U.S. Department of Health and Human Services
Assistant Secretary for Planning and Evaluation
Office of Disability, Aging and Long-Term Care Policy

AN ANALYSIS OF FEDERAL AND STATE POLICIES AFFECTING SERVICES TO MENTALLY RETARDED AND OTHER DEVELOPMENTALLY DISABLED PERSONS:

STATE PERSPECTIVES FINAL REPORT

July 1987

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This report was prepared under contract #HHS-100-84-0035 between HHS's Office of Social Services Policy (now DALTCP) and Macro Systems, Inc. For additional information about this subject, you can visit the DALTCP home page at http://aspe.hhs.gov/_/office_specific/daltcp.cfm or contact the office at HHS/ASPE/DALTCP, Room 424E, H.H. Humphrey Building, 200 Independence Avenue, S.W., Washington, D.C. 20201. The e-mail address is: webmaster.DALTCP@hhs.gov. The Project Officer was Margaret Porter.

AN ANALYSIS OF FEDERAL AND STATE POLICIES AFFECTING SERVICES TO MENTALLY RETARDED AND OTHER DEVELOPMENTALLY DISABLED PERSONS:
State Perspectives Final Report

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EXECUTIVE SUMMARY

1. Purpose of the Study

The Developmental Disabilities Act of 1984 required the Department of Health and Human Services (HHS) to submit a report to Congress on improving services to mentally retarded and other developmentally disabled (MR/DD) persons. That report, prepared by the Assistant Secretary for Planning and Evaluation (ASPE), Office of Social Services Policy, recommended the establishment of an intradepartmental Working Group to develop cost effective Federal policy options for enhancing independence, productivity, and community integration for MR/DD people.

The purpose of this study is to provide information to the Working Group on the impact of Federal programs and policies on state policies regarding community-based services (CBS) for MR/DD people. The objective of the investigation and analysis was to develop an understanding of the factors which influence state policy choices and the environment that is created for implementing Federal policies and programs at the state level. The study identifies those factors, especially those relevant to Federal policy, which either encourage or inhibit the development of services that promote autonomy and integration for MR/DD people and minimize inappropriate institutionalization.

2. Methodology

This report presents the results of an in-depth review of six state MR/DD service systems. To obtain an understanding of the elements which play a critical role in state policy, decisions regarding the degree of emphasis to be placed on CBS, it was decided to focus on the two ends of the CBS "continuum." Colorado, Michigan, and Nebraska (hereafter referred to as high-CBS emphasis states) were selected as states which have developed extensive CBS systems. Illinois, Texas, and Virginia (low-CBS emphasis states) provide the perspectives of states which continue to rely heavily on institutional services. Factors used to classify states in relation to their relative emphasis on CBS included: the distribution of expenditures between CBS and large public residential facilities (PRFs); the population in PRFs and small (15 beds or less) community residential facilities (CRFs); and trends in the reduction of the population in PRFs. State characteristics, such as population size and geographic location, also were considered in the state selection process.

Data collection and analysis emphasized discussions with key policy makers and program operators in each of the six states, as well as a review of relevant documents and reports supplied by the state informants. A profile of each state system was developed to serve as the primary instrument of analysis for a cross-state comparison.

3. Major Determinants of State Policies

The analysis of state MR/DD service systems reveals that state policy decisions and the state's overall emphasis on CBS are the results of the interaction between a complex array of factors specific to individual state's political and MR/DD service systems and the requirements and incentives imposed by Federal programs and policies. Although Federal policy is not the primary influence on state policy decisions, it does play a fundamental role in the financing and delivery of MR/DD services on the state level.

Colorado, Nebraska, and Michigan demonstrate a strong philosophical commitment to CBS, and have translated that philosophy into concrete policy. Michigan's orientation toward CBS reflects, in part, a traditionally strong commitment to human services. Advocates for CBS in Nebraska and Colorado were able to articulate the importance of CBS in terms of their states' conservative political values which emphasize individualism, independence, and local control. The high level of philosophical commitment in these three states created an environment conducive to CBS development. The three high-CBS emphasis states also benefited from the presence of strong, well-organized advocacy for community services. Several respondents in the low-CBS emphasis states cited the lack of effective advocacy as barrier to the development of CBS.

