

Description of Wisconsin's Current Long Term Care System

*Wisconsin Council on Long Term Care, October 2002
Adapted from Appendix A to the Phase I ADA Title II Plan dated January 2002*

Over 260,000 adult Wisconsin residents have a permanent or long term disability that is severe enough to interfere with their ability to live their daily lives with complete independence. The long term care that they may need includes many different services, like personal care, housekeeping, nursing or getting a ride to work, and can be provided in any setting. Long term care is provided in people's homes, in nursing homes, in small and large residential care facilities or group homes, and in the workplace. Most long term care is actually provided by family members; up to two-thirds of older people with severe disabilities rely exclusively on help from family and friends.

Long term care is an issue that affects almost all of us. If we don't need long term care ourselves, we almost always have a family member or friend who does. One out of four households in America is involved in helping to care for an older person. Caregiving responsibilities can reduce business productivity if full-time employees need to alter work schedules or take work time to help manage paid services for a family member.

People pay directly for a lot of care and long-term care insurance pays for some. Medicare and private health insurance pay only for limited care that is associated with an acute episode of illness or injury. Yet government in Wisconsin still spends nearly \$2 billion a year paying for care that people themselves cannot afford.

Over the past twenty years, Wisconsin has developed a long term care system composed of an array of programs and funding sources to support frail elders and people with disabilities in nursing homes and other institutions, small and large group settings and at home. Historically, Wisconsin has invested significantly in nursing homes and other institutional care, as well as community long term care. Although the state has significantly expanded community-based services, nursing homes and other institutions still constitute a large part of the current system in Wisconsin.

Wisconsin's Medicaid State Plan covers all mandated and optional services permitted under the federal Title 19. Wisconsin also provides broad eligibility, including a comparatively high medically needy limit, a Medicaid Purchase Plan for individuals with disabilities, and through the "Katie Beckett" program, extends eligibility to 4,000 disabled children at the institutional level of care need. Medicaid provides many services that help support individuals with disabilities in the community. In addition, Wisconsin Medicaid has a prescription drug benefit that provides necessary medications to enable many people to remain in the community. The new SeniorCare program extends prescription drug assistance to elderly people of modest means who are not Medicaid eligible. State Plan services, however are neither as flexible nor as coordinated as home and community based waivers.

The System for Frail Elders and Adults with Physical or Developmental Disabilities

- **Demographics**

The proportion of people age 65 and older in Wisconsin is higher than that of the nation as a whole (13.1 percent versus 12.4 percent). In 2000, 702,553 people in Wisconsin were age 65 and older, and 95,625 of these were age 85 and older. By 2020, the number of people age 65 and older is projected to increase by 45 percent (312,400 people), to a total of over a million people – one in six of us. The number of people age 85 and older (those most likely to need long term care) is projected to increase by 35 percent (33,200 people) in the same time period, to a total of 128,800 people. The growth in the elderly population (age 65+) is projected to account for 45 percent of the total growth in Wisconsin’s population between 2000 and 2020, and 63 percent of the total growth between 2000 and 2030. By 2040, Wisconsin’s over 65 population will double and the over 85 group will triple. Only a relatively small percentage of those over age 65 will need long term care at any given time, although the percentage increases with age.

The number of younger adults with physical and developmental disabilities is also growing, due to advances in medical technology that allow younger people with chronic diseases or disabling injuries to live longer. Methods of estimating total need for long term care vary, but just to stay even with the percentage of elderly people and younger adults now receiving care in one of Wisconsin’s formal long term care programs, we would need to create approximately 17,000 additional “slots” by 2020 and another 18,500 in the following ten years.

- **Community Based and Integrated Benefits**

Community Options Program and Related Medicaid Waivers. The Community Options Program (COP) is a state-funded, county-administered home care program for frail elders and persons with disabilities to reduce the use of nursing homes. Wisconsin has expanded its community support resources using four Medicaid s. 1915(c) waivers serving frail elders and people who have a physical disability or a developmental disability.

Wisconsin provides a wide range of services under COP and the Home and Community Based Waiver (HCBW) programs: COP Waiver (nursing home diversion program for elderly and physically disabled persons), Community Integration Program II or CIP II (nursing home relocation program for elderly and physically disabled persons), Community Integration Program 1A or CIP 1A (relocation program for persons with developmental disabilities from the State Centers for Developmental Disabilities), Community Integration Program 1B or CIP 1B (institutional diversion program for persons with developmental disabilities), Community Supported Living Arrangements (CSLA for people with developmental disabilities) and the Brain Injury Waiver (BIW). The Medicaid waivers can pay for most social and environmental supports (as noted in the chart below) not covered by the Medicaid fee-for-service program or the family.

Community-Based Services under COP and Waivers

Adult Day Care	Respite Care	Supportive HomeCare
Chore Service	Homemaker	Housing/Energy Assistance
Specialized Transportation/Escort	Prevocational Services	Daily Living Skills Training
Personal Emergency Response Systems	Communication Aids	Specialized Medical Supplies
Home Modifications	Adaptive Aids – Vehicle	Adaptive Aids – Other
Adult Family Home (Foster Home)	Group Home	Shelter Care
Court Intake/Studies	Congregate Meals	Home Delivered Meals
Recreation/Alternative Activities	Protective Payment/Guardianship	Supported Employment
Community-Based Residential Facilities	Advocacy and Defense Resources	Day Treatment
Residential Care Apartment Complexes	Home Accessibility Screening	Day Center Service Treatment
Counseling and Therapeutic Resources	Skilled Nursing	

Community-Based Long Term Care Services under Medicaid Fee-For-Service

Case Management	Home Health Aide	Personal Care
Therapies (Speech, Occupational, Physical)	Transportation for Medical Care	Medical Supplies
Skilled Nursing	Orthotics	Durable Medical Equipment
Mental Health Crisis Stabilization	Community Support Program	In-home psychotherapy
Mental Health Outpatient Services	Mental Health Day Treatment	

COP funds are even more flexible and can be used for expenditures not covered by the waivers, such as room and board, community services for persons still in a nursing home, or relative caregiver services. COP can also serve people who are not eligible for Medicaid. All COP and/or Waiver participants receive assessment, care planning and care management. Essential services such as durable medical equipment, mental health services, home health and personal care are provided under Wisconsin’s Medicaid State Plan and authorized through a separate process.

