Wisconsin State Site Visit

Introduction

Since the 1970s, Wisconsin has been a leader in embracing the principles of person-centered supports as the fundamental basis of publicly funded services for individuals with disabilities. Wisconsin pioneered "community options" as an alternative to institutional services. The Wisconsin "experiment" in supporting people in their communities served as a foundation for the Medicaid Home and Community-Based Services (HCBS) waiver program that now enables all states to offer diverse and innovative services and supports for people with developmental and other disabilities and concurrently sharply cut back on the use of institutions. Wisconsin was one of the first states where "supported living" took root. Wisconsin showed how supports could be tailored around each individual in the person's own home. Wisconsin's experiences in supported living opened new vistas for other states to rethink how they support individuals in leading everyday lives in the community. Wisconsin also was one of first states to make a serious commitment to family support. Here again, Wisconsin served as model/exemplar upon which many other states based their family support initiatives.

Indeed, in innumerable ways, Wisconsin demonstrated the practicality of person-centered supports. As a result of Wisconsin's leadership, there was hard evidence for other states that person-centered supports worked. Group homes were not the only or even the most effective way to furnish community living services; supported living was not only feasible but also led to positive outcomes. Family support was not only the right thing to do but worked by keeping families intact and sharply reduced out-of-home placement of children with severe disabilities. Many Wisconsin counties shuttered their workshops in favor of supporting all individuals in community jobs or other forms of active participation in community life. Much of what is now understood about how to support people with developmental disabilities to enjoy community membership stems from Wisconsin's pioneering "new ways of thinking."

Steadily, state and local advocates in Wisconsin have continued to drive the system toward increasingly person-centered and inclusive approaches. Wisconsin was one of the first states to actively embrace "self-determination" so that individuals and families could design their own supports based on their choices and preferences. In Wisconsin, there is a vibrant willingness to engage in "active learning" in order to better exemplify the principles of person-centered supports.

Wisconsin remains in the top tier of states insofar as concrete indices of accomplishment (e.g., size of living arrangements, level of fiscal commitment). At the same time, in the past and still today, Wisconsin has struggled to unify its services and supports for people with developmental disabilities under the principles of person-centered supports. Despite Wisconsin's well-deserved reputation as an innovator and community-centered state, relatively high numbers of people continued to be served in large facilities. As in other county-based service systems, the types and quality of services and supports available to people and families remains uneven.

Our May 2001 visit to Wisconsin revealed that stakeholders remain fervently committed to the principles of person-centered supports. Those principles describe the fundamental expectations and vision for services and supports in Wisconsin. We saw continuing evidence of the practicality and exciting outcomes that result when the principles are put into practice. There was no sense that the job is over or that Wisconsin can rest on its well-deserved laurels. However, it also was abundantly clear that the strategies that worked in the past to create community alternatives may not be the ones to guide the system to the next plateau. Moreover, Wisconsin faces many of the same challenges that other states face in order to solidify community services.

I. History of System Change in Wisconsin

The 1970s

Wisconsin's community developmental disabilities system first took root in the 1970s and was more developed than comparable systems elsewhere. In the early 1970s, the state began undertaking significant efforts to place people out of institutions. Some of these people were placed in community group homes, but many were simply shifted to other institutions such as nursing homes.

The early state legislation that established community services for people with developmental disabilities was passed over a four-year period (1971 to 1975) and remains part of the state's Alcohol, Drug Abuse, Developmental Disabilities and Mental Health Act. This legislation permitted each county to establish a developmental disabilities advisory board. These boards subsequently were subsumed under mandated Mental Health, Substance Abuse and Developmental Disabilities Boards. Today, many counties operate a unified human services department and board for all human services.

A second important legislative step during the 1970s was the enactment of the Special Education Act (chap. 89) of 1975 to mandate the creation of special education programs within public schools and, thereby, making it possible for children with DD to grow and learn in their local community.

In 1979, Wisconsin launched the Community Options Program to provide an alternative to institutional services for seniors and people with developmental and other disabilities disabilities. The Community Options Program initially was state funded. As previously noted, Wisconsin's success in supporting people with disabilities of all ages in the community was enormously important in prompting Congress to create the Medicaid HCBS waiver program in order to broaden access to community services and supports nationwide.

The 1980s

The 1980s saw significant expansion of the community system. Wisconsin launched its HCBS waiver programs (the Community Integration Program (CIP)) early in the 1980s. Wisconsin was noteworthy among the states for rapidly seizing on the HCBS waiver program as an important opportunity to underwrite and expand community services and supports for people with developmental disabilities. By way of CIP, Wisconsin was able to underwrite the costs of returning individuals to their communities from the State Centers as well as extend increased supports to individuals and families in the community.

During this period, Wisconsin put into place a multi-faceted approach in support of families who have children with severe disabilities. The state launched its family support program, founded on the "… belief that parents of children who have severe disabilities know best what they need." The program links families to community resources and other families to strengthen natural supports. It also furnishes limited funding to buy needed goods and services. Wisconsin also established its "Katie Beckett Program" program so that children with severe disabilities who live with their families could obtain Medicaid benefits. Wisconsin's program was designed to provide proactive assistance to families. In the 1980s, Wisconsin also started up its Birth-to-3 Early Intervention program. By the end of the 1980s, Wisconsin was clearly a leader among states in offering children and families robust services and supports, emphasizing family-centered principles.

The 1980s also saw considerable efforts to embed a "person-centered culture" throughout the Wisconsin service delivery system. In order to anchor the system in the principles of person-centered supports,

"normalization" training and values-based training for case managers was introduced. The state actively stressed and supported the use of person-centered planning, including serving as a fundamental strategy for identifying the services and supports that individuals would receive via the HCBS waiver program.

The 1990s

The 1990s were a decade characterized both by inclusion and exclusion. Community services were of high quality and inclusive. At the same time, many people with disabilities were unable to receive any services at all. In fact, in the 1990s, the state ostensibly capped the waiver while allowing individual counties to put up match if they were interested in expanding supports.

In 1992 through 1995, Wisconsin was one of eight states that participated in the Community Supported Living Arrangements (CSLA) Medicaid demonstration. Wisconsin's CSLA program embraced furnishing services and supports to individuals in living arrangements that they controlled. When the CSLA demonstration ended, the state decided to continue the program by launching the Community Supported Living Arrangements HCBS waiver program that captured much of what was learned during the three year demonstration. The main cornerstones of the CSLA Waiver remain:

- "The person/guardian, through a person-centered planning process, identifies the supports and services which best meet his or her needs. If provider agency staff and the person receiving the services have a parting of ways, it is the agency that must be replaced, not the person.
- "The person must live in his or her own home (including an apartment, condominium or house, owned or rented) where the setting is controlled by the person/guardian and not a service provider. Control may be shared with other people who live in the home. No more than three unrelated people excluding live-in caregivers may reside in the home for it to qualify as an allowed living arrangement for CSLA. Participants may also reside with their families or with a relative."