Although a political commitment to CBS and the presence of able and dedicated individuals are essential to the development of CBS, these factors are not sufficient for such development. A variety of other internal and external factors also appear to influence whether and how CBS develops in a particular state. For example, although community-level service delivery systems and a high degree of community involvement appear to be crucial to CBS implementation, their presence does not guarantee CBS development.

The health of a state's economy also is an important factor affecting state support for MR/DD services, especially in the Initial stages of the move toward an emphasis on CBS. Respondents in two of the three high-CBS states reported that the major expansion of CBS coincided with periods of economic prosperity in the state. Economic difficulties can have one of two effects on CBS development: scarcity of resources may encourage a state to consider less costly alternatives to institutional care; and, conversely, a shortage of funds may prevent a state from developing new services. Financial issues are a major concern, especially for the low-CBS-emphasis states which are struggling with pressures to expand CBS while maintaining service quality in large PRFs.

Federal policy has been critical to the development of CBS, but factors internal to individual states shape the nature and degree of Federal influence. For example, the ability to use Federal funds to finance CBS was an enabling factor for the three high CBS states--the availability of Title XIX funds and the Title XX Social

Services Block Grant made CBS development possible. However, faced with the same alternatives, other states chose to continue to rely on institutional services. States' responses to the original Medicaid Intermediate Care Facility for the Mentally Retarded (ICF-MR) regulations illustrate another aspect of Federal influence: in two of the three high-CBS states, the regulations were explicitly cited as an additional impetus for the depopulation of PRFs; in the three low-CBS states, the investments in PRFs associated with complying to Federal standards are seen as an important barrier to CBS development.

4. Implications for Federal Policy

State perspectives on the impact of Federal policy focused on: the limited availability of funding; the relative inflexibility of federally funded programs; ambiguities and inconsistencies across the myriad of Federal programs serving the MR/DD population; and the perceived absence of clear and consistent policy and leadership on the Federal level. In general, state respondents were likely to describe Federal policies and programs, with the exception of the Home and Community Based Care waiver, as barriers to the development of individualized, integrated, nonmedical service models. This tendency is partially due to the heavy dependence among five of the six states examined on the ICF-MR program and other Medicaid funding to finance MR/DD services. Respondents in all of the states supported CBS objectives, such as increasing independence and productivity for MR/DD people, but felt that overall Federal policy and programs (especially ICF-MR) are oriented toward facility-based, medical/institutional models.

State responses to specific Federal policy changes are difficult to predict. However, several themes emerge from respondents' perceptions of current Federal programs and suggestions for future policy changes:

- States would be receptive to changes which would increase their flexibility to use Federal dollars for CBS, but would be reluctant to accept reduced Federal financial participation (FFP) in exchange for increased flexibility.

- A combination of the various Federal-funding streams would probably be attractive to states, although interagency turf battles at the state level might develop.

- Some type of preferential funding for CBS would probably be favorably received if such changes incorporate incentives for future expansion of CBS rather than penalties for choices made in the past.

The potential for Federal policy to encourage a greater emphasis on CBS, as well as the development of service models which facilitate community integration and independence for MR/DD individuals, is significant. State respondents repeatedly stressed the need for a clear, unequivocal Federal commitment to CBS, accompanied

by programmatic guidelines and funding mechanisms which are consistent with that philosophical commitment.

Federal policy changes can perhaps make the greatest impact in states such as Virginia, Illinois, and Texas. These states want to expand CBS and have already begun to do so, but the size of their institutional populations and their relative lack of CBS experience will hinder expansion efforts. Federal involvement in technical assistance and service system development, in addition to financial assistance and strong leadership could be highly effective in increasing community service options for MR/DD people.

I. OVERVIEW OF STUDY

The analysis of Federal and state policies affecting services to mentally retarded and other developmentally disabled (MR/DD) persons recently conducted by Macro Systems, Inc. (Macro), and its subcontractor, Systemetrics, was designed to assist the Office of the Assistant Secretary for Planning and Evaluation (ASPE) in chairing the Working Group on Policies Affecting MR/DD Persons. The background, objectives, and methodology of this study are described in this chapter.

