

CHAPTER IV
HCB WAIVER SERVICES FOR PERSONS
WITH DEVELOPMENTAL DISABILITIES

IV. HCB WAIVER SERVICES FOR PERSONS
WITH DEVELOPMENTAL DISABILITIES

One of the more noteworthy recent trends in state utilization of the HCB waiver program on behalf of persons with developmental disabilities is the continuing diversification in the types of services that states offer under their waiver programs. In this chapter, the types of services states offer through the HCB waiver program are described. In addition, state utilization of the waiver program to furnish vocationally-oriented services also is discussed. Finally, the increasing emphasis in waiver programs on non-facility based, support services is examined as are other noteworthy trends in services that states are offering as part of their waiver programs.

A. Services Offered By States

The appendix to this report provides a complete list of all HCB waiver programs serving persons with developmental disabilities which had been approved by HCFA as of December 1990. Included in this list are the specific services offered by states under each of these programs as well as information on state officials responsible for managing each of the listed waiver programs.

Table IV-A below contains summary information on the number of states which offer various categories of HCB waiver services. This table includes only those services offered by the 43 states which operated full-scale HCB waiver services on behalf of persons with developmental disabilities as of December, 1990.

TABLE IV-A:

Services Offered by States
"In MR/DD Waiver Programs

<u>Service</u>	<u>Number of States</u>	<u>Percentage Offering</u>
Case Management	28	65%
Day Habilitation	38	88%
Prevocational Services	17	40%
Supported Employment	24	56%
Residential Services	39	91%
Personal Care/In-Home Supports	34	79%
Respite Care	35	81%
Therapies/Speciality Services	11	26%
Assistive Devices/Adaptive Aids	13	30%
Home Modifications	17	40%
Transportation	18	42%

As can be seen from this table, the services most commonly offered by states under their HCB waiver programs are : (a) daytime habilitation

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services; (b) various types of community residential services; (c) personal care and other in-home supports; and, (d) respite care.

As pointed out in NASMRPD's 1989 report on the HCB waiver program, state-federal waiver spending on MR/DD services is dominated by the provision of community residential services (Smith, Katz, and Gettings, 1989). States employ their HCB waiver programs to pay for residential services furnished in a wide variety of settings, including group living arrangements, family care homes, and, increasingly, supported living arrangements (see discussion below). HCB waiver dollars support the non-room and board costs of furnishing these services.

Increasingly, states seem to be redirecting waiver expenditures to personal care and other home-based services and supports for children and adults with developmental disabilities. Over the past eighteen months, several states have modified their HCB waiver programs to cover personal care, habilitation, and homemaker-type services for individuals who live with their families or in their own homes. For example, during 1990, both Nebraska and Oklahoma added such services to their HCB waiver programs.

While still common in many state HCB waiver programs, the coverage of case management services has declined over the past couple of years. A growing number of states have received approval to cover case management services under their Medicaid state plans, in accordance with the so-called "targeted case management" (TCM) coverage option authorized under Section 1915(g) of the Social Security Act. In a number of instances, approval of a TCM plan amendment has prompted states to shift case management services previously covered under their HCB waiver programs to the state plan coverage.

In other cases, however, states have chosen to maintain HCB waiver coverage of case management services, even though reimbursement for such services could be covered under their Medicaid state plan. While there are similarities in the types of case management services which may be furnished under both the HCB waiver program and Section 1915(g) of the Social Security Act, there also are differences. Generally, a wider range of case management activities may be covered under the HCB waiver program than under Section 1915(g). In a few cases, states which do not cover case management services under either the HCB waiver program or their Medicaid state plan obtain federal financial participation for case management activities by claiming Medicaid reimbursement for such costs as administrative expenses.

Daytime habilitation services are covered by nearly every state under their HCB waiver programs. These services usually involve training program participants in various self-help skills but do not have a vocational orientation. More than one-half the states now cover supported employment services on behalf of previously institutionalized individuals. [N.B., Under current statutory provisions, such services maybe offered only to persons who previously resided in a nursing facility or ICF/MR (including state MR institutions).] Somewhat fewer states, however, cover prevocational services under their HCB waiver programs.

