

Medicaid Home and Community-Based Services for Persons with Developmental Disabilities in Six States

Observations from Site Visits Between February and August, 2000

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ABSTRACT

The Medicaid Home and Community Based Services “waiver” program (HCBS) was first authorized in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35), passed on August 13, 1981. This law granted the Secretary of U.S. Department of Health and Human Services the authority to waive certain Medicaid requirements and allow states to finance "non-institutional" services for Medicaid-eligible individuals with mental retardation or a related condition (MR/RC) who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid institution. In this report the eligible recipients of services are referred to as having “mental retardation or related conditions” as in Medicaid law, although states increasingly use “developmental disabilities” to refer to these persons. The Medicaid-certified institutions serving the vast majority of persons with MR/RC are certified as Intermediate Care Facilities for the Mentally Retarded (ICFs-MR).

The Medicaid HCBS program has been recognized in states as a significant resource for providing community services. Beginning in the early 1990s, requirements that prevailed in the HCBS program's first decade to control the number of HCBS participants and expenditures were considerably relaxed, and were then deleted the 1994 revised regulations. The result was dramatic growth in the number of HCBS participants. On June 30, 1999 states were providing HCBS to more than 4 times as many people with MR/RC (261,930) as in June 1992 (62,429). HCBS financed long-term care services on June 30, 1999 for more than twice as many people as the ICFs-MR for which HCBS was the non-institutional “alternative.” Within these national trends there has been substantial variability among states in the size and nature of HCBS programs and in goals, accomplishments and ongoing challenges.

This report summarizes findings and observations of site visits to six states between February and August, 2000 to view and discuss with key state officials, service providers, program participants and others implementation, outcomes and challenges of the states’ Medicaid HCBS programs. States were chosen based on an array of data reflecting levels HCBS program “development.” During these visits, in-person interviews were conducted with government officials, administrators and staff of service agencies, case managers, advocates, service recipients and family members. The site visits examined key program features, including (a) the context of the program, (b) the philosophy and goals, (c) coordination with the State Medicaid agency, (d) administration, (e) eligibility criteria, (f) financing and reimbursements, (g) quality assurance, and (h) challenges for the future.

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SECTION I. INTRODUCTION TO HCBS SITE VISITS

This report summarizes findings and observations of site visits to six states between February and August, 2000 to view and discuss with key state officials, service providers, program participants and others the implementation, outcomes and challenges of each state's Medicaid Home and Community-Based Services (HCBS) "waiver" program. The six states were chosen based on an array of statistical data on state HCBS programs to reflect the full range of "development."

The Medicaid Home and Community Based Services "waiver" program (HCBS) was first authorized in Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (PL 97-35), passed on August 13, 1981. This law granted the Secretary of U.S. Department of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance "non-institutional" services for Medicaid-eligible individuals with mental retardation or a related condition (MR/RC). In this report the eligible recipients of services are referred to as having "mental retardation or related conditions" as in federal Medicaid law. States increasingly use the term "developmental disabilities" to refer to this group of persons, who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid-certified institutional facility. The Medicaid-certified institutions serving the vast majority of persons with MR/RC are certified as Intermediate Care Facilities for the Mentally Retarded (ICFs-MR).

Given both its flexibility and its potential for promoting the individualization of services, the HCBS program has been recognized in all states as a significant resource in the provision of community services to persons with MR/RC. Beginning in the early 1990s, administrative requirements that prevailed in the HCBS program's first decade that required that state applications to provide HCBS show reductions in projected ICF-MR residents and expenditures roughly equal to the projected increases in HCBS participants and expenditures were considerably relaxed, and were then deleted the 1994 revised regulations. As a result, there has been in recent years dramatic growth in the number of HCBS participants. On June 30, 1999 states were providing HCBS to more than 4 times as many people with MR/RC (261,930) as in June 1992 (62,429). It financed long-term care services on June 30, 1999 for more than twice as many people as the (ICFs-MR) for which HCBS are the non-institutional "alternative." Within these national trends there has been substantial variability among states in the size and nature of HCBS programs in goals, accomplishments and challenges among relatively "well-developed" and "developing" HCBS programs.

A. Purpose

All states have been expanding their services to individuals with MR/RC and their families through community services programs. States use a variety of mechanisms to fund these services, including their generic Medicaid program (e.g., home health and personal care), and MR/RC targeted Medicaid Home and Community-Based Services (Section 1915[c] waivers), state-financed services, and in most states (40) small community ICFs-MR. Over the past decade by far the most significant and rapidly growing program for financing services for persons with MR/RC has been the Medicaid HCBS program.

Despite its commitment to promoting non-institutional services, the Health Care Financing Administration has had relatively little systematically gathered information about how states have organized and delivered HCBS. Information about the effectiveness of HCBS in contributing to the health, well-being and quality of life of HCBS recipients is also limited. Although states were originally required to conduct an independent assessment of such outcomes prior to submitting application for renewal authorization to provide HCBS, that requirement was removed in the 1994 revision of regulations.

To obtain information on the current HCBS program, HCFA contracted with the Lewin Group to design and implement a study of the impact of Medicaid Home and Community Based Services (HCBS) programs on quality of life, quality of care, utilization and cost. The Lewin Group subcontracted with the Urban Institute, Mathematical Policy Research, the University of Minnesota and the MEDSTAT Group to assist in aspects of the study. One aspect of this study involved site visits to 6 states to describe the financing, delivery and outcomes of Medicaid HCBS for people with MR/RC. (Site visits were also conducted in another six states to describe similar features of HCBS programs for older and younger people with physical disabilities.)

The University of Minnesota conducted the site visits related to HCBS administration and services delivery for people with MR/RC. Site visits were conducted between February 2000 and August 2000. During these visits, site visitors conducted in-person interviews with state and regional government officials who were associated with different aspects of the HCBS program, administrators of service agencies, case managers, direct care staff, advocates, and service recipients and their family members. The site visits examined key program features, including (a) the context of the program, (b) the philosophy and goals, (c) coordination with the State Medicaid agency, (d) administration, (e) eligibility criteria, (f) financing and reimbursement of services, (g) quality assurance and monitoring, and (h) challenges for the future.

At the completion of site visits single state reports were drafted. These were provided to the states and HCFA officials for review comments, questions, and corrections. Revisions were made as warranted.

This report is a summary of the individual state site visit reports. Individual state site visit reports are available by contacting the address of telephone number listed on the cover.

B. Methodology

State Selection

States were selected for participation in the site visits based on a variety of indicators intended to represent HCBS programs on a continuum from relatively “well-developed” programs to those that were still “developing”. With the assistance of the project’s Technical Advisory Group indicators were identified for arraying states along a continuum of “development” of their HCBS programs. These factors included a) the number of HCBS recipients as a proportion of all long-term care recipients with MR/RC, b) HCBS recipients per 100,000 of state population, c) HCBS expenditures as a percentage of all Medicaid long-term care expenditures for people with MR/RC, d) the proportion of all ICF-MR and HCBS recipients served in congregate housing, and e) the regional location of the state. Based on these factors and index ranking was created and states were statistically arrayed by regional along a continuum from which they were selected.

The six states involved in the site visits described in the report held rankings of 1, 4, 9, 33, 44 and 50 on these indexes, reflecting the desired distribution from “well-developed” to “developing” that was desired for the study. Two states that were invited to participate declined. One requested release because of an impending HCFA Regional Office review scheduled to coincide with the site visit. The other was advised by the State Attorney General’s office to decline because of a recently filed federal District Court complaint alleging that the state was in violation of Medicaid law and the Americans with Disabilities Act for failure to develop sufficient access to community services for persons with MR/RC. Both states declining to participate were within the “developed” range of states. Replacement was done within the same region by a state with similar placement along the continuum from “developing” to “developed.”

Site Visit Goals

Individual state site visits, were designed to be a “process evaluation.” Its primary focus was on the organizational aspects of delivering HCBS services and how key informants in the states viewed the effectiveness of the programs and policies created to achieve the goals established for the program. Site visitors probed for the perceptions of a range of stakeholders about what was working well in the various state HCBS programs and what they felt might be improved and how.

In all descriptions of the purpose of this study site visitors made clear to all interviewees that they had no federal or state regulatory role in the Medicaid HCBS program and that the questions asked were

asked only to better understand the program. It was also explained to stakeholders that a second “outcome evaluation” stage of the study would focus directly on the effects of HCBS on the lives of a large sample of actual HCBS recipients who would be sampled from each state and interviewed about experiences of community and on their satisfaction with the services received.

The site visits to the states attended to broad topics in HCBS program design and implementation. The general themes of the visits were guided by suggestions of the Technical Advisory Group (TAG), representing key HCBS constituencies, ranging from state agency directors to service users. Among the themes and associated questions developed for the visits were:

Purpose. What principles, goals and objectives guide the states uses of the Medicaid HCBS program? How were those principles, goals and objectives defined? What was the nature, status and effects of the overall state effort to achieve them?

Design. What were the origins, design, internal organization, financing and program relationships of the public and private agencies delivering HCBS? What was the nature and extent of their cooperation and coordination with each other and with the state in pursuing the principles, goals and objectives established for the HCBS program?

Assessment. What was the nature and effectiveness of efforts within the state to define, monitor and improve the quality of services and to provide consumer protections? How well did these achieve the minimum standards established by Congress and the specific principles, goals and objectives established by the state?

Outcomes/Challenges. What were the primary accomplishments and challenges facing the state and its service providing agencies and individuals in achieving state goals and meeting the expectations of service recipients? What planning, staff recruitment and training, service delivery, quality management and/or improvements were needed to realize more completely state goals and consumer expectations?

Case Study Approach

A primary approach of this study was to interview representatives of major stakeholders and “implementers” of state HCBS policy and programs in order to describe the nature, quality, and outcomes of HCBS in the state. relationships among state and regional agencies, the agencies that provide and receive HCBS. Interviews were supplemented by obtaining and reviewing a wide range of documents both prior to and during the actual visits.

In case studies it is typical to find topics about which there is a great deal of consensus and other topics that elicit differences in perception of outcome and effectiveness. The goal of the case study approach is to synthesize and summarize information from different sources in order to describe areas and

shared and differing perceptions about the HCBS program in general, and more specifically about how different policies, practices, and organization factors have affected HCBS design, growth, outcomes, and challenges for the future. The information used to develop the site visit reports came primarily from interviews or available documents.

Interviews. The primary method of obtaining information during the site visits was a series of interviews built around the general themes and research questions identified above. Interview schedules were drafted by the project team. Separate interview schedules were developed for different constituencies including service users, service coordinators, service providers and state agency staff and directors. Draft interview schedules were reviewed by members of the TAG and HCFA staff and were subsequently revised. The interview schedules were organized to provide multi-level, multi-respondent corroborating interviews. For example, the interviews with state officials asked about the state's objectives for HCBS. The interview schedule for service providers gathered corresponding information about how the state's objectives were communicated, understood, and supported through policy, training, written materials, technical assistance and in other methods with local agencies, support providers and service users.

Document review. In addition to interviews there was extensive collection and use of documents and data available from the states. Among the documents gathered and examined were: 1) the state HCBS applications; 2) state HCBS manuals, administrative rules and written information about program requirements; 3) the procedures and protocols used in state agency reviews of service providers and the reports of findings from those reviews; 4) state laws, court decisions and settlements and other documents establishing standards and expectations for services to persons with MR/RC; 5) procedural requirements and training materials related to HCBS administration in areas such as eligibility determination or billing procedures; 6) evaluation reports developed by government agencies or private contractors on consumer satisfaction, service recipient characteristics and needs, service outcomes or other topics; 7) documents developed by individual service provider agencies on their mission, goals, history, programs, and performance; 8) descriptions of the status of social services generally within the state and of the social, economic, and/or political contexts in which the HCBS program operates; and 9) other state or provider agency reports, materials and correspondence relevant to HCBS.

Collaboration with the State HCBS Administrative Agencies Division

The site visit teams enjoyed extremely positive and helpful support from state agency leaders and staff in each of the states visited. State officials assisted the site visit teams in identifying representatives of key organizations, agencies and consumer groups. Their assistance often went beyond assistance in helping

to identify the key informants to assisting substantially with the logistics and transportation requirements of the visits.

Reviews of the Draft Reports

Drafts of site visit reports on each of the six states were provided to selected key state informants. They reviewed and shared drafts with colleagues, and provided corrections, criticisms, and questions. Draft reports were also submitted for HCFA review and comments. Clarifications in response to state and HCFA critiques were accomplished through follow-up correspondence and telephone interviews. Corrections and additions were made as appropriate in completing a final state site visit report. This summary report is derived from the contents of the final revised reports for the individual states.

Selection of Sites and Interviews

The selection of individuals and sites that were visited was done by the site visit team in consultation with the site visit key contacts, usually a state agency administrator responsible for the HCBS program. The visit to each state was designed to include key staff members of the state's administrative apparatus for HCBS, including 1) key staff members of the agency responsible for HCBS, representatives of the Medicaid single state agency, and other state or regional personnel with key roles in HCBS implementation; 2) directors of the state Protection and Advocacy System (PAS) and the Planning Council on Developmental Disabilities (PCDD); 3) personnel engaged in licensing, quality assurance and technical assistance to service agencies; 4) service coordinators (case managers) whether employees of state agencies, local governments or private agencies; 5) service providers, including organization administrators, direct support staff, and respite and "family care" providers; and 6) HCBS recipients and their family members and/or guardians. In selecting service sites state agency contacts were asked to help the site visit team identify a range of sites, including: 1) sites representing geographic diversity; 2) sites reflecting fairly typical practices; and 3) sites in which exemplary non-traditional supports were being provided.

In each state site visit team members interviewed between 42 and 75 persons during a week long visit. Virtually everyone approached about participation agreed to be interviewed. Most key informants were interviewed individually. Some were interviewed in small groups. The largest interview session was a two hour meeting with 17 members of a state's Planning Council on Developmental Disabilities.

All respondents were promised anonymity. It was made it clear to all respondents that site visitors were not employees of HCFA and that they had no regulatory or enforcement roles with regard to HCBS. Key informants were extremely accommodating of the site visit team's requests and schedules to allow data collection to be completed in between 4 and 4.5 work days.

