HOME AND COMMUNITY-BASED SERVICES FOR OLDER PEOPLE AND YOUNGER ADULTS WITH PHYSICAL DISABILITIES IN WISCONSIN

FINAL REPORT

Prepared for:

U.S. Department of Health and Human Services
Health Care Financing Administration

Prepared by:

Joshua M. Wiener, Ph.D.
The Urban Institute

and

Steven M. Lutzky, Ph.D.
(formerly of) The Lewin Group

August 19, 2001

This research was supported by Health Care Financing Administration Contract No. 500-96-0005. In this contract, the Urban Institute is a subcontractor to the Lewin Group. The opinions expressed in this report are those of the authors and do not necessarily reflect the views of the Health Care Financing Administration, the Urban Institute, or the Lewin Group. We gratefully acknowledge the many people in Wisconsin who generously answered our many questions

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HOME AND COMMUNITY-BASED SERVICES FOR OLDER PEOPLE AND YOUNGER ADULTS WITH PHYSICAL DISABILITIES IN WISCONSIN

INTRODUCTION

Wisconsin is a relatively small Midwestern state with a total population of 5.3 million people in 1999, of whom 13.2 percent were age 65 and over.[1] The state's economy is strong and only about 8.5 percent of the total population lives in below the federal poverty level, well below the national average.[2] Wisconsin provides home and community-based services to a substantial number of older people and younger adults with physical disabilities through the Medicaid home health and personal care benefit, a fairly large Medicaid home and community-based services waiver, and some significant state-funded programs. Wisconsin has a national reputation as a leader in innovative and flexible home and community-based services, relying heavily on consumer-directed home care and nonmedical residential services. Despite these innovations, of the approximately 71,000 elderly and disabled Wisconsin residents receiving publicly funded long-term care in the 1998/1999 budget period, two-thirds of clients were receiving care in an institutional setting rather than in the community.[3] Wisconsin is currently embarking on an ambitious "Family Care" demonstration project that will provide the full range of long-term care through capitated, county-run Care Management Organizations, which the state hopes will create incentives to provide more home and community-based services and create a more balanced financing and delivery system.

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1 "Wisconsin," http://quickfacts.census.gov/qfd/states/55000.html.

2 "State Poverty Rates and Standard Errors: 3-Year Averages, 1980-82 Through 1997-99," http://www.census.gov/hhes/poverty/povanim/pumaptxt.html.

3 Wisconsin Legislative Audit Bureau, An Evaluation: Community Options Programs: Department of Health and Family Services, (Madison: Wisconsin Legislative Audit Bureau, 1999). In 1997, 82 percent of public spending for long-term care for older people was for institutional care and 18 percent for home and community-based services. Wisconsin Department of Health and Family Services, "Why Older People Need Family Care," http://www.dhfs.state.wi.us/LTCare/whyolder.htm. For younger persons with physical disabilities, 40 percent of long-term care spending was for institutional care, 21 percent for Medicaid home and community-based services waiver services, and 39 percent on other Medicaid services. (Wisconsin Department of Health and Family Services, "Why People With Physical Disabilities Need Family Care," http://www.dhfs.state.wi.us/LTCare/whypd.htm).

The long-term care policy environment in Wisconsin is shaped by four factors. First, while Wisconsin has explored the integration of acute and long-term care services and other approaches relying on capitated payment methods, the bedrock of state policy is "aging in place" and a social rather than medical model of home and community-based services. Second, although the state has a very well organized and politically effective nursing home industry, strong consumer advocates, especially for older people, have provided an effective counterbalance and a strong voice in favor of noninstitutional options. Consumer advocates have provided much of the political will to redesign the long-term care system. Third, despite the prosperousness of the state, budget priorities have favored tax cuts and services other than long-term care, leaving the home and community-based service system with large, politically controversial waiting lists for services. And fourth, counties play an extremely important role in designing and administering home and community-based services in Wisconsin, with the state providing most of the funding, but recognizing that counties will vary in their approaches.

This paper analyzes the home and community-based service system for older people and younger adults with physical disabilities in Wisconsin, and focuses on the state administrative structure, eligibility and assessment, case management, services covered by Medicaid and other public programs, cost containment strategies, and quality assurance mechanisms. This study does not address home and community-based services for people with developmental disabilities or mental retardation or children. Information was obtained from the following sources: public documents; state of Wisconsin websites; and interviews with federal and state officials, provider associations, consumer advocates, and other stakeholders. In-person interviews were conducted in Madison, Wisconsin, during March 2000, followed by telephone interviews in June 2000. Questions were asked using an open-ended interview protocol. To encourage candor in their answers, respondents were told that they would not be quoted by name.

THE LONG-TERM CARE SYSTEM IN WISCONSIN

Wisconsin has a much higher-than-average supply of nursing home and nonmedical residential care beds as well as a substantial number of home health agencies.

Wisconsin had 48,135 nursing home beds in 429 facilities in 1998—69.7 beds per 1000 people age 65 and over, compared to a national average of 52.5 beds per 1000.[4] This relatively high supply of nursing home beds persists in Wisconsin despite a two-decade old moratorium on new construction. Average occupancy rates have fallen from 90.6 percent in 1994 to 84.6 percent in 1999, reportedly because of the expansion of alternative services and the growing importance of short-term post-acute care, which makes it harder to maintain high occupancy rates.[5] Despite an increasing elderly population, the average daily census of nursing home residents actually declined from 44,485 in 1994 to 40,004 in 1999.[6] The state has a very large supply of nonmedical residential facilities, 1,922 facilities with a total of 23,853 beds in 1998—34.5 beds per 1000 persons age 65 and over, compared to the national average of 25.5 beds per 1000 age 65 and over.[7] In 1998, Wisconsin had 192 licensed home health agencies.

Long-term care for older people, persons with physical disabilities, and people with mental retardation or developmental disabilities accounts for the majority of Wisconsin Medicaid program expenditures. Wisconsin's total Medicaid long-term care expenditures (nursing facility, ICF/MR, home and community-based services waivers, home health, and personal care) were $1.448 billion in 1998, 30 percent of which was for home and community-based services, somewhat higher than the national average of 26 percent.[8] Table 1 presents a detailed breakdown of state expenditures for selected long-term care services.

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[4] There were 142.6 beds per 1000 elderly age 75 and over in Wisconsin, compared to a national average of 113.2. Charlene Harrington, James H. Swan, Valerie Wellin, Wendy Clemena, and Helen M. Carrillo, *1998 State Data Book on Long-Term Care Program and Market Characteristics*, (San Francisco: University of California, San Francisco, 2000); U.S. Bureau of the Census, "State Population Estimates: 1998," http://www.census.gov.

[5] While the average nursing home occupancy rate has fallen sharply, the number of admissions has increased dramatically—from 36,237 in 1994 to 51,186 in 1999, suggesting a large decline in the average length of stay. Department of Health and Family Services, *Wisconsin Nursing Homes and Facilities for the Developmentally Disabled, 1999.* http:/www.dhfs.state.wi.us/provider/pdf/99nhfdd.pdf.

[6] Ibid.

[7] Harrington et al., op. cit..

[8] Urban Institute estimates based on data from HCFA-64 reports, 2000.