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A growing number of states are covering both home modifications and assistive devices/adaptive aids under their HCB waiver programs. With respect to the former services, HCB waiver dollars are used to cover the costs of making an individual's own home (or that of his or her family) more accessible. The types of home modifications which states pay for under their waiver programs include the installation of ramps as well as bathroom and kitchen modifications. In the area of assistive devices and adaptive aids, states claim reimbursement under their waiver programs for items such as wheel chairs that may not be reimbursable under the Medicaid state plan. In addition, a growing number of states are covering augmentative communication devices and aids as well other types of assistive technology under their programs. For example, Wisconsin purchases computers on behalf of waiver program participants. In other cases, states use HCB waiver dollars to pay for vehicular adaptations on behalf of waiver program participants.

Less than one-half the states cover transportation services as a free-standing HCB waiver service. In many instances, however, coverage of such services are an integral component of the state's coverage of residential, daytime habilitation, prevocational and supported employment services. Present HCFA administrative policies have more or less forced states to limit HCB waiver coverage of transportation services to move waiver participants between HCB waiver program sites (e.g., from a person's residence to a daytime habilitation program) or transport directly associated with HCB waiver-covered services (for example, transportation for participants in supported employment services). These same policies more or less require states to rely on state Medicaid plan coverage to meet the costs of transporting program participants to and from health care services.

It is interesting to note that only about one-quarter of the states have included distinct coverage of therapeutic or specialized services (i.e., psychology) under their HCB waiver programs. In some cases, this reflects the fact that such services may otherwise be claimed as part of the state's regular Medicaid program. In other instances, such services may be furnished in conjunction with another covered service (e.g., daytime habilitation), rather than broken out as separately reimbursable HCB waiver services.

On average, states operating HCB waiver programs on behalf of persons with developmental disabilities cover eight distinct services. Some states cover as few as one service while others cover fifteen or more. Although it is difficult to pinpoint trends in this area with precision, it appears that generally states are increasing the number and variety of services that they cover under their waiver programs.

This trend reflects a growing recognition among responsible state officials that the effectiveness of their HCB waiver programs can be increased by offering a wide variety of services and supports to program participants. The flexibility of the HCB waiver authority offers a ready means for states to avoid unnecessarily restricting the types of services that might be needed by program participants. In addition, the growing diversity of the HCB waiver services offered by the states is

more or less reflective of the broader underlying trend toward greater diversity in community developmental disabilities services.

B. Prevocational and Supported Employment Services

In 1986, federal statutes were amended to allow states to cover prevocational and supported employment services on behalf of previously institutionalized individuals under their HCB waiver programs. In late 1987, Congress clarified the terms of this coverage to remove an administrative policy barrier to offering these services to many otherwise qualified waiver participants (Smith, Katz, and Gettings, 1989). In NASMRPD's 1989 report on the HCB waiver program, it was noted that this statutory change prompted a number of states to add these coverages to their HCB waiver programs but that actual utilization of supported employment and prevocational services by program participants appeared to be relatively limited.

In its 1990 HCB waiver survey, NASMRPD asked states to: (a) indicate their plans to cover prevocational and supported employment services under their HCB waiver programs if they did not do so already; and, (b) if already covered, to report how many individuals were receiving such services.

Fifteen of the 24 states which cover prevocational and/or supported employment services furnished figures on current utilization of such services. Of the remaining nine states that cover one or both of these services, six were unable to supply the requested information while another two had only recently received HCFA approval to initiate an HCB waiver program and, hence, obviously had no data to report. One other state which covers such services did not respond to the survey.

The fifteen states that provided information on the use of prevocational and supported employment services expect to serve roughly 18,000 individuals in their HCB waiver programs during 1991, or about one-third of all program participants nationwide. Collectively, these states report that 3,032 individuals (or roughly 17 percent of all program participants) are receiving prevocational services through the HCB waiver program. However, only 977 individuals (or 5.5 percent of all participants in these states) are receiving supported employment services via the HCB waiver program.