1. Background

The Developmental Disabilities Act of 1984 called for a Report to Congress on Policies for Improving Services to Mentally Retarded and Other Developmentally Disabled Persons Under Title XIX of the Social Security Act. The Office of Social Services Policy, ASPE, prepared the report in consultation with other departmental agencies, including the Office of Human Development Services (HDS) and the Health Care Financing Administration (HCFA), as well as two other Federal agencies: the Office of Special Education and Rehabilitative Services, Department of Education, and the National Council on the Handicapped. The report was transmitted to Congress on January 21, 1986.

The report identified four goals for increasing the independence, integration, and productivity of this population: (1) increasing incentives for community living; (2) improving standards for the Medicare Intermediate Care Facilities for the Mentally Retarded (ICFs-MR); (3) meeting the needs of adults; and (4) improving coordination and cooperation. In an effort to address these goals, the Department of Health and Human Services (HHS) said it would examine options which reduce incentives toward inappropriate institutionalization and provide states with greater flexibility to provide a continuum of services while establishing workable cost controls.

ASPE recommended the establishment of an intra-agency Working Group to conduct a systematic examination of policies related to mentally retarded and other developmentally disabled people and to develop cost-effective policy options. Areas to be addressed by this Working Group included the high cost of the ICF-MR program and its medical and institutional orientation; the shift to smaller facilities and the use of Medicaid home and community-based service waivers; concern about health and safety and enforcement of standards; controversy over support for educational and vocational services; and various options for restructuring the financing of services.

The Secretary concurred with the recommendation and a Working Group, chaired by ASPE, was established. The Working Group is conducting a systematic

examination of policies related to this population and is developing policy options for the Secretary. Specifically, the Working Group is considering cost-effective options which will enhance the productivity, independence, and integration of developmentally disabled people. Emphasis is being placed on policies which could enhance self-sufficiency and encourage access to community living arrangements.

2. Study Objectives

The overall goal of this study is to provide information to ASPE and the Working Group to assist them in the delineation and assessment of policy options being considered for recommendation to the Secretary. One component, conducted primarily by Systemetrics and reported in other documents, focused on the analysis of existing data on the impact of current Federal policy with respect to the major Federal programs financing services to the MR/DD population, in particular the Medicaid program. This component has attempted to provide the Working Group with an overview of the relationship between the structure of these financing programs, the manner in which services are delivered, and how much they cost, as well as an analysis of programmatic and cost implications of alternative financing and delivery systems.

The component conducted by Macro focused on state perspectives regarding organizational, political, regulatory, and other factors which encourage or inhibit community-based services (CBS) for MR/DD individuals. State perceptions about the influence of Federal policy on state development of CBS received particular attention. The study was not limited to a review of Federal policy influence, however, but rather was designed to gain a better understanding of the bases for states' MR/DD policy decisions and the context in which Federal programs and policies operate. The analysis of state perspectives is being provided to ASPE and the Working Group to assist them in their assessment of proposed policy options, including the projected impact on state policies in further development of CBS for MR/DD people, especially services that meet Federal policy goals of promoting the population's independence, integration, and productivity.

The analysis of state perspectives is summarized in this report. Detailed information on the six states visited in developing this analysis is presented in the Appendix volume which accompanies this report.

3. The Approach

The approach to our analysis of state perspectives entailed four components:

- Review of national trends in state MR/DD systems
- Consultation with knowledgeable individuals

- Selection of six states for in-depth review
- Plan for data collection and analysis

Our activities in these areas are highlighted in this section.