Table 1

State Expenditures for Selected Long-Term Care Services, Fiscal Year 1990-00

	Actual
Home and Community-Based Programs	$613,892,900
COP-R and COP-W	154,618,800
MA Waivers excluding COP-W	276,214,100
Family Care CMOs	6,973,600
PACE/Partnerships	42,802,300
MA Personal Care	73,576,500
MA Home Health	59,707,600
Total Institutional Care (Nursing Homes)	$1,017,580,900
All Long-Term Care	$1,631,573,800

Source: Wisconsin Legislative Fiscal Bureau, 2001

Table 2 summarizes the characteristics of Wisconsin's home and community-based services programs. Medicaid is the dominant source of financing for home and community-based services, but state-funded programs fund a substantial amount of services. The three main sources of Medicaid funding for noninstitutional long-term care services for older people and younger adults with physical disabilities are the Medicaid home health and personal care benefits and a home and community-based services waiver—the Community Options Program-Waiver (COP-W).[9] Many persons receiving waiver services also receive “card" services (i.e., regular Medicaid services), as do persons on the waiver waiting lists. Within Wisconsin, the waiver has two sources of state funding. Most financing is made generally available to the program to divert or relocate persons from nursing homes, but is not directly linked to the number of nursing home beds. However, under the Community Integration Project II (CIP II), the number of “slots” is limited to the number of nursing home beds that have been closed. In 1999, there were 5,500 personal care beneficiaries and 13,900 COP-W clients. Excluding persons with developmental disabilities, approximately 70 percent of COP-W clients are elderly and 30 percent are younger persons with disabilities.

[9] There is also a small Medicaid home and community-based services waiver for persons who are substantially handicapped by a brain injury and receive or are eligible for post-acute rehabilitation institutional care—the "Brain Injury Waiver."

Table 2: Home and Community-Based Services for Older People and Younger People with Physical Disabilities in Wisconsin

	Regular Medicaid: Home Health and Personal Care	Medicaid Program Community Options-Waiver (COP-W) and Community Integration Project (CIPII)	Regular Community Options Program (COP-R)
Administrative Responsibility	Division of Health Care Financing of the Department of Health and Family Services (DHFS).	Bureau of Aging and Long Term Care Resources in Division of Supportive Living of the Department of Health and Family Services (DHFS) and counties. Counties do assessments, determine eligibility, develop care plans, provide case management, and pay and certify providers. For COP-W, counties receive fixed allocation of money rather than a fixed number of slots. For CIP II, counties allocated a fixed number of slots based on number of nursing home beds that have closed.	Same as COP-W and CIP II.
Functional Eligibility	Home Health: Ordered by physician and "medically necessary". Prior authorization generally required. Personal Care: Need for help with medically-oriented assistance with activities of daily living. Prior authorization required.	Nursing home level of care. Includes some persons with developmental disabilities.	Same as COP-W and CIP II with the addition of persons with chronic mental illness or diagnosis of Alzheimer's Disease.

Table 2: Home and Community-Based Services for Older People and Younger People with Physical Disabilities in Wisconsin (Cont.)

	Regular Medicaid: Home Health and Personal Care	Medicaid Community Options Program-Waiver (COP-W) and Community Integration Project (CIP II)	Regular Community Options Program (COP-R)
Financial Eligibility (2000)	Supplemental Security Income (SSI) plus State Supplemental Payment (SSP): $596 per month for individual. Assets: $2,000 for individual. Medically needy income level: $592 per month for individual. Assets: $3,000 for individual.	Medically needy and persons with income up to 300 percent of SSI, $1,536 per month for individual.	Income up to $626 per month and $5,000 assets for individual. Alternative criteria: would become Medicaid eligible in nursing home after 6 months.
Number of Beneficiaries (1999)	Home health 13,299. Personal care 5,524	13,898[a]	9,454[b]
Funding Source	Medicaid.	Medicaid.	State-funded.
Expenditures (CY 1999)	$126.8 million	$105.0 million	$61.3 million
Covered Services	Home health and personal care. Services must be provided in home except for medical appointments.	Adaptive aids, adult day care, adult family homes, case management, communication aids/interpreter services, community-based residential facilities, counseling and therapeutic resources, daily living skills training, day services, home modifications, home-delivered meals, nursing services, personal emergency response systems, protective payment/guardianship, residential care apartment complex, respite care services, supportive home care, and specialized transportation. Services may be provided outside of home.	All COP-W and CIP II services. In addition, any service necessary to maintain an individual in the community. Services may be provided outside of home.

[a] Includes 3,688 beneficiaries who also receive COP-R services.

[b] Includes 3,688 beneficiaries who also receive COP-W and other Medicaid waiver services.

Table 2: Home and Community-Based Services for Older People and Younger People with Physical Disabilities in Wisconsin (Continued)

	Regular Medicaid: Home Health and Personal Care	**Medicaid Community Options Program-Waiver (COP-W) and Community Integration Project (CIP II)**	**Regular Community Options Program (COP-R)**
Nonmedical Residential Services	Not covered.	Community-based residential facilities (only facilities with 8 or fewer beds or all apartments), residential care apartment complexes (lower level assisted living), and adult family homes.	Same as COP-W and CIP-II. Some overall limits on percentage of people in community-based residential facilities. Residential care apartment complexes excluded.
Consumer Direction	No.	Yes, but extent varies by county. Family members may be hired.	Same as COP-W and CIP II.
Cost Containment Mechanisms	Payment rates and required prior authorization.	Large waiting lists, payment rates, fixed allocation to counties, average cost must be less than nursing home care but no individual cap, use of consumer-directed care and nonmedical residential facilities.	Same as COP-W and CIP II.
Quality Assurance	Home health agencies are licensed and personal care agencies are certified by counties.	Training requirements for home care workers; clients can do training. Licensure for residential settings. Sample home review and satisfaction survey.	Same as COP-W and CIP II.

The main state-funded programs financing home and community-based services are the "regular" Community Options Program (COP-R) and, to a lesser extent, the Community Aids program.[10] Although COP-R mostly targets the same functional disability level as COP-W, it serves persons who do not meet the nursing home level-of-care criteria, as well as persons with a somewhat higher financial status. The COP-R program began in 1981, and in 1987 the state shifted those program recipients eligible for Medicaid into the new COP-W program. The COP-R program is designed to be the funding of last resort.

The Community Aids program is a block grant to the counties to fund a variety of social, mental health, alcohol/drug abuse and disability services.[11] While mostly targeted to children and people with mental illness and developmental disabilities, the program also funds some home and community-based services for older people and adults with physical disabilities. Community Aids dollars are a combination of state and federal sources, including the federal Social Services Block Grant. State statutes require counties to provide a small percentage of matching funds (less than 10 percent) for the basic county allocation and some specific programs. Most counties exceed the required match.

The COP-W and COP-R programs have been the principal focus of Wisconsin policy attention and advocacy over the years. Flexibility of services and consumer-orientation have been the hallmarks of the programs and help account for their political popularity. According to consumer advocates, one of the best things about COP-R is that it cuts across disability groups. As one observer put it, "The emphasis is on the functional assessment rather than slotting people into a label with a predetermined set of services." Except for reimbursement issues, the Medicaid personal care option and home health receive relatively little policy attention.