COP and its related waiver programs are administered through 72 county governments and one tribe. (In the five counties piloting the Family Care benefit, COP remains to serve people not in Family Care’s target groups.) The amount of funding for COP and Waiver Programs is established each year by the State Legislature and the Governor. For the most part, funds are allocated to counties by formula, and counties in turn serve as many people as available funds allow. Some funds are reserved at the state level and counties apply for them to assist in relocations from institutions. There is no entitlement to COP or the Waivers; people are served as funds allow.

A total of 25,981 people were served under Wisconsin’s COP and Waiver programs during 2000, distributed as shown in the table below.

COP/Waiver Participants and Expenditures by Target Group, CY 2000

	Percent of People Served*	Percent of Expenditures*
Elderly	45.7	25.7
Physically Disabled	13.3	10.7
Developmentally Disabled	35.4	60.5
Seriously Mentally Ill	4.5	2.9
AODA /Other	1.2	0.2

*Served at any time during 2000. May not total to 100 percent due to rounding.

In CY 2000, Wisconsin’s home and community based waivers accounted for \$333,324,877 in expenditures (state and federal funds). The state-funded COP program had expenditures of \$69,378,624 for the same year. In addition, counties use other state and federal funding sources and county tax levy to support individuals in their homes. DHFS annually reports to the legislature comparative costs for elders and people with physical disabilities for the COP-Waivers and nursing homes. For 2000, taking into account all Medicaid and other public funds (includes all Medicaid benefits, state and county funds, and SSI), participants in the CIP II and COP-Waiver had total public long term care costs of \$266.2 million while costs for the same group in a nursing home were estimated at \$374.9 million. Average daily costs were \$64.16 for waiver participants compared to an estimated daily cost of \$79.80 for nursing home care for the same group of people, adjusting for level of care.

Medicaid community-based card services. Wisconsin Medicaid’s fee-for-service budget for home care services is \$184.6 million for this state fiscal year (2002-03). Home care services include personal care, home health services, hospice and private duty nursing. The Personal Care services covered under the Medicaid fee-for-service card benefit include assistance with many activities of daily living. The personal care benefit is “prior-authorized” by the state Medicaid agency. The services provided by personal care workers are under the supervision of a registered nurse, ordered by a physician and delivered according to a written plan of care. The personal care benefit is one of the faster growing components of the state Medicaid budget. While the number of recipients receiving services is not increasing significantly, the average annual cost per recipient has increased from \$4,310 in 1996 to \$10,146 in 2002. The budget for personal care for state fiscal year 03 is \$115.4 million. Home health accounts for another \$61.7 million. The Medicaid reimbursement rate for personal care rose to \$15.50 an hour on July 1, 2000 and is now \$15.84 an hour. Medicaid covered skilled nursing services in the home enable consumers with extensive nursing needs to live in community settings. Private duty nursing is covered in the community and other settings.

Medicaid also covers a wide range of other services that help people stay in their homes, including durable medical equipment and disposable supplies (\$35.9 million), virtually all FDA approved prescription drugs (\$421 million), specialized medical vehicle transportation (\$19.9 million), case management (\$36.8 million), physical and occupational therapy and

speech language pathology (\$17.2 million), and mental health and substance abuse services (\$61 million). The amounts shown here are those budgeted for state fiscal year 2002-03 for coverage provided to elderly people and people with disabilities. These figures do not include expenditures in Family Care, special managed care programs and Medicaid's managed care program for children and their caretakers.

It is unclear to what extent and of the services described in this section are provided to people with ongoing need for long term care, versus short term rehabilitation and recuperation following acute illness or injury (i.e., as substitutions for longer hospital stays). These services are an entitlement for people who qualify for Medicaid and have a demonstrated need for them. Medicaid pays providers on a fee-for-service basis.

PACE/Partnership. Wisconsin has four managed care projects that combine Medicaid and Medicare primary and acute care with long term care services. The PACE program serves elderly individuals and the Wisconsin Partnership Program serves elderly people and people with physical disabilities who meet the Medicaid nursing home level of care criteria. Many people who need long term care and who also have complex or intensive medical needs have benefited from the integrated model in Partnership. As of June 30, 2002, 1280 people were enrolled in PACE and Partnership. \$57,146,400 (all funds) is budgeted for PACE and Partnership in state FY 02, anticipating an increase in enrollment.

There is no entitlement to PACE and Partnership; enrollments are accepted to the extent that funding is available. Waiting lists have existed for these programs, either because enrollments were limited while the organizations were gearing up, or because of funding limits. However, new funding in the budget repair bill of 2002 is expected to eliminate these waiting lists.

PACE/Partnership organizations are paid by Medicaid and Medicare on a capitated basis and assume risk for costs, creating an incentive to keep people as healthy and well-functioning as possible, and in the most cost-effective setting that will meet their needs. For people not in PACE/Partnership, the average monthly Medicaid cost of nursing home and related services is \$3,177 per person per month. In contrast, the average Medicaid capitation payment for these individuals when enrolled in Partnership or PACE is \$3,018 per person per month. This is a savings to Medicaid of \$159 per person per month for those who would have entered a nursing home using the Medicaid card.

Family Care. In 1995, Wisconsin began an extensive strategic planning process to redesign the long term care system. This was a very extensive process involving hundreds of consumers, consumer advocates, providers, and county and state staff. Together they drafted a set of guiding principles for redesigning the system as well as key strategies. Three parallel planning efforts evolved to implement this new vision, including Family Care for adults with developmental disabilities, physical disabilities and frailties of aging; a redesign of the public mental health and substance abuse system; and a redesign of the system for children with severe disabilities. All three efforts share the values of consumer choice: streamlined, flexible and comprehensive services, improved access, cost-effectiveness, and consumer outcome focused quality.

Family Care is the most evolved of the redesign processes. Wisconsin began piloting its new model of long term care delivery for adults with physical and developmental disabilities and frail elders in 1999. Family Care is a managed long term care program that combines the state, federal and local funding for community and institutional long term care into a single capitated benefit. Individuals who live in Family Care counties, who meet functional and financial requirements, and who wish to enroll, are entitled to receive the benefit. A local Care Management Organization is responsible for providing services and is paid each month for each enrollee.

An Aging and Disability Resource Center in each Family Care county provides a one-stop shop for a wide variety of information and assistance, pre-admission counseling for institutional and residential services, prevention activities, and access to long term care programs. A Care Management Organization is responsible for enrolling interested individuals and providing assessment, care planning and services through a network of providers created to provide quality, cost-effective services and to offer maximum consumer choice. In Family Care, the money follows the person across care settings, and all eligible and entitled individuals must have access to services, including community-based care, as appropriate. Decisions regarding a care plan are to be done in a structured process that begins with identifying the consumer's key outcomes and building a care plan with the consumer to achieve those goals. Quality is measured by the extent to which each member's self-identified outcomes are being met and how well the CMO is providing supports to help the member meet those outcomes.

