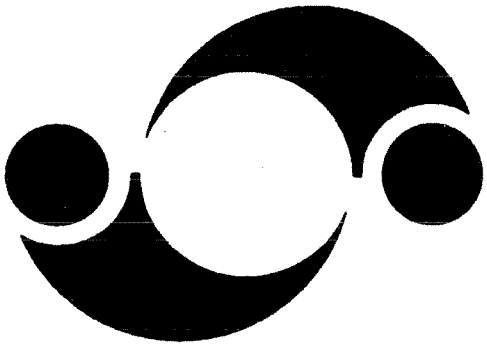
Academic and practicing family physicians must work together to correct physician maldistribution and assure access to medical care in rural areas. There is beginning evidence to suggest that rural training tracks are able to produce graduates who enter rural practice. A recent survey by Rosenthal et al[33] showed that 76 percent of graduates of one-two rural residency tracks entered rural practice after graduation. Further studies are needed to determine whether rural track residents are as well prepared as their core program colleagues and whether rural training tracks are an equivalent or preferred method of preparing residents for rural practice. Broad qualitative studies can measure the costs and effects of rural training on community physicians, community hospitals, and the community itself. If evaluation results show that the effort is worth the outcome, traditional models of residency training should be modified to include more rural training options.

References

1. Program information form for residencies in family practice. Chicago: Accreditation Council for Graduate Medical Education, 1997:iii.
2. Rosenthal TC, Maudlin RK, Sitorius M, Florence JA, Markowski G, Cleveland PD, et al. Rural training tracks in four family practice residencies. Acad Med 1992;67:685-91.
3. Damos JR, Sanner LA, Christman C, Aronson J, Larson S. A process for developing a rural training track. Fam Med 1998;30:94-9.
4. Dalen JE, editor. US physician manpower needs: generalists and specialists: achieving the balance. Arch Intern Med 1996;156:21-24.
5. STFM Group on Rural Health. Concerns raised re-

garding graduate locations. Am Fam Physician Newslett, Summer 1997.

6. Kindig DA, Movassaghi H. The adequacy of physician supply in small rural counties. Health Aff Millwood 1989;8(2):63-76.
7. Institute of Medicine. Medical professional liability and the delivery of obstetric care. Washington, DC: National Academy of Press, 1989.
8. Larimore WL. Pregnancy care liability misperceptions among medical students in Florida. Fam Med 1994;26:154-6.
9. Greenberg DM, Hochheiser LI. Family practice residents' decision making regarding future practice of obstetrics. J Am Board Fam Pract 1994;7:25-30.
10. Nesbitt TS, Arevalo JA, Tanji JL, Morgan WA, Aved B. Will family physicians really return to obstetrics if malpractice insurance premiums decline? J Am Board Fam Pract 1992;5:413-8.
11. Nesbitt TS, Kahn NB, Tanji JL, Scherger JE. Factors influencing family physicians to continue providing obstetric care. West J Med 1992;157:44-7.
12. Larimore WL, Davis A. Relation of infant mortality to the availability of maternity care in rural Florida. J Am Board Fam Pract 1995;8:392-9.
13. Allen DI, Kamradt JM. Relationship of infant mortality to the availability of obstetrical care in Indiana. J Fam Pract 1991;33:609-13.
14. Nesbitt TS, Connel FA, Hart LG, Rosenblatt RA. Access to obstetric care in rural areas: effect on birth outcomes. Am J Public Health 1990;80:814-8.
15. Clifford WB, Lilley SC. Rural elderly: their demographic characteristics. In: Bull CN. Aging in rural America. Focus Editions Ser Vol 162. Newbury Park, Calif: Sage Publications, 1993:3-20.
16. Fuguitt GV, Beale CL. The changing concentration of the older nonmetropolitan population, 1960-90. J Gerontol 1993;48:S278-88.
17. Zedlewski SR, Narnes RO, Burt MK, McBride TD, Meyer J. The needs of the elderly in the 21st century. Washington, DC: The Urban Institute, 1989.
18. Doty PJ. The oldest old and the use of institutional long term care from an international perspective. In: Suzman RM, Willis DP, Manton KG, editors. The oldest old. New York: Oxford University Press, 1992:251-67.
19. Besdine RW, Rubenstein LZ, Snyder L, editors. Medical care of the nursing home resident: what physicians need to know. Philadelphia, American College of Physicians, 1996:xiii.
20. Bowman RC, Penrod JD. Family practice residency programs and the graduation of rural family physicians. Fam Med 1998;30:288-92.
21. Mangus JH, Tollan A. Rural doctor recruitment: does medical education in rural districts recruit doctors to rural areas? Med Educ 1993;27:250-3.
22. Lebel D, Hogg W. Effect of location on family medicine residents' training. Can Fam Physician 1993; 39:1066-9.
23. LeFevre ML, Colwill JM. Practice location as a function of medical school and residency location: implications for resident selection. J Fam Pract 1983;16:1157-60.
24. Bowman RC. Continuing family medicine's unique contribution to rural health care. Am Fam Physician 1996;54:471-4, 479, 483.
25. Dalen JE. US physician manpower needs. Generalists and specialists: achieving the balance. Arch Intern Med 1996;156:21-4.
26. Turkal N, Christman C. Graduates' comment on issues related to the decline of Wisconsin family physicians providing maternity care. Wis Med J 1996;95:17-21.
27. Smith MA, Howard KP: Choosing to do obstetrics in practice: factors affecting the decisions of third-year family practice residents. Fam Med 1987;19:191-4.
28. Hayes E. Helping preceptors mentor the next generation of nurse practitioners. Nurse Pract 1994; 19(6):62-6.
29. Taylor LJ. A survey of mentor relationships in academe. J Prof Nurs 1992;8(1):48-55.
30. Sakornbut EL, Dickinson L. Obstetric care in family practice residencies: a national survey. J Am Board Fam Pract 1993;6:379-84.
31. United States, Prospective Payment Assessment Commission. Medicare and the American health care system: report to the Congress. Medicare and Medicaid guide, issue no 964, no 960, part 2. Washington DC: The Commission, 1997.
32. Rural primary care. American College of Physicians. Ann Intern Med 1995;122:380-90.
33. Rosenthal TC, McGuigan MH, Osborne J, Holden DM, Parsons MA. One-two residency tracks in family practice: are they getting the job done? Fam Med 1998;30:90-3.