The state also has two Program of All-inclusive Care of the Elderly (PACE) sites and four Wisconsin Partnership Program sites. PACE is a capitated delivery system that

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[10] Other programs include the Alzheimer Family and Caregiver Support program, which provides funds to counties to assist individuals to purchase goods and services related to the care of someone with Alzheimer's Disease.

[11] Wisconsin Legislative Fiscal Bureau, Community Aids: Financial Assistance to Counties for Human Services, Informational Paper #49, (Madison: Wisconsin Legislative Fiscal Bureau, January 1999).

integrates acute and long-term care services for older people who need a nursing home level of care. It functions as a staff-model HMO and includes a large adult day health component. The Wisconsin Partnership Program is a variant of the PACE model, which does not require day care attendance and allows enrollees to maintain their own doctors. Unlike PACE, it serves both older and younger people with disabilities. As of 2000, average monthly enrollment in the two programs was approximately 1,200 persons.[12]

ADMINISTRATIVE STRUCTURE

Administrative and financial responsibility for home and community-based services is shared by the state, its 72 counties, and one Native American tribe. At the state level, the Department of Health and Family Services (DHFS) is responsible for long-term care, with COP-R, COP-W, and CIP II administratively residing in the Bureau of Aging and Long-Term Care Resources within the Division of Supportive Living (DSL). The review and inspection of facilities that provide Medicaid-reimbursed care is the responsibility of the Bureau of Quality Assurance in DSL. Responsibility for Medicaid home health, personal care, nursing facility care, and other services are located in the Division of Health Care Financing in DHFS.

Counties are primarily responsible for administering the Medicaid home and community-based services waiver, the COP-R program, and the Community Aids program. Counties are not involved in the administration of non-waiver Medicaid home and community-based services. Within state and federal guidelines, counties have considerable freedom to design their programs. As such, there is considerable variation in benefits, service provision, and program administration. At the county level, home and community-based services are mostly administered by human services departments. Counties provide assessment and case management and pay providers for COP-W and COP-R services. In addition, many counties are direct providers, operating nursing homes and personal care agencies.

[12] Richard Megna, *Community-Based Long-Term Care Programs,* (Madison, WI: Wisconsin Legislative Fiscal Bureau, 2001).

The state allocates counties a set amount of COP-R and COP-W funds rather than a specific number of "slots" or placements. Thus, the number of clients served in a county depends upon on average client costs. Some counties spend more than their allocation for COP-W and pay the state Medicaid share in order to draw down additional federal funds. While DHFS is authorized to, and does, make some modifications in how funds are distributed, the county allocation formula is based on each county's share of the Medicaid caseload, the county's relative rank on an urban/rural scale in which very urban and very rural counties receive larger allocations, and each county's full value of taxable property per capita. The county allocation formula has been criticized for being antiquated and not sensitive to need. Counties can use up to 7 percent of their COP-W and COP-R funds for administration.

To ensure a “fair” allocation of COP-R funds, the state imposes a minimum percentage of participants across eligibility groups. Known as the "significant numbers" or "significant proportions" requirement, the standards require that at least 57 percent of beneficiaries be older people, 14 percent be persons with developmental disabilities, 6.6 percent be persons with chronic mentally illness, and 6.6 percent be persons with physical disabilities. Persons with substance abuse problems are also a target population, but do not have a quantitative target. To give counties some flexibility in determining service priorities, the total minimum allocation does not equal 100 percent. Reportedly, the requirements were imposed because elderly advocacy groups complained that additional funding for COP was not resulting in additional services for older persons, even though the increases were largely due to lobbying by groups representing older people. In part, this distributional issue was due to the high costs and low turnover of younger people with disabilities (especially persons with developmental disabilities).

The county-based system is believed to maximize responsiveness to local conditions and preferences, but at the cost of variation in access, expenditures, and program design. According to one observer, "Wisconsin has a long history of decentralization of services for people with disabilities that goes back to the mid-1800s. Local folks feel that they have responsibility for people with disabilities and they try to keep them integrated into their communities. The downside of the decentralization is the lack of uniformity and consistency across counties. There is a lot of variation across the

counties. There are 72 different programs." According to one state official, "County governments are not all the same. It is important in Wisconsin that you can't have 'one size fits all.' "

ELIGIBILITY AND ASSESSMENT

Functional and financial eligibility standards vary for regular Medicaid card services, home and community-based waiver services, and COP-R. Functional eligibility for Medicaid card services is determined using more traditional concepts of medical necessity, while requirements for COP-W is based on meeting the nursing home level of care. The functional eligibility criteria for COP-R mirrors the requirements of the Medicaid home and community-based waivers, but includes some additional groups.

All Medicaid home health services must be approved and ordered by the client's physician in a written plan of care. Most home health services require prior authorization from DHFS before they are initiated or after they have reached a certain threshold of number of visits. The need for home health services is evaluated on the basis of medical necessity.

To receive personal care, individuals must require medically-oriented assistance with activities of daily living necessary to maintain the individual in his or her place of residence in the community. Prior authorization by DHFS is required for personal care in excess of 50 hours a year.

As required by federal law, beneficiaries receiving Medicaid waiver services must need the nursing facility level of care. The functional eligibility requirements for COP-R services are broader than those of the Medicaid home and community-based services waiver. In order to be eligible for COP-R services, clients must meet one of the following requirements: 1) require nursing home level of care; 2) be a current resident of a nursing home or a state center for the developmentally disabled; 3) have a chronic mental illness and be likely to require long-term or repeated hospitalization without community services; or 4) be diagnosed as having Alzheimer's Disease.

Financial eligibility for Medicaid card services, the home and community-based services waiver, and COP-R are relatively liberal. In 2000, individuals financially

eligible for Medicaid include those individuals receiving Supplemental Security Income (SSI) and a state supplemental payment up to $596 per month and individuals deemed medically needy with incomes up to $592 a month. Financial eligibility for the Medicaid home and community-based services waiver includes the medically needy and persons with incomes up to the "special needs cap" of 300 percent of the SSI level or $1,536 per month for individuals in 2000. The use of the "special needs" cap allows individuals to retain more of their income for living expenses. Medicaid spousal impoverishment rules established for married nursing home residents also apply to clients of home and community-based services waivers.

Financial eligibility for COP-R is more generous than for Medicaid. In 2000, the program covered individuals with incomes up to $626.00 per month and who owned up to $5,000 in nonhousing assets. In addition, COP-R provides an alternative eligibility test, providing coverage for persons who would likely become eligible for Medicaid within six months of entering a nursing home. In 2000, this provision allowed adult individuals to have up to $25,725 in nonhousing assets. COP-R beneficiaries must be Wisconsin residents for at least six months before receipt of services. Although COP-R is a purely state-funded program, it uses both the spousal impoverishment and the transfer of assets provisions of the Medicaid program.

For the waiver and the COP-R programs, counties commonly use two persons to conduct functional assessments—a nurse and a social worker. In many cases, one of the assessors is not a county employee, although county employees make the final eligibility determination. State guidelines require that assessments include face-to-face discussion with the applicant and, if applicable, his or her guardian. Any elderly or disabled individual can obtain an assessment and care plan, but counties are authorized to charge an assessment fee to higher-income individuals using a DHFS-determined schedule.

