United States General Accounting Office

GAO

Report to Congressional Requesters

July 1996

MEDICAID

Waiver Program for Developmentally Disabled Is Promising But Poses Some Risks

GAO/HEHS-96-120

GAO

United States
General Accounting Office
Washington, D.C. 20548

Health, Education, and
Human Services Division

B-266320

July 22, 1996

The Honorable William S. Cohen
Chairman
The Honorable David H. Pryor
Ranking Minority Member
Special Committee on Aging
United States Senate

The Honorable Bill Frist
Chairman
Subcommittee on Disability Policy
Committee on Labor and Human Resources
United States Senate

Adults with developmental disabilities are highly dependent on public programs for meeting their long-term care needs. Most persons with developmental disabilities have mental retardation, but others have severe, chronic disability resulting from cerebral palsy, epilepsy, or other life-long conditions, except mental illness, that began before they were 22 years old. The population with developmental disabilities receives more than $13 billion annually in public funding for long-term care, second only to the elderly. More than 300,000 adults with developmental disabilities receive government long-term services financed primarily through Medicaid and to a lesser extent through state and local programs. Long-term care services can include supervision and assistance with everyday activities such as help in dressing, going to the bathroom, managing money, and keeping out of danger. Persons with developmental disabilities have traditionally received their long-term care in institutional settings.

Recently, states have begun to significantly expand the use of the Medicaid 1915(c) home and community-based waiver, enacted by the Congress in 1981, to provide alternatives to institutional care for persons with developmental disabilities.[1] The waiver program has two advantages. First, it gives states a tool to control costs by allowing them to limit the number of recipients served. In contrast, states must serve all eligible individuals in the regular Medicaid program. Second, it permits states to meet the needs of many persons with developmental disabilities by offering them a broader range of services in less restrictive settings such as group or

[1]States also use the waiver for other populations. See Medicaid Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs (GAO/HEHS-94-167, Aug. 11, 1994).

family home, rather than in a Medicaid intermediate care facility for mental retardation (ICF/MR), the setting where most of the institutional care for this population is provided.

At your request, we examined states' experiences in utilizing the flexibility offered by the Medicaid waiver program to provide care for adults with developmental disabilities in alternative settings. To understand changes in services, cost, and quality assurance, we reviewed national data and conducted three case studies on issues and choices states faced in using the waiver program. Specifically, we examined (1) expanded state use of the waiver program, (2) the growth in long-term care costs for individuals with developmental disabilities, (3) how costs are controlled, and (4) strengths and limitations in states' approaches to assuring quality in community settings.

To conduct our work, we reviewed the literature, interviewed Health Care Financing Administration (HCFA) officials responsible for waiver programs and national experts, and analyzed national data on Medicaid expenditures and recipients. We also performed case studies in three states: Florida, Michigan, and Rhode Island. We chose these states because they have large waiver programs, provide a range in state size and geographic representation, and have different strategies for using the waiver program. In visits to these states, we interviewed program officials, providers, recipients, families, and advocates. We also reviewed data on costs and program participation for these states. We conducted our review between May 1995 and May 1996 in accordance with generally accepted government auditing standards. For a complete description of our scope and methodology, see appendix I.

Results in Brief

State use of the Medicaid 1915(c) home and community-based waiver has changed the face of long-term care nationally for persons with developmental disabilities by providing more persons with the kind of services that most recipients and families prefer. It has significantly expanded the number of persons served overall and resulted in more people being served by the waiver program in group home and home settings than in the more restrictive and often large ICFs/MR. Florida, Michigan, Rhode Island, and other states have used the waiver program to pursue various objectives, such as closing many large and some small ICFs/MR, expanding services to persons previously in state-financed programs, and including persons not previously served. Waiver program services have been provided primarily in group homes. However, some

states have begun to shift the focus of their waiver programs to serve more people at home—their own home, their family's home, or an adult foster care home—and to provide a broader range of services tailored to individuals' needs and preferences.

From 1990 to 1995, Medicaid costs for long-term care services for persons with developmental disabilities nationwide rose at an average annual rate of 9 percent. Although most of the increase reflected increased costs for waiver program services, increased costs for ICF/MR program services also were a factor. Waiver program costs grew primarily because more people were served as per capita costs for the program increased slightly less than inflation. ICF/MR program costs increased even though the number of ICF/MR residents declined 7 percent. The program's cost increases resulted solely from per capita cost growth for the ICF/MR program, which was somewhat higher than inflation.

If not for a cap on the number of waiver program recipients in each state and state management practices, cost growth would likely have been higher. HCFA requires each state to set limits on the number of persons to be served in the waiver program subject to federal approval. Therefore, HCFA allows states to deny services to otherwise eligible individuals once the cap is reached. In contrast, the regular Medicaid program requires that states serve all those who meet eligibility requirements. In addition, states use their own management practices to control costs. In the three states we visited, these management practices include fixed agency budgets for waiver program services and linking of the management of the care plan and use of non-Medicaid services to individual budgets for each person served.

A 1994 change in federal rules could result in higher caps and costs. In this change, HCFA eased the process by which waiver program caps were established, giving states more discretion in determining the number of waiver program recipients. In doing so, HCFA recognized the risk of cost increases if states increased the number of people served, but it expected that state budget pressures would likely inhibit the size of the increase. If states elect to use this discretion, as two states we visited said they planned to do, a risk exists that the number of waiver program recipients and costs could increase more rapidly.

Some states are changing their quality assurance approaches to improve quality as services offered by the waiver program continue to evolve, but more development is needed to reduce risks. States continue to use

traditional mechanisms such as provider certification to assure recipient safety. At the same time, states are introducing promising innovations to customize quality assurance for an individual's circumstances. For example, states may use a combination of methods to monitor quality, including arranging for a roommate to live with a disabled individual; home visits from community volunteers to check on an individual's status; and visits from program staff at locations where the individual is likely to be, such as his or her home or local park or library. At the heart of this effort is the recognition that reducing the level of program restrictions and the amount of supervision in these individuals' lives and increasing their choices of where they live, whom they live with, and what they do during the day are desirable goals but can pose risks because of the cognitive and physical impairments of the population served. State officials recognize that increasing recipient choice and making providers compete can play an important role in improving the quality of services provided. But they and HCFA officials acknowledge that more remains to be done to fully develop the quality oversight mechanisms being used. Until this occurs, some recipients may not have better service quality and may face some health and safety risks.

Background

Medicaid funds most publicly supported long-term care services for persons with developmental disabilities. In 1995, Medicaid provided more than $13.2 billion to support over 275,000 individuals with these services. To be eligible for Medicaid, individuals must generally meet federal and state income and asset thresholds. To be considered developmentally disabled, individuals must also have a mental or physical impairment, with onset before they are 22 years old, that is likely to continue indefinitely and they must be unable to carry out some everyday activities, such as making basic decisions, communicating, taking transportation, keeping track of money, keeping out of danger, eating, and going to the bathroom, without substantial assistance from others.

Until recently, states provided the bulk of services for this population through the Medicaid ICF/MR program. The ICF/MR program funds large institutions and smaller settings of 4 to 15 beds, and both sizes of settings are subject to the same regulatory standards. ICF/MR program services are available and provided as needed on a 24-hour basis. These services include medical and nursing services, physical and occupational therapy, psychological services, recreational and social services, and speech and audiology services. ICF/MR program services also include room and board. Providers of ICF/MR program services must adhere to an extensive set of

regulations and are subject to annual on-site inspections as mandated by Medicaid.

In 1981, the Congress enacted the 1915(c) waiver allowing states to apply to HCFA for a waiver of certain Medicaid rules to offer home and community-based services. By 1995, 49 states had 1915(c) home and community-based waiver programs for persons with developmental disabilities.[2] Waiver program services vary by state, but include primarily nonmedical services such as chore services, respite care, and habilitation services, which are all intended to help people live more independently and learn to take care of themselves. (See apps. II and III for a list of waiver program services and definitions in the three states we visited). Unlike ICF/MR program services, waiver program services do not include room and board and are often provided on less than a 24-hour basis.

HCFA carries out its waiver program oversight responsibilities through review of applications and renewals and monitoring of implementation through on-site compliance reviews. In approving waivers,[3] HCFA reviews applications to ensure that (1) services are offered to individuals who, "but for the provision of such services . . . would require the level of care provided" in an institutional setting such as an ICF/MR;[4] (2) total Medicaid per capita costs for waiver program recipients are not greater than total Medicaid per capita costs for persons receiving institutional care; and (3) states properly assure quality.

The waiver program enables states to control utilization and costs in ways not permitted under the regular Medicaid program. The waiver program has a cap for the number of persons served at HCFA-approved levels. It also allows states, with HCFA permission, to target services to distinct geographic areas or populations, such as persons with developmental disabilities or the elderly; offer a broader range of services; and serve persons with incomes somewhat higher than normal eligibility thresholds. In contrast, the regular Medicaid program generally requires that each state provide eligible beneficiaries with all federally mandated services and any optional services it chooses to offer.