(1) Review Of National Trends

Literature with information on state MR/DD systems was reviewed to identify national trends in such key areas as expenditures for MR/DD services; use of the ICF-MR Program; use of the Medicaid Home and Community-Based Care (HCB) Waiver; and overall community service configurations. Three sources were particularly helpful:

- An Analysis of Medicaid's Intermediate Care Facility for the Mentally Retarded (ICF-MR) Program (Lakin, et al., 1985)
- Persons with Mental Retardation in State-Operated Residential Facilities: Years Ending June 30, 1984 and June 30, 1985 with Longitudinal Trends from 1950 to 1985 (Lakin, et al., 1986)
- Public Expenditures for Mental Retardation and Developmental Disabilities in the United States: State Profiles (Second Edition) (Braddock, et al., 1986)

A copy of our general bibliography may be found in the Appendix. Additional information was obtained from review of such "fugitive" literature as technical assistance reports of the National Association of State Mental Retardation Program Directors and an informal survey on state use of the ICF-MR program, which included the following: public and private sponsorship; numbers of clients and numbers of facilities with more than 15 beds vs. 15 beds or less; and projected reaction to the proposed Community and Family Living Amendments (CFLA), then being considered by the 99th Congress.

(2) Consultation With Knowledgeable Individuals

Early in the study, we consulted with several knowledgeable individuals to obtain guidance in the development of the plan for data collection and analysis. In addition to the ASPE Work Group and fellow investigators Brian Burwell (Systemetrics) and Charlie Lakin (University of Minnesota), we consulted with representatives of major interest groups, including the National Association of State Developmental Disability Councils, the National Association of State Mental Retardation Program Directors, the National Association of State Mental Health Program Directors, the American Public Welfare Association/State Medicaid Directors, and the National Association of Private Residential Facilities for the Mentally Retarded. We also consulted with Federal officials knowledgeable about state programs and the states' response to Federal policies, in particular representatives of the Administration on Developmental Disabilities (ADD) and HC FA.

The discussions with knowledgeable individuals focused on four areas:

- Data sources for national trends and state-specific information
- Criteria for selecting the six states for in-depth review
- Suggested states
- Data collection strategies

Their guidance was of considerable value in the development of recommendations on states to be visited and the plan for data collection and analysis. The prior consultation with some of the national organization representatives also may have been helpful in gaining access to some of the key informants at the state level.

(3) State Selection

The approach to analysis of state perspectives included in-depth review of MR/DD systems in six states and the influences on CBS development. To focus more sharply on the understanding of state choices in CBS development, it was decided to divide the reviews evenly between states with extensive CBS emphasis and states which continued to rely more on services in large institutions and had relatively little CBS emphasis. Factors used to identify states in relation to their emphasis on CBS included: proportionate expenditures for CBS vs. (usually large) public residential facilities (PRFs); trends in reduction in PRF population; and relative numbers of small (15 beds or less) community residential facilities (CRFs).

Although CBS emphasis was the primary selection criterion, a variety of additional factors were considered as follows:

- **Population**--A range in total size of state population was considered; however, states with extremely large and extremely low populations were avoided.

- **Geographic Region**--A mix in geographic regions of the United States was sought.

- **Use Of The HCB Waiver**--Both waiver and nonwaiver states were included.

- **MR/DD State Authority**--A mix in state approaches to administration of its MR/DD system was sought, in particular the use of substate MR/DD authorities vs. a centralized system.

The study team's knowledge of current trends in state MR/DD systems and observations from knowledgeable individuals were used to assess ways in which states under consideration were representative of the overall nationwide mix. The six states selected in consultation with ASPE as a result of this assessment were:

- **High CBS Emphasis**: Colorado, Michigan, and Nebraska
- **Low CBS Emphasis**: Illinois, Texas, and Virginia

It should be emphasized that these designations are relative; i.e., this is not to say that Illinois, Texas, and Virginia are without CBS for their MR/DD citizens or that they are not moving to place more emphasis on CBS. As described in the following chapter, it is clear that these three states are actively pursuing strategies to develop an expanded community service system. Relatively speaking, however, they currently rely more extensively on large congregate institutions for MR/DD care than do Colorado, Michigan, Nebraska, and other strong CBS emphasis states.