CASE MANAGEMENT

Case management is a key component of COP-R and COP-W, but is not routinely provided to individuals receiving only Medicaid personal care or home health services. Case management is a covered Medicaid service, but only for some persons needing long-term care services. Case managers for COP are county employees and have an

average caseload of 40 clients, although some have higher caseloads. Face-to-face contact with clients is required on a quarterly basis. Some counties provide basic case management to individuals on the COP waiting lists.

The case manager, client, and the client's informal support network collaborate on developing a care plan that will use informal and community resources to the extent possible, filling in with paid services when appropriate. In addressing the needs of clients with cognitive impairments, the case manager works with the informal support system to become familiar with the client's preferences.

Approaches to case management differ greatly across counties. For example, case managers vary in how much input they obtain from clients in devising a care plan. According to one consumer advocate, case managers "have a lot of say" about what services people receive.

SERVICES

Wisconsin offers a very wide range of home and community-based services through its Medicaid program, Medicaid waivers, and state-funded programs. The state's COP program is nationally recognized for its service flexibility.

Under the regular Medicaid program, the state covers home health, which is a mandatory service, and personal care, which is an optional benefit. Home health services include skilled nursing, home health aides, therapy services provided by physical, occupational, speech and language therapists, private duty nursing, respiratory care services, and personal care services. Services must be provided in the client's home and are capped at eight hours of direct nursing services per day. Home health aide services must include at least one medically necessary, medically-oriented task per visit.

Personal care services are medically-oriented activities related to assisting an individual with activities of daily living necessary to maintain the recipient in his or her place of residence. Covered personal care services include help with activities of daily living, meal preparation, and accompanying an individual to obtain medical diagnosis and treatment. Personal care in Wisconsin does not provide for "supervision" of the disabled individual and cannot be used to enable attendance at social activities outside of

the home. Prior authorization is required for personal care services in excess of 50 hours in a calendar year. Advocates for persons with disabilities argue that both home health and regular personal care are too medically-oriented, and that personal care is more flexible under the Medicaid waivers.

The COP-R and COP-W programs cover a very broad range of services, although some observers commented that the programs are not as flexible and creative now as they were when they were smaller. COP-W covers adaptive aids, adult day care, adult family homes, case management, children's foster home, communication aids/interpreter services, community-based residential facility, counseling and therapeutic resources, daily living skills training, day services, home modifications, home delivered meals, nursing services, personal emergency response systems, protective payment/guardianship, residential care apartment complex services, respite care, supportive home care, and specialized transportation. From the consumer's perspective, one problem with obtaining services is that an eligible service may not be provided by the county if the provision of the service would increase the average county costs above the average cost of Medicaid nursing home care or if the county does not want to cover that service. Unlike regular Medicaid home health and personal care, COP-R and COP-W will pay for services provided outside of the home, such as escorting clients to beauty parlor appointments

In addition to all of the COP-W services, under COP-R, counties are free to select any service necessary to implement a community-based living arrangement for an individual, except for certain limitations on the use of nonmedical residential facilities (described below). COP-R funds are spent on services that are not coverable under the Medicaid waivers, to supplement state waiver funding where the amount of services provided are insufficient to support an individual in the community, and to provide services to a Medicaid waiver-eligible individual while his or her waiver application is processed.[13] A substantial number of COP-W beneficiaries also receive COP-R services.

[13] Some items, such as a room and board in nonmedical residential settings, security deposit for an apartment, telephone and some medical services, cannot be covered under the waivers. Further, Medicaid waiver services cannot be provided until the person has been certified as eligible under

One example illustrates the flexibility of the COP-R program: A client with dementia was experiencing significant psychological distress and wanted to jettison modern plumbing and revert to his childhood on the farm. This client was assisted in remodeling his bathroom to appear like an outhouse. This flexibility is not unlimited, however. In 1998, there was controversy over some COP training materials that approvingly described the use of boarding services for pets while clients were hospitalized, veterinary fees to neuter cats, and wedding party expenses as examples of creative flexibility in the program (although it is uncertain whether COP funds were actually ever used for these purposes). Critics questioned whether these were appropriate use of public funds. In response, DHFS amended program guidelines to emphasize the selection of cost-effective services and to prohibit the use of COP funds to support services or equipment costs that are not directly related to a participant's documented needs or are not a cost-effective means of meeting those needs. In addition, higher-level local authorities are now required to review and approve funding for extraordinary services.

NONMEDICAL RESIDENTIAL SERVICES

Services (but not room and board) in nonmedical residential facilities including, adult family homes, community-based residential facilities, and residential care apartment complexes, are covered by the Medicaid waiver, although most residents in these facilities pay privately for their care. COP-R also funds these services, except for residential care apartment complexes, which are excluded as a cost containment mechanism. Community-based residential facilities consist mostly of rooms with baths rather than individual apartments. Residential care apartment complexes, formerly known as assisted living facilities, can provide up to 28 hours a week of care and are not heavily regulated. The apartments in these facilities have locking entrances, individual bathrooms, and a kitchen, which includes a stove (i.e., at least a microwave oven). In

Medicaid or while that person is still residing in an institution. Consequently, Medicaid funding is not available immediately for certain pre-relocation services, such as home modifications, while the person is in an institution. In addition, for someone who requires services immediately, Medicaid funding may not be available, although retroactive payment can be made once eligibility is certified.

1997, about 11 percent of COP-W beneficiaries lived in nonmedical residential settings. Care provided in these settings accounted for about 20 percent of expenditures. These facilities are not subject to the moratorium on construction of new nursing homes or by certificate of need restrictions. Nonprofit nursing homes, in particular, are heavily involved in community-based residential facilities

Unlike some states, such as Oregon and Washington, which have embraced nonmedical residential settings as a desirable setting for some persons with disabilities (particularly those needing extensive supervision), Wisconsin has been more ambivalent about their use. According to one state official, "Historically, COP has been a 'home care' program and the state has been reluctant to use this money to support residential services." Community-based residential facilities were criticized by several observers as being too large, and too much like "little nursing homes" with "an institutional feel." According to one official, "The need for 24-hour a day care pushes the system towards residential care, but there are alternative mechanisms that can be effective [in enabling an individual to remain at home], such as electronic monitoring. Moreover, many people have a family member available or a neighbor who can be asked to keep tabs on the person." To try to make facilities more homelike, COP-W and CIP II are currently limited to community-based residential facilities that have eight or fewer beds or those that consist completely of independent apartments. Moreover, until 1998, counties could not spend more than 25 percent of their COP funds on community-based residential facilities, unless they received a state waiver.

Despite certain reservations, any service that increases the options available to persons with disabilities is thought desirable. Another state official added, "There is a strong preference not to move people, but it is not realistic for everyone to stay in their own home or apartment. Thus, there is the search for some middle ground." State officials are investigating how to use the state's 40,000 units of "Section 8" subsidized housing for long-term care.