Wisconsin's participation in the CSLA demonstration had substantial and lasting impact. It opened up new vistas for supporting individuals in the community employing the principles of person-centered supports.

In part as an outgrowth of the CSLA demonstration, Wisconsin stepped forward to become one of the Robert Wood Johnson Foundation's self determination initiative. Three counties (Dane, LaCrosse and Winnebago) volunteered to serve as pilot demonstration sites to test and implement new ways to enhance individual and family control and direction over services and supports.

By the end of the 1990s, however, the movement of individuals out of the State Centers had plateaued and there was an appreciable slowing of the growth of community services due to the increasing reliance on county dollars to underwrite the costs of services.

The Present

In recent years, Wisconsin – like nearly every state – has struggled to sustain and expand funding for disability services. These struggles have prompted the formation of especially vibrant coalitions (Disability Advocates – Wisconsin Network (DAWN), People Can't Wait, and The Survival Coalition of Wisconsin Disability Organizations) that actively advocate for system change and better funding for community services. People First has been especially active in encouraging people to get out of institutions and into supported living. These coalitions have been especially energetic in advancing concrete policy proposals that address a wide range of issues and problems in Wisconsin.

At the state-level, Wisconsin is engaged in looking at steps it might take to address a multitude of issues in the arena of long-term services. These include the "children's redesign" effort to take a fresh look at the full range of services and supports Wisconsin offers for children with severe disabilities. As is the case in other states, Wisconsin also is looking at ways to reduce reliance on institutional services and further strengthen community services. The state continues to sponsor alternative approaches to marshalling public dollars to meet the needs of individuals who need long-term services and supports. These approaches include the Partnership Program that is designed to foster better integration of Medicaid community services for people with disabilities and the five county "Family Care" demonstration project to restructure the provision of long-term services and supports along managed care lines. Family Care features a "one-stop" approach that is designed to integrate intake and other activities in order to identify the lowest cost alternatives for meeting the needs of individuals with disabilities and seniors who require long-term services.

II. The Organization of the Wisconsin Public System

A. Developmental Disabilities Services at the State Level

The Bureau of Developmental Disabilities Services (BDDS) – located in the Wisconsin Department of Health and Family Services Division of Supportive Living – is the primary state agency responsible for the development and implementation of statewide policy, services and supports for people with developmental disabilities. The common goal of BDDS activities is "…inclusion, that is, people living, working, learning and playing in communities of their choice."

The Bureau also provides leadership and assistance throughout the system to promote best practice to improve the overall quality and safety of services and supports. It directly manages a supported employment program, the Birth to 3 program, the Katie Beckett Program, Wisconsin HCBS waiver programs for people with developmental disabilities (e.g., the CIP and CSLA waiver programs), another HCBS waiver program – the "Brain Injury Waiver" – and the Family Support program. By statute, Wisconsin has included brain injury as a "developmental disability." Dating back several years, the Bureau also has been very proactive in promoting opportunities for people with developmental disabilities to secure a home of their own.

The Bureau has four units: (a) Family-Centered Services; (b) Waiver Management and Quality Assurance; (c) Program Operations and Management; and (d) System Design and Program Development. Several BDDS staff are out stationed around Wisconsin to provide direct technical assistance to counties as well as conduct program oversight and quality review of HCBS waiver services. A notable characteristic of the Bureau is the longevity of the agency's leadership. The current director has been with the developmental disabilities program for the past two decades, and the previous director likewise played key roles in the system for many years.

The Division of Supportive Living (DSL) responsibilities cut across the full spectrum of disability. Its charge is to assure quality of care and quality of life through services provided for persons with developmental disabilities, mental illness, substance abuse problems, physical disabilities, sensory disabilities, and the elderly. The Division also licenses and certifies health and community care providers and facilities (including non-state ICFs/MR) and long-term support programs.

The Division's Core Values are:

- Integrity – Trust in one another that goals are shared, see the good in each person and build on it, conduct all activities in a professional way.
- Client-Consumer Focused – Be customer driven, value the individual, empower people by focusing on their assets/capabilities, contribute/add value to their quality of life.
- Interdependence – Consumers, citizens, government and the community must all be involved as part of the solution. Build competencies in communities and enable them to be responsive to the needs of individuals, work from the perspective of inclusion.
- Commitment – Strive for excellence in contributing to the quality of life, enhance outcomes at the individual as well as organizational level, recognize that this is a position of stewardship relative to the people of Wisconsin.
- Innovation – Be willing to experiment and try new ways of doing things to enhance the quality of life. Keep an open mind in searching for solutions, embrace change.

The location of BDDS within DSL reflects the trend among states (e.g., Kansas and Nebraska) to locate state administration of services for people with developmental disabilities within larger organizational units that have wider crosscutting responsibilities for long-term services and supports.

Wisconsin still operates three public institutions for people with developmental disabilities – Central, Northern and Southern Wisconsin Centers. A separate organizational unit – the Division of Care and Treatment Facilities at the Department of Health and Family Services – manages these facilities.

The Department of Health and Family Services also operates Wisconsin's Medicaid program. The Department of Workforce Development houses the Vocational Rehabilitation program. This Department also manages Wisconsin's Pathways to Independence Program, which aims at expanding employment opportunities for people with disabilities of all types. Wisconsin also has expanded Medicaid eligibility to help people with disabilities who work to obtain health care. The Department of Public Instruction is responsible for preschool services as well as the Special Education program.

B. DD at the County Level

In Wisconsin, the delivery and management of community services for people with developmental disabilities is highly decentralized and administered through 72 separate county human services programs. Like other Midwestern states such as Minnesota, Ohio, and Iowa, there is a long history in Wisconsin of local management of human services programs. In 2000, Wisconsin counties underwrote 20.4% of all expenditures for community services for people with developmental disabilities; state tax dollars funded another 26.7% of community spending with federal dollars accounting for the remainder. This proportion of local tax dollar funding for community developmental disabilities services is among the highest nationwide. In Minnesota, local tax dollars account for only 5% of community spending; nationwide the figure is lower still – about 3%. Wisconsin counties clearly play a linchpin role in funding community services.

Wisconsin county human services agencies are responsible for purchasing community services and the provision of case management. They also have ongoing responsibilities for monitoring provider performance, providing budget oversight, and managing intake and eligibility determination.

The high level of county involvement in service provision has decided strengths but poses ongoing challenges as well. The strengths include the ability to tailor services to local needs and the flexibility to innovate. In addition, many counties have stepped forward with increased dollars in order to enable more of their citizens to receive services and supports. The drawbacks – which have become particularly apparent in the last few years – include variability in the quality and availability of services county-by-county and ongoing difficulties in adhering to a central policy vision across the state.