Services Included in the Family Care Benefit

All services listed above for COP and Waivers. plus:

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| Alcohol and Other Drug Abuse Day Treatment (in all settings) | Community Support Program |
| AODA services (outpatient, non-physician) | Home Health |
| Case Management (including Assessment and Planning) | Medical Supplies |
| Durable Medical Equipment (except hearing aids and prosthetics) | Nursing Facility, ICF-MR and IMD |
| Mental Health Day Treatment Services (in all settings) | Personal Care |
| Mental Health services (outpatient, non-physician) | Speech and Language Pathology Services |
| Nursing Services (including respiratory care, intermittent and private duty nursing) | Occupational, speech and physical therapy |
| Transportation Services beyond those covered in COP/Waivers | |

Five counties are piloting the full Family Care benefit and Aging and Disability Resource Centers: Fond du Lac, Portage, La Crosse, Milwaukee (aging only) and Richland Counties. In addition, four counties are providing only Resource Center services: Kenosha, Trempealeau, Marathon and Jackson. The original plan for implementing Family Care included expansion to several more counties during the 2001-2003 biennium, but expansion was put on hold pending formal evaluation results.

Family Care has an annual budget of \$110,553,800 all funds for state FY 02. In 2000, the average monthly payment per enrollee was \$1,731. Purchasing the same services fee-for-

service through Waivers and the MA card would have cost \$1,884 per month. The average monthly per person savings was \$153 or 8%.

As of September 30, 2002, of the 6,634 total enrollees in Family Care, 4,977 were elderly and 1,657 were younger adults with disabilities. Outside of Milwaukee, where only elderly people are served by Family Care, enrollees include 1,355 elderly people and 1,570 people with physical or developmental disabilities.

- **Community Aids and County Funds**

Community Aids and county funding are two additional significant sources of funding for long term care services, primarily for people with developmental disabilities and people with mental illness. These funding sources pay for both institutional and home and community based services. They may be used as match or supplementary funding for waiver programs, to pay for inpatient and outpatient mental health care, and to fund a variety of locally available services. Both the array of services covered and the amount of funding committed to these purposes vary widely from county to county.

- **Housing Options and Issues**

Assisted Living. Wisconsin has several assisted living residential options for elderly people and younger adults with disabilities. Although the Community Options Program and its related Waiver Programs place limits on the size of facilities in which participants may receive services, Family Care and Partnership do not. In 2002, the supply of Assisted Living includes:

- 690 Adult Family Homes (AFHs – 1 to 4 residents), with 2,672 beds
- 1,359 Community-Based Residential Facilities (CBRFs – 5+ residents) with 21,417 beds
- 125 Residential Care Apartment Complexes (RCACs) with 4,452 units.

There are a number of additional RCACs in the development phase.

Housing. According to a state survey, about 79 percent of people age 60 and over who live in the community own their own homes. As age increases, the likelihood of home ownership decreases. Home ownership is much more limited among younger people with disabilities.

Wisconsin has 82,632 federally assisted rental housing units. Of those, 42,272 or 51 percent are elderly units, while 3,466 (4 percent) are units for people with disabilities. In addition, the Wisconsin Housing and Economic Development Authority (WHEDA) subsidizes rental housing construction to provide reduced rents for low income tenants.

- **Institutional Services.**

Nursing Homes. The 2000 annual nursing home survey conducted by DHFS reports that Wisconsin had 419 nursing facilities, with 45,978 licensed beds. Wisconsin nursing homes

had 38,381 residents on December 31, 2000 (84 percent occupancy rate). For 67 percent of these residents, Medicaid was the primary pay source with an average per diem cost of \$101 for Medicaid recipients. To the extent that a bed is available, any person who meets the level of care requirements and qualifies for Medicaid is entitled to Medicaid payment of nursing home costs.

Most people (89 percent) receiving care in nursing homes on December 31, 2000 were at the Intensive Skilled Nursing or Skilled Nursing level of care. About 93 percent were age 65 or older, and just over half were age 85 or older. About one-fourth of nursing home residents had been in the same nursing facility for four or more years, while 36 percent had been in the facility for less than one year. About 80 percent of admissions to nursing facilities were from acute care hospitals. About 46 percent of discharges were to a less restrictive community setting, while 29 percent of the discharges were due to the death of the resident.

Intermediate Care Facilities for the Mentally Retarded. As of December 31, 2000, Wisconsin had 37 intermediate care facilities for the mentally retarded (ICFs-MR), also known as facilities for the developmentally disabled (FDD). These facilities had a total licensed capacity of 2,096 and 1,933 residents (92 percent occupancy rate). Over 99 percent of residents had Medicaid as the primary pay source and an average daily cost of \$141. More than 78 percent of residents of ICFs-MR were under age 65. Over 75 percent of residents of ICFs-MR have been in the facility for five years or more. Most (52 percent) admissions during 2000 were from a community setting. Fifty-five percent of discharges were to the community. As with nursing facilities, Medicaid payment of ICFs-MR is an entitlement to those who meet financial and level of care requirements, to the extent that a bed is available.

Centers for the Developmentally Disabled. DHFS also operates three State Centers for persons with developmental disabilities. The census as of October, 2002 included 26 children and 759 adults, of whom 30 were over age 65. These numbers include short term admissions for evaluation and special treatment. The average per diem cost is approximately \$420. The State controls admission to the Centers and no new long term admissions are being accepted.

Expenditures. The Medicaid budget for nursing homes is over \$1 billion annually. In addition, the State spends roughly \$118 million a year in Medicaid funding on residents in the three State Centers for Developmental Disabilities.