The relationships among the Medicaid program, residential care, and nursing homes have become an important issue. Several respondents noted that people who exhaust their own financial resources in nonmedical residential settings may find that

public funding through COP is not available to them because they do not meet the functional or financial requirements or because there is a waiting list. They will then have no choice but to leave what has become their home and move to a nursing home, typically a greater public cost. In particular, the nursing home industry is concerned that this spending down of financial resources in paying for nonmedical residential services may ultimately lead to a higher proportion of nursing home residents relying on Medicaid to pay for their care. In order to address both of these issues, some observers urged that there be a preadmission review for nonmedical residential facilities.

CONSUMER DIRECTION

The Medicaid home and community-based services waivers and the COP-R program allow consumers to direct their own services, but the regular Medicaid program does not. Home health and personal care services are only available through agencies. However, according to one state official, clients will occasionally identify persons that they want to be their worker and the home health or personal care agency will then hire that individual. Most home health agencies have stopped providing personal care, though they still provide home health aide services. Instead, most personal care agencies are county governments and independent living centers. Since many personal care agencies are run by counties, workers are said to receive better fringe benefits and wages than is often the case in the private sector. However, union rules requiring double-time payment for weekend and evening work have resulted in counties eliminating these services because of their high cost.

In contrast, clients of the Medicaid home and community-based services waiver and COP-R may hire, train, direct and fire their own workers, although the extent to which clients can direct services varies greatly by county. State officials believe that younger adults with disabilities are more likely to embrace consumer direction than older adults, although individual personality is believed to be the decisive factor.

Persons with cognitive impairment are not automatically excluded from using consumer-directed services. According to one government official, "People with cognitive impairment direct their own care to the extent they are able to do so. The case manager works with the applicant and his or her support network to determine the best

package of services. Supervision is built into the care plan. For example, some people with advanced dementia live alone with electronic monitoring and neighbors are enlisted to report when the client is not following his or her normal routine."

Counties can use Medicaid waiver funds and COP-R to pay informal caregivers. Federal Medicaid rules prohibits the payment of spouses and parents of minor children, but they are sometimes reimbursed under COP-R. The use of informal caregivers is believed by state officials to be an effective way of finding personnel to work the often odd hours that are needed for people with disabilities, which typically involve assisting a person out-of-bed early in the morning or assisting them into bed late in the evening. The state will only pay informal caregivers for services that the worker does not already supply to the rest of the family

Case managers, independent living centers and county agencies typically offer managerial assistance to self-directed clients, such as assistance with recruiting workers. Payment is handled through a fiscal intermediary. Milwaukee County has started an organization which serves as an employment agency for private, individual providers. The new agency has a registry of workers, and will help clients interview prospective workers, provides training to workers, and has in-service programs that enable workers to have contact with one another to help alleviate the isolation that often accompanies this type of work.

In contrast to disability advocates, the home health industry is skeptical of consumer direction. As one industry representative argued, “It sounds wonderful, but has a lot of pitfalls. You hire your sister at lower cost, but she does not have the training that she needs. In a lot of cases, hiring the family does not work and people do not get the care they need. Consumer-directed care also exploits women because they do not receive the wages and fringe benefits that people in agencies do."

QUALITY ASSURANCE

As part of the COP-R and COP-W programs, the state emphasizes a consumer-oriented definition of quality, with a focus on respectful relationships, empowerment, enhancement of self-worth, community involvement, and independence. To ensure

quality of care, DHFS contracts with The Management Group to operate a consumer-based quality assessment and improvement program. The Management Group reviews every care plan and visits a random sample of consumers at home. A total of 22 personal standards (called “RESPECT”) have been developed that capture participant-defined outcomes in relation to the program's values. In addition, the Long-Term Care Ombudsman Program responds to reported problems and complaints in COP, nonmedical residential facilities, and in nursing homes.

As part of the quality assurance process, 400 to 500 clients are surveyed per year to determine their program satisfaction. In 1997, beneficiaries rated the program quite highly, with 86 percent of respondents saying that they were either "very satisfied" or "satisfied" with COP services, and 92 percent were either "very satisfied" or "satisfied" with care management.[14]

Nonskilled home care workers are certified by the county that they meet state Medicaid waiver standards. Agencies and individuals providing supportive home care are required to receive training in administrative policies, the specific disabilities of the persons to be served, medical and safety emergencies, interpersonal skills, personal care and home management services. Training must be completed within six months of employment. Exemptions to the training requirements may be granted to providers who can demonstrate that they already possess these skills. Individual clients who act as employers may provide the training if, in the county's judgment, they are capable of doing so.

Licensure requirements for community-based residential facilities and residential care apartment complexes have been topics of considerable debate, with new requirements adopted in the last few years. Community-based residential facilities are subject to fairly extensive nursing home-style regulation, while requirements for residential care apartment complexes are much less extensive. Indeed, one observer characterized the residential care apartment complexes as "virtually unregulated." The

[14] Wisconsin Department of Health and Family Services, " Scorecard Rating COP's Performance in 1999," http://www.dhfs.state.wi.us/outcomes/cop.htm, accessed July 2000.

relatively small number of adult family homes are licensed by the state and certified by the counties.

A major issue for all long-term care providers in Wisconsin is the shortage of paraprofessional workers, which is affecting access to services and may be affecting quality of care. Most informants used the term "crisis" to describe the staffing situation. The overall unemployment rate in Wisconsin was only 3.7 percent in July 2000, making it difficult to recruit workers.[15] According to one provider, "Paraprofessional long-term care workers can do better at McDonalds, but there is a shortage of registered nurses as well." The recent increase in Medicaid payment rates for personal care may not result in higher wages because it is up to the counties to decide whether to raise rates. Reportedly, some counties are closing their personal care agencies because they cannot recruit workers and this, reportedly, has resulted in some Medicaid clients being unable to obtain personal care and home health services.

COST CONTAINMENT

Controlling public long-term care expenditures is a major concern in Wisconsin. Long-term care, including services for people with developmental disabilities as well as older people and persons with physical disabilities, accounts for about half of Medicaid expenditures in the state, one of the highest percentages in the country.[16] For noninstitutional long-term care services, cost control is important because expansion of home and community-based services has been sold to the legislature and others as a way of saving money. Also, the large waiting lists that exist for COP services underlines the importance of finding ways to make limited state funds serve as many people as possible.

Nursing home expenditures are controlled through limiting the supply of beds and through tightening Medicaid payment rates. As noted earlier, there has been a moratorium on the construction of new nursing home beds since the early 1980s and, coupled with declining occupancy rates, there is little demand for additional beds.

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[15] U.S. Bureau of Labor Statistics, "Regional and State Employment and Unemployment: July 2000," *United States Department of Labor News*, Washington, DC, August 18, 2000.

[16] Urban Institute estimates based on data from HCFA-64 and HCFA-2082 data.

Despite the long moratorium and the increasing number of older people, the state still has a relatively high supply of beds compared to the rest of the country.