States, however, provide some community-based services to developmentally disabled individuals through the regular Medicaid

[2]Arizona provides similar services through a Medicaid 1115 demonstration waiver.

[3]Initial waiver program approvals are for a 3-year period and renewals are for a 5-year period.

[4]Section 1915(c)(1) of the Social Security Act.

program. These services include federally mandated services, such as home health care, and other services that states may elect to provide, which are called optional services. Some of the more important optional services for the population with developmental disabilities are rehabilitative services,[5] case management, and personal care. Because the regular Medicaid program operates as an entitlement—that is, all eligible individuals in a state are entitled to receive all services offered by the state—states have less control over utilization and the cost of services than in waiver programs.

States Use Waivers to Expand and Change Programs for Developmentally Disabled

Through the use of waivers, states have changed long-term care nationally for persons with developmental disabilities in two ways. First, states have significantly expanded the number of individuals being served. Second, states have shifted the program balance from serving most people through the ICF/MR program to serving most through the waiver program. Generally the shift to the waiver program has been part of an evolution of services away from large and more restrictive settings to providing services in small and less restrictive settings, which are preferred by recipients and their families. Some state waiver programs are continuing to evolve from their earlier approach of providing services primarily in group home settings to one of serving people at home.

States Serve More People and Shift Balance by Serving More in Waiver Than in ICF/MR Program

From 1990 to 1995 the number of persons served by the waiver and ICF/MR programs combined rose at an average annual rate of 8 percent (see table 1). The number served by the waiver program more than tripled to over 142,000 persons during this period and accounted for the entire increase in the number of persons served by both programs. States dramatically increased the number of people who received waiver program services using a variety of strategies, including substituting waiver program for ICF/MR program services, services provided under state-only programs, and services to persons who were not being served before.

[5]Some states use the Medicaid optional service of rehabilitation to provide services to persons with developmental disabilities. However, HCFA considers the services provided under this option for the developmentally disabled population to be habilitation rather than rehabilitation because these services are intended to help individuals learn to perform tasks rather than restore their ability to perform tasks they have lost the capacity to perform. HCFA no longer allows states to select the rehabilitation plan option to offer habilitation services. However, states that had received approval to do so before June 30, 1989, can continue providing such services.

Table 1: Growth of Developmental Disabilities Population Served by Medicaid Long-Term Care

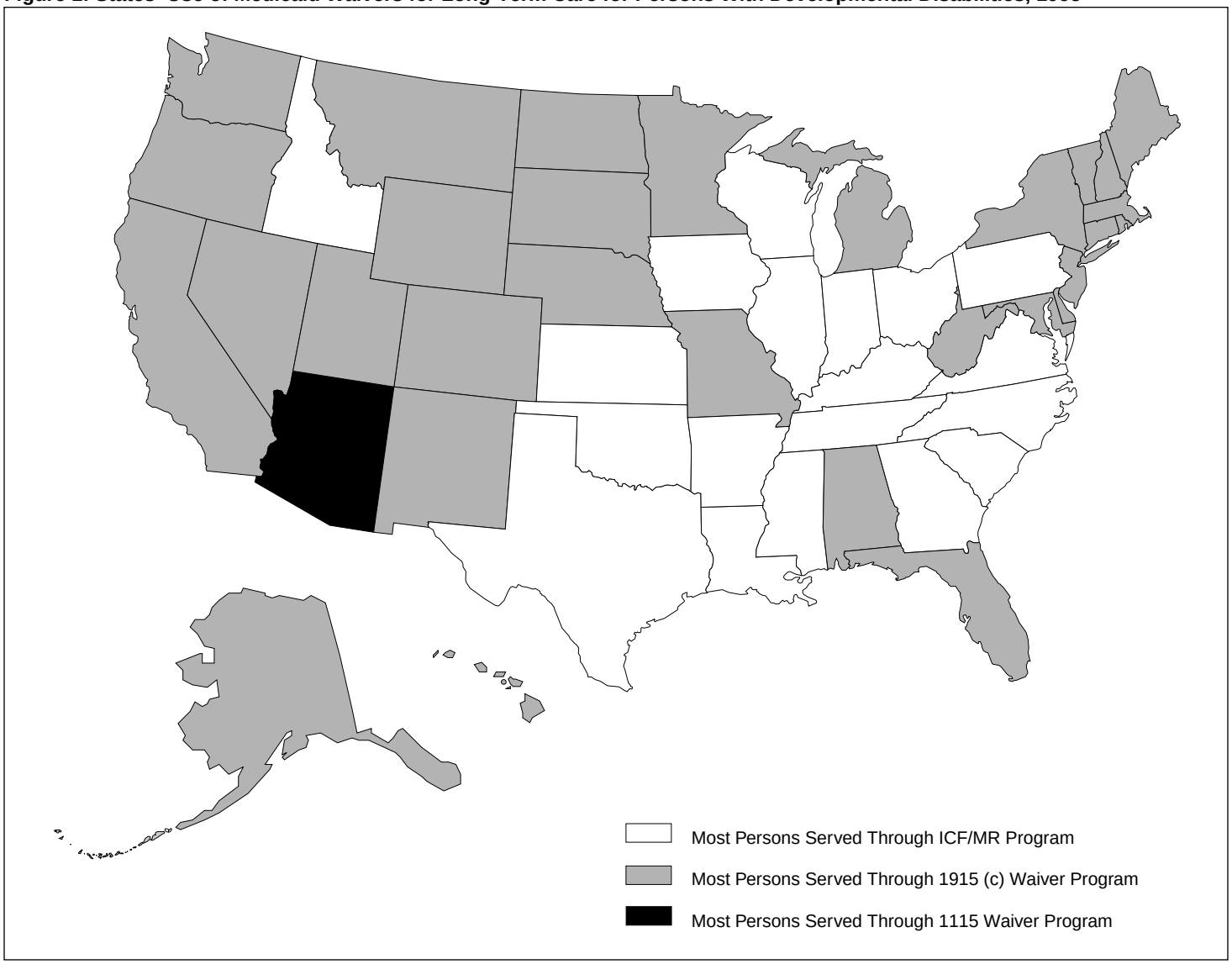
Recipients	1982	1986	1990	1994	1995
Total	**140,593**	**156,505**	**184,126**	**257,420**	**276,452**
Served by waiver program[a]	1,381	17,180	39,838	115,302	142,068
Served by ICF/MR program	139,212	139,325	144,288	142,118	134,384

[a]Does not include those served by Arizona's 1115 waiver program who live in alternative settings.

Source: Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, University of Minnesota, Minneapolis.

More people are now served through the waiver program than the ICF/MR program. Although the percentage of persons served through the waiver program varies by state, 30 states provide services to more people through the waiver program than the ICF/MR program (see fig. 1).

Figure 1: States' Use of Medicaid Waivers for Long-Term Care for Persons With Developmental Disabilities, 1995



Source: Calculated from data obtained from the Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, University of Minnesota, Minneapolis.

With the support of recipients and their families, state officials have made changes to serve more people through the waiver program. All three

groups have come to believe that the alternatives possible through the waiver can better serve persons with developmental disabilities. They believe that in many cases individuals can have a higher quality of life through greater community participation, including relationships with neighbors, activities in social organizations, attendance at public events, and shopping for food and other items. This can result in expanded social networks, enhanced family involvement, more living space and privacy, and improvements in communication, self-care, and other skills of daily living.

States believed that they could use the waiver program to expand services while simultaneously reducing or limiting access to ICF/MR program care as a means to control growth in expenditures. As a result, many states have closed large institutions or held steady ICF/MR capacity even as the population in need has grown. Some states have also reduced smaller ICF/MR settings by converting them to waiver programs. The number of people in ICF/MR settings has dropped 7 percent from 1990 to 1995. These actions have been part of an overall strategy to change the way services are provided and financed.

Flexibility of the Waiver Program Has Allowed States to Pursue Distinct Strategies

States have used the flexibility of the waiver program to pursue distinct strategies and achieve different program results as shown in the three states we visited (see table 2). These states used the waiver program to substitute for ICFs/MR that were being closed, expand the number of persons being served, or both.

Table 2: Changes in Number of Waiver and ICF/MR Program Recipients, 1990 and 1994

	1990		1994	
State	Waiver program recipients	ICF/MR program recipients	Waiver program recipients	ICF/MR program recipients
Florida	2,488	3,243	6,547	3,395
Michigan	1,647	3,337	3,130	3,205
Rhode Island	738	903	1,262	458

Note: Some double counting occurs for recipient numbers because the same individual may receive services through the waiver and ICF/MR programs in the same year.

Source: State agencies.

Rhode Island targeted waiver program services as a substitute for ICF/MR program care with little change in the number of persons served. The state

began the 1990s with short waiting lists for services and a goal of closing all large institutions of 16 or more beds. Providing waiver program services to many of its former residents, the state closed the Ladd Center, its last large institution, in 1994 to become one of only two states along with the District of Columbia to close all its large institutions.[6] Rhode Island also substantially reduced the number of recipients of services in smaller ICFs/MR by converting the ICFs/MR to the waiver program. As a result, a substantial number of persons who had been supported through the state's ICF/MR program are now supported by its waiver program. The number of developmentally disabled persons served through the waiver and ICF/MR programs in Rhode Island, however, did not expand significantly.