III. What Facts and Figures Say About Wisconsin

"Facts and figures" reveal quite a lot about the seriousness of a state's commitment to support its citizens with developmental disabilities. Here we assemble information about Wisconsin concerning the state's funding for developmental disabilities services and other measures that reveal how Wisconsin deploys its dollars.

Expenditures

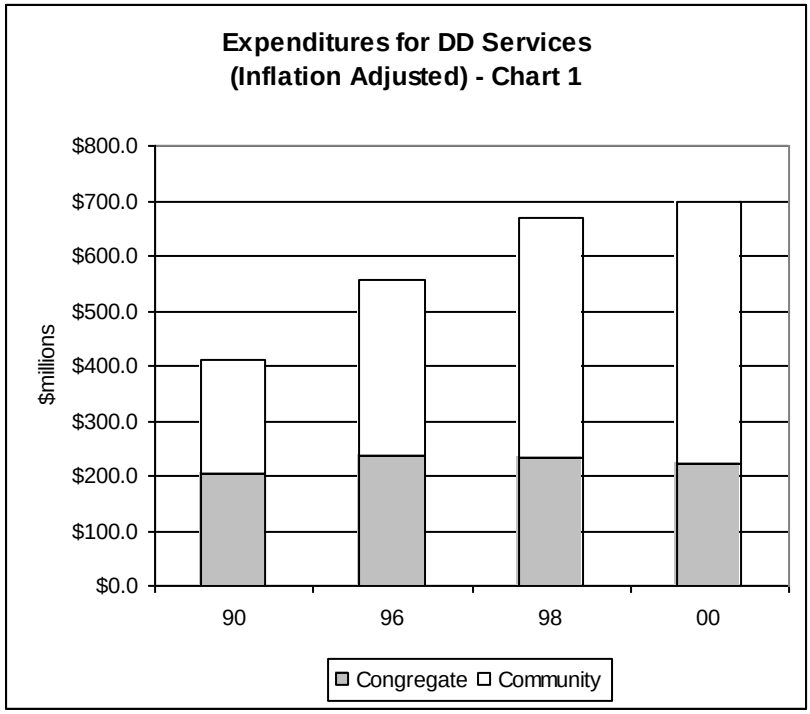
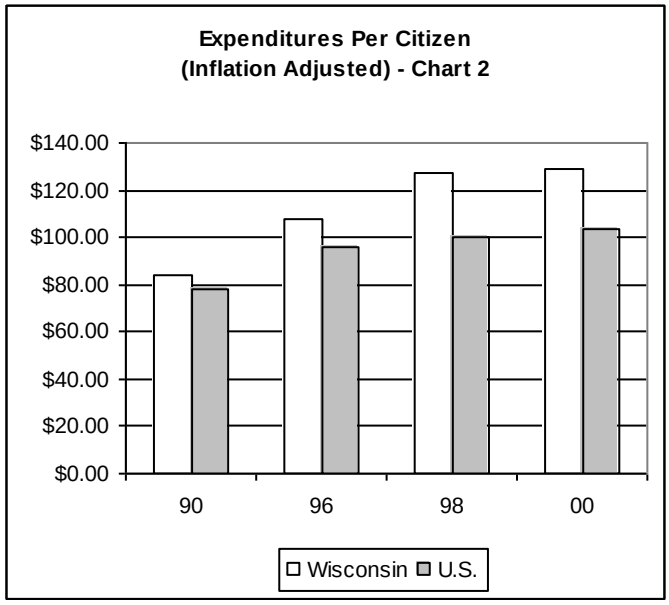


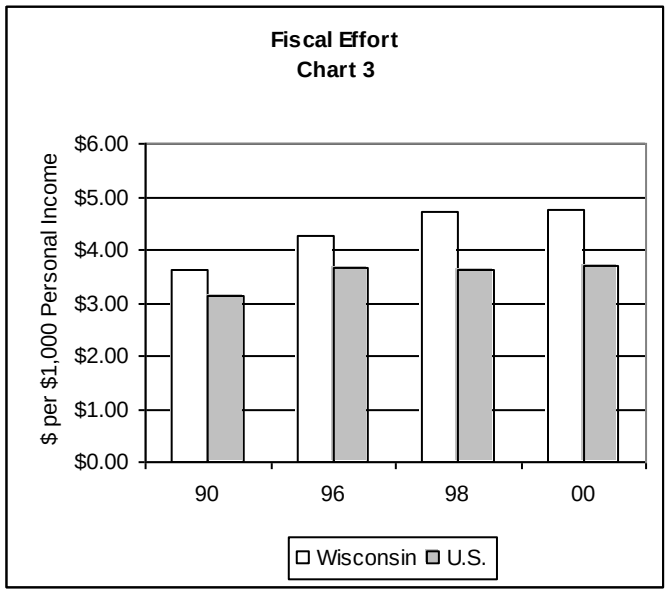
Chart 1[1] shows trends in Wisconsin's total inflation-adjusted expenditures for specialized developmental disabilities services during the period 1990 to 2000. The chart also breaks down expenditures between "congregate services" furnished in large (16 beds or more) facilities such as the State Centers and "community services." As can be seen, the 1990s saw Wisconsin substantially step up its spending for developmental disabilities services. After taking into account the effects of inflation, total expenditures grew by almost 70% between 1990 and 2000. During this period, Wisconsin increased its financial support for developmental disabilities services more rapidly than the nation at large. Nationwide, expenditures increased by

[1] These figures are based on: David Braddock, Richard Hemp, Mary C. Rizzolo, Susan Parish and Amy Pomeranz (February 2002). The State of the States in Developmental Disabilities: 2002 Study Summary. Boulder Colorado: University of Colorado, Coleman Institute for Cognitive Disabilities and Department of Psychiatry. Figures for years prior to 2000 are from preceding "State of the States" reports. Expenditures are expressed in year 2000 dollars. These figures include only expenditures for specialized services. They do not include expenditures for other publicly funded benefits available to people with developmental disabilities (e.g., health care services that individuals receive through the state's Medical Assistance program).

52% during the same period. Throughout the 1990s, virtually all the new dollars Wisconsin infused into its service system were devoted to community services. Spending for community services more than doubled in real dollar terms during the 1990s. At the beginning of the decade, about one-half of Wisconsin's dollars underwrote congregate services. By the end of the decade, 68% of all dollars were devoted to community services. However, in 2000 the proportion of dollars Wisconsin earmarked for congregate services was significantly greater than in other states where less than 25% of all dollars are spent on congregate services.