Site visits concluded with a “debriefing” with state officials on the final day of the visit. The purpose of the debriefing was to clarify information obtained during the visit, share what had been learned in the visit, to test the site visitors’ impressions with key officials, to request other documents, reports and information that were identified during the site visits, to explain the next steps in the process, and to elicit continued participation and assistance from state agency leaders.

Major Areas of Inquiry

The major areas of inquiry described in this summary report correspond to primary topics of the interview protocols and the individual state reports. These major areas of inquiry that are reflected in the outline of the report include: 1) the context of HCBS programs, 2) program and administrative structures, 3) eligibility and assessment, 4) services and service providers, 5) consumer direction, 6) financing and reimbursement, 7) quality assurance and monitoring, and 8) issues and challenges for the future.

SECTION II. HCBS PROGRAM FOR PERSONS WITH MR/RC

A. Context Of HCBS Program

Medicaid Coverage of Long-Term Care for Persons with MR/RC

Before 1965 there was no federal participation in long-term care for persons with mental retardation and related conditions (MR/RC). In 1965, Medicaid was enacted as Medical Assistance, Title XIX of the Social Security Act. It provided federal matching funds of from 50% to 82%, depending on each state’s per capita income, for medical assistance provided to people in the categories of blind, disabled, and their dependent children and their families as well as to elderly people. Otherwise eligible persons who resided in large public facilities, except "medical institutions," were excluded. Persons in large public facilities for persons with mental retardation were still excluded from coverage.

Title XIX created an incentive for states to convert their large public facilities into "medical institutions," that is, Skilled Nursing Facilities (SNFs) to make them eligible for inpatient coverage under Title XIX. Eleven states did so between 1966 and 1969, financing long-term care for 37,821 people with MR/RC in large state mental retardation facilities at a cost of 168 million dollars in Fiscal Year 1969 (Boggs, Lakin, & Clauser, 1985).

Establishment of the ICF-MR Program

Shortly after the introduction of federal reimbursement for skilled nursing care in 1965 Congress noted rapid growth in the numbers of people who were becoming patients in Skilled Nursing Facilities (SNF). This led to the creation in 1967 of a less medically oriented and less expensive "Intermediate Care Facility" (ICF) program for elderly and disabled adults was authorized within the Social Security Act. In

1971 the SNF and ICF programs were combined under Title XIX. Within the legislation combining the two programs was a little noticed, scarcely debated amendment that for the first time authorized federal financial participation (FFP) for "intermediate care" provided in facilities specifically for people with mental retardation.

Three primary outcomes were intended for the new ICF-MR legislation: 1) to provide substantial federal incentives for upgrading the physical environment and the quality of care in large public facilities; 2) to neutralize incentives for placing persons with MR/RC in nursing homes; and 3) to provide a program for care and habilitation ("active treatment") specifically focused on the needs of persons with MR/RC. The new ICF-MR program enlisted the federal government in assisting states with their rapidly increasing public institution costs, which were averaging real dollar increases of 14% per year in the five years prior to the passage of the ICF-MR legislation (Greenberg, Lakin, Hill, Bruininks, & Hauber, 1985).

States quickly opted to participate in the ICF-MR program. By June 1977 forty states had at least one ICF-MR certified state facility. In the context of growing support for community residential services, there was concern that the ICF-MR program had: 1) created incentives for maintaining people in large state facilities by contributing 50% to 80% of the costs of care; 2) diverted funds that could have been spent on community service development to institution renovations to make them eligible for certification; and 3) promoted inefficiency and individual dependency by establishing a single uniform standard for care despite the differences in peoples' needs, preferences, and circumstances. These concerns, the commitment to increase community residential services, and the continued desire of states to avail themselves of Medicaid cost-share of ICFs-MR care, led to a number of states relatively small, community ICFs-MR. It also caused HCFA in 1981 to issue "Interpretive Guidelines" for the development of community ICFs-MR. Immediately following the issuance of the Interpretive Guidelines for community ICFs-MR, the number of such settings began to grow steadily (from 9,985 residents in June 1982 to 23,528 in June 1987). But the most significant event of 1981 for services for persons with MR/RC was the creation of the Medicaid "waiver" program.

Home and Community Based Services (HCBS) "Waiver" Program

Section 2176 of the Omnibus Budget Reconciliation Act of 1981 (P.L. 97-35), passed on August 13, 1981, granted the Secretary of Health and Human Services the authority to waive certain existing Medicaid requirements and allow states to finance certain "non-institutional" services for Medicaid-eligible individuals. The HCBS program was designed to provide home and community based services for people who are aged, blind, disabled, or who have MR/RC and who, in the absence of alternative non-institutional services, would remain in or would be at a risk of being placed in a Medicaid facility (i.e., a Nursing

Facility or an ICF-MR). Non-institutional services that can be provided under the HCBS waiver include case management, personal care services, adult day health services, habilitation services, respite care, or any other service that a state can show will lead to decreased costs for Medicaid funded long-term care. Unlike the ICF-MR program, HCBS reimbursements cannot be used to pay for room and board. For most HCBS recipients cash assistance from other Social Security Act programs are used to pay room and board costs.

The HCBS program was quickly recognized among states as a significant resource in the development of community alternatives to institutional care (Greenberg, Schmitz & Lakin, 1983). Initially, however, growth in state HCBS programs was limited to existing or projected ICF-MR capacity and expenditures that could be replaced by HCBS. As a result HCBS recipients grew steadily but relatively slowly in the first decade of the program. By June 1987 they reached 22,687 and by June 1992 there were 62,429 HCBS recipients. The relaxing in the early 1980s of the requirement of one-for-one reduction in projected ICF-MR “beds” for each new HCBS “slot” and then the rescission of the required in the revised regulations of 1994, dramatically changed the dynamics of Medicaid programs for persons with MR/RC. Between June 30, 1992 and June 30, 1999, HCBS programs grew from 62,400 to 261,930 recipients (319.6%). During the same period the number of ICF-MR residents began to decline steadily for the first time, decreasing by 19.4% to 117,917 residents.

Variations in HCBS programs

Despite the notable national trend in HCBS development, the trend has been by no means of consistent dimensions among the states. Table 1 provides descriptive statistics on a number of these dimensions of status, growth and variability among states. The states included in the site visits summarized in this report are identified by shading.

Table 1: Status Trends and Interstate Variabilities in Medicaid HCBS Program, June 1999

State	HCBS Recipients (6/99)	HCBS Expenditures (\$ in 1,000s) FY 99	% Change in Recipients 1992-2000	% Change in Expenditures 1992-2000	HCBS Recipients per 100,000 State Residents	HCBS Expenditures per Average Daily Recipient (\$)	Annual HCBS Expenditures per State Resident (\$)	HCBS Recipients as % of All HCBS & ICF-MR	HCBS Expenditures as % of All HCBS & ICF-MR
AL	3,891	77,810.0	78.2	527.5	89.04	20,466	17.81	85.2	56.8
AK	466	23,071.0	NC	NC	75.16	51,845	37.21	100.0	100.0
AZ	10,180	252,771.0	91.4	156.1	213.06	26,021	52.90	97.9	93.4
AR	1,647	25,213.1	296.9	124.1	64.56	21,991	9.88	48.3	17.8
CA	30,386	461,810.0	804.3	754.4	91.68	14,525	13.93	73.0	52.8
CO	6,043	176,383.3	174.2	193.0	148.99	32,154	43.49	97.3	88.8
CT	4,493	294,791.3	165.4	252.7	136.90	74,887	89.82	77.4	58.8
DE	455	18,451.8	56.9	261.4	60.34	44,090	24.47	63.3	36.0
DC	0	0.0	0.0	0.0	0.00	0	0.00	0.0	0.0
FL	13,809	122,002.1	423.7	502.6	91.38	9,196	8.08	80.3	31.3
GA	2,847	98,200.0	693.0	858.0	36.59	37,431	12.62	66.0	47.4
HI	975	19,700.0	115.7	349.2	82.28	22,722	16.62	91.1	67.3
ID	509	10,804.4	126.2	809.5	40.65	22,746	8.63	46.9	18.1
IL	6,500	149,300.0	224.0	87.6	53.59	23,818	12.31	37.8	19.2
IN	1,554	73,133.6	NC	NC	26.15	49,431	12.31	20.7	21.0
IA	4,118	74,235.2	2,905.8	9,497.3	143.53	18,159	25.87	64.7	28.7
KS	5,120	156,893.2	822.5	1,042.1	192.84	31,344	59.09	85.9	70.5
KY	1,039	42,191.8	26.9	112.9	26.23	40,686	10.65	47.0	33.0
LA	2,973	74,549.0	216.6	4,076.4	68.00	27,713	17.05	34.6	17.9
ME	1,610	93,074.0	216.3	602.4	128.49	62,994	74.28	84.1	69.6
MD	3,660	172,822.4	85.6	138.9	70.77	49,286	33.42	86.7	76.3
MA	10,678	408,875.2	224.8	354.3	172.92	38,950	66.21	88.8	64.5
MI	8,024	310,750.7	192.7	283.5	81.35	45,259	31.50	96.7	84.9
MN	7,102	355,967.5	145.7	273.2	148.70	51,545	74.53	69.6	65.4
MS	550	2,640.9	NC	NC	19.86	5,485	0.95	18.4	1.8
MO	7,926	186,560.5	253.7	183.6	144.95	22,663	34.12	84.2	65.0
MT	929	27,315.1	109.2	152.3	105.21	29,371	30.93	87.1	62.5
NE	2,294	75,600.5	223.1	196.2	137.70	34,224	45.38	77.9	62.6
NV	800	9,182.0	488.2	282.6	44.22	15,406	5.08	73.1	25.6
NH	2,276	102,433.8	114.9	130.7	189.51	45,145	85.29	98.9	98.5
NJ	6,635	284,536.0	67.1	162.0	81.48	44,341	34.94	65.3	43.0
NM	1,765	100,117.4	428.4	1,034.0	101.44	59,206	57.54	85.4	86.7
NY	33,699	1,561,068.4	8,791.6	4,425.3	185.19	48,549	85.79	76.7	42.3
NC	4,974	136,043.3	429.7	883.4	65.01	30,367	17.78	51.9	25.7
ND	1,875	37,634.4	40.6	98.3	295.74	20,376	59.36	76.4	45.5
OH	5,325	179,811.8	1,241.3	1,302.2	47.30	38,698	15.97	41.0	26.0
OK	2,795	134,251.3	194.5	241.0	83.23	49,898	39.98	58.5	56.9
OR	5,500	161,500.0	277.2	175.6	165.86	35,093	48.70	97.0	70.8
PA	10,119	532,018.0	274.1	298.0	84.37	52,498	44.36	66.5	50.7
RI	2,393	97,626.8	141.0	579.5	241.47	41,641	98.51	98.2	94.9
SC	4,073	92,203.0	764.8	1,758.6	104.81	23,721	23.73	64.4	35.5
SD	1,971	47,366.8	131.3	191.4	268.89	26,388	64.62	89.6	71.9
TN	4,315	135,111.0	512.9	836.2	78.68	33,205	24.64	72.9	36.2
TX	6,158	265,239.8	536.2	567.2	30.72	44,865	13.23	32.2	31.1
UT	2,857	65,767.7	109.0	185.9	134.13	23,898	30.88	78.3	56.2
VT	1,540	54,437.8	272.9	284.6	259.26	35,992	91.65	99.2	97.2
VA	3,579	113,354.5	566.5	609.6	52.07	33,752	16.49	63.9	40.0
WA	8,165	128,863.3	325.7	222.4	141.85	16,856	22.39	86.4	49.9
WV	1,851	66,636.0	260.8	404.8	102.43	37,754	36.88	80.7	59.3
WI	8,375	237,380.2	362.2	507.4	159.52	30,340	45.22	74.3	59.9
WY	1,112	40,983.4	249.7	227.7	231.67	37,842	85.38	90.3	74.0
US Total	261,930	8,368,484	309.7	405.2	96.05	33,324	30.69	69.0	46.6

NC= not calculable because state did not have a HCBS program in 1992

Note: Average daily recipients was estimated from the number at the beginning of the year, plus the number at the end of the year divided by 2.

Source: State reports to the National Residential Information System Project, University of Minnesota

As shown in Table 1 shows that as the number of HCBS recipients grew nationally by 310% between June 30, 1992 and June 30, 1999. There were, however, 8 states that increased HCBS program

participants by less than 100% while 12 states increased by more than 500%. There was also wide variability among states in the financial commitment to HCBS. HCBS expenditures increased by 405% to nearly 8.4 billion dollars between FY 1992 and FY 1999. During that period expenditures increased by more than 700% in 12 states, but less than 200% in 15 other states. An average of about \$33,300 in HCBS funds was spent annually per average daily HCBS participant. Expenditures were less than \$25,000 on average per year in 15 states; more than \$45,000 per year in 12 states. Average per state expenditures varied from less than \$20 in 18 states to more than \$50 in 14 states. On average states spent \$30.69 per state resident in FY 1999 for HCBS. Nationally, HCBS recipients make up 69% of the combined numbers of HCBS and ICF-MR recipients. Total HCBS expenditures in Fiscal Year (FY) 1999 were 46.6% of those for ICFs-MR. Again Table 1 shows remarkable variability among the states in these indicators with the District of Columbia having no one receiving HCBS and Alaska having no one not receiving HCBS.

Overview of HCBS in Case Study States

As noted in the methodology an effort was made to select states for the case studies that reflected the full range of states' varying use of HCBS options. Table 2 presents summaries of this variety among the 6 states participating in the HCBS site visits. It also provides statistics that allow comparison to the U.S. average.

Table 2: Comparison of Site Visit States on Selected Indicators of HCBS Participation, FY 1999

	States						
	IN	KS	LA	NJ	VT	WY	US
HCBS participants per 100,000 of state population 6/30/99	26.1	192.8	68.0	81.5	259.3	231.7	96.1
HCBS expenditures in FY 1999 per state resident on 6/30/99	\$12.49	\$59.09	\$17.05	\$34.94	\$91.65	\$85.38	\$30.69
% of Total HCBS and ICF-MR recipients in HCBS	20.7%	85.9%	34.6%	65.3%	99.2%	90.3%	69.0%
% of Total HCBS and ICF-MR expenditures in HCBS	21.0%	70.5%	17.9%	43.0%	97.2%	74.0%	46.6%
% of all residential service recipients in settings of 6 or fewer - 6/30/99	49.6%	81.6%	39.5%	53.8%	100.0%	77.9%	62.4%
% reduction in state institution populations - 6/1990 – 6/1999	48.4%	60.7%	33.2%	28.3%	100.0%	66.2%	40.6%
People waiting as % of total number of persons receiving and waiting for services.	Not known	1.9%	8.4%	49.0%	1.2%	0.0%	18.3%

Vermont was most notable in its use HCBS to finance services for persons with MR/RC. Its number of HCBS recipients per 100,000 state residents and its Fiscal Year 1999 expenditures per state resident were both nearly three times the national average. Almost all of Vermont's total of HCBS and ICF-MR service recipients and expenditures were within the HCBS program. Through expansion of its HCBS program, Vermont had closed its state institution, virtually eliminated all ICFs-MR (12 total "beds") and almost eliminated its waiting list for community services. Although not quite as dramatic in exclusive use of HCBS, Wyoming and Kansas were moving in the same general direction.