When the number of individuals receiving prevocational or supported employment services are combined, the states of Connecticut, Delaware, Michigan, and Oregon are employing these coverage options at an above average rate. When utilization of supported employment services is isolated, Connecticut, Delaware, Michigan, and Utah emerge as the states making the broadest use of this coverage option. In Utah, 12 percent of all program participants are receiving supported employment services.

It is difficult to interpret the utilization rates of vocationally-oriented services reported by the states. The rate at which HCB waiver program participants can be expected to participate in prevocational and supported employment services depends on: (a) how many of a state's HCB waiver program participants were previously institutionalized; (b) the

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mix of children and adults in a state's program; (c) the general availability of supported employment services independent of the state's HCB waiver program; and, (d) a variety of other factors. Thus, it is impossible to predict just how many program participants might be: (a) eligible to receive such services; and, (b) if eligible, likely to receive them.

In NASMRPD's 1989 HCB waiver survey, states reported somewhat lower but roughly comparable levels of utilization of these services. The lack of data from some states which cover these services (and which also have particularly broad-based supported employment programs) suggests that utilization of these options may be more widespread than indicated above.

At best, the 1990 survey data suggests that some states have had a degree of success in furnishing prevocational and supported employment services to waiver program participants. However, it also is clear that the HCB waiver program plays only a minor role in most states in financing on-going supported employment services. Strangely, some states which reported little or no utilization of supported employment services under their HCB waiver programs are among the national leaders in the provision of such services.

These results strongly suggest the need for further investigation of this dimension of the HCB waiver program. In particular, why have some states been more successful than others in financing prevocational and supported employment services through their HCB waiver programs? More broadly, are there impediments to using the HCB waiver program to cover these services?

Of the seventeen states responding to NASMRPD's 1990 waiver survey which do not presently cover prevocational or supported employment services, eight reported that they planned to do so during 1991, by either submitting an amendment, initiating a new HCB waiver program, or adding such services in conjunction with the submission of a renewal application to HCFA. If these states follow through on these plans, the number of states covering such services would grow to 32. In the case of many of the states that do not plan to cover such services, the principal sources of their reluctance to add these coverages appeared to be: (a) concerns about the unequal eligibility of program participants for such services (i.e., these states are reluctant to offer services to some waiver participants that cannot be offered to others); or (b) the potential effects of infusing Medicaid financing into the provision of supported employment services.

Again, while there is little doubt that coverage of prevocational and supported employment services is playing a significant role in some states by widening the community services options available to HCB waiver program participants, the overall impact of these coverages appear to be limited at present.

C. The Waiver and the Supports Paradigm

An emerging trend in community developmental disabilities services is what might be termed the "supports" paradigm. Under this paradigm, the use of specialized service settings and clinical treatment modalities is being deemphasized in favor of designing individual service packages intended to support people with developmental disabilities to continue to live with their families or live and work in integrated settings in the community. Moreover, the supports paradigm stresses "functional programming", which emphasizes providing training within integrated, "natural" settings rather than training individuals at more segregated sites with the goal of their ultimately moving to a less restrictive setting (Bradley and Knoll, 1990).

One example of this paradigm is the emergence of "supported living" programs as an alternative to the more conventional "continuum of care" model of furnishing community residential services (Smith, 1990). Family support programs also are being broadened to include the provision of a wider array of services than respite care, which has predominated the delivery of such services (Bradley et al., 1990). Increasingly, states are paying increased attention to supporting families with an adult son or daughter with developmental disabilities who continues to live at home.

The emergence of this supports paradigm is challenging the domination of the "continuum of care" model as the central organizing principal for the delivery of community daytime and residential services to persons with mental retardation and other developmental disabilities (Smith, 1990; Bradley and Knoll, 1990). Increasingly, state officials, policy-makers, consumers, service providers, and families are questioning the need for and effectiveness of relatively restrictive, "facility-based" programs as the core of community developmental disabilities service delivery systems.