As in other parts of the country, nursing facilities that are heavily dependent on Medicare have had financial problems, in part as a result of the reimbursement changes implemented as part of the Balanced Budget Act of 1997. A number of facilities are in Chapter 11 bankruptcy, including facilities owned by Vencor and Mariner. Given the relatively low occupancy rate, some facilities are actually closing rather than being sold, but with substantial numbers of empty beds, state officials are not worried about inadequate access.[17]

The state has tightened nursing home payment rates in recent years, mostly by reducing payment ceilings to median costs by cost center and by limiting inflation adjustments. Nursing home payment rates averaged $91.70 per day in 1998, slightly below the national average of $95.72.[18] It is unclear what impact the Balanced Budget Act of 1997's repeal of federal minimum requirements for nursing home reimbursement, known as the Boren Amendment, will have on reimbursement levels. Several respondents characterized the nursing home industry as having significant political clout and benefiting from rate increases that other providers did not receive. However, with repeal of the Boren Amendment, the state eliminated its own law that required it to pay nursing homes the costs which must be incurred by an economically and efficiently operated facility. One state official expected that the repeal of federal and state minimum standards would mean further tightening of reimbursement rates, but a knowledgeable consumer advocate contended that reimbursement levels were determined by politics and not by statutory minimum standards.

Whether home and community-based services save money has been the subject of ongoing, often heated, debates among state officials, the nursing home industry, and

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[17] Patricia Simms, "It's a Crisis, Nursing Homes Say," *Wisconsin State Journal*, September 18, 2000.

[18] Charlene Harrington, James H. Swan, Valerie Wellin, Wendy Clemena, and Helen M. Carillo, *1998 State Data Book on Long-Term Care Program and Market Characteristics*, (San Francisco: University of California, San Francisco, 2000).

consumer advocates. Proponents of home and community-based services make two arguments. First, they argue that the existence of these services has allowed the state to substantially reduce nursing home utilization over the last twenty years. The state has not added to its bed supply since 1981 and occupancy rates are low, especially for for-profit facilities. There is, however, no direct evidence linking the decline in nursing home use to the expansion of COP and other programs, and there may be other causes. Second, proponents point to the fact that the average cost for waiver participants is lower than for nursing home residents. In 1997, the average daily cost for clients in the COP-W and CIP II (including Medicaid, Supplemental Security Income, Community Aids, and other publicly-funded services) was $66.74, while it was $85.85 per day in nursing homes. After a crude adjustment for casemix differences, the differential narrows slightly, but not significantly. Citing studies by Sager and Arling and by DHFS' Office of Strategic Planning, the nursing home industry contends that the cost comparison is faulty because it does not address expenditures associated with additional utilization in the community nor does it adequately address differences in casemix between people serviced in nursing homes and in the community.[19] The nursing home industry contends that it supports COP as part of the continuum of care, but that its expansion should not be at the expense of nursing homes.

In addition to using low-cost consumer-directed care and nonmedical residential facilities, Wisconsin controls expenditures for home and community-based services by budgeting expenditures, maintaining waiting lists, setting limits on average expenditures, tightly controlling payment rates, and by cost shifting to Medicare and beneficiaries.

The main mechanism for controlling state costs for COP-R and COP-W is an overall budget cap. The state allocates the counties a set amount of money--a global cap. No additional state funds are available if counties overrun their budgets. However, counties can increase expenditures beyond this level by spending their own money and

[19] Mark A. Sager and Greg Arling, "A Review of Community-Based Long-Term Care with Emphasis on Wisconsin's Community Options Program," (Madison: University of Wisconsin, 1995); and, Tun Mei Chung, *Public Costs of Serving a Long-Term Care Client in a Nursing Home or in a Community-Based Program*, Office of Strategic Planning (Madison: Department of Health and Family Services, 1997).

by providing the state Medicaid match to obtain additional federal Medicaid funds in some circumstances.

The most controversial mechanism for controlling the public costs of home and community-based services in Wisconsin has been the establishment of large waiting lists. As of January 1, 2000, there were approximately 11,353 people on waiting lists for COP, roughly the same number of people actually receiving COP services.[20] This represents roughly a third increase in the number of people on the waiting list since 1997. Counties are legally required to provide clients who have been assessed as eligible for COP services an opportunity to be placed on a waiting list if services are not immediately available. Of the waiting list population, about half were older people, nearly a fifth were people with physical disabilities, and the rest were persons with developmental disabilities and other conditions.[21] As noted previously, Medicaid eligible individuals on the waiting list may receive regular "card" services (e.g., personal care and home health), although they will not be eligible for the more flexible services available under COP-R and the waivers. However, many individuals on the waiting list only financially qualify for Medicaid under the special waiver rules; they do not qualify for Medicaid under regular eligibility rules.

There are wide variations across counties in managing the waiting list. Thus, whether someone can access home and community care depends on where they live and when they happen to need services. In general, people are taken from the waiting list on a "first come, first served basis." However, the "significant proportions" requirements can affect the order in which people come off the list. For example, if older people are underserved in a county according to the "significant proportions" requirements, then older people can jump the queue in terms of receiving services. Some observers contend that the long waiting times for COP result in a structural bias in favor of serving

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[20] Richard Megna, *Community-Based Long-Term Care Programs,* Madison: Wisconsin Legislative Fiscal Bureau, 2001.

[21] Wisconsin Department of Health and Family Services, "Why Older People Need Family Care," http://www.dhfs.state.wi.us/LTCare/whyolder.htm; and, Wisconsin Department of Health and Family Services, "Why Younger People with Physical Disabilities Need Family Care," http://www.dhfs.state.wi.us/LTCare/whypd.htm.

individuals with stable home supports because they are the only ones who can stay in the community for substantial periods of time without services. According to this theory, people without these supports end up being admitted to nursing homes.

As is required by federal rules governing the Medicaid waivers, the state must limit its average expenditures per person under the waiver, a constraint that the state imposes on each of the counties. The maximum expenditure for each county is limited to an average of $48.33 per day per person.[22] Unlike some other states, Wisconsin does not establish rigid per person limits on expenditures and some clients cost over $100,000 a year to maintain in the community. Indeed, the state requires that at least 20 percent of a county's caseload be individuals with high costs of care.[23] Earlier attempts to establish "hard caps" on individual expenditures were strongly opposed by the consumer advocacy community, especially by advocates for younger persons with disabilities, and were withdrawn before they could be implemented. If a county's average expenditures exceed the allowable level, counties may request a waiver from DHFS, which is almost always granted because many counties have average expenditures below the limit. Indeed, in 1999, the average Medicaid waiver costs were approximately $30 per day, well below the average Medicaid cost of nursing home care.[24]

Reimbursement levels for home and community-based services is a source of great tension between the state and providers. In particular, providers complained that personal care payments have been frozen for several years. In addition, Medicaid audits have resulted in substantial disallowances of care provided due to inadequate documentation of clients' conditions. The Medicaid payment rates, reportedly, have also resulted in a shortage of personal care workers and registered nurses. Providers argue that the low reimbursement levels is creating a serious problem for people with disabilities, who cannot find workers to provide services. In addition, many family

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[22] Richard A. Megna, *Community-Based Long-Term Care Programs*, Madison, WI: Wisconsin Legislative Fiscal Bureau, 2001.

[23] Richard A. Megna, *Community-Based Long-Term Care Programs*, Madison, WI: Wisconsin Legislative Fiscal Bureau, 2001.