In contrast the HCBS option has had much less impact in Louisiana and Indiana. HCBS enrollments, per 100,000 and expenditures per state resident were well below the national average. ICF-MR still predominated as the primary long-term care program for people with MR/RC, and most residential service recipients in the states lived in settings of 7 or more people.

New Jersey tended to be near although consistently below the national average on most indicators of HCBS participation. New Jersey stood out most from other states in its relatively slow reduction in state institution populations over the past decade and in the rapidly growing and very large number of people waiting for services by mid-1999. In general then the site visit states well reflected the range and change in services available for persons with MR/RC as states have exercised with various degrees of commitment and funding the opportunities available through the Medicaid HCBS program.

B. Programs and Administrative Structure of HCBS

General Organization

Policy and administration. Medicaid law requires that each state designate a single state agency to operate its Medicaid program. This is usually the state human services, health, or combined health and human agency. A few states have a state Medicaid agency as an independent entity for Medicaid administration. As shown in Table 3 the single state agencies in the site visit states were as is typical the state human services, health or combined health and human services agencies.

Table 3: Administrative Authority for HCBS for Persons with MR/RC in Six States

State	Single State Agency	Primary HCBS Policy Agency	Primary HCBS Administrative Agency	Level of Authority/Influence of State MR/RC Program Agency (low, mod, high)
Indiana	Division of Disability, Aging and Rehabilitation Office of Medicaid Policy and Planning	Office of Medicaid Policy and Planning	Area Agencies on Aging through contract with Division of Aging and In-Home Services	Low-Administration is contracted to Area Agencies on Aging. State MR/RC program agency involvement is limited in HCBS
Kansas	Department of Social and Rehabilitation Services	Mental Health and Developmental Disabilities	Division of Developmental Disabilities	Moderate
Louisiana	Department of Health and Hospitals	Bureau of Health Care Financing – Division of Home and Community Based Waivers	Bureau of Health Care Financing – Division of Home and Community Based Waivers	Low – Substantially different view of rights of people with MR/RC to live in community within Medicaid Waiver Unit than within Office for Citizens with DD
New Jersey	Department of Human Services, Division of Medicaid Assistance and Health Services	Department of Human Services	Division of Developmental Disabilities	Moderate – MR/RC policy operates in environment in which change comes slowly. HCBS is viewed only as mechanism to finance eligible community services for eligible people as those are developed as part of general policy
Vermont	Agency for Human Services	Division of Developmental Disabilities of Department of Development and Mental Health Services	Division of Developmental Disabilities	High – Budget issues pass through Agency for Human Services, but administrative matters are primarily managed by the Division with consultation with AHS
Wyoming	Department of Health	Developmental Disabilities Division of Department of Health	Developmental Disabilities Division	High – Budget issues pass through Department of Health, but there is great trust in DDD, which manages both state ICF-MR institution and community services (all HCBS)

There were no detectible differences in HCBS program development associated with states designating a health, human services or combined health and services agency as the single state agency. There were very significant differences among the states associated with nature and location of primary policy and administrative responsibilities for the HCBS program. Specifically, the more state HCBS policy was controlled by traditional Medicaid bureaus (as in Louisiana and Indiana), the less well-developed the programs according to statistical indicators the less the sense of collaboration in program

development and responsibility across key constituencies, the lower the satisfaction with and confidence in quality definitions, assessments and enhancements and the lower the level of trust that the people making policy understand or have concern about the needs expectations and aspirations of people with developmental disabilities or are aware of the major changes taking place with services for persons with MR/RC in other states.

In sharp contrast to Louisiana and Indiana in which HCBS policy and program administration was largely controlled by Medicaid and non-MR/RC agencies, in two states (Vermont and Wyoming) there was general consensus that both HCBS policy and program administration was directed primarily by the state MR/RC program agency. This status was generally attributed to and accompanied by a sense of strength, trust and pride in the accomplishments of these programs. Leaders of the MR/RC program agency were careful to protect relationships with their superiors in the state organizational hierarchy by acknowledging, consulting with and involving them in the decisions of HCBS and other program development. They were careful to attend to issues of concern within the agendas of the governor and legislature, but worked equally seriously through information and advocacy to shape those agendas. In the process they have appeared to have built an important sense of pride and participation among key officials and constituents for the programs, the accomplishments of those programs and the status of the state as a result.

In four of the six states, the authority to manage Medicaid HCBS was designated to the traditional state agency for services to persons with MR/RC. Reasons for this reflect the history of community services in these states. Community services existed to a considerable, albeit varying, extent in each of the states prior to the states' participation in the HCBS program. The HCBS option provided a mechanism to finance community services for which licensing standards, rules, service definitions and so forth existed prior to HCBS. These community service programs with their existing service provider agencies, administrative organization, public support and established plans for ongoing development constituted a major reason why enthusiasm for HCBS was notably greater in state MR/RC agencies than among agencies administering programs for elderly and disabled persons from the very beginning of the program (Greenberg, Schmitz, & Lakin, 1983). It was, of course, also a major factor in the more rapid growth of HCBS programs for persons with MR/RC.

In striking contrast in the two states in which state MR/RC agencies were given neither policy or administrative authority over HCBS (Indiana and Louisiana), the state HCBS program was markedly smaller, less well developed, less well integrated into a comprehensive state program of support, less reflective of contemporary goals and objectives for services to persons with MR/RC, and less effective in providing substantial quantity and quality of community service through the HCBS option.

Local Level management. Each of the states visited had a somewhat different mechanism for administering the HCBS at the “local level.” These included a range of public and private entities. These are shown in Table 4.

Table 4: Primary “Street Level” Administrative Entities for HCBS to Persons with MR/RC

State	Name of Primary Administrative Entity	Type of Entity	Number in State
Indiana	Area Agencies on Aging	Private, non-profit contractors with primary focus on aging	16
Kansas	Community Developmental Disabilities Organizations	Regional, private, non-profit contractors	28
Louisiana	Medicaid Waiver Units Regional Offices and Office for Citizens with Developmental Disabilities (OCDD) Regional Offices	Regional state-operated offices	8 – MWU regions 10 – OCDD regions
New Jersey	Regional Offices with Regional Community Services Offices	Regional state-operated county-based offices with primary focus on MR/RC, services from private agencies	4 community services offices with 9 county-based offices
Vermont	Regional Designated Agency	Regional, private, non-profit agencies that are also the primary source providers	10
Wyoming	Regional Serve Providers	Regional, private, non-profit agencies that are also the primary service providers	9

In Kansas, Vermont and Wyoming, HCBS programs were managed by private non-profit entities that serve as quasi-public administrative entities. These were organizations with historical commitments to developmental disabilities services. These entities serve regional catchment areas, with responsibilities for system point of entry; needs assessment and resource coordination; information and referral and access to service providers. New Jersey’s regional “Community Services” with their county-based offices serve similar functions of intake, eligibility, information and referral, service development and case management. These are, however, staffed by state employees. In Louisiana and Indiana major control over the development and implementation of HCBS services for persons with MR/RC is entrusted to agencies that do not have a primary and historical focus on services for persons with MR/RC. This appears to have had a substantial effect on the overall development and quality of those HCBS programs, and was viewed as a substantial impediment to HCBS program development by many of the stakeholders interviewed.

State Goals/Philosophies on HCBS

In the visits to the 6 states state leaders were asked to identify and provide copies of documents that defined the goals that state held for its HCBS program (or the community services that were financed by HCBS). Table 5 summarizes the articulated goals for HCBS (or community services generally) within the official documents identified and supplied by the 6 states visited. The specific sources of state goals were goal statements from: (1) Indiana Division of Disability, Aging and Rehabilitation Services; (2) Louisiana Department of Health and Hospitals; (3) Kansas Department of Social and Rehabilitation Services; (4) Principles and Goals of Division on Developmental Disabilities and State Goals for Human Services of New Jersey; (5) Vermont Developmental Disabilities Act of 1996; and (6) the language within Westin Settlement Agreement in Wyoming.

States did vary to some extent to the specific articulations of goals for HCBS (or general community service financed by HCBS). Summary of the goals articulated identified 18 different, although rated goal areas. The only universally articulated goal for HCBS or community services financed by HCBS was that people’s health and safety will be protected. At least 4 states identified goals that: a) adults will have the right to live in typical community homes and enjoy normal daily lives; b) services will be individualized to respond to personal needs and preferences with people playing an active; and c) meaningful role in service planning, services will increase/support community participation in preferred activities. Goals are obvious importance to program planning and evaluation and improvement. Goals do not however, dictate accomplishment. For example, New Jersey has a goal of providing people with “needed services in a prompt manner,” but also has a very large number of people waiting for services (about 5,000).

Perhaps the most striking features of goals established by the individual states was the limited effort to evaluate the achievement of the articulated goals. Evaluation programs within the sampled states rarely gathered and analyzed individual outcomes as related to stated goals.

Table 5: Articulated Goals for HCBS or Community Services within Six Visited States

Goals	IN	K S	LA	NJ	VT	WY
1. Children will grow up in families				X	X	
2. Adults will have the right to live in typical community homes and enjoy normal daily lives	X	X			X	X
3. Adults will make decisions about their lives for themselves	X	X			X	
4. A variety of services will be available and people will have information about their options and possible choice	X			X	X	
5. Services will be individualized to respond to personal needs and	X			X	X	X

preferences with people playing an active, meaningful role in service planning.						
6. Services will increase/support community participation in preferred activities.	X	X			X	X
7. People who want to work for pay will be supported to do so.					X	
8. Needed services will be available in the places where they are needed					X	
9. People's health and safety will be protected	X	X	X	X	X	X
10. People will be supported by people who are appropriately trained					X	
11. Services will be efficient, cost-effective and/or well-managed			X	X	X	
12. People's rights and dignity must be protected, promoted, and/or cherished		X		X		X
13. All people can grow and develop and have the right to the support they need to do so				X		X
14. People who provide direct support people with developmental disabilities will be respected, valued				X	X	
15. Provide needed services in prompt manner				X		
16. Provide for access to and use of needed generic community services'				X		
17. Increase public awareness, understanding acceptance of persons with developmental disabilities.				X		
18. Services will support new and continuing relationships with family and friends.		X				

C. Eligibility and Assessment

General Eligibility Requirements

The eligibility of persons with mental retardation and related conditions (MR/RC) for Medicaid, ICF-MR and, thereby, alternative HCBS, is generally linked to eligibility for the federal Supplemental Security Income (SSI) program. SSI eligibility for persons with “mental retardation and related conditions” who are under 65 years and who demonstrate financial need by both income and asset tests is determined from Social Security Administration condition listings and associated definitions.

Mental retardation is generally defined as significant sub average general intellectual functioning (i.e., I.Q. below or 70) and associated impairments in adaptive behavior (i.e., self-care, interpersonal, learning, economic and other daily living skills appropriate to one's age) that is manifested during the developmental period. The SSI determination parallels this accepted standard, determining mental retardation to be evident if persons have IQs of 59 or less, or IQs of 60-69 with physical and mental impairments that impose significant work-related limitations.

Persons with “related conditions” are eligible for ICF-MR and HCBS when they have a severe, chronic disability that is attributable to cerebral palsy, epilepsy or any other condition, other than mental illness, when that condition: a) is closely related to mental retardation in that it impairs intellectual

functioning or adaptive behavior so that services like those needed by persons with mental retardation are required, b) is manifested before age 22, c) is likely to continue indefinitely and d) results in substantial functional limitation in three or more of the following areas: self-care, understanding and use of language, learning mobility, self-direction, and capacity for independent living.

In addition its categorical and financial eligibility standards, HCBS eligibility is also governed by a “level of care” standard that establishes that persons receiving HCBS have service needs that would otherwise require the level of care provided in an ICF-MR (or Nursing Facility). This requirement, of course, relates to the Congressional intent that HCBS provide community alternatives to institutional services, without expanding the range of persons eligible for those services.

State Eligibility Requirements

States have their own specific definitions of the persons eligible for HCBS. While the agencies administering the HCBS programs are identified as being for persons with “developmental disabilities,” in each of the states, eligibility is determined in terms of categorical and functional assessment. Table 6 briefly summarizes the eligibility criteria in the six states that were visited.

Table 6: Categorical and Functional Standards for HCBS Eligibility

State	Categorical Standard	Functional Standard
Indiana	Must have mental retardation defined as a condition that is characterized by sub average general intellectual functioning (IQ of 70 +/-5) and concurrent deficits in adaptive behavior or a diagnosed motor or organic brain disorder that originated prior to age 22 with substantial functional limitations.	Adaptive behavior is assessed to establish substantial limitations the effectiveness with which the individual meets the standards of personal and social responsibility expected of his/her age and cultural group; substantial functional limitations in 3 or more of the 7 major life areas: self-care, language, learning, mobility, self-direction, independent living and economic self-sufficiency.
Kansas	Must have mental retardation, which means substantial limitations in present functioning that is manifested from birth to 18 years of age and is characterized by significantly sub average intellectual functioning.	Intellectual limitations must be evident with deficits in adaptive behavior including related limitations in two or more of the following areas: (a) communication, (b) self-care, (c) home living, (d) social skills, (e) community use, (f) self-direction, (g) health and safety, (h) functional academics, (i) leisure,

		and (j) work.
Louisiana	Must have developmental disability, that is severe or chronic disability that is attributable to mental retardation, cerebral palsy, epilepsy, or autism; or any other condition other than mental illness, found to be closely related to mental retardation, because this condition results in impairment of general intellectual functioning or adaptive behavior similar to that of mentally retarded persons, or requires treatment or services similar to those required for these persons.	Substantial limitation in three or more areas: (a) self care, (b) understanding and use of language , (c) learning ability, (d) mobility, (e) self-direction, and (f) capacity for independent living as the result of a disability occurring prior to age 21.
New Jersey	Must have mental retardation, that is, an I.Q. below 59 or below 69 with additional adaptive, medical adaptive, sensory or motor impairments or developmental disability, that is severe disabilities attributable to mental retardation, autism, cerebral palsy, epilepsy, spina bifida, other neurological impairments such that substantial functional limitations are evident before age 22.	Substantial functional limitations on 3 or more of the major life activities of self-care.
Vermont	Must have mental retardation (I.Q. below 70) or diagnosis of Pervasive Developmental Disorder (autism-like conditions) determined by appropriately licensed psychiatrist or psychologist and concurrent deficits in adaptive behavior	Requires “substantial” (or “severe” depending on source) deficits in adaptive behavior as in accepted diagnoses of mental retardation
Wyoming	Must have mental retardation, that is I.Q. below 70 or 2 standard deviations below average	Adaptive behavior/maladaptive behavior must yield at “service” score of below 70 on the ICAP rating scale (2 or more standard deviations below average).