In contrast, Florida's strategy for the waiver program was to expand services to a much broader population rather than using the waiver program to close ICF/MR settings. Florida began the 1990s with substantial waiting lists for services and fewer ICF/MR beds than most of the country relative to the size of the population with developmental disabilities. Florida chose to greatly expand the number of persons with developmental disabilities served to include people who had not been served or who needed more services. The overwhelming source of growth has been from the large increase in waiver program recipients, although Florida has also experienced modest growth in the number of ICF/MR recipients. The state's increase in waiver program recipients includes persons who were receiving services from state-only programs and persons who were not previously served.

Michigan used the waiver program in the 1990s to continue pursuing its goals of closing large institutions, offering placements for persons leaving small ICFs/MR, and expanding services to those with unmet needs. Michigan, like Florida, began the 1990s with many persons who needed but had not received services. Michigan, however, had more ICF/MR capacity than Florida. Most of Michigan's ICF/MR capacity was in smaller settings, many of which had been developed to help the state close some of its large institutions. As a result, Michigan has closed all but about 400 beds in large institutions and significantly increased the number of persons served. State officials told us that by 1995, Michigan was serving more individuals in the waiver program than in its ICF/MR program.

[6]Vermont is the other state to close all its ICFs/MR of 16 or more beds. New Hampshire is the only other state to close all its large state institutions, but it still has one large private institution in operation.

States Are Changing Their Waiver Programs to Serve More Individuals at Home

In the continuing evolution of services for persons with developmental disabilities, some states, such as Florida, Michigan, and Rhode Island, are changing the focus of waiver program services from group home care to more tailored services to meet individuals' unique needs and preferences at home. These states and most others began their waiver programs by providing services primarily in group homes. Recently, state officials have come to believe that for many persons, services are best provided on a more individualized basis in a recipient's home—his or her family's home or own home or an adult foster care home—rather than in group home settings. The three states we visited became convinced that this was possible even for persons with severe disabilities, in part, because of their success in using this approach in the recently concluded Community Supported Living Arrangements (CSLA) program.[7]

Slightly more than one-half of all waiver program recipients nationally are estimated to have been living in settings other than group homes in 1995.[8] In each of the three states we visited, many 1915(c) waiver recipients now live in their family's home or their own home. In Florida, more than one-half of all waiver recipients live in settings other than group homes, including nearly 50 percent who live in their family's homes. The majority of Michigan's waiver program recipients live in small settings other than licensed group homes. Just under one-half of Rhode Island's recipients live in settings other than group homes. Each state expects the percentage of waiver program recipients living in nongroup home settings to increase.

Officials in the states we visited and other experts told us that serving individuals with developmental disabilities who live in their own or their family's home and receive less than 24-hour support often requires changes in the service delivery model. For example, these settings may need environmental changes and supports to make them suitable for persons with developmental disabilities. Such changes could include the installation of ramps for persons with physical disabilities or emergency communication technology and other equipment for persons with communication or cognitive impairments or a history of seizures who may need quick assistance. Paid assistance may also be needed to provide a

[7]Starting in 1990, the Congress funded the CSLA program for a 5-year period. The eight states selected to participate in the program used CSLA to expand or test a fundamentally different approach to supporting people with disabilities in the community, often referred to as the supports model. The program ended in 1995. CSLA expenditures were $38 million in 1995.

[8]Robert Prouty, and and K. Charlie Lakin, eds., Residential Services for Persons With Developmental Disabilities: Status and Trends Through 1995 (Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, 1996), p. 102.

variety of other services, such as supervision of or assistance in toileting, dressing, bathing, carrying out routine chores, managing money, or accessing public transportation and other community services. Assistance for such services is often provided on an individual basis rather than for several persons in a group home. Respite care may also be provided for family caregivers.

Although the three states we visited have made major commitments to convert their waiver programs to individualized supports at home, these changes will require significant change on the part of everyone involved and could take years to fully implement. For example, some public agencies own or have long-term contracts for the use of group homes or have encouraged the development of private group homes. In addition, state officials told us that public agencies and other service providers may find it difficult to adapt to designing services for each individual living at home rather than offering services in the more familiar group home program setting. In addition, some family members and advocates have expressed concern that the level of funding available for and the range of services offered under the waiver program may not be sufficient for individuals who require constant supervision and care.

Medicaid Costs Rose During Planned Expansion in Persons Served

Nationwide, Medicaid costs for long-term care services for persons with developmental disability rose at an average annual rate of 9 percent between 1990 and 1995 as states implemented their planned increases in the number of persons served. Costs rose from $8.5 billion in 1990 to $13.2 billion in 1995. (See table 3.) Most of the increase reflected increased costs for waiver program services, but increased ICF/MR program costs also were a factor. Waiver program costs grew primarily because more people were served as per capita waiver costs increased slightly less than inflation. ICF/MR program cost increases resulted solely from growth in per capita ICF/MR program costs, which rose somewhat faster than inflation, as the number of residents declined. In 1995, per capita waiver program costs ($24,970) remained significantly lower than per capita ICF/MR spending ($71,992).[9]

[9]Although Medicaid costs are much lower for waiver program recipients than ICF/MR program recipients, government savings are less for waiver program recipients than this comparison might suggest. For example, waiver program recipients receive other government funding not available to ICF/MR program recipients. Furthermore, although waiver program recipients can receive federal Supplemental Security Income (SSI) payments for general income, ICF/MR program recipients can only receive the SSI personal needs allowance. In 1995, the general income maximum was $458 a month or $5,496 annually, while the personal needs allowance was $30 a month. The amount of SSI payments can be greater if states choose to supplement the federal payment. Waiver program recipients may also benefit from the Food Stamp program, some federal housing programs, and state and local government programs.

Table 3: Growth in Medicaid Long-Term Care Costs for Persons With Developmental Disabilities, 1990, 1994, and 1995

Dollars in billions

Program	1990	1994	1995
Total	**$8.478**	**$12.085**	**$13.222**
Waiver program[a]	0.846	2.862	3.547
ICF/MR program	7.632	9.222	9.675

Note: Numbers may not add due to rounding.

[a]Does not include costs for Arizona's 1115 waiver program for services in alternative settings.

Source: Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, University of Minnesota, Minneapolis.

State Costs and Cost Increases Vary

In the three states we visited, average per capita costs and average increases in per capita costs varied according to each state's waiver program strategy and other factors (see table 4). Florida per capita waiver costs, for example, were among the lowest in the nation, in part, as a result of the state's strategy to expand services to more persons. According to state officials, limited resources were stretched to cover as many people as possible by providing each individual with the level of services required to prevent institutionalization rather than providing all the services from which an individual might benefit.

Table 4: Per Capita Costs and Cost Increases Vary

	Per capita costs, 1994		Average annual percentage increase in per capita costs, 1990-94	
	Waiver program	ICF/MR program	Waiver program	ICF/MR program
United States	$24,824	$64,892	4	5
Florida	9,955	62,815	9	8
Michigan	27,537	66,361	5	1
Rhode Island	49,884	117,118	27	11

Source: Calculated from national data obtained from the Research and Training Center on Community Living, Institute on Community Integration/UAP, College of Education and Human Development, University of Minnesota, Minneapolis, and state data provided by state officials. Because 1995 data were not available from the states, we use 1994 national data for comparison purposes. See appendix I for details on national and state data comparison.

By contrast, from 1990 to 1994 Rhode Island's per capita costs under the waiver and ICF/MR programs were much higher than the national average.[10] The large increase in per capita waiver program costs resulted because unlike Florida and Michigan, Rhode Island substituted waiver program services for persons receiving high-cost ICF/MR care and closed its last large institution. As a result, Rhode Island was serving a substantial number of persons through the waiver program who had previously received expensive ICF/MR care. At the same time, ICF/MR per capita costs were also higher, in part, because as the number of people in ICF/MR settings declined, the fixed costs were spread over a smaller population. In addition, the population that remained in ICF/MR settings was substantially disabled and required intensive services.

Enrollment Caps and Management Practices Helped Limit Cost Growth

Cost growth has been limited by two factors. First is a cap on the number of program recipients. Second, states have employed a variety of management practices to control per capita spending.

Fundamental to waiver program cost control has been the federal Medicaid rule which, in effect, capped the number of recipients who could have been served each year. HCFA approves each state's cap, and states are allowed to deny admission for services to otherwise qualified individuals when the cap is reached. By contrast, under the regular Medicaid program, all eligible recipients must be served and no limits exist on the number of recipients. As a result, waiver caps have given states a greater ability to control access and thereby cost growth than would have been possible if they had expanded services through the regular Medicaid program.