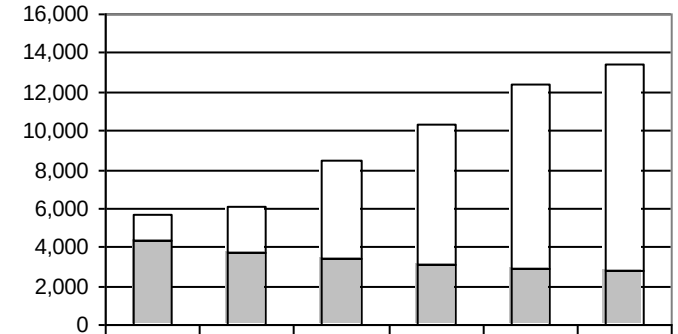
Wisconsin's financial level of effort in support of developmental disabilities services has been much stronger than the nation as a whole. One way of appraising a state's level of effort is by measuring "expenditures per citizen" (total expenditures divided by state population). Chart 2 shows that, when effort is measured in this fashion, Wisconsin's level of effort exceeded the nation at large throughout the 1990s. In 2000, Wisconsin's level of effort was about 25% greater than the nationwide average. Wisconsin's expenditures for developmental disabilities services not only more than kept pace with inflation but also with population growth during the 1990s. In constant dollar terms, expenditures per citizen increased by a little more than 50% during the 1990s.



A second way to assess a state's financial support of developmental disabilities services is the "fiscal effort" measure developed by Coleman Institute researchers. This measure describes the extent to of a state's spending for services disabilities relative to its overall economic well-being[2]. Chart 3 shows how Wisconsin's fiscal effort changed during the 1990s compared to the nation as whole. In the 1990s, Wisconsin's level of fiscal effort increased by about 30% and in 2000 was about 29% greater than the nationwide level. Only a dozen other states had a higher level of fiscal effort than Wisconsin. The 1990s were a prosperous period for Wisconsin (and the nation). Clearly, services for people with developmental disabilities benefited appreciably from that prosperity.

In relative terms, Wisconsin has demonstrated greater willingness than most other states to devote taxpayer dollars to services and supports for people with developmental disabilities. The state's financial support of these services was above average in 1990 and increased at a significantly faster pace than in most other states throughout the 1990s. However measured, there were substantially more dollars to pay for developmental disabilities services at the end of the decade than at its start.

People Receiving Medicaid Long Term Services - Chart 4



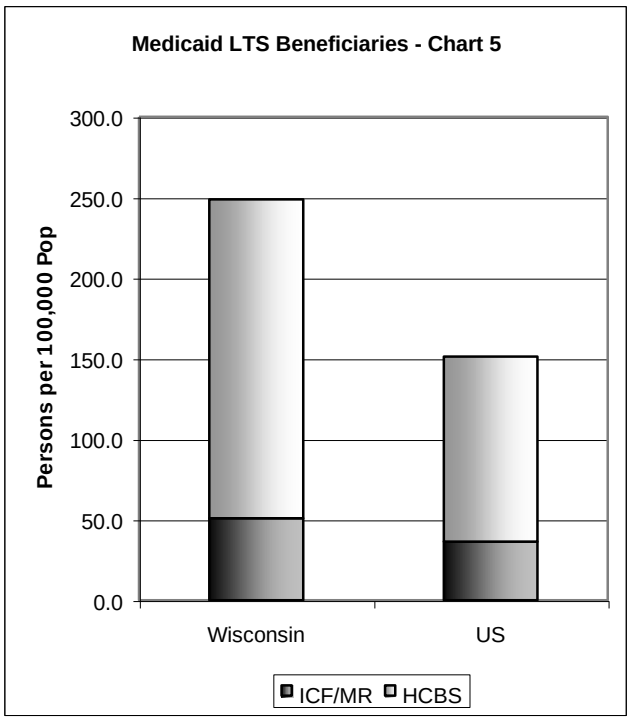
	90	94	96	98	00	01
HCBS	1,302	2,315	5,063	7,273	9,547	10,686
ICF/MR	4,368	3,749	3,382	3,056	2,865	2,748

How Wisconsin Finances Services

Nationwide, the federal-state Medicaid program has emerged as the principal financing source for long-term services for people with developmental disabilities. In Wisconsin, Medicaid paid for about 86% of all services in 2000. Nationwide, the comparable figure was roughly 75%.

[2] "Fiscal effort" is calculated by dividing total spending by total personal income, expressed in thousands of dollars. The figures that appear in Chart 3 differ from those published by the Coleman Institute. Instead, they are based on revised, updated estimates of personal income published by the U.S. Bureau of Economic Analysis.

Chart 4[3] shows the total number of persons with developmental disabilities receiving either ICF/MR or Medicaid home and community-based services (HCBS) via Wisconsin's developmental disabilities waiver programs. The number of HCBS waiver participants jumped eight-fold between 1990 and 2001, while the number of persons served in ICFs/MR (the State Centers and non-state ICF/MR facilities) declined by about 37%. During the 1990s, there was a net increase of almost 8,000 people individuals receiving Medicaid-financed long-term services. In 2001, the state's HCBS waiver spending topped $300 million. About 41% of the increase in Wisconsin's total spending during the 1990s was underwritten by federal HCBS waiver Medicaid dollars. Increased federal HCBS waiver dollars underwrote about one-half of the increased spending for community services during the 1990s. Overall, increased federal Medicaid payments to Wisconsin in the 1990s financed about two-thirds of the increase in state spending for developmental disabilities services. These dollars grew at four times the rate of increase in state and local funding.



Wisconsin clearly has made more extensive use of the Medicaid program than most states to meet the needs of its citizens with developmental disabilities. Chart 5 shows the number of persons who received ICF/MR or HCBS waiver services relative to population for Wisconsin and the nation at large in 2001. About two-thirds again as many people receive Medicaid-funded long-term services in Wisconsin as nationwide. Relatively more individuals were served in ICFs/MR in Wisconsin than elsewhere. However, the number of people participating in Wisconsin's

[3] The Wisconsin and U.S. figures are from: Robert Prouty, Gary Smith and K. Charlie Lakin (Eds) (in press). Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2002. Minneapolis MN: University of Minnesota, Research and Training Center on Community Living.

HCBS waiver programs for people with developmental disabilities was approximately 70% greater than the nationwide norm.

The rotation of system financing in Wisconsin from the ICF/MR to the HCBS waiver program parallels nationwide trends. This has been a positive development for Wisconsin's citizens with developmental disabilities. A state's employing HCBS funding promotes greater flexibility and person-centeredness in the provision of Medicaid-financed services.

Where the Dollars Go and What They Buy

There was sustained growth in Wisconsin's support for community services during the 1990s. In 2000, Wisconsin's expenditures per citizen for community services were roughly 13% greater than the nationwide norm. But, also in 2000, Wisconsin's spending for congregate services (measured again on an expenditures per citizen basis) was 63% above the nationwide average. During the 1990s, spending nationwide on congregate services dropped by about 21% in real dollar terms, principally as a result of state efforts to downsize and close their large public institutions. In contrast, Wisconsin's spending for congregate services increased by almost 8%.