Level of Care Determination

Medicaid HCBS is an alternative to institutional care. One of the duties required of states is to establish that everyone receiving HCBS would otherwise qualify for institutional care by the criteria established by that state. Level of care determinations are generally based on the judgment of interdisciplinary teams, objective assessments of functional, physical social/behavioral and health needs, and reviews of determinations by officially designated agencies. The importance of level of care determination is that it assures that the availability of HCBS does not substantially alter the “population “ of persons eligible for HCBS in the state from that which would otherwise have been eligible for the institutional alternative. This important “gate-keeping” function is recognized by states, but is also a frequently noted source of tension and frustration in that by the nature of the specific criteria that must be established, people who are recognized to have significant needs are frequently denied access.

Objective assessments obtain information on each person's ability to perform specific ADL and IADL activities; their types, frequency and severity of challenging behavior and the specific impairments in sensory, motor and other areas. These assessments may be used to develop a single "service" score, domain scores related to important areas of independent living skills and/or to provide item-by-item summaries of individual abilities. The process of using such information for determining need for the "ICF-MR level of care" varies from state from specific numerical cut-off scores in Wyoming based on two standardized assessment instruments (an I.Q. test and the Inventory for Client and Agency Planning) to more subjective determinations in most other states. The level of care management in which HCBS recipients are expected to demonstrate the characteristics of ICF-MR residents in order to demonstrated need for the ICF-MR level of care is not in evidence, although state officials noted that in the past such comparisons were sometimes expected. Today as the number of people in ICFs-MR decreases and those in ICFs-MR increasingly represent those persons with extensive care needs and a rapidly aging group, the significance of direct comparisons for establishing appropriate level of care determination procedures is no longer viewed as valid.

In all the visited states level of care determination is managed and reviewed by state employees or by employees of quasi-public contracted agencies. In practical application it is not always easy to distinguish eligibility determination based on categorical and functional assessment and level of care determination in that they are done by the same people, using the same information within the same process. On the other hand each of the states visited recognized the significance and responsibilities of level of care scrutiny and have developed level of care determination procedures for their state. Indiana has the most complex of these procedures. In Indiana a case manager of the Area Agency on Aging (AAA) arranges for and receives results of a clinical and physical examination, and then puts together a "Level of Care" packet for submission to the Office of Medicaid Policy and Planning (OMPP) Level of Care Unit. The OMPP Unit reviews the information, makes a determination and then forwards the level of care determination back to the AAA case manager. A plan of care and cost of comparison budget are developed by the AAA case manager. A plan of care and cost of comparison budget are developed by the AAA case manager who then submits both the Medicaid Waiver Unit for approval. Upon approval, the AAA case manager then implements the plan.

In other states the process is much simpler. In Kansas a case manager or a Qualified Mental Retardation Professional (QMRP) from the Community Developmental Disabilities Organization (CDDOs) conducts an evaluation to determine eligibility and level of care need. Based upon the evaluation, the case

manager develops an individual plan of care (POC). The level of care and plan of care are submitted for the approval of the State Medicaid agency.

In Louisiana staff or regional Office for Citizens with Developmental Disabilities screens eligibility based on recently completed or new assessments. Once eligibility is established the individual selects case management agency to complete a final packet, which includes determination of eligibility, level of care needed and the plan of care. This information is submitted back to the OCDD and the Medical Waiver Unit regional staff for approval. In Wyoming an individual applying for HCBS is directed to select an independent service coordinator (ISC). The ISC determines clinical and level of care (LOC) eligibility. The LOC eligibility is reviewed by the State Level of Care Committee (SLOCC) made up of Developmental Disabilities Division and Medicaid staff.

In Vermont the regional, non-profit “designated agencies” manage eligibility and level of care determination. In New Jersey the determination of eligibility and level of care are integrated into the same eligibility determination process and then annually re-determined as part of the Individual Habilitation Plan (plan of care) development.

Level of care determination serves different functions in different states. To the extent that states have defined eligibility for services and need for ICF-MR level of care by the same standards (e., Wyoming), level of care determination is largely an administrative review. However, in states in which eligibility for services is defined more broadly (e.g., mental retardation), the determination of need for ICF-MR level of care process is the primary determinant of the nature and size of the HCBS population. This process then has substantial significance in determining whether an individual receives services (e.g., Indiana) or whether the state claims HCBS reimbursements for services provided to individuals (e.g., New Jersey). It is, of course, not surprising that states have developed greater congruence in their definitions of eligibility for state services and of demonstrating need for ICF-MR level of care are the states which claim Medicaid match for great portions of their total states expenditures for persons with MR/RC (see Hemp et al., for estimates of matched/unmatched state expenditures).

D. Services and Service Providers

Types of Services

States offer a wide range of services under their state HCBS programs. Within the HCBS programs of the six states visited, thirty-two different services were offered. Table 9 summarizes the types of services offered by state. Individual states provided from nine to nineteen different types of services. The only universal services provided was case management, but each of the states in under one name or

another also provided: a) residential supports to people living outside their family homes; b) personal assistance, in-home support or respite assistance for families; and c) daytime vocational/habilitation services. A majority of states (4 or more) also provided home/environmental modifications; homemaker services; specialized consultation or therapy; and specialized equipment, devices or other assistive technology.

Table 8: Type of HCBS Services Offered by State

Type of Services	States					
	IN	KS	LA	NJ	VT	WY
Case Management	X	X	X	X	X	X
Attendant Care/Personal Assistance Services	X	X	X		X	X
Adult Day Health Services		X				
Habilitation Services					X	
Adult Day Care	X			X		
Pre-vocational Training	X		X			X
Sheltered Workshop				X		
Day Habilitation	X	X	X			X
Supported Employment	X		X	X	X	X
Residential-based	X	X				X
In-home Support				X	X	X
Habilitation at Family Home						
Respite Services	X		X			
In-home					X	X
Out-of-home					X	X
Self-Determination				X		
Home/Environmental Modifications	X		X	X	X	X
Specialized Medical Equipment/Supplies		X			X	X
Adaptive Aids and Devices	X		X			
Assistive Technology	X					
Personal Emergency Response	X	X	X			
Specialized Consultation/Therapy	X	X		X	X	X

Crisis Services	X					
Transportation	X			X	X	
Substitute Family Care			X			
Homemaker Services	X	X			X	X
Home Delivered Meals	X					
Supported Living	X					
Family and Caregiver Training	X	X				

Service Providers

The service provider agencies are recognized as the foundation of the community services systems that provide HCBS. They and the personnel they employ, especially the direct support staff, are viewed as the primary determining factor in the experiences and benefits that HCBS provides. State HCBS programs were able to develop rapidly because of large numbers of community service organizations that existed prior to the states' entry into the HCBS program. Continued need to expand capacity and variety of services continues to challenge states to recruit and nurture new service providing agencies and approaches.

Existing providers. Most HCBS services are provided by established community organizations that have a history in and strong sense of responsibility to and standing within the areas in which they provide services. In general existing HCBS providers in the states visited experienced a sense of trust, security and comfort within the communities served. Visits with families provided remarkable stories of love, support and compassion. Service providers in the visited states were primarily non-profit entities, although for-profit providers were evident in some states (e.g., Indiana, New Jersey). The service provider agencies were contracted by the public or quasi-public administrative agencies that manage HCBS-funded and other community services. In Vermont and Wyoming, and in some parts of Kansas, the same entities responsible for HCBS administration within a regional catchment area were also the primary service providers in that area, but in other states the service provider agencies generally operate independently of the entities involved in service purchasing. Most of these providers of HCBS-financed services were community service providers prior to the implementation of the HCBS program in their state. Service provider agencies were certified and/or licensed by state agencies. They served from one to several hundred persons. The service provider community in each of the visited states is briefly described below.

Indiana's service providers are both non-profit and for-profit entities. They varied in size ranging from a small provider serving as few as 20 people in one region to a larger provider serving several hundred people virtually across the entire state. Most of the agencies in Indiana were multi-service

agencies that provided more than HCBS waiver services. Most had been providing services to people with developmental disabilities prior to HCBS being an option. HCBS services were not viewed as a type of service, but instead the “waiver” was viewed by providers as a “funding stream.”

Kansas’ service providers are non-profit organizations. Agencies varied in size from 20 people in one region to a larger provider serving several hundred people in more than one region. Almost all of the providers provided both vocational and residential services. Many also provided case management. In some instances provider agencies also served the area’s CDDO. Most HCBS agencies had been providing services to people with developmental disabilities prior to HCBS being an option.

Louisiana’s service providers were non-profit and varied in size and scope ranging from a small provider serving as few as 20 people in one region to a larger provider serving several hundred people virtually across the entire state. Most of the agencies were multi-service agencies that provided more than HCBS waiver services. In many cases they also provided early intervention to young children, family supports, work-based supports and in some cases ICF/MR services. Most had been providing services to people with developmental disabilities prior to HCBS being an option.

New Jersey’s community services are primarily provided by established non-profit community organizations. Most of these have a history in and strong sense of responsibility to and standing within the area they serve. Most agencies providing HCBS pre-existed the use of it to finance community services. Agencies included residential in-home support, vocational/day and multi-service organizations. “Agencies” ranged in size from developmental homes serving individuals to large community agencies providing a wide range of HCBS-funded to hundreds of people.

Vermont’s community services are provided primarily by the service component of non-profit organizations that also serve as the quasi public designated agencies that authorize HCBS. A small number of other agencies also serve people with developmental disabilities in Vermont. There are 16 total HCBS providers in Vermont, ten of which also serve as Designated Agencies (DAS). In addition there are “Specialized Service Agencies,” which operate with direct state funding and 2 are certified agencies from which DAs purchase services for members of their “caseload.” Each of these agencies must be certified to provide specific DDS-financed services (i.e., home supports, community/social supports, work supports, support coordination, family supports, and crisis supports).

Wyoming’s community services are provided primarily through nine non-profit Regional Service Providers (RSP) that were created prior to the existence of the HCBS program. They serve a total of more than 1,200 people, including 900 adult HCBS recipients. RSP cover broad catchment areas ranging from 1 to 5 counties. They provide a comprehensive range of residential and habilitation services to about 100 to

125 people each. As Wyoming has recognized the need to assure choice of service providers, a large number of small and individual providers have been developed to provide various HCBS services. Still, in 1999, only 6 non-RSP organizations in Wyoming served 3 or more residential or day service recipients and these averaged fewer than 8 service recipients in each.

Variations among agencies. Actual visits to community service agencies providing HCBS found them to considerably in how they view the nature and goals of their service, and the challenges they face. It is clear that there is considerable range in organizational cultures and orientations to community supports. These differences are reflected not only in the ways that agency administrators describe their services, but also in how direct care staff and front-line supervisors describe their roles. Because the system entrusts so much to community agencies, the leadership of those agencies and their levels of knowledge and commitment, their interpretation of the mission and goals of the agency and their attention to their own personal and professional development are very important to agency effectiveness. They are also clearly related the innovation and personalization of the service provided by the agencies.

It also seemed apparent across the states that within agencies with leadership and goals focused on personalized services, direct care staff not only shared the goals, but tended to view themselves about being valued, independent and supported to take initiative. This was reflected in comments from direct support staff including: “This agency listens more to direct care staff.” “The agency finds money or makes the changes to make things happen.” “We are really supported to be creative.” “The agency responds quickly to new ideas.” In interviews with state administrators, case managers and service providers it was clear that service provider agencies are differentially viewed as motivated to learn, change, provide greater numbers of options, and provide greater control to service users. In each of the states visited specific agencies were identified as leaders in doing so. Others were viewed as having invested less and accomplished less in the development of “person-centered” services. There were examples provided of service agencies beginning to work together as learning communities focused on agency and system improvement, but the examples were limited and were inconsistently and modestly supported by state HCBS administrative agencies

Developing new agencies. While service recipients and families tended to view themselves as having adequate choice, it was evident that in all or regions of states choice of service provider is oftentimes restricted by a relative low number of agencies serving certain areas. This is sometimes by historical “ownership” of regions and/or low population densities that make impractical multiple agencies. Despite such circumstances, efforts were evident in the states visited to open the HCBS system to new providers. Such efforts while sometimes wounding the pride of agencies that have traditionally served

specific catchment areas, were viewed by state officials, case managers and often by the service provider agency administrations as both a responsibility under Medicaid program administration and generally a positive contribution to variety, choice and spirit of competition that makes services more responsive to individuals. There were, however, case managers who worried that developing growing number of provider agencies could affect their ability to develop and maintain positive relationships with the growing number of agencies. This concern seemed greatest where caseloads were highest (e.g., among the “program case managers” in New Jersey).

Personnel Recruitment, Retention and Training

State program and quality assurance staff, case managers, service provider agency administrators, family members and direct support staff themselves identified recruitment and retention of qualified staff as the most serious problem currently affecting the quality of and access to authorized HCBS-financed community services. The crisis in recruitment and retention was viewed as particularly affecting support for people living in family homes and people receiving residential services. Recruitment and retention in residential programs was consistently identified as the most serious problem facing residential service agencies. There were also significant recruitment and retention problems noted among vocational/day habilitation programs, but in general these were viewed as being less serious than in the types of services required to provide support on a 24-hour a day, 7 days a week schedule. In addition to the serious problem of recruiting sufficient numbers of staff respondents noted changing characteristics of the applicants for open positions, including generally more non-native English speakers, people with less formal education, and more people working part-time hours. These changes were viewed as having significant ramifications for recruitment and retention, but also for training.