States have also used several management practices to help contain costs. In the three states we visited, these management practices include fixed agency budgets for waiver services and linking management of care plan and use of non-Medicaid services to individual budgets for each person served.

Fixed Agency Budgets

States have developed fixed agency budgets within limits established under waiver rules. In Florida, Michigan, and Rhode Island, appropriations for waiver program and other services are in the budgets of developmental disability agencies. In Florida, budgets are allocated among 15 state district offices. In Michigan, budgets for serving persons with

[10]Per capita costs for both programs are substantially higher in New England than in most other parts of the country.

developmental disabilities are allocated among 52 local government community mental health boards and three state-operated agencies, each responsible for serving a local area. State or local agencies are responsible for approving individual service plans, authorizing budgets for the costs of these services, and monitoring program expenditures on an ongoing basis to ensure that total expenditures are within appropriated budgetary amounts as the three states transition to a person-centered planning basis in their waiver programs.

Management of Care Plan Linked to Individual Budgets

The three states we visited require that case managers or service providers in consultation with case managers develop a plan of care linked to an individual budget for each person being served in the person-centered planning approach. This care plan and its costs must be approved by the state developmental disability agency, state district office, or community mental health board, depending upon the state. Upon agency approval, the case manager oversees the implementation of the care plan and monitors it on an ongoing basis. Significant variation from the plan requires agency approval and changes in service and budget authorizations. This process provides more stability for the budget process and allows state agencies to monitor their overall spending on an ongoing basis and plan for contingencies to remain within budget levels.

Use of Non-Medicaid Services Linked to Individual Budgets

State developmental disability agencies in the three states we visited also require that case managers build into the care planning process and individual budget determination the use of non-Medicaid services, both paid and unpaid. State officials told us that this is a part of better integration of persons with developmental disabilities into the community and making it possible to extend available waiver dollars to serve as many people as possible. When paid services are needed, states try to take advantage of services funded for broader populations, such as recreation or socialization in senior citizen centers or the use of public transportation. States also attempt to use unpaid services when possible by increasing assistance from families, friends, and volunteers. State officials told us that use of these paid and unpaid services reduces the need for Medicaid-financed supervision and care.

Change in Federal Rule Could Result in Higher Caps and Costs

A change in federal rules could result in high waiver caps on enrollment and therefore higher costs. Until August 24, 1994, HCFA limited the number of waiver recipients in a state under the so-called cold bed rule. This rule required that each state document for HCFA approval that it either had an unoccupied Medicaid-certified institutional bed—or a bed that would be built or converted—for each individual waiver recipient the state requested to serve in its application. However, in 1994, HCFA eased waiver restrictions by eliminating the cold bed rule so that states were no longer required to demonstrate to HCFA that they had "cold beds."

HCFA took this action because it believed that the cold bed rule placed an unreasonable burden on states by requiring them to project estimates of additional institutional capacity. HCFA now accepts a state's assurance that absent the waiver the people served in the waiver program would receive appropriate Medicaid-funded institutional services. As HCFA recognized when it eliminated the cold bed rule, this change could result in higher waiver costs if states elect to increase the number of waiver recipients more rapidly than before. HCFA, however, recognized that the state budget constraints could play a restrictive role in waiver growth.

State officials told us that elimination of the cold bed rule allows them to expand waiver services more rapidly than in the past, both to persons not currently receiving services and to others receiving services from state-only programs. State officials told us that converting state program recipients to the waiver was particularly advantageous given the federal Medicaid match.[11] Officials in Florida and Michigan told us that they are planning to expand the number of people served in the waiver program more rapidly than they could have under the cold bed rule. This could increase costs more rapidly than in the past. Officials in Florida and Michigan said that they will phase in increases in the number of waiver recipients to stay within state budget constraints and to allow for a more orderly expansion of services to the larger numbers of new recipients.

[11]The federal government matches state expenditures for Medicaid according to a prescribed formula, providing on average 57 cents of every Medicaid dollar spent.

More Development of Promising Quality Assurance Approaches Needed to Reduce Potential Risks

To increase quality for recipients and families, states are introducing promising quality assurance innovations while simultaneously building in more flexibility in traditional quality assurance mechanisms. These changes are intended to provide recipients and families with a greater choice of services within appropriate budget and safety limits. However, until states more comprehensively develop and test these approaches, some recipients may face health and safety risks and others may not have access to the range of choices state programs seek to provide.

States Continue to Use Traditional Mechanisms to Assure Adequate Quality

One of the most important mechanisms that states use to assure adequate quality is service standards. Each state, as required by HCFA guidelines, adopts or develops standards for each waiver service. Waiver standards are specified in state and local laws, regulations, or operating guidelines and are enforced by specific agencies. As a result, waiver standards reflect specific state processes and choices in how states assure quality, and are not uniform across the nation as are ICF/MR standards. (For example, see app. IV for a summary of how Florida meets HCFA requirements for specifying waiver standards.) Waiver standards may include professional licensing standards, minimum training requirements for staff, and criminal background checks for providers. The standards may also include requirements for certification of group home or other facilities and compliance with local building codes and fire and safety requirements.

States review providers and services on an ongoing basis and have abuse and neglect reporting procedures in place. Florida, Michigan, and Rhode Island, for example, conduct routine and unannounced reviews of providers. As a result of these reviews, providers can be required to provide plans of correction for identified problems and implement improvements. In some cases, providers have lost their certification to participate in the program. These states also have formal grievance procedures and a grievance unit, such as a state agency or human rights committee, to investigate complaints on a statewide, regional, or agency basis. Through these processes, the states have also identified problems in quality and taken steps to ensure corrective action.

In addition to state quality assurance efforts, HCFA regional staff conduct a compliance review of each state's waiver program before its renewal. HCFA uses a compliance review document for this process. HCFA reviews involve random selections of recipients for interviews and visits to their homes. The reviews also involve interviews with and visits to service providers

and advocates. If HCFA determines that quality is not satisfactory, it can require that a state take corrective action before a waiver can be renewed.

States Are Introducing Innovations to Promote Better Quality for Recipients

States are taking steps to develop or enhance existing mechanisms to promote better quality in waiver program services. Many of these mechanisms were used in the recently concluded CSLA program to provide individualized services to people at home and are now being incorporated into the home and community-based waiver program even for persons with substantial disabilities. Advocates, family members, and recipients have been generally positive about this shift to support individuals in more integrated community settings.

Person-centered planning is a key element of providing better quality in waiver services, according to officials in the three states we visited and national experts. The planning process and the resulting plans are individualized to incorporate substantial recipient and family input on how the individual will live and what assistance the individual will need. The case manager, called support coordinator in some states, has primary responsibility in person-centered planning, which includes working with the recipient to develop the plan, arranging for needed services, monitoring service delivery and quality, and revising the plan as necessary. A budget for the individual is established to provide the services identified as appropriate and cost-effective. Recipients and case managers choose providers on the basis of their satisfaction with services. State officials told us that this approach not only gives recipients more say in how they are served but that the resulting competition motivates providers to increase service quality.

Linking persons living in the community with volunteers who can provide assistance and serve as advocates is seen as another important mechanism for promoting quality. For example, some states, including the three we visited, have a circle of friends or similar process for individual recipients. A circle of friends is a group of volunteers, which can include family, friends, community members, and others, who meet regularly to help persons with disabilities reach their goals. These volunteers help plan how to obtain needed supports; help persons participate in community, work, or leisure activities they choose; and try to help find solutions to problems. By integrating recipients in the community, recipients have more choice and can get better quality services, according to national experts and state officials we interviewed. This community integration increases the number

of persons who can observe and identify problems in service quality and notify appropriate officials when there are deficiencies.

Because program quality depends on the active participation of recipients, families, and service providers, states are also providing substantial training to these groups to encourage and strengthen their participation. Training can include informing recipients and families of available service providers, procedures for providing feedback about services, and steps to take if quality is not improved. Training for service providers may focus on reinforcing the fact that the recipient and family have the right to make choices about services and that staff must be responsive to those choices unless they are inappropriate for safety concerns or for other compelling reasons, such as available financial resources.

States are also modifying how they monitor quality. Traditionally, they emphasized compliance with certain criteria, such as maintaining a minimum level of staff resources and implementing standard care processes. Some states are focusing their quality monitoring more on outcome measures for each individual while still assessing providers' compliance with program standards. For example, states, including the three we visited, are trying to determine whether the recipients are living where and with whom they chose, whether they are safe in this environment, and whether they are satisfied with their environment and the services they receive.

States are also attempting to make their oversight less intrusive for the recipients. For example, some states use trained volunteers to interview recipients at their homes on a periodic basis to check the quality of services received. In other instances, although case managers are required to meet recipients on a regular basis, meetings can be arranged at the recipient's convenience, including in the evening or on weekends or at a place the recipient likes to meet at, such as at his or her home or local park or library. Case managers talk with the recipients and their families about the quality of the services they receive and take any actions necessary to correct deficiencies.