WISCONSIN COUNCIL FOR THE DEAF & HARD OF HEARING
2917 International Lane, 3rd Floor
P.O. Box 7852
Madison WI 53707-7852
(608) 243-5626 TTY/Voice

TABLE OF CONTENTS

MESSAGE FROM THE CHAIRPERSON ..... Alex Slappey

The Wisconsin Council for the Deaf and Hard of Hearing is comprised of nine members, appointed by the Governor. As part of its purpose, the Council serves to provide advice and consultation to the Office for the Deaf and Hard of Hearing, the Division of Supportive Living, governmental bodies, private groups and individuals. The activities of the Council are driven by the desire to support people who are deaf, deafblind or hard of hearing in their efforts to achieve an equal place in their mainstream communities.

The *1999-2001 Legislative Initiatives* of the Council support the prudent allocation of public funds to enhance the contributions made by individuals and families in their support of people who are deaf, deafblind or hard of hearing. In addition, the Council's initiatives support the provision of comparable accommodation services that are critical to accessing essential basic services that are accessed by the general public.

If questions arise, please contact a Council member listed in the back of this document.

Alex H. Slappey

Alex Slappey
Chairperson

WISCONSIN COUNCIL FOR THE DEAF & HARD OF HEARING

POLICY RECOMMENDATIONS

STATUTE TO ESTABLISH BASIC CREDENTIAL REQUIREMENTS FOR SIGN LANGUAGE INTERPRETERS

Many people arranging interpreting services are unaware of the skill levels required to provide safe and effective communication. Approximately 500,000 Wisconsin citizens are deaf, deafblind and hard of hearing, resulting in a high demand for interpreting services. The consequences of utilizing unqualified interpreters can be physically dangerous, if not fatal, in medical situations. In legal situations, people can, and have been, denied basic civil rights.

A statute is needed to establish guidelines for the basic skill and quality levels required of Sign Language Interpreters to interpret in a variety of settings. Proposed statutory language includes guidelines for the skill levels required to interpret in legal, mental health and emergency medical settings. Guidelines are also included for skill levels required to interpret in all other settings. Educational interpreters will be exempted from the statutory requirements. In addition, there are administrative sanctions for Sign Language Interpreters providing interpreting services in settings for which they are not qualified, including a fine structure and an appeal process.