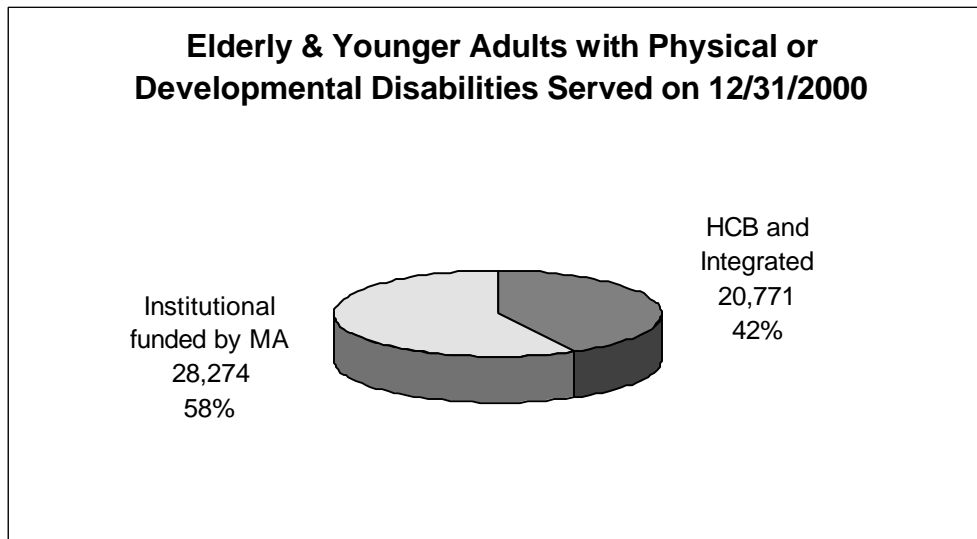
- **System Overview**

People. As of December 31, 2000, 58 percent of all elderly people and younger adults with physical or developmental disabilities served with public funds in the formal long term care system were in institutions, while 42 percent were in home and community based or integrated programs. Of the total elderly people (35,519) served on this date, 68 percent were in institutions; some of them for short-term stays such as post-hospital recuperation. Of the total younger adults (13,789) served on this date, 30 percent were in institutions. The table and chart below summarize this information.

It should be noted that this summary does not include people who may have received some publicly funded home and community services outside of these formal programs. Some people who are not COP or Waiver participants receive Medicaid personal care, home health or other home and community based services. In addition, some people with disabilities who were not in COP or the Waivers received services funded by Community Aids and/or county funds. However, the programs shown here are the only ones for which unduplicated counts of people at a given point in time are available.

It should also be noted that an additional 12,748 people were in nursing homes on December 31, 2000, whose primary pay source on that date was Medicare, private pay, or another non-Medicaid source. Many of those who stay for an extended time would be likely to turn to Medicaid funding when Medicare coverage ceased and/or they spent down private funds. An unknown number of people were also purchasing home or community based services with private or other funding sources.

Adults served on 12/31/00 (unduplicated across programs)	Elderly	PD/DD 18-65	Total
Community Options Program and all Waiver Programs	9,020	8,296	17,316
Family Care	1,175	839	2,014
PACE/Partnership	1,025	416	1,441
Total Home/Community Based	11,220	9,551	20,771
Nursing Facilities ¹	23,839	1,794	25,633
Non-state facilities for the Developmentally Disabled (FDDs)	419	1,514	1,933
State Centers for the Developmentally Disabled	28	718	746
Total Institutional	24,258	4,108	28,366
Grand Total	35,293	10,613	45,906

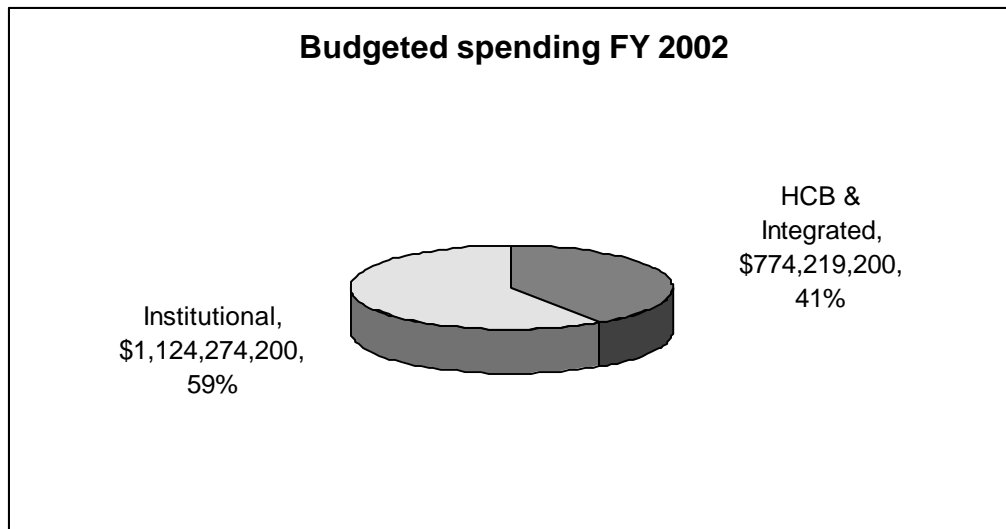


¹ Age breakout estimated; assumes same proportion of Medicaid-funded residents in both age groups.

Funding. Although funding for the long term care system in Wisconsin is much more balanced than in previous decades, 59 percent of the funds are still spent on the institutional side of the system. Funds budgeted for State Fiscal Year 2002 include the amounts of state, federal and segregated funds for long term care services shown in the following table and chart.

Note that this summary of budgeted funds includes Medicaid funded personal care and home health care, which are not included in the above summary of people served, and which may serve people who have only short term needs. It also includes funding for children, people with mental illness, and others served by the programs listed – not just the elderly and adults with physical or developmental disabilities.

Budgeted Funding for FY 02	State	Federal	Segregated	Total
COP – Regular	\$60,509,700	0	0	\$60,509,700
COP-W / CIP II	\$34,438,500	\$69,894,300	\$14,636,300	\$118,969,100
CIP I A & B	\$7,358,500	\$194,612,900	\$35,363,700	\$237,335,100
CSLA	0	\$4,152,300		\$4,152,300
Brain Injury Waiver	\$5,781,200	\$9,601,300	0	\$15,382,500
Family Care	\$47,467,600	\$63,086,200	0	\$110,553,800
PACE/Partnership	\$23,572,900	\$33,573,500	0	\$57,146,400
MA Personal Care	\$44,712,900	\$64,354,500	\$472,200	\$109,539,700
MA Home Health Care	\$24,711,200	\$35,623,300	\$296,200	\$60,630,600
Sub-total Home/Community	\$242,771,300	\$461,144,700	\$50,768,400	\$754,684,400
MA Nursing Facilities and FDDs (including State Centers)	\$319,547,700	\$659,979,300	\$144,747,200	\$1,124,274,100
Grand Total	\$568,100,200	\$1,134,877,600	\$195,515,600	\$1,898,493,400