Some Recipients May Face Avoidable Risks Until States More Fully Develop and Implement Evolving Approaches to Quality

While officials in the three states we visited and other experts agree that many persons prefer services provided at home to services provided in institutions or other group settings, they also note that providing services at home presents unique problems in ensuring quality. Because the new focus is on providing individual choice, the types of services that are

offered and the means for providing these services can vary greatly. To promote quality and ensure that minimum standards are met requires a broad range of approaches.

Although states continue to develop quality assurance mechanisms, state officials acknowledge that these are not yet comprehensive enough to assure recipient satisfaction and safety. In the three states we visited, state officials and provider agencies told us that they are still developing guidance and oversight in a number of key areas. Michigan, for example, is revising its case management standards and statewide quality assurance approaches. Rhode Island is developing a more systematic monitoring approach statewide, and Florida is continuing to implement and evaluate its independent service coordinator approach.

One of the greatest difficulties in developing quality mechanisms for services in alternative settings is balancing individual choice and risks.[12] Where greater choice is encouraged and risks are higher, more frequent monitoring and contingency planning need to be built into the process. Yet some professional staff and agency providers in the states we visited believe that they do not have sufficient guidance on where to draw the line between their assessment of what is appropriate for the disabled person and the individual's choice. For example, some persons with mental retardation cannot speak clearly enough to be understood by people who do not know them; cannot manage household chores, such as cooking in a safe manner; or have no family member to perform overall supervision to keep them from danger. Yet these people express a desire to live independently, without 24-hour staff supervision.

Florida, Michigan, and Rhode Island each attempt to customize supports to reduce risks for individuals who live in these situations. They may arrange for roommates, encourage frequent visits and telephone contact by neighbors and friends, enroll individuals in supervised day activities, install in-home electronic access to emergency help, and provide paid meal preparation and chore services. As this new process evolves, states and providers seek to develop a better understanding of how to manage risks and reduce them where possible. This should lead to improved guidance for balancing risks and choices for each recipient's unique circumstances.

[12]HCFA has also recognized the need to balance these issues. See The Role of Medicare and Medicaid in Long-Term Care: Opportunities, Challenges, and New Directions (Baltimore: U.S. Department of Health and Human Services, HCFA, Sept., 1995), p. 44.

Determining what recipients' choices are can be difficult for a number of reasons. First, many of these individuals have had little experience in making decisions and may also have difficulty in communicating. In addition, some recipients have complained that they are not being provided the range of choices to which they should have access and that quality monitoring is too frequent or intrusive despite the changes states have introduced. However, concern has been expressed that quality assurance is not rigorous enough to reduce all health or safety risks and that the range of choices is too great for some individuals.[13]

State officials and other experts we interviewed have emphasized the need for vigilance to protect recipients and ensure their rights. They have been especially concerned with assuring quality for recipients who are unable to communicate well and for those who do not have family members to assist them. The states we visited are taking special precautions to try to assure quality in these cases—such as recruiting volunteers to assist and asking recipient groups to suggest how to assure quality for this vulnerable population. However, state officials and HCFA agree that more development of quality assurance approaches is needed.

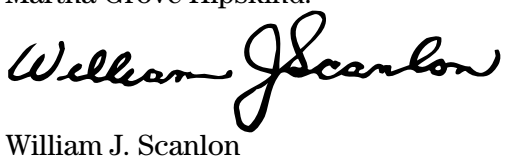
Agency Comments

Officials from the Office of Long-Term Care Services in HCFA's Medicaid Bureau and from Florida, Michigan, and Rhode Island reviewed a draft of this report. They generally agreed with its contents and provided technical comments that we incorporated as appropriate.

[13]See Robert G. Erb, "Perspectives: Where, Oh Where, Has Common Sense Gone? (Or If the Shoe Don't Fit, Why Wear It?), Mental Retardation: A Journal of Policy, Practices, and Perspectives, Vol. 33, No. 3 (1995), pp. 197-99.

We are sending copies of this report to the Secretary of Health and Human Services; the Administrator, Health Care Financing Administration; and other interested parties. Copies of this report will also be made available to others upon request.

If you or your staff have any questions, please call me at (202) 512-7119; Bruce D. Layton, Assistant Director, at (202) 512-6837; or James C. Musselwhite, Senior Social Science Analyst, at (202) 512-7259. Other major contributors to this report include Carla Brown, Eric Anderson, and Martha Grove Hipskind.



William J. Scanlon
Director, Health Systems Issues

Contents

Figures

Abbreviations

ASPE	Assistant Secretary for Planning and Evaluation
CMHB	Community Mental Health Board
CSLA	Community Supported Living Arrangements
DS	Developmental Services
F.S.	Florida statutes
HCFA	Health Care Financing Administration
HIV/AIDS	human immunodeficiency virus/acquired immunodeficiency syndrome
HRS	Department of Health and Rehabilitative Services
ICF	intermediate care facility
ICF/MR	intermediate care facility for mental retardation
NASDDDS	National Association of State Directors of Developmental Disabilities Services, Inc.
NF	nursing facility
PERS	Personal Emergency Response System
SNF	skilled nursing facility
SSI	Supplemental Security Income
UAP	University Affiliated Program

Scope and Methodology

We focused our work on Medicaid 1915(c) waivers for adults with developmental disabilities. We also examined related aspects of institutional care provided through ICF/MR, state plan optional services, and the CSLA program, all under Medicaid.

To address our study objectives we (1) conducted a literature review, (2) interviewed national experts on mental retardation and other developmental disabilities, (3) collected national data on expenditures and the number of individuals served, and (4) collected and analyzed data from three states. National experts interviewed included officials at HCFA; the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in the Department of Health and Human Services; the Administration on Developmental Disabilities; the President's Committee on Mental Retardation; the National Association of Developmental Disabilities Councils; the Administration on Aging; the National Association of State Directors of Developmental Disabilities Services, Inc. (NASDDDS); and the ARC, formerly known as the Association for Retarded Citizens. We also interviewed researchers at University Affiliated Programs (UAP)[14] on developmental disabilities at the Universities of Illinois and Minnesota and Wayne State University.

We conducted our case studies in Florida, Michigan, and Rhode Island. We chose these states for several reasons. The three states provide a range of state size and geographic representation. Each state has a substantial developmental disability waiver program that serves more people than its ICF/MR program. Experts told us that these states would provide examples of different state strategies for utilizing the Medicaid waiver. This included their policies regarding large and small institutions as well as the design and implementation of their waiver programs. The three states also have important differences in the administrative structure of their developmental disability programs. Rhode Island administers its waiver program statewide through the Division of Developmental Disabilities in the Department of Mental Health, Retardation and Hospitals. Florida places statewide administration and oversight responsibility for its waiver program in Developmental Services, the Department of Health and Rehabilitative Services, but operational responsibility rests with its 15 district offices of Developmental Services. Michigan places statewide administration and oversight responsibility for its waiver programs in the state Department of Mental Health, but operating responsibilities rest with 52 Community Mental Health Boards (CMHB), which are local government

[14]University affiliated programs are funded by the Administration on Developmental Disabilities as part of the Developmental Disabilities Act to provide information and analysis on developmental disability programs.

entities covering one or more counties and three state-operated agencies each responsible for serving a local area. Florida district offices and Michigan CMHBs have discretion in the design and implementation of waiver program and other services within the broad outlines of state policy.

We visited each state to conduct interviews with state and local officials, researchers, service providers, advocates, families, and recipients. These interviews included state Medicaid officials and developmental services officials and officials in agencies on aging and developmental disability councils. In Florida, we also visited state district offices in Pensacola and Tallahassee to conduct interviews with district government and nongovernment representatives. In Michigan, we visited the Detroit-Wayne and Midland/Gladwin CMHBs to conduct interviews with government and nongovernment representatives. We followed up with state agencies to collect additional information.

The national waiver and ICF/MR program expenditure and recipient data used in this report are from the UAP on developmental disabilities at the Research and Training Center on Community Living, Institute on Community Integration, at the University of Minnesota. The Institute collects these data, with the exception of ICF/MR expenditures, directly from state agencies. The Institute uses ICF/MR expenditure data, compiled by the Medstat Group under contract to HCFA. National data from the Institute were available through 1995. The expenditure and recipient data we report for Florida, Michigan, and Rhode Island were provided to us by the state agencies responsible for developmental services and the Medicaid agencies. The latest complete data available from these three states were for 1994. We therefore used 1994 national data for comparison purposes.

Some differences occur in the recipient counts among the national data we used from the Institute and data we collected from agencies in Florida, Michigan, and Rhode Island. These differences could affect some aspects of our comparisons of national trends and trends in the three states. Institute data on recipients show the total number of persons receiving services on a given date—June 30 of each year—whereas data for the three states show the cumulative number of persons receiving services over a 12-month period. Therefore, data supplied by the states could result in a larger count of program recipients than the methodology used by the Institute. This could have the impact of making per capita expenditure calculations smaller for the state data than for the national data. Our

comparisons of data from the two sources, however, showed few substantial differences in the data for the three states.