[24] Richard Megna, *Community-Based Long-Term Care Programs*, (Madison, WI: Wisconsin Legislative Fiscal Bureau, 2001).

workers provide more hours than they are paid to supply. Payment rates for workers in 1998 varied by county, but ranged from $6.00 to $15.00 an hour. The agency payment rate in 2000 for personal care was $11.20 an hour. Reportedly, Wisconsin's payment level for personal care is the lowest in the Midwest, and several observers characterized the wages of personal care and consumer-directed workers as "not a living wage," "pretty minimal amount," and "not enough to support a family."

Wisconsin has been aggressively pursuing Medicare maximization in the area of home health, attempting to shift costs from Medicaid to the extent possible. This strategy has included extensive retrospective audits of home health agency payments and directives that agencies bill Medicare—and not Medicaid—first. This strategy reportedly caused problems for many home health agencies since Medicare penalizes agencies if too many claims are submitted and ultimately rejected. In addition, audits of previous bills of home health agencies for services the state believes should have been billed to Medicare were claimed to be "hell" for providers and came after the Medicare window for billing had closed. Providers allege that the state also uses a different definition of what constitutes being "homebound," than does Medicare, a key element in Medicare eligibility for home health services.

The Medicare home health reimbursement changes in the Balanced Budget Act of 1997 reportedly had a major impact on providers in Wisconsin, with reimbursement falling drastically and many agencies closing. Providers claim to be "hanging on by their fingernails," with the hope that the Medicare prospective payment system will alleviate their problems. According to industry sources, agencies have tried to compensate for the Medicare shortfall by cost shifting to private insurance and private pay. Providers also complained about the administrative burden of the Outcome and Assessment Information Set (OASIS), the new Medicare home health patient data set.

Finally, Wisconsin recovers the costs of long-term care expenditures from the estates of persons receiving state-funded services as well as Medicaid-funded care. The state requirements are more stringent than the federal ones in that they provide less protection for the surviving spouse.

REDESIGNING LONG-TERM CARE: FAMILY CARE

In recent years, Wisconsin has proposed two different strategies to dramatically "redesign" its long-term care system. In 1997, a DHFS proposal to integrate acute and long-term care services was withdrawn shortly after it was proposed after heavy criticism from consumer advocates and counties. The initial "redesign" featured "one-stop shopping" for individuals through newly created county resource centers and care management organizations which would receive capitated payments for both acute and long-term care services. Opponents of the plan worried about the expertise of the new managed care organizations, the potential impact on the allocation of resources to long-term care within the managed care organization, the degree to which services might be medicalized and less consumer directed, and the transfer of authority over much of long-term care from counties to potentially for-profit managed care organizations.

In its place, the state has proposed to start the long-term care reform process by integrating the delivery and financing of long-term care through "Family Care." The main goals of Family Care are to end the institutional bias, consolidate funding, establish coordinated care, increase consumer choice, improve access, and establish a more efficient system of care. Enacted on a demonstration basis in 1999, Family Care initially will be limited to counties representing no more than 29 percent of the target disabled population. In the initial projects, Family Care will serve older people, younger people with physical disabilities, and persons with developmental disabilities. In order to implement the project, the state has applied for a Medicaid freedom-of-choice waiver (section 1915(b) waiver) and a Medicaid home and community-based services waiver (section 1915(c) waiver).

Family Care has two major components--the Aging and Disability Resource Centers and the Care Management Organizations. Currently, five counties—Fond de Lac, La Crosse, Portage, Richland, and Milwaukee County (only for the older population)—are operating the full model of Family Care under the demonstration. Run by the counties, the Resource Centers (RCs) offer a wide range of information and counseling on long-term care services and providers, conduct functional assessments and determine financial eligibility for Family Care and other public programs, and, if appropriate and

chosen by the client, assist with enrollment into a Care Management Organization. The goal is for the resource centers to provide "one-stop" shopping and a "single point of entry" into the long-term care system (including residential options) for persons of all income levels. With its single point of entry, the RCs are intended to simplify the long-term care system for consumers, who, according to one consumer advocate, are "mystified by the existing system." The RCs will also provide prevention, early intervention and outreach services.

Care Management Organizations (CMOs) are also operated by the counties and serve as capitated, managed care organizations for institutional and noninstitutional long-term care services. Funding for long-term care from Medicaid card services, Medicaid home and community-based waivers, COP-R, Community Aids, county funds, and many other smaller programs are consolidated into single monthly capitated payments to the Care Management Organization. The goal is one "pot" of money that can be used to create a seamless system in which individual’s needs dictate service provision rather than program demarcation determining the individual’s care.

The capitation amount from the state to the CMO will be ultimately related to the projected need for long-term care services based on the individual's level of functional disability. While the monthly per person payment amount will be based on average costs for groups of people at various functional levels, the actual cost for any given person will likely be higher or lower than the payment. The monthly payment that a CMO receives related to a given individual does not limit the amount that may be spent on that individual's care, nor does it entitle the person to services at the level of the monthly payment amount. Each CMO is responsible for meeting the needs of its enrollees within the funds that it receives. The state and the CMO will share financial risk and other protections are in place to assure the financial stability of CMOs.

Each CMO is required to offer a state-established minimum array of service types. A personalized assessment will determine the preferred package of services, with a great deal of opportunity for flexibility. Since meeting individualized needs while maintaining cost-effectiveness is central to Family Care, case management is a key component of the program. Each CMO is required to develop, in consultation with local

consumers, a network of service providers that provide adequate consumer choice of readily accessible providers for all types of services. Consumers must be able to choose from among a broad array of providers meeting the CMO's price and quality standards. CMOs are free to negotiate their own reimbursement arrangements with providers, although, in general, they cannot exceed the Medicaid payment rate (although a waiver to pay more is possible). Enhancing consumer direction is a main goal of the program and CMOs are required to develop and offer a consumer-directed option.

Eligibility for the new benefit is based on the degree to which an individual's physical or cognitive condition limits his or her ability to manage independently the everyday activities of living such as moving around, eating, bathing, and dressing. Two functional levels of eligibility are used: comprehensive (equivalent to the level of care requirements for nursing home care), and intermediate (less severe than comprehensive).

A major advantage of Family Care over the existing system is that it provides an entitlement to a comprehensive array of flexible home and community-based services to everyone who meets certain criteria. Everyone who meets the comprehensive level of functional eligibility, or who meets the intermediate level and is eligible for Medicaid, or has a confirmed need for adult protective services is entitled to services. There will be no waiting list for services.

In addition, there is no cliff of financial eligibility. All clients will be required to share in the cost of their services to the extent of their ability to pay, from nothing to the full cost of services. Cost sharing is determined using the combined factors of income and assets, offset by several types of deductions and exemptions. Private pay clients have access to the program as well. State officials hope to reduce the stigma of applying for public aid.

Individuals are free to choose whether or not to enroll in a CMO. Those persons who are Medicaid eligible will have the option of obtaining services through the Medicaid fee-for- service system, which will continue to offer the current range of benefits available under the regular Medicaid program. However, the new flexible Family Care benefit will be available only through a CMO, creating a strong incentive to enroll in the CMO. Moreover, where a CMO is available, COP-R and the home and

community-based waivers will not operate as separate programs. Thus, individuals who do not enroll in the CMO will not be eligible for those services.