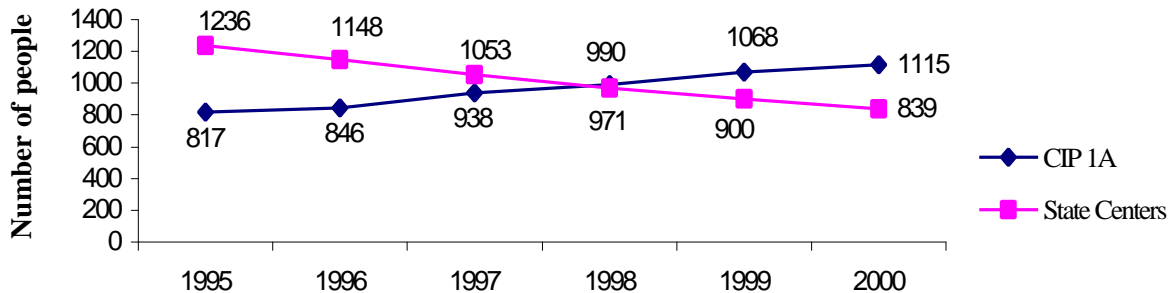


- **System Trends**

Nursing homes have changed considerably over recent decades. Between 1990 and 2000, the number of staffed nursing home beds declined nearly 11 percent, from 48,000 to 42,883. The number of residents declined 14 percent, from nearly 44,800 to 38,381. In this time period, the elderly population grew by 51,332 (7.9 percent), so that the utilization rate of nursing homes by the elderly has fallen significantly. Several statistics point to the fact that nursing homes are being increasingly used for post-hospital rehabilitation and recuperation, or end-of-life care. The percent of residents who were receiving intense skilled nursing or skilled nursing care increased from 70 percent in 1990 to 89 percent in 2000. Eleven percent of residents in 2000 were receiving intermediate (ICF-1) or limited (ICF-2) care in 2000, compared to 30 percent in 1990. Over the last decade, while the number of beds was declining, annual admissions rose 31 percent, from 39,207 to 51,277. The number of Medicare certified beds nearly tripled, from 10,900 to 30,100 (70 percent of all staffed beds in 2000). Over 65 percent of all admissions in 2000 were Medicare funded. In addition, more nursing homes are providing specialized care for people with Alzheimer’s disease. The number of facilities with special Alzheimer’s units increased from 49 to 133 between 1990 and 2000, and the number of beds in such units increased from 1,838 to 3,821 (108 percent).

Capacity and utilization of State Centers for the Developmentally Disabled have declined. The population of the State DD Centers is less than one-third what it was 20 years ago. The chart below shows the trend over the five years between 1995 and 2000.

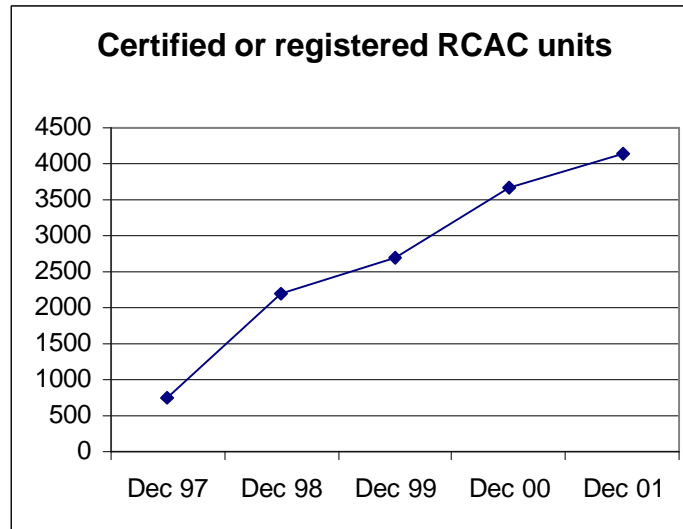
Number of People in the State Centers vs. Number of CIP 1A Participants



Capacity and utilization of other Facilities for the Developmentally Disabled (FDDs) have declined. Between 1990 and 2000, the number of staffed FDD beds declined 27 percent, from 2800 to 2,038. In the five years between 1995 and 2000, the number of residents in FDDs other than the State Centers declined 12 percent, from 2,200 to 1930. The number of inpatient days declined 14 percent during that period.

Capacity and utilization of other residential facilities have increased. In part because of licensing category changes, it is somewhat difficult to track the growth of CBRF and Adult Family Home beds over time. Although some existed previously as CBRFs, Residential Care Apartment Complexes (RCACs) are a new type of facility, created in March of 1997. As of

February, 2002, there were 125 of these facilities, with 4,452 units, and several additional RCACs were under development. Fifty-six of these RCACs, with 2,185 units, were certified to receive public funding as of December 2001. The chart below shows the substantial growth in RCACs since their creation.



Capacity and utilization of home and community-based services have substantially increased. The Community Options Program (COP), Wisconsin's first home and community-based public long term care program, served 198 people in 1982, its first year of operation in the original COP pilot counties. During 2000, COP and its related Medicaid Home and Community Based Waiver Programs served a total of 25,981 people. In 1999, the first Family Care pilot was initiated, and by mid-2002 over 6,000 people were enrolled in the five pilot counties (some of whom had transferred from COP and Waiver programs). In addition, the Partnership Program, begun in 1996, was serving 1,704 people by mid-2002.

- **System Strengths**

National Reputation. In the past, Wisconsin has had a strong reputation in the field of community-based long term care and mental health. The Community Options Program is often cited as a model for community-based services and has been nationally recognized for its innovation. County care managers implement programs locally and many are tremendously creative. The programs are designed in such a way as to have care managers work with consumers to build individualized plans of support around community resources. The care managers authorize payment for the services that are included in these programs. More recently, Wisconsin has generated national interest in its innovative Family Care Program, which provides guaranteed access to a care-managed and very comprehensive long term care benefit, built in a cost-effective way around each enrollee's needs and preferences. Wisconsin's Medicaid program is recognized as one of the most comprehensive in the country, covering all Medicaid's federally mandated and optional services. Financial

resources have been added in each biennium for community based long term care programs, such as COP and the Waivers. Overall, the state provides a significant amount of financial support for a variety of long term care services.

Wisconsin reported high per capita Medicaid expenditures for home care in 1999 at \$77 per capita, compared to the national average of \$58 per capita. Part of the reason for higher than national average expenditures may be that Wisconsin has an older population than the national average. If home and community based expenditures are compared using only the elderly population, Wisconsin spends only about 75 percent of the national average—\$379 per elderly person versus a national average of \$508.²

Relocation Efforts. In 1999, Wisconsin developed a project known as Homecoming with the assistance of a federal nursing home transition grant from the Centers for Medicaid and Medicare Services and will continue these efforts with a second grant. The project was initially targeted, but not limited, to non-elderly persons with physical disabilities. During the 15 months of the first Homecoming grant, more than 80 individuals were placed in the community through the efforts of the project partners. These people are being supported in the community through a combination of COP/Waiver, Medicaid fee-for-service, and local funds. In June of 2001, DHFS announced the availability of an additional \$1 million for relocations from nursing homes. By early October, 87 people who were on waiting lists had moved out of nursing homes. A second \$1 million was set aside in January, 2002 for additional relocations.