We excluded children from our analysis because (1) their needs are different in many respects from those of adults, (2) family responsibilities for the care of children are more comprehensive than for adults, and (3) the educational system has the lead public responsibility for services for children. Recipient and expenditure data in this report, however, include some children because it was not possible to systematically exclude them. However, the percentage of children in these services is small. In 1992, for example, about 11 percent of ICF/MR service recipients were less than 21 years old.[15]

We conducted our review from May 1995 through May 1996 in accordance with generally accepted government auditing standards.

[15]Robert Prouty, and K. Charlie Lakin, eds., Residential Services for Persons with Developmental Disabilities: Status and Trends Through 1994 (Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration/UAP, The College of Education and Human Development, 1995), p. 113.

Medicaid Waiver Program Services Offered for Persons With Developmental Disabilities in Florida, Michigan, and Rhode Island

States, with HCFA's approval, choose which services they offer through waiver programs and how the services are defined. States can choose from a list of standard services and definitions in the HCFA waiver application or design their own services. In designing their own services, states can add new services or redefine standard services. States can also extend optional services to offer more units of these services to waiver program recipients than are available to other recipients under the regular Medicaid program.

The three states we visited chose to offer a number of standard services under their waiver program. Each state also modified the definition of some standard services that it provides or offered services not on the standard waiver list. (See fig II.1.) For example, Florida modified the definition of case management to include helping individuals and families identify preferences for services. Florida also added several nonstandard, state-defined services such as behavior analysis and assessments and supported living coaching. Rhode Island's modified definition of homemaker services includes a bundle of services often offered separately, including standard homemaker services, personal care services, and licensed practical nursing services. Rhode Island also added nonstandard services to provide minor assistive devices and support of family living arrangements. Michigan modified the standard definition of environmental accessibility adaptations to include not only physical adaptations to the home, but to the work environment as well. Michigan also recently added a new state-defined service, community living supports, which is a consolidation of four services—in-home habilitation, enhanced personal care, personal assistance, and transportation—previously provided separately. Florida and Michigan also chose to offer several optional services in their waiver programs.

Figure II.1: Waiver Program Services Provided in Florida, Rhode Island, and Michigan

	Florida	Rhode Island	Michigan
Services Used From Standard Waiver List			
Adult Companion Services	☐		
Case Management	■	☐	■
Chore Services	☐		☐
Day Habilitation		☐	☐
Educational Services			☐
Environmental Accessibility Adaptations	☐	■	■
Family Training			☐
Homemaker	☐	■[a]	
Personal Care Services	☐		
Personal Emergency Response System (PERS)	☐		☐
Prevocational Services			☐
Private Duty Nursing	☐		☐
Residential Habilitation	☐	☐	
Respite Care	☐	☐	☐
Skilled Nursing	☐		
Specialized Medical Equipment and Supplies	☐		
Supported Employment Services		☐	☐
Transportation	☐		

	Florida	Rhode Island	Michigan
Extensions of State Plan Optional Services			
Dental			☐
Enhanced Medical Equipment and Supplies			☐
Occupational Therapy	☐		
Physical Therapy	☐		
Prescribed Drugs			☐
Speech Therapy	☐		
Nonstandard Waiver Services Provided by States			
Behavior Analysis and Assessments	☐		
Community Living Supports			☐
Day Training	☐		
Family Living Arrangements		☐	
Minor Assistive Devices		☐	
Nonresidential Support	☐		
Psychological Services	☐		
Special Medical Home Care	☐		
Specialized Homemaker		☐	
Supported Living Coaching	☐		

☐ Service Offered
■ State Definition Differs From Standard HCFA Definition

[a]Rhode Island's definition of homemaker includes not only homemaker services as typically defined, but personal care and licensed practical nursing services as well.

Source: HCFA 1915(c) Waiver Application Format (June 1995) and state waiver applications.

The HCFA definition for each standard waiver service offered in Florida, Michigan, and Rhode Island is shown in appendix III.

Standard Services as Defined in HCFA's 1915(c) Waiver Application Format

This appendix shows HCFA's definition for each standard waiver service offered in Florida, Michigan, and Rhode Island. These service names and definitions are written as they appear in the latest version of the HCFA 1915(c) waiver application format, dated June 1995. Because states have the flexibility to modify these definitions, the definitions and how services are implemented vary among the states.

Adult Companion Services: Non-medical care, supervision and socialization, provided to a functionally impaired adult. Companions may assist or supervise the individual with such tasks as meal preparation, laundry and shopping, but do not perform these activities as discrete services. The provision of companion services does not entail hands-on nursing care. Providers may also perform light housekeeping tasks which are incidental to the care and supervision of the individual. This service is provided in accordance with a therapeutic goal in the plan of care, and is not purely diversional in nature.

Case Management: Services which will assist individuals who receive waiver services in gaining access to needed waiver and other State plan services, as well as needed medical, social, educational and other services, regardless of the funding source for the services to which access is gained.

Chore Services: Services needed to maintain the home in a clean, sanitary and safe environment. This service includes heavy household chores such as washing floors, windows and walls, tacking down loose rugs and tiles, moving heavy items of furniture in order to provide safe access and egress. These services will be provided only in cases where neither the individual, nor anyone else in the household, is capable of performing or financially providing for them, and where no other relative, caregiver, landlord, community/volunteer agency, or third party payor is capable of or responsible for their provision. In the case of rental property, the responsibility of the landlord, pursuant to the lease agreement, will be examined prior to any authorization of service.

Environmental accessibility adaptations: Those physical adaptations to the home, required by the individual's plan of care, which are necessary to ensure the health, welfare and safety of the individual, or which enable the individual to function with greater independence in the home, and without which, the individual would require institutionalization. Such adaptations may include the installation of ramps and grab-bars, widening of doorways, modification of bathroom facilities, or installation of specialized electric and plumbing systems which are necessary to accommodate the medical equipment and supplies which are necessary for the welfare of the individual. Excluded are those adaptations or improvements to the home which are of general utility, and are not of direct medical or remedial benefit to the individual, such as carpeting, roof repair, central air conditioning, etc. Adaptations which add to the total square footage of the home are excluded from this benefit. All services shall be provided in accordance with applicable State or local building codes.

Family Training: Training and counseling services for the families of individuals served on this waiver. For purposes of this service, "family" is defined as the persons who live with or provide care to a person served on the waiver, and may include a parent, spouse, children, relatives, foster family, or in-laws. "Family" does not include individuals who are employed to care for

the consumer. Training includes instruction about treatment regimens and use of equipment specified in the plan of care, and shall include updates as necessary to safely maintain the individual at home. All family training must be included in the individual's written plan of care.

Habilitation: Services designed to assist individuals in acquiring, retaining and improving the self-help, socialization and adaptive skills necessary to reside successfully in home and community-based settings. This service includes:

-- Residential habilitation: Assistance with acquisition, retention, or improvement in skills related to activities of daily living, such as personal grooming and cleanliness, bed making and household chores, eating and the preparation of food, and the social and adaptive skills necessary to enable the individual to reside in a non-institutional setting. Payments for residential habilitation are not made for room and board, the cost of facility maintenance, upkeep and improvement, other than such costs for modifications or adaptations to a facility required to assure the health and safety of residents, or to meet the requirements of the applicable life safety code. Payment for residential habilitation does not include payments made, directly or indirectly, to members of the individual's immediate family. Payments will not be made for the routine care and supervision which would be expected to be provided by a family or group home provider, or for activities or supervision for which a payment is made by a source other than Medicaid.

-- Day habilitation: Assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills which takes place in a non-residential setting, separate from the home or facility in which the individual resides. Services shall normally be furnished 4 or more hours per day on a regularly scheduled basis, for 1 or more days per week unless provided as an adjunct to other day activities included in an individual's plan of care. Day habilitation services shall focus on enabling the individual to attain or maintain his or her maximum functional level and shall be coordinated with any physical, occupational, or speech therapies listed in the plan of care. In addition, they may serve to reinforce skills or lessons taught in school, therapy, or other settings.

-- Prevocational services not available under a program funded under section 110 of the Rehabilitation Act of 1973 or section 602(16) and (17) of the Individuals with Disabilities Education Act (20 U.S.C. 1401 (16 and 17)). Services are aimed at preparing an individual for paid or unpaid employment, but are not job-task oriented. Services include teaching such concepts as compliance, attendance, task completion, problem solving and safety. Prevocational services are provided to persons not expected to be able to join the general work force or participate in a transitional sheltered workshop within one year (excluding supported employment programs). Prevocational

services are available only to individuals who have previously been discharged from a SNF [skilled nursing facility], ICF [intermediate care facility], NF [nursing facility] or ICF/MR [intermediate care facility for mental retardation]. Activities included in this service are not primarily directed at teaching specific job skills, but at underlying habilitative goals, such as attention span and motor skills. All prevocational services will be reflected in the individual's plan of care as directed to habilitative, rather than explicit employment objectives.