In broad terms, the 1990s saw Wisconsin step up its support for community services but make slower progress than most other states in reprogramming congregate services dollars into the community. Wisconsin reduced the number of people served at its State Centers by about 50% during the 1990s. Throughout the past decade, the number of persons served at the Wisconsin's State Centers was about the same as the nationwide average, measured relative to population. In 2001, 15.4 persons per 100,000 population were served in Wisconsin's centers compared to the nationwide average of 16.1 persons per 100,000 population.[4]

Despite the significant reduction in the number of persons served at the Centers, their total operating costs fell by only 15%, causing the annual cost of serving individuals at the Centers to rise to almost $150,000 per person in 2001 versus about $91,000 in 1992[5]. The per person costs of operating the Wisconsin Centers was about 23% higher than the nationwide average. In Wisconsin, there also are a relatively large number of individuals served in large non-state ICFs/MR and other

[4] Ibid.
[5] Ibid.

institutional facilities (including nursing facilities). During the 1990s, spending for these services in these facilities shot up by about 55% in real dollar terms even though the number of people served in these facilities declined. In combination, Wisconsin serves appreciably more individuals in large congregate facilities than is the norm nationwide. While Wisconsin's support for community services has been well above the nationwide norm, it is evident that the state has yet to come to grips with its relatively large congregate services sector.

A large proportion of Wisconsin's dollars underwrite residential services and supports, both in licensed settings (including congregate facilities) and in individually-controlled living arrangements. In 2001, 13,830 people received residential services and supports, an increase of about 37% from 1990[6]. Indexed to population, Wisconsin furnished residential services and supports at the rate of 256.0 persons per 100,000 people in the population. This was nearly twice the rate at which these services are furnished nationwide. Even though a relatively large number of people receive congregate residential services in Wisconsin, the substantial majority does not. On average in Wisconsin, two people with developmental disabilities occupy a living arrangement where residential services and supports are furnished. Nationwide, an average of about 3.3 persons are served in each state-funded living arrangement. The substantial majority of Wisconsin citizens with developmental disabilities receive residential services and supports in "everyday" settings. In 2000, the proportion of individuals receiving residential services in a "home of their own" was twice as great in Wisconsin (42%) than the nation as a whole (20%). Only a handful of other states have managed to reconfigure residential services as extensively as Wisconsin in order to support individuals in homes of their own rather than living arrangements controlled and operated by provider agencies.

Wisconsin has a well-deserved reputation for supporting families who have a child with a developmental disability. As noted previously, the state has employed multiple strategies to meet the needs of these families, including its long-standing family support program, the "Katie Beckett" Medicaid eligibility option, the HCBS waiver program and "Birth to 3" early intervention services. Reportedly 4,000 children with severe disabilities are gaining access to health care services via the Katie Beckett option, a number that likely positions Wisconsin as the leader among states in this regard. Fewer than one-half the states make this

[6] Ibid.

option available. When all of Wisconsin's services in support of children with severe disabilities and their families are taken into account, the state's level of effort stands head-and-shoulders above nearly all other states.

In contrast, Wisconsin's efforts to aid people with developmental disabilities to obtain integrated community jobs has been no better (but no worse) than the record nationwide. In 2000, about 24% of all individuals who participated in "day activities" in Wisconsin received employment supports in the community compared to 23% nationwide[7]. Between 1990 and 2000, the number of people receiving such supports increased by about 70% in Wisconsin but 160% nationwide. About one-half of the states support a greater percentage of people who receive day services in integrated community program than Wisconsin.

Pretty Darn Good but the Job Is Not Done

What "facts and figures" reveal about Wisconsin is that it has been a state significantly more willing than most to underwrite services and supports for people with developmental disabilities. The state's especially strong funding for developmental disabilities services reflects Wisconsin's historical willingness to support its vulnerable citizens. By almost any measure, Wisconsin's level of effort has been especially strong. Services and supports are more robust in Wisconsin than most other states. Access to services is broader across the entire age spectrum.

However, it also is clear that there remains much left to accomplish in Wisconsin, a sentiment expressed by nearly every stakeholder with whom we spoke. In particular:

- Even though Wisconsin's level of financial effort is relatively high compared to most other states, it has been insufficient to ensure that all individuals who need and qualify for services are able to obtain them right away. Indeed, the late 1990s saw the rate of increase in state spending slow appreciably. According to the Disability Advocates: Wisconsin Network (DAWN), there are 4,400 adults with developmental disabilities waiting for critical services in the community, including 2,300 people waiting for community living/residential services and 2,100 who need employment/day services. In addition, there are more than 2,000 families who have a child with a severe disability waiting for family support[8].

[7] Braddock et al., op. cit.
[8] February 2002

Nationwide, there is rising demand for developmental disabilities services. Absent the infusion of more resources in the community, Wisconsin's waiting list will continue to grow. Wisconsin presently is falling short in assuring that all people are able to receive the services and supports they need. We return to this topic below.

- The high concentration of individuals in large congregate facilities also needs attention. Elsewhere, we discuss some of the barriers that pose serious obstacles to significantly further downsizing the State Centers and ultimately closing one or more. There are similar barriers in scaling back the number of persons served at large non-state facilities. Reducing the high concentration of people served in large facilities undoubtedly would contribute to closing the waiting list gap since an inordinate share of Wisconsin's dollars are tied up in supporting a relatively small number of persons in large facilities.
- There is a very evident need in Wisconsin to revitalize its family support program. The program has served both families and the state well by avoiding costly out-of-home placements. However, funding has not kept pace with demand and many families who presently participate in the program need additional services because the dollars available to participating families have not changed since 1987. The "Children's Redesign" is a promising step in the right direction. This initiative is discussed elsewhere in this report.
- Finally, while Wisconsin's performance along many dimensions is very strong, the state's efforts with respect to employment have not been exemplary. Greater attention is needed along these lines.

IV. Case Study Findings

A. Formal System Invites Wide Variations

As noted in the section on system organization, the Wisconsin system has historically been shaped and operated by county government. While this structure allowed for significant flexibility as the system was developing, it now presents challenges as waiting lists grow, health and safety concerns increase, and workforce issues persist. All of these problems require uniform strategies – strategies that are difficult to implement when the central authority – in this case BDDS – has limited power and authority.

Historically, leaders at the state level have used continuous training all over the state to influence the adoption of best practices in such areas as

individualized supports. This "jawboning" approach to service enhancement had an appreciable impact on the performance in many counties. However, as reported by informants during the site visits, there still remains still wide variation in the quality of services and supports from county to county. The problem of unevenness is exacerbated by the differences county wealth and income. In counties like Dane (Madison) that have a substantial tax base, the county is able to "over-match" the state/federal contribution by investing more of their own resources. Poorer counties do not have this option. This problem has been exacerbated by the steady shift in system financing from the state to counties.