The Family Care legislation mandates that there be independent advocates for program beneficiaries. To fulfill this requirement, the Wisconsin Board on Aging and Long-Term Care (an advocacy body created by the Wisconsin Legislature in 1982) contracted with the Wisconsin Coalition for Advocacy. The Wisconsin Coalition for Advocacy has been in the process of awarding contracts to local advocates, who will have a role similar to that of the long-term care ombudsman and will assist consumers in conflicts surrounding benefits and services.

The design and implementation of Family Care has raised at least five major issues. First, in the view of the state, Family Care levels the playing field between institutional and noninstitutional services by creating an entitlement to home and community-based services that mirrors the entitlement to nursing home care. For consumer advocates, the principal attraction of Family Care is the promise to eliminate the COP waiting lists. However, the state will only be able to substantially increase the number of people receiving home and community-based services without dramatically increasing expenditures if it can significantly reduce the number of people using nursing home care. According to state officials, the long-run goal is to reduce utilization of nursing homes from about 70 percent of long-term care beneficiaries to about 40 percent of long-term care users. Based on the experience of Oregon, they believe that this is achievable, a contention that is hotly disputed by the nursing home industry. State officials profess confidence that this can be done, in part because the state already spends about 50 percent more per capita on long-term care than the U.S. average. However, some consumer advocates would prefer simply to increase funding for home and community-based services without developing this new system.

Second, a primary issue affecting the implementation of Family Care concerns conflict of interest issues related to program governance. Both the Health Care Financing Administration and the state have concerns about the potential for conflict of interests if the entity that receives capitated funds to provide Family Care services also sets the level of care and/or provides enrollment counseling. For example, the entity could overstate

disability in order to obtain higher reimbursement for the CMO or discourage enrollment in the CMO by individuals who might require substantial amounts of care, causing the organization to lose money. In discussions about approving the necessary Medicaid waivers, HCFA has insisted that the entity that determines eligibility and counsels the consumer about which service provider to choose must be separate from the entity that provides services. DHFS had originally assumed that locating the Aging and Disability Resource Centers and the Care Management Organizations in separate parts of the county government and requiring separate contracts and separate governing boards would be sufficient, but HCFA has not felt that this was enough to avoid conflict of interest. To date, this issue has not been resolved, which has delayed the implementation of some aspects of Family Care in the pilot counties.

A related issue is whether counties will permanently be the operators of the Aging and Disability Resource Centers and the Care Management Organizations. Both entities initially will be "sole sourced" to the counties for a period of time, but after December 31, 2003, CMO contracts will be open to competition among public and private entities. Awards are to be based on quality rather than price, whereby the state sets the standards for quality. The potential loss of the county involvement is disturbing to some because, according to one consumer advocate, the county-based system is "sacred" in Wisconsin. In addition, some observers fear that the ultimate goal of state officials is privatization and elimination of the role of counties in long-term care. As one consumer advocate put it, "People are afraid of private, for-profit HMOs taking over."

Third, although Family Care will provide an entitlement to home and community-based services, the extremely broad range of services potentially available raises the question of what does this entitlement consist. This is particularly an issue because each individual does not receive a set budgeted amount within which he or she has flexibility. According to state officials, individuals will be entitled to a flexible set of services that meet their needs in a cost-effective manner. How that will be measured could be extremely difficult and the lack of a defined benefit could be confusing to consumers.

Fourth, the use of a managed care model has raised concerns about the potential for a limited network of providers. The state has not set numerical minimum standards,

preferring to rely on "outcome" measures to assess the adequacy of the network. At least initially, counties appear to be including the majority of providers in their geographic area.

Fifth, as might be expected, the setting of the capitation rates has been a difficult process, in part because of the complexity of gathering all of the relevant expenditures from the state and the counties on an individual, systematic basis. The pilot counties and providers contend that the capitation rates are based on incomplete data. In addition, since differences in capitation rates across counties reflects differences in historical spending per recipient, there is concern that the capitation rates will freeze forever existing inequalities across counties.

CHALLENGES FOR THE FUTURE

Wisconsin has a well-developed system of home and community-based services for older people and younger persons with physical disabilities. There is a substantial Medicaid home and community-based services waiver, Medicaid coverage of personal care, and a large state-funded program that supplements Medicaid. A very wide range of services are available, including nonmedical residential services and consumer-directed care. Philosophically, public home care programs, especially the Community Options Program, are very oriented towards giving consumers the power to make choices. As Wisconsin looks forwards, it's home and community-based services face at least three major challenges.

The first and most pressing challenge is to implement the Family Care program and to evaluate its impacts. Family Care is one of the country's most ambitious long-term care experiments and implementing it has been a major administrative task in which the state has invested heavily. Of particular interest will be whether Family Care will succeed in substantially reducing nursing home use. Being able to do so is the principal underlying assumption in the state's estimate that it will be able to make home and community-based services an entitlement and eliminate the large COP waiting list without significantly increasing expenditures. This assumption challenges most of the previous research on cost effectiveness of home and community-based services, but this literature is very old and does not incorporate more recent developments in service

provision.[25] If the state is not successful, then it could face large increases in expenditures.

The second challenge involves the growing manpower shortage that most states face, but which is particularly acute in Wisconsin because of the extremely low unemployment rate. Eliminating the COP waiting lists, as promised by Family Care, will substantially increase the demand for home and community-based services, placing additional strain on the labor supply. Already, there are reports of difficulty recruiting long-term care staff, to the extent that some services could not be provided because of inadequate number of staff. Staff shortages clearly relate to issues of wages and benefits, but also are probably a function of the organization of work and the potential for advancement.

The third challenge relates to the balance between health and social services, especially as the home and community-based services system takes on increasingly disabled and chronically ill individuals. Like Washington and Oregon, Wisconsin has emphasized nonmedical home and community-based services, including consumer-directed home care and nonmedical residential settings. How to make sure that these severely disabled individuals receive adequate care without overly medicalizing the service system will require close monitoring of quality and will be a test of the Wisconsin home and community-based system.

In sum, Wisconsin has a highly developed system of home and community-based services that is among the country's most innovative. It's ambitious plans to "redesign" its long-term care system will be watched closely by other states.

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[25] Peter Kemper, Robert Applebaum, and M. Harrigan, "Community Care Demonstrations: What Have We Learned?" *Health Care Financing Review*, 8(4): 87-100, 1987; Rosalie A. Kane and Robert L. Kane, *Long-Term Care Principles, Programs and Policies*, (New York: Springer, 1987); William Weissert, Cynthia Matthews Cready, and James E. Pawelak, "The Past and Future of Home and Community-Based Long-Term Care," *The Milbank Quarterly*, 66: 309-388; and, Joshua M. Wiener and Raymond J. Hanley, "Caring for the Disabled Elderly: There's No Place Like Home," in: *Improving Health Policy and Management*, eds. Stephen M. Shortell and Uwe Reinhart, (Ann Arbor, MI: Health Administration Press), pp. 182-212. For a more recent and more optimistic view of the cost effectiveness of home and community-based services (albeit with a less rigorous methodology), see: Lisa Maria B. Alecxih, Steven Lutzky, and John Corea, *Estimated Savings from the Use of Home and Community-Based Alternatives to Nursing Facility Care in Three States*, (Washington, DC: AARP, 1996).