-- Educational services, which consist of special education and related services as defined in sections (15) and (17) of the Individuals with Disabilities Education Act, to the extent to which they are not available under a program funded by IDEA.

-- Supported employment services, which consist of paid employment for persons for whom competitive employment at or above the minimum wage is unlikely, and who, because of their disabilities, need intensive ongoing support to perform in a work setting. Supported employment is conducted in a variety of settings, particularly work sites in which persons without disabilities are employed. Supported employment includes activities needed to sustain paid work by individuals receiving waiver services, including supervision and training. When supported employment services are provided at a work site in which persons without disabilities are employed, payment will be made only for the adaptations, supervision and training required by individuals receiving waiver services as a result of their disabilities, and will not include payment for the supervisory activities rendered as a normal part of the business setting. Supported employment services furnished under the waiver are not available under a program funded by either the Rehabilitation Act of 1973 or P.L. 94-142.

Homemaker: Services consisting of general household activities (meal reparation and routine household care) provided by a trained homemaker, when the individual regularly responsible for these activities is temporarily absent or unable to manage the home and care for him or herself or others in the home. Homemakers shall meet such standards of education and training as are established by the State for the provision of these activities.

Personal care services: Assistance with eating, bathing, dressing, personal hygiene, activities of daily living. This service may include assistance with preparation of meals, but does not include the cost of the meals themselves. When specified in the plan of care, this service may also include such housekeeping chores as bedmaking, dusting, and vacuuming, which are incidental to the care furnished, or which are essential to the health and welfare of the individual, rather than the individual's family. Personal care providers must meet State standards for this service.

Personal Emergency Response Systems (PERS): PERS is an electronic device which enables certain individuals at high risk of

institutionalization to secure help in an emergency. The individual may also wear a portable "help" button to allow for mobility. The system is connected to the person's phone and programmed to signal a response center once a "help" button is activated. The response center is staffed by trained professionals. PERS services are limited to those individuals who live alone, or who are alone for significant parts of the day, and have no regular caregiver for extended periods of time, and who would otherwise require extensive routine supervision.

Private duty nursing: Individual and continuous care (in contrast to part time or intermittent care) provided by licensed nurses within the scope of State law. These services are provided to an individual at home.

Respite care: Services provided to individuals unable to care for themselves; furnished on a short-term basis because of the absence or need for relief of those persons normally providing the care.

Skilled nursing: Services listed in the plan of care which are within the scope of the State's Nurse Practice Act and are provided by a registered professional nurse, or licensed practical or vocational nurse under the supervision of a registered nurse, licensed to practice in the State.

Specialized Medical Equipment and Supplies: Specialized medical equipment and supplies include devices, controls, or appliances, specified in the plan of care, which enable individuals to increase their abilities to perform activities of daily living, or to perceive, control, or communicate with the environment in which they live. This service also includes items necessary for life support, ancillary supplies and equipment necessary to the proper functioning of such items, and durable and non-durable medical equipment not available under the Medicaid State plan. Items reimbursed with waiver funds shall be in addition to any medical equipment and supplies furnished under the State plan and shall exclude those items which are not of direct medical or remedial benefit to the individual. All items shall meet applicable standards of manufacture, design, and installation.

Transportation: Service offered in order to enable individuals served on the waiver to gain access to waiver and other community services, activities and resources, specified by the plan of care. This service is offered in addition to medical transportation required under 42 CFR 431.53 and transportation services under the State plan, defined at 42 440.170(a) (if applicable), and shall not replace them. Transportation services under the waiver shall be offered in accordance with individual's plan of care. Whenever possible, family neighbors, friends, or community agencies which can provide this service without charge will be utilized.

Extended State plan services: The following services, available through the approved State plan, will be provided, except that the limitations on amount, duration and scope specified in the plan

will not apply. Services will be as defined and described in the approved State plan. The provider qualifications listed in the plan will apply, and are hereby incorporated into this waiver request by reference. These services will be provided under the State plan until the plan limitations have been reached.

-- Physical therapy services
-- Occupational therapy services
-- Speech, hearing and language services
-- Prescribed drugs
-- Other State plan services

Licensure, Certification, and Other Standards for Waiver Program Services

HCFA requires that each state specify licensure, certification, or other standards for each service in its waiver application. These requirements are detailed in state and local laws, regulations, or operating guidelines and enforced by state and local agencies. Such requirements may include professional standards for individuals providing services, minimum training requirements, criminal background checks, certification for facilities, local building codes, and fire and health requirements. For example, the information below shows how Florida addresses HCFA requirements for licensure, certification, and other standards for each of its waiver program services. The information, unless otherwise noted, was obtained from Florida's Department of Health and Rehabilitative Services' July 1995 Services Directory, which provides the details of service standards in Florida's approved waiver.[16]

Services

Behavioral Analysis and Assessment

Provider Types	Psychologists, clinical social workers, marriage and family therapists, mental health counselors, or providers certified by the Department of Health and Rehabilitative Services (HRS) Developmental Services (DS) Behavior Analysis Certification program.
Licensure/Registration	Psychologists shall be licensed by the Department of Business and Professional Regulation in accordance with Chapter 490, Florida statutes (F.S.). Clinical social workers, marriage and family therapists, and mental health counselors shall be licensed in accordance with Chapter 491, F.S. Others must be certified under the HRS Behavior Analysis Certification program.
Other Standards	Background screening is required for those certified under the HRS Developmental Services Behavior Analysis Certification program.

[16]All providers of Developmental Services (DS) waiver services must be certified by the district level Department of Health and Rehabilitative Services (HRS) DS program office.

Chore

Provider Types	Home health agencies, hospice agencies, and independent vendors.
Licensure/Registration	Home health and hospice agencies must be licensed by the Agency for Health Care Administration. In accordance with Chapter 400, Part IV or Part VI, F.S. Independent vendors are not required to be licensed or registered.
Other Standards	Independent vendors must have at least 1 year of experience working in a medical, psychiatric, nursing, or child care setting or working with developmentally disabled persons. College or vocational/technical training, equal to 30 semester hours, 45 quarter hours, or 720 classroom hours can substitute for the required experience. Background screening required of independent vendors.

Companion

Provider Types	Home health agencies, hospice agencies, and independent vendors.
Licensure/Registration	Home health and hospice agencies shall be licensed by the Agency for Health Care Administration, Chapter 400, Part IV or Part VI, F.S. Independents shall be registered with the Agency for Health Care Administration as companions or sitters in accordance with Section 400.509, F.S.
Other Standards	Background screening required for independent vendors.

Day Training (Adult)

Provider Types	Centers or sites designated by the district DS office as adult day training centers.
Licensure/Registration	Licensure/registration is not required.
Other Standards	Background screening required for all direct care staff.

Environmental Modifications

Provider Types	Contractors, electricians, plumbers, carpenters, handymen, medical supply companies, and other vendors.
Licensure/Registration	Contractors, plumbers, and electricians will be licensed by the Department of Business and Professional Regulation in accordance with Chapter 489, F.S. Medical supply companies, carpenters, handymen, and other vendors shall hold local occupational licenses or permits in accordance with Chapter 205, F.S.
Other Standards	None.

Homemaker

Provider Types	Home health agencies, hospice agencies, and independent vendors.
Licensure/Registration	Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S. Independent vendors must be registered as homemakers with the Agency for Health Care Administration in accordance with Section 400.509, F.S.
Other Standards	Background screening required for independents.

Nonresidential Support

Provider Types	Independent vendors and agencies.
Licensure/Registration	Licensure/registration is not required.
Other Standards	Independent vendors must have at least 1 year of experience working in a medical, psychiatric, nursing, or child care setting or in working with developmentally disabled persons. College or vocational/technical training that equals at least 30 semester hours, 45 quarter hours, or 720 classroom hours may substitute for the required experience. Agency employees providing this service must meet the same requirements. Background

	screening required of agency employees who perform this service and of independent vendors.

Occupational Therapy and Assessment

Provider Types	Occupational therapists, occupational therapy aides, and occupational therapy assistants. Occupational therapists, aides, and assistants may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Occupational therapists, occupational therapy aides, and occupational therapy assistants shall be licensed by the Department of Business and Professional Regulation in accordance with Chapter 468, Part III, F.S. and may perform services only within the scope of their licenses. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Personal Care Assistance

Provider Types	Home health and hospice agencies and independent vendors.
Licensure/Registration	Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S. Independent vendors are not required to be licensed or registered.
Other Standards	Independent vendors shall have at least 1 year of experience working in a medical, psychiatric, nursing, or child care setting or working with developmentally disabled persons. College or vocational/technical training that equals at least 30 semester hours, 45 quarter hours, or 720 classroom hours may substitute for the required experience. Background screening is required of independent vendors.

Personal Emergency Response System (PERS)

Provider Types	Electrical contractors and alarm system contractors.
Licensure/Registration	Electrical contractors and alarm system contractors must be licensed by the Department of Business and Professional Regulation in accordance with Chapter 489, Part II, F.S.
Other Standards	None.