The "ethos" of services also varies from a heavy emphasis on person-centered approaches in some counties to more paternalistic and traditional approaches in others. Given the growing complexity and extent of community services, a singular reliance on the powers of persuasion and example may no longer be as effective as it was in the past. Such an approach is also constrained by resources. Informants reported that, while there has been some investment in training case managers in person-centered planning techniques, there has not been a statewide effort.

The other challenge that smaller less sophisticated counties face is securing the infrastructure needed to manage a burgeoning community system that must be accountable for federal waiver expenses and that is increasingly moving toward individualized budgeting and planning. Further pressure comes from the necessity to mount computerized tracking systems for events such as critical incidents and abuse/neglect reports.

Another constraint with respect to county-based programs is the reported lack of flexibility that exists among case managers in some areas of the state. While they make strong contributions in most areas, the fact of their unionization reportedly causes inflexibility and a lack of willingness to change in other counties.

B. Self-Determination in Wisconsin

As noted earlier, Wisconsin was one of the 19 states awarded a Robert Wood Johnson grant to implement self-determined supports. Three counties, La Crosse, Dane and Winnebago, participated in the project. With respect to resources, Dane county has one of the highest overmatch budgets, while La Crosse County ranks near the bottom. This contributed to a wide variation in the ability of service brokers to be responsive to the needs of participants. In Dane and Winnebago, the broker/participant ratio

was about 1/30. In LaCrosse it was closer to 1/60. Further, the average amount spent on waiver recipients in Dane and Winnebago approached $40,000 annually in the first year of the demonstrations, which is well above the national average of about $27,000. [9]

Two of the counties (Dane and Winnebago) did not treat the demonstration as a "pilot," but rather embraced it as a way to transform their entire system to person-centered practices. According to key informants, the Dane and Winnebago efforts have had a substantial impact on the way services are delivered in both counties. In LaCrosse, however, inadequate resources coupled with a reported inflexibility among case managers resulted in only modest changes.

Dane's approach to the allocation of individual funding was designed to assure that individuals new to services would have an amount of dollars that more or less matched the dollars spent on behalf of current individuals with similar support needs and circumstances. Specifically, the process entailed:

- Meeting with a county intake planner
- If eligible, the planner gathers information to set a budget
- The planner suggests a list of potential brokers from whom the individual can secure assistance
- The budget is set using a "triangulation process" that considers historical costs, personal income, existing supports, supports needed, etc.). Once the range is set, the person can spend within a 10% of the amount
- A broker is chosen and personal support plans are set
- The broker sets up services and supports
- Services and supports are delivered
- The money transfer can be handled through one of five options (person can do it on his/her own, traditional billing, use of Goodwill as a fiscal intermediary that acts as an employer, use of a payroll-only fiscal intermediary, or use of another existing business)
- A voucher system is used (previously the voucher went to the individual but now goes directly to the provider)
- The provider the bills billing agent (local UCP)

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9 This discussion based on findings in: John Agosta, Valerie Bradley, Sarah Taub, John Ashbaugh, Julie Silver, and Minona Heaviland, The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report (2001), Human Services Research Institute. Cambridge MA

- UCP sends a check and bills Medicaid

Winnebago County relies more on historical rates to set budgets and offers six options to transfer money. In Winnebago, individuals were given the maximum flexibility and the county took no options – including sheltered workshops – off the table.

Based on the observations of the site visit team, self-determination certainly appears to have taken root in Dane and Winnebago counties. In both counties, self-determination has become the standard "business model." Individuals (and families) exercise considerable choice and control over their services and supports. However, the application elsewhere of self-determination principles and approaches is patchy and, based on key informant interviews, varies widely among the 72 county programs.

C. Families and Family Support

The Wisconsin Legislature created the Family Support Program in 1987. Since then, the Family Support Program has provided a small amount of very flexible funding for families to use to support their children with disabilities. Family Support is often the only assistance some families receive. The program provides individual services and supports to families that include a child with severe disabilities. A maximum of $3,000 per year is available. According to the Bureau's website, the program offers:

- Information and help in finding services and maximizing community resources
- Limited funding to buy needed services and goods that can't be bought through other sources
- Help in linking families with other families to strengthen natural supports

Families apply for services through their county's Family Support Program. The application process includes eligibility determination and a needs assessment. Once eligibility has been determined, a Family Support Coordinator schedules a home visit with the family. Together the family and coordinator develop a service plan that addresses the family's unique situation, identifying support needs and setting priorities. Formal supports that may be included are medical, social services, educational and funding resources. In addition, the Family Support Coordinator may help families learn about and use services in their community, help coordinate services and advocate on behalf of the child and family.

According to Beth Swedeen, in her policy monograph, Waiting for Family Support: Supporting Families Who Have Children with Disabilities, (Wisconsin Developmental Disabilities Council, 2001), the program currently serves about 2400 families across the state. Unfortunately, the number of families on waiting lists exceeds the actual number of families served. She noted that at least 2600 families wait for Family Support, some for more than five years. Further, according to key informants, the family support program has grown very little over the past eight years.

The first increase since 1994 occurred during the last year biennial budget and reduced the waiting list by approximately 400 families at the average of $1600/year. According to the DAWN, in order to serve all families on current Family Support Program waiting lists including those who are underserved or receive one time funding would $5.1 million in new state revenue to serve 3,196 families at an average of $1600/year for each year of the biennium. In addition, more dollars would be necessary to increase the $3000/year maximum per family, which has remained unchanged since 1987.

D. Children's Redesign

In December 1998, a working group finished its report outlining major changes in the provision of long-term supports to children with disabilities and their families. Dubbed the "children's redesign," the reform, according to a working paper by DAWN[10] had the following vision:

> Children with disabilities and their families will pursue their unique hopes and dreams with assistance that: is family-designed and controlled; is individualized and seamless; lasts as long as needed; and involves a variety of community partners. Families, in collaboration with providers and state and county staff, have developed the following recommendations for redesigning the system of supports and services for children with severe disabilities and health care needs.

Following completion of the workgroup's report[11], the Wisconsin Legislature directed the Department of Health and Family Services to write a new waiver for children based on the recommendation for the Children's Redesign committee. According to the DAWN report, it was

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[10] *Children and Families (Draft), 2002, p. 2.*

[11] Children's Long-Term Support Committee. *A Foundation for a System of Long-Term Support for Wisconsin Children and Families: Phase I.* December 1998.

anticipated that this would generate 60% additional new federal dollars to match any state dollars spent. The next step would be to initiate pilots in 6 to 12 counties around the state. This will optimally require:

- $3,000 in infrastructure costs that can be matched with $300,00 in federal funds.
- $3.6 million additional state funds to serve 1/3 of the eligible children with severe disabilities (this presumes a fully funded Family Support Program) to implement Children's Long Term Care Redesign in pilot counties. This would generate $5.7 million in federal match.
- The development of a unified prior authorization process coordinated between DHFS and the Medicaid fee for service system and the home and community-based waivers.