COUNCIL RECOMMENDATION

- Support implementation of statutory guidelines to specify basic credential requirements for Sign Language Interpreters

WISCONSIN COUNCIL FOR THE DEAF & HARD OF HEARING

FISCAL RECOMMENDATIONS

SERVICE FUND FOR THE DEAF, DEAFBLIND AND HARD OF HEARING

The Service Fund for people who are deaf, deafblind or hard of hearing provides funding for sign language interpreters, realtime captioning and other comparable accommodations. Providing people with the means of presenting and receiving accurate information prevents exposure to life-threatening situations or situations where civil rights are denied.

- Funds support activities not covered by ADA, including support groups for battered women, substance abuse prevention, and cancer victims
- Funds support agencies in the process of obtaining funds for legal, mental health, and emergency medical activities
- In 1996, GPR funding to the Wisconsin Office for the Deaf and Hard of Hearing for the Service Fund was reduced from $113,000 to $50,000
- Funds are available to over 500,000 deaf, deafblind and hard of hearing Wisconsin citizens
- Demand for funds exceeds the $50,000 allocation.

In SFY 98, $50,000 purchased nearly 1,563 hours of interpreting services, providing services to an estimated 250 people. Service requests exceeding the $50,000 allocation amounted to an estimated 752 hours or nearly 120 participants.

COUNCIL RECOMMENDATION

- Increase GPR funding to $138,000 over the biennium from the current base of $50,000

COMMUNITY SERVICE ASSOCIATES

Community Service Associates (CSAs) provide:

- comparable accommodations in the form of interpreting services for deaf or hard of hearing Regional Coordinators of Deaf and Hard of Hearing Services
- information, assistance, education, and prevention services for deaf, hard of hearing and deafblind citizens

Funding for CSAs is supported by GPR and a combination of state/federal funds from the Division of Vocational Rehabilitation. In SFY 98, DVR funding support was reduced from $72,620 to $16,500. Efforts to compensate for the funding reduction included:

- reducing total CSA hours by over 900 hours per year
- providing interpreting services outside of normal job duties

Each of these actions reduced direct services provided to Regional Coordinators of Deaf and Hard of Hearing Services and to the deaf, deafblind and hard of hearing communities.

COUNCIL RECOMMENDATIONS

- Fully fund the services of the Community Service Associates
- Increase the base $110,500 GPR funding by $83,779 in SFY 00 and $89,607 on SFY 01

FISCAL RECOMMENDATIONS

Services to the Deaf and Hard of Hearing Fund: Increase GPR funding to $138,000 over the biennium from the current base of $50,000.

Community Service Associates: Increase the base $110,000 GPR funding by $83,779 in SFY 00 and $89,607 in SFY 01.

POLICY RECOMMENDATIONS SUMMARY

Statute to Establish Basic Credential Requirements for Sign Language Interpreters: Support the implementation of statutory guidelines to identify basic skill and quality levels required of Sign Language Interpreters in an effort to ensure that people who are deaf, deafblind, or hard of hearing have access to safe and effective communication.

GOVERNOR-APPOINTED MEMBERS OF THE WISCONSIN COUNCIL FOR THE DEAF AND HARD OF HEARING

Chairperson: Alex Slappey
(414) 728-7120 TTY/Voice
Delavan

Vice-Chairperson: Sarah Benton
(414) 728-7120 TTY/Voice
New Berlin

Members: John Boyer
(608) 257-5917 Voice
Madison

Eve Dicker Eiseman
(414) 790-1040 Voice
Mequon

Margaret Ferris
(414) 722-0436 Voice/TTY
Neenah

Mike Ginter
(608) 833-3201 TTY
Mt. Horeb

Linda Jennison
(414) 248-1234 V/TTY
Lake Geneva

Helen Rizzi
(715) 834-2797 TTY
Eau Claire

Deborah Stamm
(414) 544-9559 Voice
Pewaukee

NOTES

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 onFamily 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 employee 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, pediatrists, dematologists, opthamologists, 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 icey 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 fluxuate 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 opthamologist said, **NO BENDING OR LIFTING**. I have had 8 lazar surgeries in each eye which has left scare 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 its 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 suppiements, 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 dumbness 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 turn 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.

Gastroparysis 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,

Sandy Klopfer

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 under-funded.

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.