Physical Therapy and Assessment

Provider Types	Physical therapist and physical therapist assistants. Physical therapist and assistants may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Physical therapists and therapist assistants shall be licensed by the Department of Business and Professional Regulation in accordance with Chapter 486, F.S., and may perform services only within the scope of their licenses. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Private Duty Nursing

Provider Types	Registered nurses and licensed practical nurses. Nurses may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Nurses shall be registered or licensed by the Department of Business and Professional Regulation in accordance with Chapter 464, F.S. Home health or hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Psychological Services

Provider Types	Psychologists.
Licensure/Registration	Psychologists shall be licensed by the Department of Business and Professional Regulation, Chapter 490, F.S.
Other Standards	None.

Residential Habilitation

Provider Types	Group homes, foster homes, and adult congregate living facilities and independent vendors.
Licensure/Registration	Group and foster homes facilities shall be licensed by the Department of Health and Rehabilitative Services in accordance with Chapter 393, F.S. Adult congregate living facilities shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part III, F.S. Licensure or registration is not required for independent vendors.
Other Standards	Independent vendors must possess at least an associate's degree from an accredited college with a major in nursing; education; or a social, behavioral, or rehabilitative science. Experience in one of these fields shall substitute on a year-for-year basis for required education. Background screening required of direct care staff employed by licensed residential facilities and independent vendors.

Respite Care

Provider Types	Group homes; foster homes; adult congregate living facilities; home health agencies; hospice agencies; other agencies that specialize in serving persons who have a developmental disability; and independent vendors, registered nurses, and licensed practical nurses.
Licensure/Registration	Group and foster homes shall be licensed by the Department of Health and Rehabilitative Services in accordance with Chapter 393, F.S. Adult congregate living facilities shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part III, F.S. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.

	Nurses who render the service as independent vendors shall be licensed or registered by the Department of Business and Professional Regulation in accordance with Chapter 464, F.S. Licensure or registration is not required for independent vendors who are not nurses.
Other Standards	Background screening is required of direct care staff employed by licensed residential facilities and other agencies that serve persons who have a developmental disability and of independent vendors who are not registered or licensed practical nurses. Independent vendors who are not nurses must have at least 1 year of experience working in a medical, psychiatric, nursing, or child care setting or working with developmentally disabled persons. College or vocational/technical training that equals at least 30 semester hours, 45 quarter hours, or 720 classroom hours may substitute for the required experience.

Skilled Nursing Care

Provider Types	Registered nurses and licensed practical nurses. Nurses may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Nurses shall be registered or licensed by the Department of Business and Professional Regulation in accordance with Chapter 464, F.S. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Special Medical Home Care

Provider Types	Group homes that employ registered nurses, licensed practical nurses, or licensed nurse aides.
Licensure/Registration	Group homes shall be licensed by the Department of Health and Rehabilitative Services in accordance with Chapter 393, F.S. Nurses shall be registered or licensed by the Department of Business and Professional Regulation in accordance with Chapter 464, F.S. and may perform services only within the scope of their license or registration.

Other Standards	Background screening required of direct care staff employed by licensed group homes.

Specialized Medical Equipment and Supplies

(See Florida's approved waiver renewal application for 1993-98.)

Provider Types	Medical supply companies, licensed pharmacies, and independent vendors.
Licensure/Registration	Pharmacies must be licensed by the Department of Business and Professional Regulation in accordance with Chapter 465, F.S. Medical supply companies and independent vendors must be licensed under Chapter 205, F.S.
Other Standards	None.

Speech Therapy and Assessment

Provider Types	Speech-language pathologists and speech-language pathology assistants. Speech-language pathologists or assistants may provide this service as independent vendors or as employees of licensed home health or hospice agencies.
Licensure/Registration	Speech-language pathologists and pathology assistant shall be licensed by the Department of Business and Professional Regulation in accordance with Chapter 468, Part I, F.S. Home health and hospice agencies shall be licensed by the Agency for Health Care Administration in accordance with Chapter 400, Part IV or Part VI, F.S.
Other Standards	None.

Support Coordination (Case Management)

Provider Types	Single practitioner vendors or agency vendors.
Licensure/Registration	Licensure is not required.

Other Standards	Single practitioners and support coordinators employed by agencies shall have a bachelor's degree from an accredited college or university and 2 years of professional experience in mental health, counseling, social work, guidance, or health and rehabilitative programs. A master's degree shall substitute for 1 year of the required experience. Providers (single practitioners and agency directors/managers) are required to complete statewide training conducted by the Developmental Services Program Office, as well as district-specific training conducted by the district DS office. Support coordinators employed by agencies are also required to be trained on the same topics covered in the statewide and district-specific training; however, this training may be conducted by the support coordination agency if approved by the district and the agency trainer meets specific requirements described in Chapter 10F-13, Florida Administrative Code.

Supported Living Coaching

Provider Types	Independent vendors and agency vendors.
Licensure/Registration	Licensure is not required.
Other Standards	Independent vendors and employees of agencies who render this service shall have a bachelor's degree from an accredited college or university with a major in nursing; education; or a social, behavioral, or rehabilitative science or shall have an associate's degree from an accredited college or university with a major in nursing; education; or a social, behavioral, or rehabilitative science and 2 years of experience. Experience in one of these fields shall substitute on a year-for-year basis for the required college education. Agency employees are required to attend at least 12 hours of preservice training and independent vendors must attend at least one supported living-related conference or workshop before certification. All providers and employees are also required to attend human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) training. Background screening is required.

Transportation

Provider Types	Independent vendors and commercial transportation agencies.

Licensure/Registration	Providers shall hold applicable licenses issued by the Department of Highway Safety and Motor Vehicles and shall secure appropriate insurance. Proof of license and insurance shall be provided to the district DS office.
Other Standards	Background screening required for independent vendors.

Related GAO Products

Medicaid Long-Term Care: State Use of Assessment Instruments in Care Planning (GAO/PEMD-96-4, Apr. 2, 1996).

Long-Term Care: Current Issues and Future Directions (GAO/HEHS-95-109, Apr. 13, 1995).

Medicaid: Spending Pressures Drive States Toward Program Reinvention (GAO/HEHS-95-122, Apr. 4, 1995).

Long-Term Care: Diverse, Growing Population Includes Millions of Americans of All Ages (GAO/HEHS-95-26, Nov. 7, 1994).

Long-Term Care Reform: States' Views on Key Elements of Well-Designed Programs for the Elderly (GAO/HEHS-94-227, Sept. 6, 1994).

Long-Term Care: Other Countries Tighten Budgets While Seeking Better Access (GAO/HEHS-94-154, Aug. 30, 1994).

Financial Management: Oversight of Small Facilities for the Mentally Retarded and Developmentally Disabled (GAO/AIMD-94-152, Aug. 12, 1994).

Medicaid Long-Term Care: Successful State Efforts to Expand Home Services While Limiting Costs (GAO/HEHS-94-167, Aug. 11. 1994).

Long-Term Care: Status of Quality Assurance and Measurement in Home and Community Based Services (GAO/PEMD-94-19, Mar. 31, 1994).

Long-Term Care: Support for Elder Care Could Benefit the Government Workplace and the Elderly (GAO/HEHS-94-64, Mar. 4, 1994).

Long-Term Care: Private Sector Elder Care Could Yield Multiple Benefits (GAO/HEHS-94-60, Jan. 31, 1994).

Health Care Reform: Supplemental and Long-Term Care Insurance (GAO/T-HRD-94-58, Nov. 9, 1993).

Long-Term Care Reform: Rethinking Service Delivery, Accountability, and Cost Control (GAO/HRD-93-1-SP, July 13, 1993).

Ordering Information

The first copy of each GAO report and testimony is free. Additional copies are $2 each. Orders should be sent to the following address, accompanied by a check or money order made out to the Superintendent of Documents, when necessary. VISA and MasterCard credit cards are accepted, also. Orders for 100 or more copies to be mailed to a single address are discounted 25 percent.

Orders by mail:

U.S. General Accounting Office
P.O. Box 6015
Gaithersburg, MD 20884-6015

or visit:

Room 1100
700 4th St. NW (corner of 4th and G Sts. NW)
U.S. General Accounting Office
Washington, DC

Orders may also be placed by calling (202) 512-6000 or by using fax number (301) 258-4066, or TDD (301) 413-0006.

Each day, GAO issues a list of newly available reports and testimony. To receive facsimile copies of the daily list or any list from the past 30 days, please call (202) 512-6000 using a touchtone phone. A recorded menu will provide information on how to obtain these lists.

For information on how to access GAO reports on the INTERNET, send an e-mail message with "info" in the body to:

info@www.gao.gov

or visit GAO's World Wide Web Home Page at:

http://www.gao.gov

PRINTED ON RECYCLED PAPER

United States
General Accounting Office
Washington, D.C. 20548-0001

Bulk Rate
Postage & Fees Paid
GAO
Permit No. G100

Official Business
Penalty for Private Use $300

Address Correction Requested