Through the CIP II program, as nursing homes close, DHFS has developed a process to work with counties to relocate as many individuals as possible in the time available before closure. DHFS has also developed strategies to identify and relocate persons with developmental disabilities from the State Centers for Persons with Developmental Disabilities. A special waiver program (CIP 1A) provides funds for community services for persons relocated from State Centers. By the year 1999, the number of persons served in the community in CIP 1A (1,068) exceeded the number of residents in the State Centers (900). The trend of relocation and community development continues as community providers become increasingly skilled at developing services in the community for persons with significant disabilities. The census at the three Centers is now under 800 individuals.

- **System Challenges**

Limited resources and waiting lists for home and community based care. The Community Options Program and its related waiver programs are limited by the overall amount of funding appropriated by the state Legislature. Although resources for the home and community based services have increased over the past decade, they have not kept up with the number of people requesting services, and waiting lists continue to increase in non-Family Care counties. As of 12/31/01, counties reported 9,478 people waiting for COP and home and community based waiver services, 576 of whom were residing in nursing homes or other institutions. The number of people on waiting lists and the length of time waiting for

² *Across the States 2000: Profiles of Long-Term Care Systems.* AARP Public Policy Institute.

services vary significantly among counties and among the various target populations eligible for COP and the Waivers.

Two issues contribute to the overall inadequacy of these resources. First, the number of “slots” budgeted for has not kept up with demand. Second, the amount budgeted per slot has not been equal to the true cost per person of providing services. This is exacerbated in some of the Waiver programs, where a daily rate is set by the Legislature that is inadequate to serve some eligible people.

Reliance on Institutional Capacity. In spite of Wisconsin’s efforts to expand the availability of community-based long term care, Wisconsin still relies on the extensive capacity of its nursing homes. In 1999, Wisconsin had 67.9 nursing home beds per 1000 population aged 65 or older, compared to 52.3 beds per 1000 elderly in the United States. However, there are many vacant and unstaffed beds among the total number of licensed beds in Wisconsin.

A nursing home is still the first—and often the only—option that many people consider when addressing the care needs associated with aging and disabilities, especially when public funding is needed. Families seek a safe, predictable setting for aging parents. Elders, people with disabilities and families are often not familiar with the available community options and turn to nursing homes and institutions for help. Except in Family Care counties, information and counseling about long term care options are not available to people before they make this decision. Physicians and hospital discharge planners often rely on nursing homes for post-hospital recuperative care, and nursing home stays are increasingly substituting for the long hospital stays that were once common. In addition, Medicaid provides a powerful fiscal incentive by providing entitlement to nursing home care for eligible individuals.

Medicaid fee-for-service community-based supports are entitlements, but they are often more restrictive, expensive and formal than people want or need. Many people need assistance beyond what these care services can provide, as well as assistance in coordinating several kinds of services. Many community-based services are provided under waivers and are only available within limited budget authority. Wisconsin has a unique Community Integration Program that can shift some funding to community care when a person relocates and a nursing home bed closes. However, these funds are not available for a relocation when a bed is not closed.

State budget decisions are piecemeal. Budgeting for long term care is currently done in a piecemeal manner. Legislators and other policy makers are presented with many budget items on long term care programs and services and make these decisions separately, without benefit of seeing how these items fit into a big picture. Decisions about rates for each provider type in the Medicaid fee-for-service system are made separately from each other and separately from decisions about increases for COP and Waiver funding. Rates and assumed costs per “slot” in COP and the Waiver programs are not based on the actual costs of providing services.

Challenges built into the system for funding community based care. The community care “system” is a confusing and administratively inefficient array of separate programs, each with its own eligibility rules, covered services, and payment rates. Some people fall through the cracks, and for many people who do get into the system, funding must be patched together from a variety of programs.

“Home rule” is highly valued in Wisconsin, and the availability and quality of community based care vary from county to county because of differences in practice among counties. For example, some counties provide substantial county funds to provide services, while others provide little or no funding beyond that required to capture state and federal funds. Counties also vary in the extent to which they use county-funded CIP IB slots, in the extent to which they may add county funds to provide services not possible within the CIP IB rate, and in the extent to which they seek CIP II slots for people wishing to relocate from a nursing home. In addition, counties vary in the variety of services and service providers that are made available to participants in COP and the Waiver programs and the level of choice that participants have about when and how to receive needed services. Although some counties have begun to do so, most COP and Waiver programs do not use self-identified consumer outcomes either for care planning or for monitoring and improving quality.

Limited screening or outreach to nursing home and other institutional residents. The limited state funding for home and community care has reduced the ability of counties to do outreach to persons in nursing homes, except in Family Care counties. As a result outreach to identify people in institutions who want to return to the community is not consistent across the state. Questions have been raised about whether the current Pre-Admission Screening and Resident Review Process, required by the federal government before individuals with mental illnesses or a developmental disability can be admitted to a nursing home, is effective in assuring that individuals are appropriately placed.

Few incentives for counties or institutions to encourage relocations from nursing homes, ICFs-MR or State Centers for the Developmentally Disabled. Since the state and federal government pay for nursing homes under Medicaid, but do not pay for the full cost of some community-based services, there are disincentives to relocate people. The philosophy of some counties is that people in nursing homes are safe, and so, scarce resources should be focused on people in the community who may face greater risk to health and safety.

Nursing home staffing difficulties and increasing closures. With current shortages in staffing, it is difficult for nursing homes to identify persons appropriate for relocation and to develop transition plans and community services. Even though such relocations are difficult, they do happen as nursing homes close. However, the state has not been realistic in budgeting for nursing home bed closures, underestimating the actual closure rates in the state budget for the CIP II program. Over the past two years, more than 1,400 nursing home beds have closed.

Initial cost of relocation. Even if funds are available for on-going costs in the community through waivers and/or Medicaid card services, initial costs for relocating residents of nursing homes are higher than starting services for community-dwelling applicants for COP

or the Waivers. Since some of these costs can only be funded from scarce state-funded COP resources, counties are reluctant to develop expensive plans. Developing these more complex plans also takes a great deal of care manager time and effort.

Insufficient peer support for people needing informal support to make a transition.