Staff recruitment/retention. The primary problem contributing to the serious difficulties in recruitment and retention was consistently viewed as the reimbursement rates for services which are insufficient to permit wages that attract and retain sufficient numbers of competent employees. Secondary problems were associated with the unprecedented low unemployment rates in the states visited and the strong competition for any and all available employees. It was noted by service providers and case managers that the numbers and entry skill levels of persons applying for direct support staff openings have been changing, that improved recruitment, training and retention efforts are needed, and that responsibility for these improvements, while remaining primarily those of service providers should be shared actively and seriously by state and state-level advocacy organizations. They note that the quality and integrity of the entire community service system depends on the entire state system's success in developing and maintaining a sufficient workforce of qualified support personnel.

The problems of staff recruitment and retention were viewed by a number of observers as placing substantial burdens on those who use HCBS-financed services. In each of the states visited programs are operating with vacancies, not just in occasional shifts, but on a chronic basis. In interviews HCBS recipients report that for them, staff shortages means waiting, in the words of one HCBS recipient, “waiting to get out of bed, waiting to go to the bathroom, things like that.” Recruitment problems are reported to be leading to staff working more and more hours. It was noted that on the positive side with sufficient overtime direct support staff earn a living wage. But there are downsides. A focus group of direct support staff supervisors in one state agreed that there are problems in a system dependent on people working overtime. They agreed that many “direct support staff members are operating on empty” because of exceptionally long hours in understaffed settings. Other supervisors note that recruitment and retention problems are increasing the amount of time that experienced staff members spend training in new direct support staff. In the words of one program director, “Sometimes it’s a burden on already strained staff when they need to train new persons on site, but the people who really lose are the people who need help from the person who is busy training someone else.”

Discussions with service provider agency administrators indicated that notable differences existed among service providers in relative difficulty being experienced in recruiting and retaining sufficient members of staff and sufficient quality of staff. To some extent this variability appeared associated with the economics of the local area. But it also seemed related to intra-agency management. In New Jersey an executive director of an agency with a relatively low (continuously monitored) annual staff turnover rate of 16 percent was quite clear about efforts needed and adopted to maintain staff commitment to the organization and the people served, while agency staff reported a general sense of being empowered and supported to be creative, able to redesign programs and to view their job as working primarily for the consumer.

Staff training. Access of direct support personnel to well-designed, comprehensive entry-level and ongoing training was a consistent concern. Respondents in each of the visited states observed that providing direct support staff with access to comprehensive training focused specifically identified attitudes, skills and knowledge needed in that role is something that is being taken more seriously either by services agencies and/or state program administrators.

There was a clear sense that the comprehensiveness, quality and commitment to training varied considerably among the states visited and the agencies within them. Even within agencies there was substantial variability in the nature and quality of training for personnel who worked different schedules and shifts within the same program. The most comprehensive of the state efforts to provide consistent and

high quality training to direct support staff across the state was in Kansas. The commitment of Kansas to accessible and affordable on-going staff training is evident in its “Kansans Educating and Empowering Persons with Developmental Disabilities” program, operated by the Kansas University Affiliated Program on Developmental Disabilities. The program has a highly detailed curriculum with 15 training sessions on topics including health, functional assessment of behavior, skill development, personal choice, community inclusion and social relationships. It is offered statewide through the community colleges of Kansas in collaboration with service providing agencies. Instructors are drawn primarily from service agencies. The program has expanded through a focus on training-for trainers. Kansas demonstrates that substantial commitment is needed to develop ways of training direct support staff in the increasing decentralized nature of HCBS, but it also shows that substantial progress can be made through committed effort and resources.

There is growing discomfort across the states that the evolving community service system, primarily financed through HCBS, assumes a motivated, self-directed, and skilled cadre of support personnel, but that the reality of the people entering direct support roles is quite different. Even as the entry level competence of direct support staff is decreasing, the roles they are asked to fill and the settings in which they work demand more responsibility, judgment, and autonomy. This discrepancy between the roles people are asked to fill and their preparation to do so is expected to increase as greater numbers of people need services in the community and the effects of low wages and benefits continues to be reflected in the new recruits to direct support work. States and individual providers face a growing challenge in assuring that staff training is well-tailored to the essential entry level skills of direct support and effective in developing those skills. Stakeholders recognize a wide discrepancy in the states between what would ideally be available to respond to this challenge and what is presently in place.

Case Management

Each state provides case management services to HCBS recipients. The organization and provision of case management varies substantially from state to state.

Indiana. In Indiana a person can hire a private/contracted case manager or one from the Area Agency on Aging (AAA). Case managers assist in planning of services that address the health and safety of recipients and they monitor the delivery of services to assess the effectiveness, appropriateness and quality of the services being delivered. They convene the team that develops the plan of care, assist people in maintaining benefits and in getting connected to community services. They advocate on behalf of the client and mediate issues that arise between the client and the service providers. The caseload for private case managers is about 20 individuals and the caseload for an AAA case manager is 80 to 100 people.

Kansas. Kansas provides targeted case management. The case manager can work for affiliate organization or for CDDOs. Case managers are to support people and their support networks to find, choose, obtain, coordinate and use both paid and natural supports. These supports are to be designed to enhance the recipients' independence, integration and productivity in alignment with the person's strengths, preferences and needs as identified in their person-centered support plan. The average caseload is about 25 people.

Louisiana. The majority of HCBS recipients receive case management services through private agencies that have contracts with the Medicaid Waiver unit. Case managers are responsible to (1) develop the Comprehensive Plan of Care through an interdisciplinary process, (2) quarterly home visits to recipients, and (3) monitor agencies that deliver HCBS. The average caseload size is 35 people.

New Jersey. Case management has three levels. Primary case management is provided to people considered to be relatively more vulnerable because of potential isolation and/or need for special attention. The caseloads are ideally about 35 people but are typically 40 to 45 individuals. Primary case managers visit service recipients monthly on a face-to-face basis.

Program case management is provided to people who are enrolled in structured programs in which they can be expected to experience regular oversight by a range of people. The caseloads are recommended to be about 90 people, but actual caseloads of up to 100 individuals are common. Program case managers visit service recipients on a quarterly basis.

Resource case management is intended for people who may not need ongoing traditional case management. It is a connection to the system to identify and respond to problems with services received, to provide information and referral, and to attend to changing circumstances of people who are living with their family. The primary purpose of resource case management is to assure access to information and advice and to assure awareness within the service system of changes in people's lives that may require new or different services. The average caseload for this type of case manager is 250.

Vermont. The Designated Agency, a non-profit agency that administers services in each of the ten geographic regions, provides case management services to the individual or a family. Case management, or service coordination, assists individuals and families in gaining access to needed services irrespective of their funding source. Additionally, case managers monitor the ongoing provision of services in the person's plan of care. Vermont has the lowest consumer-to-service coordinator ratios in the United States (about 12:1).

Wyoming. Case management is called Individually Selected Service Coordinator (ISC). Individuals select their own private case manager. In most instances the case managers are employees of

the same organizations that provide services to HCBS recipients. Caseloads for HCBS case managers are 20 to 25 people. Targeted Case Management is for people with MR/RC who are eligible for and waiting for HCBS or Medicaid institutional services.

E. Consumer Direction

Self-Determination

Consumer-directed services for persons with MR/RC are often referred to under the label “self-determination”. In a general sense self-determination refers to the goals that people with MR/RC will control the homes, relationships, activities and personal life goals with the maximum autonomy they can experience with necessary assistance from others who they choose to support them. As noted, the majority of states visited acknowledge increased self-determination as a major goal and benefit of the flexibility and individual focus of the HCBS program.

In recent years the term “self-determination” has also been applied to the growing interest in consumer managed budgets and services. This relatively recent, but rapidly growing focus was nurtured among the states through demonstration projects funded by the Robert Wood Johnson Foundation between 1993 and 2000, under the label, “self-determination”. A fundamental premise of the “self-determination initiative was that although most states had been successful in shifting their service systems from institutions to the community, the lives of people in those systems remained dominated by paid staff and agencies that still held the power to determine the way that people lived. It was expected that if the money paid to staff and agencies were not paid directly from government, ultimately making the government the consumer, but was instead put in the hands of individuals and families, the balance of power would shift. People would be able with the same level of funding, indeed often by design less, to purchase services that better met their needs and desires.

All but one of the states visited described a commitment to individuals having greater direct control over the selection of their services, service providers, housemates (if any), jobs and use of resources to implement person-centered plans of care. These states have made efforts to provide for expanded options in the selection of service providers and case managers, although the pool of service providers and case managers is often limited due to geographic or systemic factors. In the states a number of formal supports have been developed to promote consumer direction, some of which were unique and worthy of monitoring for the outcomes and ability to be replicated.

In Kansas where funding for services is allocated based on an objected assessment and tiered funding structure, people are allocated an established amount in the same manner where they choose to

service-direct or receive services managed by an agency. Whether or not individuals and families choose to “self-direct” they are empowered to choose whichever service provider they want, but families report that if they self-direct they are empowered to hire, fire and train their own staff. In addition to individual management, Kansas fosters the creation of “Participant Alliances” in which individuals and families can join together in a “cooperative” in which individual allocations are pooled and managed for the common good. Participants govern the alliance, monitor administrative costs and work together in a manner similar to other co-operatives. In Vermont, HCBS recipients can choose to manage their own services and budgets and recruit their own support providers. To assist in that process, an Intermediary Service Organization has been established and made available to support individuals and families with the business aspects of purchasing their own services and hiring and managing their own staff. When people choose to self-manage services, the budget amount assigned to them is determined by the regional Designed Agencies in essentially the same manner as for persons whose services are managed and provided by a certified agency. New Jersey’s Self-Determination program is available on to people on New Jersey’s waiting list for residential services who are identified as having “urgent” need. This option allows people to hire a support broker to develop a support plan and budget with family or friends. The option is not available to purchase “packaged” residential services from an agency. Even when a person hires a support broker, the case manager assigned to the HCBS recipient is responsible for monitoring the quality of services and the person’s general well-being. Budget caps are set at what the state estimates would be the cost of traditional services for the same individual. Although individuals and families construct their own budgets within guidelines and certain cost-center limits, the budgets are actually managed by a fiscal intermediary agency.

Other states are moving more slowly into consumer-directed services, but the effects of the movement are broadly felt. For example in Indiana, efforts to use person-centered planning as a model of developing plans of care, and allowing families and individuals to select their own case managers and service providers provide a foundation that is increasing consumer direction within its HCBS program. In another state it was noted that although there is an ongoing effort to maximize the amount of choice and control that service users have over their lives and how the service dollars allocated to them are used, there was substantial concern about a clash between the providing resources directly to be controlled and managed by consumers and families and the conservative culture of the state. State officials noted that a body of experience and evaluation from other states would be helpful before implemented “self-determination” initiatives in that state.

The active movement and experience in developing “consumer-directed” budgets within HCBS programs produced a number of observations from the states visited. These included that: a) self-directed

budgets require an active educational and support component to increase people's understanding of the benefits, substantial efforts and available help for active engagement in service planning and management, b) self-directed budgeting should be one component of a much broader focus on self-determination which includes promotion of self-determination and self-advocacy in publications, presentations, assessed goals and objectives of the public/quasi-public administrative entities and service providers, and other public investments in "system quality", and c) careful monitoring and refinement of efforts must be undertaken to remove impediments to its use (e.g., availability of "up-front" monetary resources as needed in certain retrospective, fee-for-service payment systems).

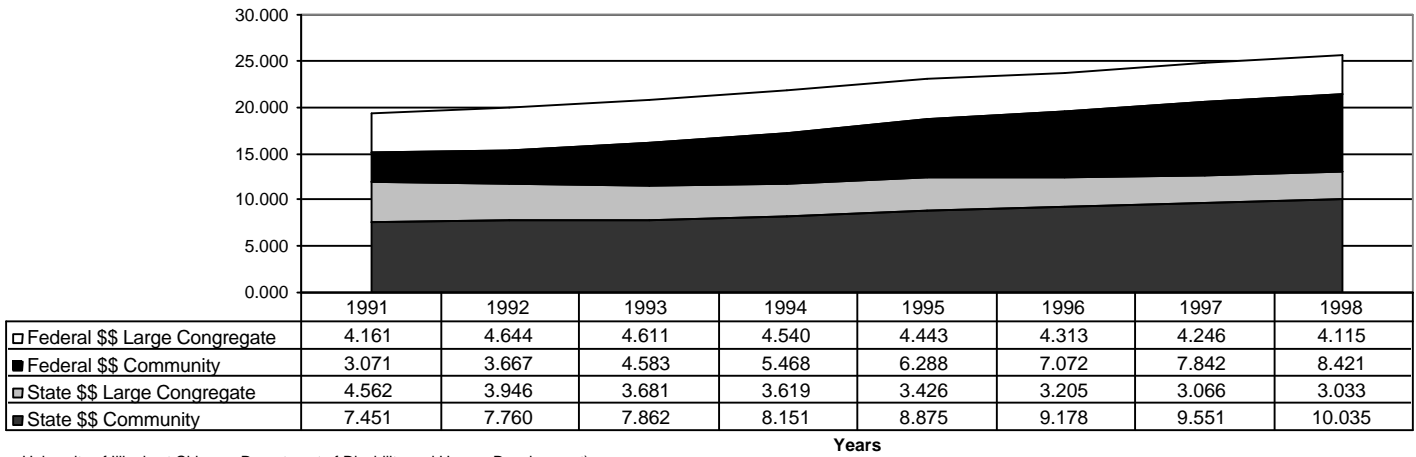
F. Financing and Reimbursement for Service

Context of HCBS Financing

To understand the issues related to state financing of HCBS programming for persons with MR/RC, it must be recognized that most states already had substantial social and financial commitments to community services prior to the creation of the federal program. States continued to develop community services after the HCBS option became available even though until the early 1990s much of that development could not be financed by Medicaid HCBS. As HCBS development was detached from ICF-MR reductions in the early 1990s, the HCBS program began not only to be used to develop new services, but to cost-share previously existing state financed services.