The emergence of this supports paradigm has lead several states to reexamine the types of services that they are furnishing via their HCB waiver programs. As a consequence, HCB waiver programs are changing to reflect this "new way of thinking."

Probably the most noteworthy trend in this regard is the use of the HCB waiver program as a means of financing supported living services on behalf of program participants. The supported living model is based on: (a) furnishing consumer-driven, individualized packages of services and supports to program participants; (b) the use of conventional, non-specialized consumer-controlled housing; and, (c) assuring access to such services regardless of the extent of an individual's disabilities (Smith, 1990).

At least eleven states (AR, CO, CT, MI, MN, MO, ND, OH, TX, VA, WA, WI) employ HCB waiver dollars to help pay for supported living services. Typically, these programs reimburse provider agencies to furnish variable levels of habilitation training and personal assistance services to individuals who live where they choose. The chief differences between these supported living programs and more traditional residential

services programs for persons with developmental disabilities lies in the ability to tailor services and supports to the individual needs of program participants rather than having them to fit into prefabricated group living programs that specialize in serving persons with particular disabilities or individuals who "need supervision." Unlike "semi-independent" or "supervised apartment" programs that can be found in most state's "continuum" of residential alternatives, supported living programs do not use disability criteria to govern program placements.

HCB waiver financing of supported living services looms large in the waiver programs of Colorado, Minnesota, North Dakota, Washington, and Wisconsin. North Dakota's program -- the largest nationwide relative to the state's population -- is briefly profiled below. In each of these programs, persons with a wide range of disabilities are served in supported living arrangements, including individuals who previously resided in large public facilities and other ICF/MRs. The experiences of these states and a growing number of others indicate that supported living services are a particularly cost-effective means of promoting independence and integration.

North Dakota's Individualized Supported
Living Arrangements Program

Under North Dakota's Individualized Supported Living Arrangements (ISLA) Program, HCB waiver program participants are assisted to live in living arrangements of their own choosing. Individual program plans identify the amount of staff support needed to assist an individual. Service plans identify either habilitation or personal care as the principal services to be furnished to program participants. HCB waiver dollars pay for staff to employ functional training to assist the individual to master skills needed to live successfully and independently in the community or to furnish personal assistance services. Each program plan is tailored to the person's specific circumstances. Payments for services are based on staff hours of support to be furnished to the program participant and are based on individual contracts which are reviewed and revised as necessary each six months. ISLA payments average \$39/participant/day, but may range as high as \$300/day, depending on the person's needs. In late 1990, about 550 persons were receiving these services under North Dakota's HCB waiver program. [N.B., See also Smith (1990) for a more extended discussion of North Dakota's ISLA program.]

The HCB waiver program has been instrumental in permitting states to initiate and expand supported living services on behalf of individuals with severe, life-long disabilities. The HCB waiver program -- by permitting access to the same level of program funding as is available for services furnished in an ICF/MR -- has substantially increased opportunities to furnish relatively intensive, non-facility-based services and supports to individuals who otherwise might have been destined for a group home placement.

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States also are employing their HCB waiver programs more widely to furnish home-based services and supports to children and adults with developmental disabilities who live with their families. Again, states are finding that the waiver program's fundamental flexibility -- coupled with the ability to access dollars equivalent to those spent on facility-based alternatives -- opens up new opportunities to support families. Over the past two years, several states have added home-based services to their HCB waiver programs. Other states have offered such services since the inception of their programs. North Carolina's HCB waiver program, for example, stresses home-based services. Montana's specialized family care is another noteworthy example of how such services can be employed to assist families in caring for a child with severe disabilities. Montana's program is profiled below:

Montana's Specialized Family Care Program

Montana's specialized family care program targets services to children with particularly severe disabilities who live with their natural family or a foster family. This program places a strong emphasis on the case manager's working very closely with the family to select the types of services and supports that will be of most benefit. Through this program, home trainers and personal care workers come to the family home to work directly with the child and the family. Other services employed in this program include home modifications, adaptive aids, and respite care. Provider agencies have the flexibility to tailor services and supports to individual family needs as well as link families with other available services.