People who have lived for a long time in an institution may have few connections to the community. They and/or their guardians may be fearful of relocation and need support both in the decision-making process to relocate and after relocation. People doing outreach in the *Homecoming* project found that even when people had asked to be on a waiting list, when confronted with the imminent possibility of relocation, they were apprehensive. Guardians of persons with developmental disabilities and mental illness often lack knowledge of the community supports available and have significant concerns about relocations to the community. Peer support strategies can be very effective in providing people with useful information and a sense of security.

Personal Care and Home Health Services have limitations. Wisconsin's Medicaid home care benefits have limitations. Personal care benefits are not covered outside the home in natural settings and cover only activities of daily living, but not many instrumental activities of daily living. DHFS has increased flexibility in these benefits, such as decreasing the frequency of nurse supervisory visits, when appropriate. DHFS is exploring offering a choice of consumer-directed care for those recipients who are interested and able to take a larger role in directing their care. Although some states use their Home and Community Based Waiver case managers to authorize Medicaid State Plan personal care services for Waiver participants (who make up the bulk of personal care recipients), Wisconsin has not done so. Prior authorization for personal care in Wisconsin is done at the state level, far from both the consumer and local providers and care managers.

Lack of independent advocacy services for people enrolled in Family Care and PACE/Partnership. Family Care and Partnership members have access to a number of avenues for resolving complaints and grievances. Overlaid on several state systems are federal regulations protecting the rights of managed care enrollees. The system is complex and confusing. In the statewide planning process for Family Care, there was strong consensus that long term care reform should include availability of advocacy assistance for Family Care applicants and enrollees who requested it, and that this assistance should be independent of the Resource Center and Care Management Organization. In the first two years of Family Care, this independent advocacy system operated through a contract between the Board on Aging and Long Term Care and the Wisconsin Coalition for Advocacy. This system and its funding were eliminated in the fall of 2001.

The Ombudsman program at the Board on Aging and Long Term Care provides advocacy and mediation services to residents of nursing homes and most other residential long term care facilities and to participants in the Community Options Program, but has neither authority nor staff resources to provide these services to Family Care, PACE or Partnership enrollees unless they reside in a facility. They also do not have authority or resources to offer help to people residing in Residential Care Apartment Complexes.

The absence of independent advocacy services compromises the ability of enrollees to understand their rights and to resolve differences with their care managers in the choice and delivery of services. In addition, an opportunity is lost for the independent advocates to identify patterns of systemic problems that could assist state and local agencies to improve overall quality.

Shortage of accessible, affordable housing. Some consumers who were identified for community placement under the *Homecoming* grant either were not relocated, or had their relocation delayed, because suitable housing was not available. The insufficient supply of affordable housing has also been a problem in starting services for a number of new Family Care enrollees in Milwaukee and other Family Care counties. Many areas have waiting lists for Section 8 vouchers or have little accessible and affordable housing available. Housing delays make it difficult to develop a plan for individuals and create frustration for community agencies working on relocations.

Lack of adequately trained workforce. Prolonged high employment rates in the state have contributed to a serious shortage of direct care workers in all long-term care services and settings. Turnover in many facilities is as high as 100 percent, and turnover among home care workers is often at least 50 percent annually. A stable, well-trained and caring workforce is the backbone of the long term care system, and shortages affect consumers, providers and workers. The workforce issue will become increasingly difficult as elderly age groups grow far more rapidly than those of working age during the coming decades. For four years, DHFS has provided special grants for Community Links Projects to COP Lead Agencies to expand and improve local long term care work forces. The Governor's Health Care Worker Shortage Committee made a number of recommendations in October of 2002. Several other initiatives are underway, including those undertaken by the statewide Long Term Care Workforce Alliance, a broad coalition of stakeholders.

The System for Adults with Serious and Persistent Mental Illness

- **Demographics**

About 277,700 adults experience a serious mental illness in a given year in Wisconsin. Of these, an estimated 144,800 have a serious and persistent mental illness.

- **Community Based Services.**

Wisconsin provides services to persons with serious and persistent mental illness in the community through Medicaid fee-for-service benefits, and through state and county-funded services. Counties in Wisconsin are responsible for adult mental health services within the limits of available funds (called the County Shield Law, s. 55.06(9)(a)). State funds, federal Mental Health Block Grant funds (part of the overall distribution of Community Aids) and county funds support a variety of flexible long term services for persons with serious mental illness and substance abuse. Medicaid pays for targeted case management, day treatment, in-home treatment, crisis stabilization, and Community Support Program (CSP) services (also sometimes called program of assertive community treatment). A key distinction between Medicaid coverage of CSP services and other Medicaid benefits is that counties pay the state match on CSP services. About 75 CSPs in 57 counties serve 6,000 individuals annually. Community Support Programs provide intensive care management, coordination and support services to prevent institutionalization. Community crisis stabilization services are successful in preventing out of home placements.

- **Institutional Services**

Nursing Homes. The 2000 Nursing Home Survey identified over 7,500 residents of nursing homes (including IMDs) in Wisconsin who had a primary disabling diagnosis of organic or non-organic psychosis. This represents 19.6 percent of all nursing home residents, and does not include those with a primary disabling diagnosis of Alzheimer's disease. Eighty-five percent of all nursing home residents with a diagnosis of any mental disorder were age 75 or older.

Institutes for Mental Disease. Institutes for Mental Disease (IMDs) are a very small subset of the nursing homes in Wisconsin. Altogether there are four licensed IMDs with a total licensed capacity of 310 beds. On December 31, 2000, 251 people resided in IMDs. Most (85 percent) admissions during 2000 were from acute care or psychiatric hospitals and another 6 percent were from other nursing homes. Twenty-eight percent of residents in IMDs were protectively placed under Chapter 51, 62 percent were protectively placed under Chapter 55, and 62 percent had a court appointed guardian. The planned closing of the Sheboygan County Comprehensive Health Care Center in 2002 will further reduce the number of IMD beds. The State currently allocates \$3.6 million in state funds annually for persons in IMDs with counties matching at least the same amount from locally administered funds.

State Mental Health Institutes. The state operates two state Mental Health Institutes that provide acute psychiatric hospital services for children and adults, with a total population of

553, as of April 2001. This includes both civil and forensic patients. The Institutes perform short-term “competency” assessments. For forensic patients they are used to advise a court as to whether a defendant is competent to stand trial. They also provide treatment for individuals who cannot be successfully treated elsewhere. About 42 percent of the beds are for civil commitments and 57 percent are for forensic patients. Length of stay varies from 2 weeks to 6 months for most civil admissions, and the length of the commitment for forensic patients averages several years. The total budget for fiscal year 2001 for the two Mental Health Institutes was \$82.3 million.