Figure 1 shows graphically the substantial impact on overall federal and state expenditures that derived primarily from the greater flexibilities available to states to use HCBS. The statistics in Figure 1 are from unpublished data of the University of Illinois at Chicago's national longitudinal study of state expenditures for institutional and community services (see Braddock Hemp, Parish, & Rizzolo, 2000). It defines expenditures for "large congregate care" as those for people in programs with 16 or more participants, and "community" as those for people in programs serving 15 or fewer individuals. The data presented in Figure 1 are adjusted for inflation to 1998 dollars.

Figure 1: U.S. Total and Federal Inflation Adjusted (1998) Expenditures for Services for Persons with Developmental Disabilities, Fiscal Years 1990-1991 through 1997-1998 In Billions of Dollars



(Source: University of Illinois at Chicago, Department of Disability and Human Development)

The top two bands in Figure 1 reflect federal expenditures for services for persons as to MR/RC (congregate on top and community below). The bottom two bands reflect state expenditures for services for persons with MR/RC (again congregate on top, community below). The effects of the greatly expanded access of states to HCBS financing are readily evident. During the 1990s states made substantial efforts to obtain federal matching funds through HCBS for both new services and for programs previously financed with state funds. As a result between Fiscal Year 1991 and Fiscal Year 1998 there were real dollar increases of 174.2% in federal contributions for community services (an increase of about \$5.35 billion) as compared with substantial, but much lower real dollar increases of 34.7% in state expenditures for community services (an increase of about \$2.58 billion). Between FY 1991 and FY 1998 there was 33% increase in inflation-controlled state and federal expenditures services for persons with MR/RC, from \$19.25 to about \$25.60 billion dollars. Over this same period, total state expenditures (in 1998 dollars) increased from \$12.01 billion to \$13.07 billion dollars (8.8%), while total federal expenditures increased from \$7.23 billion dollars to \$12.54 billion dollars (73.4%). In all, state expenditures that were unmatched by federal funds decreased by nearly 30% during that period (Hemp, Braddock, Parish & Smith, 2001). So from the perspective of states during the 1990s HCBS and related community services expenditures were controlled primarily through a process of increasing the extent of federal cost sharing of community services expenditures. Issues of reimbursement methodologies and other cost containment approaches have been secondary among approaches to restrict the growth of state costs. For the most part the site visit states have also actively engaged in efforts to increase the extent of federal financial participation in their total financing of services for persons with MR/RC. The range of success in such efforts varied in FY

1998 from New Jersey reported 25% of all expenditures for persons with MR/RC being unmatched by federal funds to only 6% of Vermont's reported expenditures for persons with MR/RC. In short, during the past several years a driving force in financing and cost-containment policy has been the expansion of the overall proportional service recipients in Medicaid programs, with the primary focus on HCBS.

Reimbursement

The six states visited varied considerably in how they establish payment rates for HCBS services. In general two of the states have rate setting methods that derive primarily from individual assessments of need (Wyoming, Kansas). Two states have methods that derive primarily from established, fixed fees per unit of specific services, with varying authorizations of units based on approved plans of care (Indiana, Louisiana). Two states had rate setting approaches based primarily on the development and pricing of a service plan without specific quantitative levels of care or unit prices to guide the determination of pricing. These methods are briefly summarized below. Wyoming has developed an innovative, personalized ("DOORS") system for distributing resources to individual HCBS recipients. Resources for service allocations are based on the assessed needs of individual service recipients using the standardized ICAP assessment instrument, as well as certain specific circumstances of each HCBS recipient. With the individual allocation established the individual and family, assisted by their case manager can develop a service plan and contract for services needed and desired by individual service recipients.

Kansas has a rate setting method that incorporates both type of service and level of need determination. Based on the Kansas "BASIS" assessment of functional skills, medical/health status and behavioral characteristics, a Developmental disabilities Profile index score is computed. From this score individuals are assigned to one of five categories or "tiers". Each tier has a different rate established within each of three service categories: a) in-home/individual supports, b) residential services, and c) day services. The in-home/individual supports category is further broken down in to adults and children, with children's rates ranging from about 70% to 75% of the adult rates across the tiers. Residential services have the greatest rate variation across the five tiers, with the rates for the tier with lowest needs being about 28% of the rate for the tier with the highest level of need.

Indiana has established specific reimbursement rates per unit of service to HCBS recipients. For example, case management is paid for at \$8.00 per quarter hour unit. Supported employment services are reimbursed at \$8.81 per quarter hour; residential habilitation at \$6.41 per quarter hour. Variations in the cost of services for different individuals derive from variations in the types and numbers of authorized units. Although, state staff stated that there are no longer any individual caps for HCBS recipients, in practice it was reported by stakeholder groups that there are artificial caps being put into place.

Respondents questioned whether plans of care were being approved based on individual needs because two people leaving the same institution with very different needs end up with the exact same daily rate.

Louisiana, like Indiana, has an established schedule for units of authorized service. Louisiana does place limits on the number of units that it will authorize for individuals. It has developed “levels” for certain services that establish different rates depending on level of need of individuals. Despite similar rate setting approaches there were notable differences in actual rates available for services in Indiana and Louisiana. For example, personal care assistants and in-home respite care providers in Indiana were reimbursed at a rate that was 46% higher than in Louisiana. Current reimbursement rates in Louisiana, largely because of the lack of CPI adjustment for nearly a decade, have created a situation in which service providers struggle to pay minimum wage to support staff.

Vermont’s HCBS funding is managed within capped annual budgets provided to Designated Agencies for the purpose of providing services to persons with developmental disabilities within the regions for which they are responsible. The base amount available for serving “current caseload” is based on the previous year allocation plus any designated adjustments. In addition to the adjusted funding for existing HCBS recipients, the state provides additional funding for persons recommended for entry into the program by Designated Agencies. The amount added to the Designated Agency’s budget to serve each new person entering the program is based on an estimated amount needed to serve him/her as determined by the local funding committee. These draft budgets are then translated into one of 10 “flat rates”, ranging from about \$7,200 to \$72,000 per year, although higher rates can be authorized as unique circumstances require.

New Jersey’s “waiver program” is operated as a billing program of standard community services. The DDD develops, monitors and finances a set of services as part of its community services program. Decisions about services needed by individuals and their costs are made at the regional level based on individual needs and the costs of meeting those needs. Overall expenditures for people receiving services in a region are controlled by the funds made available to the region. The state role in HCBS funding is to seek and obtain federal cost-sharing of the services in the state’s approved HCBS application for those persons who meet categorical and level of care standards for HCBS. The authorization of HCBS recipients requested and obtained substantially exceeds the number of people who will be provided services. This assures that as people are brought into the community services system in New Jersey all of those who qualify for Federal Financial participation can be claimed.

Cost Containment

For the most part “cost containment” in state HCBS program entails a) limiting state expenditure growth through maximizing federal financial participation all expenditures for MR/RC expenditures, b)

restricting access to the program so that the total service expenditures are controlled by predetermined amounts of funding appropriated for services to persons with MR/RC by state legislatures, and c) establishing funding allocations to an individual or to a pool on behalf of an individual that reflects a pre-established reasonable cost of services for a person presenting a particular needs “profile”. Most of the states visited are approaching full federal matching of eligible expenditures for services to persons with MR/RC, although notable variations in “unmatched” expenditures exist. A recent analysis suggests that of total expenditures for persons with MR/RC in FY 1998 in the states visited, expenditures without Medicaid match varied from 25% in New Jersey’s to 8% in Vermont (Hemp et al., 2001).

As states face major challenges in public opinion about doing something about the long waiting lists for community services and major court challenges of their failure to provide Medicaid long-term care with reasonable promptness, and as opportunities to reinvest new monies raised from obtaining federal cost-share of former state-only program expenditures become fewer, direct cost containment may become a substantially greater issue with states. Many stakeholders, however, are worried that whether even at present expenditures levels whether existing systems can survive. Clearly it is already perceived by many state officials and service providers agency administrators in the states visited, that as states have been driven to focus on new service development, there has been insufficient growth in the funds provided for existing HCBS recipients. As a result service providers have not been able to increase compensation sufficiently to attract and maintain the needed direct support workforce. Such competing needs for new development and maintaining existing programs are evident in the states and will continue to be so into the future. For the most part, however, state officials did not identify specific initiatives aimed directly at cost-containment that extended beyond their existing resources allocation methods and limits.

For example, Kansas state officials stated that there were specific no cost containment initiatives within their state, but that bundled payments for family/individual supports and participant alliances could be viewed as cost containment. A number of families and service providers noted that individuals were reassessed into lower levels of need and, as a result, ended up in a tier that would result in less money. Additionally, family respondents indicated that family alliances contained costs through excluding people with extensive service needs that could potentially drain resources that others in the alliance would need.

In Louisiana the plan for determination and authorization of services theoretically determined by the individual or family needs and not limited by caps or historical allocation patterns, but in practice case managers reported being well aware of the “practical limits” when developing plans of care. They noted an understanding not to request funding beyond “practical limits” or the plan of care would not be approved. Other case managers indicated that they were instructed to cut the number of units authorized in a plan of

care and that as plans were reviewed at regional and state offices, authorized units to day or night companion units) in order to reduce total costs of the plan.

New Jersey, of course, theoretically realizes substantial cost containment in its self-determination option, described above under “Consumer Direction”. Like New Jersey in developing its “self-determination” option, all states recognize that the single most effective strategy for containing expenditures for persons receiving HCBS is to support them and their families so that they stay in the family home as long as is feasible. In all the states visited it was recognized that average expenditures for persons with MR/RC in residential situation outside the family home would be two times or more the average cost of people supported to remain in the family home.

G. Quality Assurance

The states visited all had a number of agencies involved in the review of service settings, service practices, service plans, service outcomes and adverse incidents. These agencies included the specific HCBS program management agencies as well as other external agencies. Typically three to five different government agencies in each state have various roles in inspection and review of aspects of services, service settings and service outcomes for people receiving HCBS. These roles included licensing/certification of provider agencies, licensing of individual service settings, review of individual plans of care, periodic agency/program reviews, critical incident report and investigation programs, surveys of consumer satisfaction and so forth. These are summarized in Table 9.

Table 9: Quality Assurance: Type of Agency/Person by Type of Contact by State

State	Type of Agency/Person	Type of Contact
IN	Division of Disability, Aging and Rehabilitative Services	Certifies service providers. Conducts periodic program reviews within provider agencies
	Bureau of Aging & In-Home Services	Monitor the quality assurance plans and compliance with contracts of the Area Agencies on Aging
	Area Agencies on Aging (AAA)	Monitor the quality of services delivered through the case management process and through their own internal quality assurance processes.
	Bureau of DD Services	Reviews the plans of care.
	AAA/Independent case managers	Assures that the ongoing health, safety and well-being of HCBS recipients through quarterly face-to-face contact
	Diagnostic and Evaluation Services	Formal clinical assessment to determine initial eligibility. Conducts annual review to be certain the person still meets level of care requirements.
	Statewide Waiver Ombudsman	Receives, investigates, and attempts to resolve complaints that concern HCBS recipients.
	Adult and Child Protective Services	Investigates all reports of abuse, neglect and exploitation.
	Provider Certification	All HCBS providers have to be certified.
Mortality Review Committee	Independent committee reviews deaths.	

	Department of Health (DOH)	State licensed and Medicaid certified service providers are required to be surveyed by the DOH. Process focuses on paperwork compliance, personnel qualifications and physical plan related issues.
	Electronic Data Systems (EDS)	EDS review all Medicaid funded services to verify that authorizations, billings and payments line up.
KS	Quality Enhancement Coordinators	Administers the Kansas Lifestyle Outcomes. Monitor and license providers. Investigate and follow-up on abuse and neglect reports.
	State Registry	Registers people who are “confirmed” to have been perpetrators of abuse or neglect to individuals with developmental disabilities.
	Local Quality Enhancement Entities	Coordinated at the CDDO level
LA	State Compliant Line	1-800 telephone number
	Case Managers	Face-to-face contact on a quarterly basis
	OCDD and Medicaid Unit	Quality monitoring reviews for a sample of 5% of HCBS recipients by region.
	Division of Social Services	Annual administrative review
NJ	State case manager	Face-to-face contact. Frequency of contact is dependent upon the type of case management individual receives.
	Service providers	Internal agency quality monitoring program required
	Licensing and Inspection Unit	Assures compliance with existing standards for community residences.
	Special Response Unit	Investigates potential abuse, neglect or exploitation of service recipients in community programs licensed, contracted or regulated by the Division.
VT	Community Alternative	Annual evaluations of the performance of service provider agencies. Quality assessments also include satisfaction surveys, incident reports and reporting, reviews of residential and day service settings for safety and accessibility compliance.
	Specialist Teams	Consumer Satisfaction Surveys
	State Entity	Annual fiscal audits of contracted agencies for all Medicaid services.
WY	DDD personnel	Site review where personnel conducts “Carf-like” reviews.
	Protection and Advocacy System	Monitors the health, safety and quality of life in the state MR/DD institutions, state psychiatric institution, and community service delivery.
	Service Providers	Internal outcome measures based upon CARF standards.
	WY Institute on Disability	Conducted periodic surveys of consumer satisfaction with HCBS.
	Carf-the Rehabilitation Accreditation Commission	Conducts accreditation review of organization providing residential or vocational services to 3 or more people

In part because of this high division of labor in quality assurance functions, and the associated low frequency and/or low probability of direct contact with any particular HCBS recipient, in each of the

states visited there was consistent identification of service coordinators as the most important, if not official, component of quality assurance. Acknowledgement of service coordinators as the key component of quality assurance maintained whether service coordinators were employees of the agencies providing HCBS, or whether they worked for a public or private agency (or as an individual) that was independent from the service providing agencies.

Designing and implementing quality assurance programs for their HCBS programs presented substantial challenges in each of the states visited. The nature and success of the states' responses to these challenges were notably different. Differences noted among states derived in part from the extent to which quality assurance for community services was perceived to be fundamentally different in principle and practice than institutional quality assurance. Other differences derived from whether state quality assurance systems focused primary on inspection of compliance with standards or on improvement of outcomes for individuals and on agency capacity to improve outcomes.