On an annual basis, the cost of this program average approximately \$11,000 per participant. About 110 families participate in the program currently. Consumers, provider agency managers, and State officials all have expressed enormous satisfaction with this program and its capacity to help avoid placing a child in a group living or institutional setting.

Other noteworthy home-based services programs operated under the HCB waiver program are to be found in the "model" waiver programs operated by several states. Michigan's model waiver program, for example, has been particularly effective in helping families meet the needs of children with especially severe medical conditions. Washington State's model waiver program (an extension of the State's more broadly-based Medically Intensive Home Care Program) is successfully meeting the needs of children with developmental disabilities who might otherwise face long-term hospitalization.

Both supported living and home-based service programs illustrate the value of one of the HCB waiver program's key features: namely, the capacity to furnish authorized services without relying on specific types of settings. Under the HCB waiver program, program participants do not need to be placed in a specialized facility in order to receive

needed habilitation, personal assistance, and other services. Such services can be offered just as readily to persons who live with their families, on their own, or in a group living arrangement. In contrast, ICF/MR services cannot be extricated from the specialized, Medicaid-certified facilities in which they must be furnished.

In many states, the initiation of an HCB waiver program resulted in only modest departures from the "continuum of care", facility-dominated structure of community developmental disabilities that emerged in the 1970s and 1980s. The emergence of the supports paradigm, however, has led many states to take another look at the services offered under their waiver programs. In the process, they appear to be discovering that the HCB waiver program can play a constructive role in promoting more diverse service alternatives for people with developmental disabilities. They have learned (and are continuing to learn) that the HCB waiver program's inherent flexibility and capacity to access federal Medicaid dollars permits a state to substantially broaden the possibilities for people with severe disabilities to live in settings that heretofore may have been restricted to individuals who need intermittent only (and, thereby, low cost supports). With the HCB waiver program, "independent living" need not be restricted only to persons who require modest, periodic services.

The supports paradigm seems certain to exercise a growing influence on state HCB waiver programs. As noted in Chapter III, over the past two years states have been broadening the services they offer under their programs and, based on reports from program managers, will continue to do so for the foreseeable future. Generally speaking, this diversification is moving these programs away from reliance on group living arrangements and other types of facility-based services toward service options that reflect the supports paradigm.

D. Other Trends and Developments

There are other noteworthy trends in how states are employing the HCB waiver program to meet the needs of people with developmental disabilities. Again, these trends and developments point toward greater diversification in the services rendered to waiver participants.

First, a growing number of states are permitting family members to act as providers of HCB waiver services on behalf of their relative with developmental disabilities. In Pennsylvania and West Virginia, for example, family members can be trained and paid to furnish habilitation services to the program participant. In other states, family members serve as personal care providers. Federal policies permit this type of arrangement so long as the family member who is paid to furnish services is not the parent of a minor child.

Second, states are diversifying the types of waiver programs they are operating. The number of so-called "model" waiver programs is growing; the target populations of these programs are becoming more varied. Several states now operate model waiver programs for children with HIV/AIDS. Other states have secured HCFA's approval to offer HCB services to children who are ventilator dependent. By and large, these

waiver programs fall outside the mainstream of "MR/DD HCB waiver programs" since their focus is on children who have particular types of medical conditions. In many such cases, the type of institutionalization that is being avoided is long-term care in a hospital or other type of pediatric facility. While many of these model waiver programs waive the deeming of parental income in order to secure Medicaid eligibility for children living outside of institutional settings, they also include home and community-based supports that otherwise cannot be covered under a State's Medicaid plan. Frequently, these waivers are administered by agencies other than the State's MR/DD authority.

Along these same lines, Kansas recently obtained HCFA's approval to offer HCB waiver services to persons who have suffered from traumatic brain-injury through a model waiver program aimed at furnishing home and community-based services to individuals who might otherwise face long-term stays in rehabilitation hospitals and facilities. This program -- the first targeted to individuals with traumatic brain injuries to be approved by HCFA -- further illustrates the continuing diversification of the HCB waiver program from its historical roots as a

In other words, gradually, the waiver program is beginning to reach persons with other types of disabilities, even though the overwhelming number of participants are persons who are elderly/physically disabled or developmentally disabled.