Other inpatient hospital services. In addition to the State Mental Health Institutes, psychiatric hospitalization services are provided in County Mental Hospitals (350 beds), private psychiatric hospitals (314 beds), general medical/surgical hospitals (1,036 beds) and the two Veterans’ Administration Hospitals in Wisconsin. The average length of stay of all patients in these settings dropped significantly between 1991 (20.13 days) and 1996 (12.32 days), after which it has remained essentially the same.

- **Mental Health and Alcohol and Other Drug Abuse (AODA) System Redesign.** Initially, four sites were intended to operate as county managed care organizations to deliver mental health, substance abuse, psychosocial rehabilitation services and alternative supports to people with severe mental illness, many of whom also have substance abuse service needs. The initial design included a single funding stream to counties that combined prepaid Medicaid capitated dollars with Community Aids. The feasibility of this model is currently under review. The goal of the redesign efforts is to assure consumers have a comprehensive array of options and choices to meet an individual’s identified strengths, needs and outcomes, with a focus on prevention, early intervention and recovery. Work is currently underway to develop a uniform functional screen, as well as quality measures based on individual, self-identified outcomes.
- **System Strengths**
The Community Support Program (CSP) and several other community mental health models are often cited as models for community-based services and have been nationally recognized for their innovation and effectiveness.
- **System Challenges**

No comprehensive Medicaid Waiver for persons with mental illness. Under federal requirements, persons with only a mental illness diagnosis do not qualify for Medicaid home and community based care waivers. Their community service costs are covered only by fee-for-service Medicaid benefits, Community Aids and county funds. Relocations for these individuals can be very difficult and expensive for counties. Counties have been responsible for costs to serve adults with mental illness in the state Mental Health Institutes or other inpatient settings, creating incentives for them to develop and fund less expensive outpatient alternatives.

Serving persons with severe mental illness and challenging behavioral problems. County COP and Waiver program staff often report needing assistance when making successful placements for persons with complex needs. For persons with mental illness who reside in nursing homes or in IMDs, relocation is often difficult due to their extensive and complicated needs. These persons may have significant and multiple diagnoses (mental retardation, severe mental illness, history of physical or sexual abuse, substance abuse, brain trauma, etc.). They often experience difficulties in community living, and may have poor housing/rental histories that make finding housing in the community extremely difficult. Care managers in small counties may not have sufficient experience with dually-diagnosed or otherwise complex individuals to be able to develop a successful care plan. Many local provider agencies are not prepared to provide services to consumers with dementia or severe mental illness who require more intensive care management and advocacy by counties. Behavioral problems can pose a real barrier to nursing home discharge.

Waiting lists. Although the state does not collect wait list information from counties for Community Support Program services, through information provided by county programs it has been estimated that there are 272 people waiting for services.

Limits on mental health insurance coverage. Even though the effectiveness of mental health treatment is at least as high as that for other physical health conditions, most insurance policies strictly limit the amount of mental health service that is covered. Without sufficient coverage of needed services, many people with serious mental illness are prevented from joining the work force and being a part of their communities.

The System for Children with Disabilities

- **Demographics**

An estimated 20,000 Wisconsin children have physical or developmental disabilities and about half of them need long-term support to remain at home. Between 65,000 and 80,000 children and adolescents are estimated to have a severe emotional disturbance with substantial functional impairment.

- **Home, School and Community Services**

About 4,000 disabled children in the Katie Beckett program receive the wide range of Medicaid LTC services available through Medicaid fee-for-service. Over 2,500 children receive services through the highly flexible, state-funded Family Support Program (FSP), allowing families to direct their own services and supports. The maximum annual Family Support grant is \$3000, typically used for respite care, special adaptive devices, home modification and equipment not covered by private insurance or Medicaid. The average annual grant is \$1600, which is artificially low because some counties deliberately limit grants in order to be able to serve more families. About 1,000 children receive services through the Community Options Program and its related Waiver Programs. The Birth to 3 Program, part C of the Individuals with Disabilities Education Act (IDEA), serves 7,000 infants and toddlers. The Title V Children with Special Health Care Needs Program provides service coordination, referral and information at five regional locations to families whose children have a special need. Children also receive services under IDEA, Title I.

In addition, there are two successful, flexible county managed care programs for children with severe emotional disturbances and their families which build off the county comprehensive Integrated Services Projects for children. Wraparound programs for children with severe emotional disturbance are available in over 30 counties.

- **Institutional Services**

Fewer than 60 residents in nursing homes or facilities for the developmentally disabled (including the State Centers) are age 19 or younger. In the year 2000, 125 beds in the State Mental Health Institutes were for children and adolescents, but Mendota MHI closed a child/adolescent unit in May, 2002. In addition, children are served in some private psychiatric hospital units.

- **Children's Long Term Support Redesign.**

The special circumstances of children and families and the interactions with the education and child welfare systems led to a distinct planning process for redesign of this system. A Children's Long Term Support Redesign committee, with a parent majority, has been working to develop changes including planning a Medicaid children's home and community based waiver that would provide flexible and family centered long term support services that are appropriate for children across the spectrum of disabilities. The DHFS plans to submit a waiver application in the next few months. There are currently no plans for comprehensive, statewide reform of the children's system. The new waiver and other components of reform will be tested in 6 to 12 pilot counties. Work is also proceeding on the development of a functional screen to be used by as many different programs as possible, and the creation of

care management teams to increase coordination among the many programs, administering agencies and funding sources available to children with disabilities.

- **System Strengths**

Wisconsin's Family Support Program and Integrated Services Projects are national models, recognized for their flexibility and innovation.

- **System Challenges**

Waiting lists. Counties reported that approximately 3,200 children were waiting for Family Support Services on December 31, 1999. Some counties limit the array of available services or place lower than state-allowed caps on Family Support grants in order to spread available funds to more families. Counties report that there are a number of children with severe emotional disturbance waiting for the Integrated Services Project services.

Unintended incentives. Medicaid pays for services to children in the state Mental Health Institutes or other inpatient settings, which many claim has led to incentives for counties to use those facilities for psychiatric care for children rather than to develop and fund community-based services for children with severe emotional disturbance.

Multiple funding sources and points of responsibility. Children's services are provided by the school system, the state, counties, and private sources. Coordinating services across these varying systems, each with its own eligibility requirements, specified services, and other limitations is a challenge for all families who have children with disabilities.