Each of the visited states had formative experiences with ICF-MR and its operational definitions of quality based on compliance with specific standards prior to their experience with the much greater flexibility afforded states under HCBS. With the development of home and community based services, and particularly the expectations that such services increasingly reflect "person-centered" criteria states have struggled with formal definitions and expectations of quality in which personal interests, goals and freedom compete with expectations that quality assurance is about protecting health, safety, and assuring therapeutic habilitation. The majority of states visited have struggled with redesigning approaches to quality assurance systems that can accommodate the ambiguities of the competing concerns around freedom and protection.

Transitions in Goals and Perceived Best Practice

In the majority of states visited most HCBS quality assurance activities remain substantially a continuation of inspection of standards approaches. The standards for community services are somewhat less "institutional", but the systems remain largely definable by government inspectors of relatively low status visiting service sites with established lists of expected performance to determine agency compliance with standards. Once inspected agencies identify actions to be taken to assure that "deficiencies" will be corrected.

In recent years there has been a growing knowledge, interest and commitment within the states to redesign an HCBS service system that focuses on the outcomes that people want in their lives. Such outcomes are evident in statements of missions and goals in each of the HCBS states visited. Efforts to integrate practices of person-centered planning, consumer-controlled housing, consumer-directed

supports, individually managed budgets and so forth are evident within the states visited and these new missions and goals. Major accreditation organizations have established and systemized methods for measurement of individually valued outcomes. These had been adopted for different purposes within the states visited (e.g., Louisiana, Wyoming). The understanding and adoption of outcome-based quality assurance has challenged states to improve internal quality assurance programs to be able to assist organizations to achieve person-centered outcomes.

Being able to implement new approaches to quality assurance without simply adding on to traditional practices also challenges states. Most states do not have within their current quality assurance programs people with the practical experience, knowledge, and attitudes to move toward outcome-based quality assurance. Because of the political difficulties of substantial reorganization and renegotiation of roles, change is difficult to achieve. In some states this has counterproductive ambiguities of being evaluated by two separate and sometimes conflicting approaches. In other little changes except that the traditional approaches to quality assurance, are progressively losing both capability and credibility in the eyes of service providers.

Although change is difficult major stressors were evident to suggest very limited viability and usefulness of such systems. Some of these stressors are simply logistical. The rapid expansion in numbers of HCBS recipients (over 3 times as many in 7 years among the states visited) and the decreasing size of residential and vocational service sites has caused dramatic increases in the number and dispersion of settings. This growth in individuals and settings has occurred without commensurate growth in quality assurance resources and staff. As a result within the states visited there were examples of both reduced the frequency of quality assurance monitoring of agencies and reduced percentages of individual HCBS recipients visited by quality assurance teams.

A second stressor observed was the growing doubt about the validity of existing quality assurance in attending to the expressed missions and goals of the state and agency administering the HCBS program. Criticisms were frequently expressed about what was examined in quality assurance being incongruent with evolving expectations for services, that the standards were too inflexible to accommodate the variations that responded differently to different people, and that persons conducting quality assurance were unsophisticated about the evolving concepts and practices in service delivery. There were also clear threats to the validity of contemporary quality assurance as newspaper exposes, HCFA Regional Office reviews, and other external critiques of community services in the visited states challenged even the ability of these systems to deliver on the most basic expectations that they would keep people safe and provide people with the services they were authorized.

A third stressor observed in the current state quality assurance programs was the pervasive sense among service providers that the quality assurance processes in which they participated and the efforts required of them to do so successfully were both inefficient and ineffective in improving the performance of their agencies. That is, there was a sense that what an agency would do to be successful within the state's quality assurance program and what agency leaders did to make their agency better were essentially unrelated. Administrators observed that most of the effort invested into state quality assurance would be beneficial only a small portion of agencies that were among the very worst. Two of the visited states (New Jersey, Wyoming) have responded to the need for agency relevant quality assurance by expecting each agency to select or design and implement its own internal quality assurance program. While the quality of these efforts varies substantially across agencies, in one of the states visited, quality assurance reviews include examination and assistance in designing and using internal quality assessment and improvement systems. The provision of such assistance, however, highlights the remarkable differences across states in the knowledge, skills and capacity of quality assurance personnel to contribute to the programs of service providing agencies.

Critical Incident Reporting Systems

Incident reporting and investigation systems are valued and viewed as adequately functioning within a narrow range of responsibility. They are not, however, well-integrated into state quality assessment and improvement efforts. All of the states visited had formal requirements for reporting and formal mechanisms for investigating "critical incidents". These systems were designed to track reports of abuse, neglect, exploitation death and serious injury, criminal activities with the persons with MR/RC as the victim of perpetrator of the crime, and/or serious health treatment and medication mistakes. These systems operated independent of the HCBS administering program agencies. In addition to collecting report of critical incidents, these programs also had investigative authority for those incidents considered serious. Despite being valued within the states, critical incident systems are viewed as having limited influence on the quality of services within the states. Among the reasons were that: a) they are focused on specific negative events, but provided relatively little attention to general service practices that contributed to the negative event, b) they tended to look exclusively at physical and property violations rather than the more common violations of people's basic liberties and dignity, c) they have limited capacity or commitment to provide summative information to guide HCBS program development and training activities, and the critical incident reporting systems are isolated such that people making reports often complain that they seldom learn of the disposition of their reports and associated investigations, if any.

Efforts to improve feedback from and use of critical incident reports and investigations were of general interest to service providers, services coordinators and state officials. There was a common perception that the attention to individual incidents was essential, but as currently implemented, the reporting systems were not as beneficial to improving the service system as they might be.

The site visits also observed growing attention to and concern about developing expanded and more comprehensive study of deaths among community service recipients. This heightened attention to monitoring deaths was stimulated by the controversial mortality studies by Strauss and colleagues. There was, however, a general sense in the states visited that when questions were posed following the California studies, the states were inadequately prepared to provide the kinds of data and evidence of reviews of deaths that should have been available.

Consumer Satisfaction Surveys

Efforts to build consumer satisfaction into quality assurance programs were evident in the states visited. But the state officials, services providers and others in these states noted difficulties finding ways of gathering, analyzing and using this information to effectively evaluate and improve services. Some of the states visited (e.g., Kansas, Vermont, Wyoming) have conducted consumer satisfaction surveys to assess the extent to which the services, service providers and the residential, vocational, recreational and other aspects of daily life that services support are meeting the desires and expectations of HCBS recipients. The general commitment to engaging service users and their family members as sources of information about how well services are responding to their needs is strong, but states are struggling with identifying ways to use the data gathered to guide the specific decisions in program administration and improvement. cursory review suggests that developing and implementing data c systems that are able to do so will require better integration of the data reported by individuals, with data on the characteristics of respondents, the nature and costs of services they receive, the settings and communities in which they lives and so forth. To the extent that the surveys are viewed as useful in providing consumer feedback to the agencies that serve them, they will also require more sufficient sampling of persons served by individual agencies. For lack of hypothesis driven analyses, linkages across consumer outcome, consumer characteristic and service type and payment data bases, there were very limited examples of analyses that examined system performance related to subgroups of service users (e.g., by degree of intellectual impairment, age, mobility, behavior), by circumstances (e.g., living with parents or in residential settings of different sizes), by geographic location (e.g., urban, suburban, rural), by resource availability (e.g., costs of formal services, types and amounts of formal services) and so forth.

Consumer satisfaction surveys used in the states visited were generally detached from the formal sanctioned of quality assurance. There were no situations identified in which consumer satisfaction findings had bearing on the official licensing or certification status of service providers, on their funding or on specific requirements that they make “corrections” in their programs. The lack of official roles for consumer satisfaction surveys within the expectations for agencies affected their perceived status and probably their ability to cause change. They were viewed often as as "add-ons" for the purpose of political correctness, not being valued sufficiently as better way to provide quality assurance to replace existing rule-based quality assurance. Consumer surveys were described as adding new burden to service providers (and sometimes to consumers) without really changing the reality of what it was that service providers were expected and inspected to do, i.e., follow rules.

A primary factor in the limited appreciation of the consumer surveys attitude was the lack of clarity or demonstrable purpose of them and the role that they were playing in improving the service programs of agencies or the state system as a whole. One state official confided that the primary beneficial effect of the surveys in her state was to provide ea job and income to the several persons with disabilities who were employed as interview team members. In summary, public officials, service providers, family members and service users tended to consider the role of consumer satisfaction surveys as important and potentially valuable in their recognition that the most appropriate definitions and assessments of quality begin with the perspective of the consumer. Most are not, however, impressed that the methods of collecting, analyzing, reporting and using the data gathered were having substantial influence on the management or improvement of services. They urged that there be clearer specification of the purposes and audiences of the satisfaction surveys and planful consideration of what kind of data gathering, analysis, reporting and program and policy uses of those data that would serve those identified purposes and audiences.

Examples of Excellence in HCBS Quality Assurance

The visited states provided opportunities to review notable examples of effective, outcome-oriented, capacity enhancing systems of quality assurance. Evidence of effective, outcome-oriented quality assurance was not universal for reasons noted above. In general effective state quality assurance seemed allusive in the states with front-line personnel who were full-time career inspectors, and who operated with relatively low status, respect, pay, practical experience and passion for improving the everyday lives of people with disabilities. In contrast effective quality assurance was favored in states in which resources, investments, values and commitments to it were found at the highest levels of HCBS

administration, when the expressed vision of high quality in services and the expectations of quality assurance were congruent, and where agents of quality assurance were viewed as able, willing and responsible to help make services better. These conditions were most notably evident in the “well-developed” HCBS programs.

Ten general characteristics were evident, although not necessarily universal, in the more effective quality assurance systems. They generally reflected the following characteristics:

- Everybody in government roles was in the quality business. There was a low division of labor when it came to monitoring/working on quality and no one was in a role “too important” to be excluded from direct involvement in the quality assurance program.
- Everybody in government roles saw and knew the product in action. State and regional administrators were in touch with service delivery at the street level and knew the strengths and limitations of the system in achieving quality outcomes and were involved in making changes to improve the system.
- There was a clear definition of quality and a structure to its assessment that was based on a foundation of values derived from aspirations of real people.
- People involved in quality assessment had organizational positions/responsibilities, recognized expertise and commitments to quality that extended beyond the monitoring of quality. Quality assessment and improvement professionals were available and useful to work on matters related to quality irrespective of whether these matters were "detected" in formal monitoring activities.
- No one was employed exclusively in the role of a quality inspector and everyone who played a role in visiting an agency for a few days each year in the formal quality assessment process was available and responsive to that same agency on all the other days of the year to work on improving quality.
- People involved in the quality review process were respected because the process was respected.
- Service providers felt challenged by the quality review process and find validity in its observations and recommendations because it attended to the difficult challenges of service provision that extend beyond paper compliance.
- Observations/recommendations of the quality assurance program were integrated into program reform decisions from the service site and agency levels to the state level. The outcomes of quality reviews were known by and affected the behavior of state officials.
- There were a periodic independent consumer satisfaction and/or service assessments conducted by an agency other than the state to measure the performance of the system in satisfying consumers and attending to organizational goals (e.g., "Do you like where/with whom you live? Did you choose where/with whom you live?"). Service recipients' responses to such assessments received formal attention from and influence on persons of policy decisions affecting service delivery at the individual, service site, agency and regional/state levels.

- Outcomes of quality assessments were publicly reported because they were considered 1) to be about topics of public importance, 2) to be valid and reliable information, 3) to be useful to consumers in making service decisions and 4) to contribute to accountability of service providers and the "system" as a whole.

H. Conclusions and Recommendations

I.

This study selected six states based on a number of quantitative measures intended to reflect various degrees of “development” in their state HCBS programs for persons with mental retardation and related conditions (MR/RC). Visits to the six sampled states confirmed substantial variability, not only in the quantitative measures of relative HCBS use (e.g., HCBS recipients per 1,000 state residents, HCBS expenditures per state residents, proportion of all Medicaid long-term care recipients with MR/RC receiving HCBS), but also in the organization and administration of HCBS, procedures for quality assurance and rate setting, programs to support service availability and delivery, and other significant aspects of an HCBS/community services infrastructure. The state visits confirmed major differences in access and quality of HCBS from state-to-state and a need for serious national commitments to establish greater equality across state boundaries. The visits also confirmed a number of challenges that well-developed and “developing” HCBS programs share.

Access to Community Services

In each of the states visited, state officials, advocates and service providers identified issues of providing access to services as high on their agendas. Even in Wyoming and Vermont which, at least temporarily, enjoyed no or virtually no waiting lists, stakeholders openly expressed concern about whether future legislative appropriations would keep pace with growing demand and the extent to which the state effectively excluded many needy people who could be eligible within a less narrow definition of MR/RC than employed by the state. Stakeholders’ concerns in states with substantial waiting lists, included: 1) how to obtain new resources to meet the needs of large and growing numbers of people; 2) how to increase federal financial participation to stretch allocated state dollars; and 3) how to gain efficiencies within current services and expenditures to allow existing resources to serve the most people.

Where an individual lives in the United States greatly influences access to community services. The more community services a state has developed in the past, the greater the likelihood of access in the present. The three “developed” states visited in this study had waiting lists that constituted two percent or less of the combined total of people receiving and waiting for community residential services and had 146 or more persons presently receiving community residential services per 100,000 of the states’ population. The three

“developing” states had waiting lists greater than ten percent of the combined number of people receiving and waiting for community services and had 128 or fewer people receiving community residential services per 100,000 of the state population.

In the past few years, the visibility of restricted access to community services for individuals with MR/RC increased. Some states had very large waiting lists (e.g., New Jersey identified over 3,300 people identified as “urgent” on its waiting list for community services). As waiting lists grew, and the issue became more public, concern grew about the lack of fairness of dividing people with MR/RC and families into groups of “haves” and “have nots.” Families and advocacy groups turned with hope to federal courts for remedy. While courts had established in *Olmstead* that within parameters of adequacy, affordability, and preference, people with MR/RC enjoyed a right to community services in lieu of institutional services, until recently, courts concluded that there was no outright entitlement to community services. Because Medicaid HCBS was specifically designed to allow states latitude in where, how, and to whom they provided services, it had not been viewed as a likely source on which to base a claim for entitlement.