E. Birth to Three Services

Again, according to the DAWN working paper, funding provided by the legislature in the 2001-3 biennial budget partially alleviated the severe funding crisis experienced by many counties providing Birth-3 services. To prevent this crisis from occurring again annual cost of living increases need to be provided in future years based on the standard economic index.

F. Legacy Services: Wisconsin's Large Facilities

Wisconsin has built a strong, vibrant community system. However, the state has not come to grips with what to do with its large residential facilities – the three State Centers and the 37 large, non-state ICFs/MR. Wisconsin's large facilities serve roughly 2,700 individuals. But, they are legacies of the past when large facilities played a central role in state service systems and were regarded as "appropriate" settings for individuals. As recently as 1989, more than one-half of all individuals in Wisconsin who received residential services were served in these types of facilities. The State Centers served more than twice as many people as they do today.

The persistence of large facilities in Wisconsin clearly does not square with the broadly shared vision that people are best supported as active and contributing members of their communities. The individuals served in large facilities are cut off from their communities and do not have the opportunity to explore life on their own terms. At the end of the day, such facilities are the antithesis of the central principles of person-centered supports.

While we were in Wisconsin, we had the opportunity to visit Central State Center. At the Center, we met enormously caring and very skilled professionals. We learned that the Center is quite active in seeking opportunities for individuals to return to their communities and that Essential Life Style plans had been prepared for many residents. These plans thoughtfully spell out what it would take for these residents to live in the community. We also learned that the Center staff is very active in furnishing technical and other assistance to counties in meeting the needs of individuals in the community. It came across loud and clear that Center staff is devoted to promoting excellence in supporting individuals, whether at the Center or in the community.

The number of individuals served at Wisconsin's Centers has declined year-over-year. As we previously noted, relative to population, the number of individuals served in Wisconsin's Centers is about the same as nationwide when indexed to population. However, more than half the states serve fewer individuals in large public facilities (relative to population) than Wisconsin, including nine states that have closed out the operation of such facilities altogether and another six where half as many individuals (relative to population) are served in such facilities than in Wisconsin. There remains no especially compelling rationale for the continued operate of large state institutions.

The slow, extended downsizing of Wisconsin's Centers has carried with it a high price tag. Maintaining the same number of facilities in the face of a substantial and continuing reduction in the number of residents inevitably leads to per person operating costs spiraling ever upward. The amount of dollars spent on Center services has become increasingly disproportionate to the number of persons served at the facilities. Center spending has decreased at a much slower pace than census. Absent a decision to close one or more Centers, large amounts of dollars will continue to be locked up in Center operating budgets.

So far as we were able to determine, there are few stakeholders in Wisconsin who believe that the people presently served at the Centers cannot be supported as well or better in the community or that there is some essential role for the Centers to play in furnishing long-term residential services in the Wisconsin system. There are a significant number of individuals at the Centers who already have community placement plans.

There seem to be two main obstacles to accelerating the placement of Center residents into the community and, thereby, clearing the way to

close out Center operations. The first is financial. The present limit on the amount of dollars available to meet the needs of Center residents in the community is simply too low. Even though many current Center residents have community placement plans, they remain at the facilities because the plans are more costly than the CIP 1-A waiver rate will accommodate. Community placement hinges on counties being willing to make up the difference. This puts counties in a Catch-22 situation. Their making up the difference erodes their ability to meet the needs of other individuals in the community. The present CIP 1-A rate is pegged well below the average daily costs of the Centers. As acknowledged in the state's December 2001 ADA Title II Plan – Phase I, this rate should be boosted to at least $300/day to overcome this obstacle to individuals leaving the Centers.

The second obstacle is more complex because it stems from broader systemic issues. The Centers have taken on the role of furnishing short-stay services for a relatively large number of individuals. In 2001, there were more than 200 admissions to and discharges from the Centers. The need for these short-stays stems in part from a lack of capacity in the community to meet the needs of individuals with some types of disability challenges. Over the long-term, the feasibility of eliminating the Centers altogether will hinge on building the requisite capacities in Wisconsin communities, either locally at the county level or via cross-county networks.

At the end of the day, there is no overarching reason why Wisconsin's Centers need to remain in operation. Faster progress can be made in further reducing the number of people served at the Centers by simply upgrading the CIP 1-A rate to a more realistic level. Significant amounts of dollars would be released to meet the needs of other people in the community by linking an accelerated placement rate to the closure of one or more of the Centers. Absent outright closures, each Center will become progressively more costly to operate on a per person basis.

With respect to the non-state ICFs/MR, much the same financial obstacle seems to be at play. The CIP 1-B rate is presently pegged at too low a level and also needs to be boosted in order to make it possible to give people a realistic opportunity to leave the facilities. But additional measures will be needed as well, including actively engaging individuals and families to become aware of opportunities in the community and intervening vigorously to divert future admissions. The proposals that have been advanced by DAWN concerning how to reduce the scope of large non-state ICFs/MR services in its February 2002 draft position

paper strike us as on the mark in laying out a reasonable and constructive plan with respect to these facilities.

G. Workforce Issues

The workforce constraints in Wisconsin are – as in most states – increasingly acute. Conversations with representatives of the DD Network revealed that workforce shortages are seriously affecting the availability and quality of services all across the state.

Low wages and eroding benefits are two highly visible realities that discourage good workers from maintaining a commitment to direct service work. Local agencies cannot offer competitive wages and benefits due to eroding funding for community supports. Workers leave because their employers lack the capacity to support direct service work as a long-term commitment. The Survival Coalition has identified three critical steps for addressing Wisconsin's direct service workforce crisis:

1. An increase in the daily rates for CIP Medicaid waiver programs to support improved wages and benefits and more stable provider agencies.
2. Health insurance reform that results in increased access and affordability of coverage for community workers.
3. Funding to help agencies retain a committed workforce through training and supervision.

> **Direct Service Workforce Crisis.** To understand the workforce problem we use the image of an iceberg. Imagine that the tip of the iceberg contains only the most visible and most commonly understood issues in the workforce crisis. Real concerns such as low wages, eroding benefits, and high turnover are quantifiable and highly visible concerns.
>
> Notice that below the water line, other issues exist but are less visible. These less visible issues have to do with the low social status accorded people with disabilities and the workforce providing them day-to-day support. They have to do with the less measurable results of a system starved of adequate funding: less training, less supervision and mentoring support, less reward and recognition for a job well done, more duties piled on continuing workers as vacant positions remain unfilled, fiscal pressure to congregate people and standardize their support.
>
> The Survival Coalition

In Wisconsin, there is a clear recognition by stakeholders that the quality of community supports will only be as good as the workforce permits.