Third, there is mounting evidence through the results of independent assessments concerning the quality and effectiveness of the HCB waiver services. HCFA's regulations require that an "independent assessment" of the state's waiver program be conducted as a precondition for federal consideration of a state's request that its program be renewed. The first such independent assessments were conducted during 1988 and have accompanied a steady stream of renewal requests since that date. While these assessments look at such basic features of the waiver program as whether documentation is complete, they also examine the quality and cost-effectiveness of waiver services. These assessments must be conducted by an agency or organization other than a state's Medicaid agency or the MR/DD administering agency.

To date, these assessments have concluded that HCB waiver programs have been very cost effective. In a number of these assessments, program participants and their families have been interviewed to determine their level of satisfaction with the services that they receive through the HCB waiver program. In nearly all instances, consumers and their families have expressed a high degree of satisfaction with services provided. Other measures have been used in some assessments to examine the extent to which program participants appear to have benefitted from participation in the waiver program. Again, the results of these evaluations typically have been very encouraging.

Indeed, as a result of one such assessment, Tennessee's waiver program serving adults with mental retardation was recognized as a particularly innovative and cost-effective program by the Rutgers University Center

for Public Productivity. The State's waiver program was nominated for this award by the Tennessee State Auditor who conducted the independent assessment of the program.

Hence, there is growing verification that the HCB waiver program offers substantial advantages as a means of financing community services to people with developmental disabilities. As an interesting sidelight, as we observed in our 1989 report, similar evaluations have not been conducted of the ICF/MR program.

Fourth, it is evident that states are expressing greater confidence in the capacity of the waiver program to meet the needs of people with developmental disabilities. Over the past two years, several states which operate HCB waiver programs have taken steps to restrict the further development of additional ICF/MR beds. In other states, proactive measures are being taken to work with private provider agencies to downsize and close larger ICF/MRs in favor of placing their residents into more integrated community settings via the HCB waiver program. In New Hampshire, the HCB waiver program was used almost exclusively to assist in closing Laconia State School, the State's only publicly-operated institution for people with mental retardation and developmental disabilities.

Developments such as these reflect growing confidence in the HCB waiver program as a primary vehicle for financing a wide-range of community-based services on behalf of people with developmental disabilities. More broadly, these developments furnish additional evidence that the HCB waiver program has evolved into a more mature and better appreciated vehicle for promoting community-based services to persons with developmental disabilities and other severe handicapping conditions.

E. Conclusion

From all indications, the types of services that states are covering under their HCB waiver programs on behalf of persons with developmental disabilities are becoming more diverse. Broadly speaking, "first-generation" HCB waiver programs which were more or less designed as a means of accessing traditional alternatives to ICF/MR placement are being transformed into "second-generation" programs that place greater emphasis on furnishing supports to individuals living in their own homes or with their families. These "second-generation" programs offer a wider variety of service options and are less rigid in their overall structure, hence permitting greater latitude in tailoring services to the needs of each program participant.

Some HCB waiver programs -- particularly Wisconsin's program -- adopted this approach from the outset. In other cases, however, states have had to modify pre-existing programs in order to diversify the services that they offer. While undertaking such changes is not without its difficulties, the basic flexibility of the waiver program undoubtedly facilitates this process.

In one area -- furnishing supported employment services to HCB waiver participants -- it is less clear that the program is helping states to

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widen opportunities for program participants. Utilization of this option continues to be relatively low.

Other developments suggest a growing confidence that the "HCB waiver technology" is sufficiently mature and sound to allow states to take additional steps to contain or deemphasize ICF/MR services. The evidence furnished by "independent assessments" of the waiver program certainly indicates that these programs are succeeding in their aim of furnishing high quality, cost-effective services to individuals with developmental disabilities.