In 1998, a notable shift in this pattern began when the 11th Circuit Court of Appeals ruled that federal Medicaid law requires that services provided in the state Medicaid plan, including ICF-MR, must be furnished to eligible persons in need of that level of care with “reasonable promptness.” While this did not directly speak to access to HCBS, subsequent cases argued that a person eligible for ICF-MR would also be eligible for HCBS, and that providing access to only ICF-MR, even if with reasonable promptness, violated Title II of the ADA requiring services to be provided in the most integrated setting (as affirmed in *Olmstead*). In the nearly four years since the *Does v. Chiles* (now *Bush*) ruling, which recognized the binding nature of Medicaid’s “reasonable promptness” rule, there has been a great deal of interest in the potential to use that ruling to demand services for the large number of people currently denied access. “Waiting list” law suits have been filed in 17 states (as of December 2001). Five of these law suits have been settled with agreements for major expansion of existing services in Florida, Massachusetts, Hawaii, Oregon and West Virginia (with a settlement in Washington State pending a legislative appropriation) on the grounds of the “reasonable promptness” provision of Medicaid.

Among the visited states, only Indiana and Louisiana were engaged in law suits in which lack of community service access was being challenged in court. Indiana’s suit was based on the contention that the lack of community services violates *Olmstead* by causing people to be placed in institutions in violation of the “most integrated setting” provision. Louisiana also faces an “*Olmstead*” suit complaining that the absence of community services unnecessarily forced institutionalization.

Stakeholders indicated a growing consensus that access to HCBS should be a major priority based on fairness and possibly legal grounds (all “reasonable promptness” cases to date have been settled out of court). Although CMS provided states with much greater flexibility to use HCBS to provide access to growing numbers of persons with MR/RC, access differed remarkably from state-to-state. Awarding system change grants to states with substantial need for progress may be helpful. But in many states, much effort will also be needed to build legislative and administrative support for providing essential supports to all people with MR/RC.

Recruiting, Training and Retaining A Direct Support Workforce

States were struggling to maintain a workforce of sufficient size and with the knowledge, skills, and attitudes needed to maintain current systems, much less to increase access to persons awaiting services. Stakeholders in each of the states used repeatedly “crisis” to describe the situation with respect to the direct support staff workforce. The problem is both real and complex, and seems unlikely to get better without serious attention from not only service provider agencies, but also from federal and state agencies. Without involvement of all responsible entities, direct support staff recruitment, retention and training in community human services will be an increasingly difficult problem that will further limit opportunities for people to obtain the community services they need.

Current state programs and new federal initiatives, such as the “Systems Change” grants, depend on recruiting and retaining increased numbers of committed and qualified people to provide the direct support needed by people with disabilities. DHHS Secretary Thompson’s announcement of solicitations for new grants to states to expand community services for people with disabilities, promised that, “these grants will help to extend new opportunities and freedom to Americans who have disabilities or long-term illnesses and allow them to live and prosper in their communities.” The experiences of the states visited suggest that without finding solutions to the challenges of direct support worker recruitment, retention and training, there will be substantial limitations to their ability to “extend new opportunities.”

Respondents in all six states stressed the need to attract people to the profession of direct support. They viewed recognition of direct support work as a primary labor market in which people have specific competencies and for which they should be compensated with a commensurate wage as essential. They also stressed: 1) the importance of federal and state agencies actively promoting substantial real dollar increases in the wages and benefits provided to direct support professionals; 2) the need for substantial improvements in the public’s understanding, awareness, and appreciation of the important roles that direct support professionals performed; and 3) the need for efforts that heighten the awareness about the industry and the career opportunities it offers to people entering the labor force. School-to-work, welfare-to-work,

technical college and other formal programs need to be induced to incorporate direct support in the menus of occupational options. Efforts to create education and training programs that offer career paths and other incentives for people to remain in direct support positions need to be developed, including rewards for obtaining additional education, demonstrate new skills and/or for remaining in positions for prolonged periods of time. Tuition vouchers and community service benefits should be developed to assist organizations to compete successfully for young adults to work in direct support roles as they prepare for careers in education, nursing, law, medicine, business and other roles in which they will be able to contribute to the lives of people with MR/RC.

The study states also listed training of direct support workers as a major challenge. Entry-level direct support training, if available, tended to be limited in accessibility and quality. Few states had statewide training programs, distance learning or “on demand” instruction to improve the quality, consistency and access of training. Inadequacies in training systems were especially evident for the majority of direct support staff who work part-time and/or are employed at odd hours (e.g., all weekend, every other weekend). Kansas provided an example of a well-developed training program within the states visited. The “Kansans Educating and Empowering Persons with Developmental Disabilities” trained direct support personnel throughout Kansas on topics including health, safety, functional assessment of behavior, skill development, personal choice, person-centered planning, community participation and social relationships. It does so with a comprehensive curriculum delivered with available college credits in most of Kansas community colleges. The program provided training for instructors drawn from service providing agencies and who work together in training network to share resources. The program is operated out of the University of Kansas University Affiliated Program on Developmental Disabilities. Most states did not exhibit such concerted efforts to develop and maintain comprehensive statewide commitments to training of direct support personnel.

Most states did not monitor direct support staff recruitment, retention and skill development as components of quality assurance, even though the skills and stability of the people who provide these services are acknowledged to contribute to consumers’ and family members’ perceptions of quality of services. Providing recognition and other incentives for service organizations that have few vacancies and low turnover rates seems likely to be beneficial in promoting quality. Agencies and states in which people experience a revolving door of strangers to whom they must subject themselves for the most intimate interactions need to be of higher concern to those responsible for service quality. But it would also seem essential that responsibility be shared.

Higher expectations produce little without providing organizations the opportunity to learn more effective workforce development practices. A number of organizational and management practices that have been proven to be effective at reducing vacancies and increasing the retention of direct support personnel. However, many organizations simply do not have the necessary information about these strategies to design and implement within their organizations. To the full extent possible, federal and state governments should support technical assistance and training programs that assure that service providers have access to information and assistance to improve their recruitment, retention and training of direct support personnel.

Consumer Directed Supports/Self-Determination

Consumer-directed services (or “self-determination”) for persons with MR/RC refers both to the goals that people with MR/RC will control their lives with as much freedom and autonomy as possible, including, if they choose, actual management of the resources allocated for the support they need. “Self-determination” serves as a next step in a process of service development that moved people from institutions to the community without fundamentally changing the control that agencies and paid staff had over the lives of people with MR/RC. Consumer-directed resource management presumes that when the money that staff or agencies receive comes directly from individuals and families, the balance of power shifts. People would be able to purchase services that meet their needs and desires. Staff and agencies would be more responsive because the service user was now the purchaser of their service, not a government or quasi government agency. The study states expressed a great deal of interest in self-determination as a commitment and foundation of support for people to achieve greater control over their lives, but not all had made substantial, systematic efforts to place the resources for services directly under the control of families and individuals, but this option still generated interest.

The three states participating in the Robert Wood Johnson “self-determination” demonstration project had the most well developed efforts to promote “individually-controlled budgets.” Whether this was a cause or effect cannot easily be determined, but clearly it supported initiatives that continue to be sustained subsequent to the end of the demonstration funding. But in the states that provided a consumer-directed budget option, state and regional officials observed that a broad commitment to self-determination as a right of citizenship and as a shared goal across the state’s service system was an essential foundation to people realizing control of their own lives. Vermont officials noted the importance of investing in that commitment and of arriving at a consensus that “self-determination,” however defined, constituted the fundamental goal and expectation for HCBS-financed services. Vermont’s consensus commitment was for moving responsibility for individuals and their services to the communities in which they live, increasing

choice and flexibility in services, and putting control of real dollars and information about how they can be used into the hands of individuals and families. Self-advocacy, in the form of the Vermont Peer Network, was also stressed as a major component of building the culture and associated essential education/information system needed for self-determination.

Discussions in the states suggested a number of components that were working or were needed to promote self-determination. One consistently noted factor was that self-determination in general and, self-directed budgets more specifically, required an active educational and support component to increase people's understanding of their options and benefits. Families involved in exercising control over their own services and budgets noted the importance of hearing the stories, exploring alternative approaches and learning the "dos" and "don'ts" from other families who had actually gone through the process themselves.

Families expressed a need for effective assistance with the regulatory aspects and management of controlling their own services. States have created various intermediary service models to assist families. These vary not only in approach, but also knowledge and effectiveness. Few individuals can: 1) put together support plans that make the most efficient use of available HCBS resources by utilizing to the maximum extent the benefits of Social Security, Medicaid state plan services, federal and state programs providing subsidies for housing, food, and transportation; 2) be knowledgeable and attentive to restrictions of income, HCBS rules and other important regulatory considerations; 3) possess skills in the application of person-centered planning approaches and so forth. Access to training and networking opportunities appear needed by people in such roles so that they can obtain effective support when they need it. Such networks should also be engaged in identifying those aspects of program design that may be causing problems for people (e.g., as noted in one state the need for "up-front" monetary resources needed in retrospective, fee-for-service payment systems).

Families reported challenges of recruiting, training and retaining support staff similar to, but often even more complex than those reported by service agencies. Families expressed need for assistance in the recruitment and training of direct support staff. They need to learn the basics of positive management techniques to assure that they support the effectiveness and retention of the valuable people they hire. They also need assistance with identifying and using strategies to enhance the compensation available to their employees. Written materials, websites, town meetings and other opportunities to learn such skills should be available to people who take on this challenging role of directing their own supports. The risks of failing to provide proper support to families to manage their own services include: 1) making the option less attractive, 2) reducing the length of time people choose to manage their services, and 3) continuing high staff turnover and inadequate training.

Interviews with stakeholders emphasized the importance to promoting “self-advocacy” by persons with MR/RC and creating a culture around self-determination/consumer directed services. Self-advocacy promotes the rights and abilities of people with MR/RC to speak on their own behalf. It acknowledges the importance of people with MR/RC being part of discussions about policies and programs that will have an effect on them. It recognizes the need to assist and prepare people with MR/RC for new roles in understanding, analyzing and speaking about programs and policies. It assists people with MR/RC to come together on their own behalf to learn from each other and to plan concerted efforts on their own behalf. It builds the confidence and self-esteem needed to speak out. In states with the most rapidly and effectively developed consumer-directed supports, stakeholders recognized self-advocacy organizations as one of the important ways for individuals to learn the needed skills, attitudes and knowledge to take more control of their own lives.

Quality Assurance/Improvement

Quality assurance approaches that contribute to quality in services as defined by emerging principles of person-centered services and by the desires and aspirations of service users remain a substantial challenge for states. This challenge is technical in that it requires new and substantially reformed approaches to quality assurance. It is exacerbated by the existence in most states of quality assurance systems and personnel that are poorly prepared and experienced in outcome-based assessments of quality, that have limited experience and credibility in contributing to achieving quality as newly defined, that are overburdened by the rapidly growing numbers of individuals and service settings for which they are responsible, that are often compartmentalized into various licensing, critical incident investigation, service plan review, quality assessment, case management and other functions with limited, if any, communication across functions.

State officials recognize and openly discuss the challenges of quality assurance and their desire to make it more relevant to quality improvement. They note that the independence of the various components of quality assurance and their assignment to different agencies, often limits the effectiveness of the overall quality assurance “program” and its ability to use resources efficiently, coordinate activity, avoid duplication and create an integration of quality assessment, training, technical assistance, and other activities that might contribute to quality as experienced by consumers.

In visiting the study states the differences in status and respect for quality assurance programs and the personnel was remarkable. That variation in status and respect was associated with the extent to which a) state administrators of HCBS and other community services were directly engaged in and committed to the quality assurance program; b) successes and problems in quality were perceived to belong to the state

as well as to the provider agencies; c) the quality assurance program attended to outcomes that if achieved would actually reflect quality as experienced by service users; d) that the results of quality assessments were both useful and used to improve services; e) the quality assurance program was staffed by people who had the skills and experience to contribute to improving quality and to solving problems that impeded it; f) quality assurance personnel were available at times before and after formal reviews to assist agencies and remained in ongoing and on-site contact with agencies; and g) the various components of quality assurance were integrated and that the burdens of quality assessment were efficiently coordinated, and focused on a consistent definition of the goals and purposes of services and of their monitoring.

Even as attention is drawn to improving operational definitions, assessment methodologies and programs of supports for evolving standards of quality, states are increasingly aware of limitations in basic health and safety protections for many individuals receiving HCBS. Reports of these limitations and the devastating consequences to individuals with MR/RC have been reported in the media nationwide. These reports have questioned the adequacy of current protections as deaths have gone without investigation, as felons have slipped by required background checks, as critical incident reports are submitted without any effort to aggregate them to identify patterns of incidents by type, by agency or by service setting, or otherwise use them to improve service quality.

States feel challenged by multiple expectations that they improve their effectiveness in promoting contemporary, person-centered outcomes as well as attend better to traditional health and safety protections. States are reexamining their whole infrastructure of supporting quality: support for consumer-direction, choice, information and technical assistance; programs for recruiting, training and retaining suitable, qualified personnel; approaches to improve the responsiveness of service coordination; systems of service monitoring and assessment of individual outcomes.

It is not surprising that states have been struggling with the magnitude and speed of change in their HCBS-financed community services. In size alone on average HCBS programs grew 22% each year between 1992 and 2000. State infrastructures to respond to this degree of change, not to mention the philosophical change, in areas of workforce development, consumer information, service coordination, quality assessment and so forth have been hard pressed to keep pace. Some states need assistance in developing, investing and supporting infrastructures for the service systems they have created over the past several years. There are good models of doing so with one or more of the essential elements evident in most of the states visited. There should be substantial interest as assisting states to integrate fuller sets of such elements into comprehensive infrastructures of quality monitoring and improvement.

Concluding Note

In most ways, the development and expansion of HCBS-financed community services for persons with MR/RC in the states visited has been a success, in some a truly remarkable success. In most of these states, the vast majority of people receiving services outside their family home are living in regular houses and participating in regular activities of their community. Families have access to support to keep their family members living in their family homes of variety and amounts that could only have been a dream before HCBS. In each of the states visited there are ever-growing expectations that people deserve and should enjoy greater freedom, expanded options, the full measure of citizenship, inclusion in their neighborhood and acceptance in their community. These successes, however, are perceived to be fragile, demanding vigilance and ongoing development of supports within service systems to sustain accomplishments and support future growth. Most states are struggling to pull together the resources, time, and necessary partners to build the reformed systems that are needed to support the ever-growing, ever changing programs of HCBS-financed community services, which have for all practical purposes become the long-term care program for persons with MR/RC.

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