G. Systemic Funding Issues

Even though Wisconsin's level of financial effort in support of people with developmental disabilities is appreciably greater than most other states, there was a clear sense among key informants that funding has been eroding in recent years. HCBS waiver payment amounts have not kept up with the costs of providing day-to-day supports. According to the Survival Coalition:

> Moving people into a system that is already under-funded further stresses over-burdened counties and provider agencies. These pressures limit fair wages and benefits and increase the risk that counties and providers will be pushed to ration, water down, and standardize available services in ways that contradict Survival Coalition's advocacy priorities. Especially at a time when the fiscal integrity of our county-based service system is in jeopardy, these advocacy priorities should be the foundation that guides our examination of workforce issues and our allocation of time, energy, and money. Survival Coalition's advocacy priorities are grounded in the principles of self-determination, opportunity, interdependence, and inclusion. These principles function as goals, touchstones, outcomes and road maps .…

The lack of consistent increases in HCBS waiver payment rates appears to be eroding the quality of services and supports in Wisconsin by increasingly limiting the ability of the system to craft individualized support strategies and acquiring competent workers. The lack of increased state support is placing greater and greater stress on counties to make up the difference. It also is causing waiting lists to persist and grow across the system. As previously noted, low payment rates severely truncate the ability to promote the community placement of persons served at Wisconsin's Centers and other ICFs/MR.

According to the Survival Coalition, catching waiver payment rates up for missed cost-of-living adjustments in previous years requires about $15 million in additional state funds and would require boosting state spending $3 million per year to keep pace with future inflation. Another $8 million is needed to adequately fund community placements from state and private facilities. Yet another boost in state funding is necessary for Wisconsin to make appreciable progress in reducing or eliminating service waiting lists.

In recent years, Wisconsin has relied on boosting federal Medicaid dollars to sustain system growth. At the same time, more and more responsibility for financing services has shifted from the state to counties, which themselves face their own financial troubles. There is a clear sense among stakeholders that the state must step up to reinvigorate its direct financial support of developmental disabilities services in order to stem further erosion in the quality of services and supports.

H. Person-Centered Planning

The developmental disabilities program in Wisconsin has consistently offered training throughout the state regarding person-centered planning and its relation to individually tailored services. This is an important contribution to the state's reputation for progressive services. To augment previous efforts, informants in the state told us that there are plans to create a statewide consortium of individuals and organizations for the purpose of providing support to people doing person-centered planning. Informants also noted, however, that while the practice of person-centered planning is widespread, there are still case managers in some counties that prefer a more paternalistic approach and who are reluctant to change practices especially where collective bargaining agreements spell out more routine and standardized approaches. Informants also noted that the county monopoly on case management was beginning to change as some independent brokers were beginning to emerge.

I. Use of the Waiver and Anticipated Changes

For almost 20 years, Wisconsin has exploited the flexibility of the HCBS waiver program to strengthen and expand community services and supports for people with developmental disabilities. Wisconsin's HCBS waiver programs have been especially noteworthy in enabling the provision of person-centered supports, including the use of person-centered planning methods to identify each person's goals, aspirations and preferences. Wisconsin was one of the first states to incorporate a "consumer-directed" benefit in its HCBS waiver program. Wisconsin's waiver programs have changed over the years to add additional progressive benefits (e.g., support for individuals to secure a home of their own, supported employment and consumer education and training to enable individuals to exercise more choice and control over their services and supports).

However, these programs are now showing their age. There are increasingly artificial distinctions in the amount of dollars available to

individuals depending on whether the person is being placed from an institutional setting or is already in the community. Over the years, more and more overlays have been added on that result in consider complexity. There is a growing sense in Wisconsin that the time may be ripe for the state to undertake a stem-to-stern reassessment of its present programs with a view toward unifying the benefits available and restructure funding.

J. Quality Assurance and Quality Enhancement

Wisconsin has had an especially vigorous approach to promoting quality in the provision of HCBS waiver services. In advance of most other states, Wisconsin has deployed staff "on the ground" to conduct detailed review of HCBS waiver plans of care to ensure compliance and, more importantly, provide a vehicle for promoting quality enhancement.

Since the site visit, Wisconsin has developed a *Quality Assurance Plan for MA Home and Community-Based Waivers*[12] that lays out a comprehensive approach to ensuring quality across relevant agencies in the state and across levels of government. The underlying values that drive the plan include:

- Community presence and participation
- Participant and/or guardian choice and control
- Participant and/or guardian preferences
- Opportunity to function in social roles and valued by the community
- Individualization

The plan is an important step in an effort to integrate and/or coordinate existing QA activities and to produce data in formats that will facilitate service improvement and enhancement. This plan speaks frankly about the importance of county programs in overall quality management and proposes specific steps to ensure communication and collaboration. It also recognizes that one strategy will not fit the range of living arrangements across the state. While consumer outcomes are not an explicit part of the plan, there is recognition that this is an area still to be addressed. Further, the plan does not appear to address how quality data can be disseminated to families and individuals with disabilities.

[12] Wisconsin Bureau of Developmental Disabilities Services (October 8, 2001). *Quality Assurance Plan for MA Home and Community-Based Waivers.*

K. The Power of Self-Advocacy

Our interviews with self advocates revealed that the movement is definitely alive and well in Wisconsin and in fact thriving. Informants noted that the presence of the self-determination demonstrations in the state had a very salutary influence on the formal self-advocacy organization and resulted in significant expansion. The agenda of the state group is clearly the continued decline of the institutional population and there appears to be a well organized effort to continually bring these issues before state decision-makers. All in all, the self-advocates seemed to be one of the brightest lights and loudest voices in the state.

V. Challenges

- Need to maintain momentum and pass the torch to the next generation of reformers
- Meeting the needs of people on the waiting list
- Preserving what is best about county management while moving the system forward
- Establishing statewide expectations and goals
- Retooling county case managers
- Finding opportunities in the move to integrate DD services with elderly and behavioral health services
- Unifying waivers and approaches to funding services
- Moving people out of public and private institutions

VI. Lessons Learned

- Continuous training on person-centered practices is critical – especially in decentralized systems
- Continuity of progressive leadership at the state and local level is important to the continuing momentum for change
- Treating the Medicaid waiver as instrumental to person-centered practice rather than as a program in and of itself is critical
- Cooperation and division of labor among the three organizations in the ADD network promotes change and person-centered practice
- The presence of a strong family organization is key
- Ensuring that the waiver provides a flexible framework for service provision is crucial

- Continually updating the vision for the state based on emerging trends and best practice accelerated reform
- Exploration of integrated services makes more sense once the "culture" for the DD system is solidly in place
- Gains can be fragile and need continual nurturings