(4) The Plan For Data Collection And Analysis

The plan for data collection was to gain understanding of state MR/DD system influences and state perspectives on Federal MR/DD policy through review of descriptive reports and documents, for example, state MR/DD budgets, and discussions with key informants. The informants included people in the following positions, or their designees, as appropriate to the individual states:

- MR/DD state agency director
- State mental health (MH) agency director where MR/DD is part of combined MH/MR department
- Director of special education services
- Director of state Medicaid agency or coordinator of Medicaid long-term care program
- Director of vocational rehabilitation services and/or supported employment program
- Director of the state Developmental Disabilities Council
- Director of the state DD Protection and Advocacy agency
- Representative(s) of the substate MR/DD authorities
- Director of the state Association for Retarded Citizens
- Director of the association of parents and other advocates for the maintenance of PRFs
- Representative(s) of the private providers

The study team's discussions with the informants were generally held person-to-person, as planned; telephone consultation was used for followup and to talk with those we were unable to meet with during our site visit. We also were fortunate in having Peg Porter, the ASPE delivery order officer, accompany us on two of the six visits.

The discussions were tailored to reflect the individuals' responsibilities in the state's MR/DD system. To obtain perspectives on the overall influences, however, and the degree of consensus on Federal policy perspectives, we attempted to cover the following topics with virtually all informants:

- Characterization of the state's degree of emphasis on community-based vs. state institution services
- Operational definition of community-based services
- Range of state-supported services available in the community, both residential and nonresidential (e.g., case management and off-site habilitation programs)
- Service administration responsibilities, including relevant interagency agreements
- Characteristics of MR/DD clients participating in CBS, and any significant differences between the CBS and PRF client populations
- Gaps in the CBS system
- Financing mechanisms for CBS, including use (if any) of the Medicaid HCB waiver and service development funding
- Financing of state PRFs and other system costs
- Major influences on MR/DD expenditures
- Cost controls on CBS programs
- Quality assurance mechanisms affecting CBS
- Factors which have contributed to the expansion of CBS; barriers to CBS development and how they might be overcome
- Short- and long-term goals for CBS and factors affecting their implementation
- Federal policy changes that would assist the state in achieving these objectives

The key informants who provided information on these topics in each state are listed as part of the state profiles found in the separate Appendix, as well as the state-specific documents used. The full text of the discussion guide also is included in the Appendix.

Information from the key informants and the documents provided by the informants were used to prepare a profile of each state's MR/DD system and a synthesis of perspectives on Federal policy and other influences on the state's development of community services for MR/DD individuals. The draft profile was sent to each key informant in the respective state for review and comment. Their clarifications, and, in some cases, additional information, are reflected in the state profiles found in the Appendix and in the discussion of state perspectives in this report.

The Plan For Analysis

The approach to our analysis of state perspectives focused on the need to provide information to ASPE and the Working Group that would be useful in the development and assessment of cost-effective policy options. The four major areas selected for analysis are as follows:

- Characteristics which differentiate high-CBS from low-CBS states
- Major influences on state CBS emphasis/how CBS has developed
- Influence of Federal policies on CBS development to date
- Probable state responses to the kinds of changes in Federal MR/DD policy being discussed by the Working Group

The influence of Federal Medicaid policies--policies either real or perceived--was, understandably, a major focus, along with the potential response to changes in the Medicaid program, given its dominance in financing MR/DD services. Perspectives on other Federal programs were included. However, less information was generally available to the study team on programs other than Medicaid, especially those that are generally administered at the local level (e.g., use of HUD 202/Section 8 funds in combination with client (SSI) payments).

The descriptions of the policy options being developed by the Working Group include coverage of five areas: (1) organization and administration; (2) client eligibility implications; (3) service array and delivery systems; (4) the financing approach, including potential cost-sharing; and (5) quality assurance strategies. Our analysis of possible state reactions to changes in Federal policy is designed to address these same areas, as well as an assessment of the likely effect on states' overall movement toward the goal of enhanced productivity, independence, and community integration of MR/DD individuals.

II. SUMMARY OF STATE PROFILES

The six states selected for the study exhibit significant variation with regard to the degree of emphasis on CBS, the range of services provided at the community level, the structure for service delivery, and the financing of CBS. Exhibit II-1, following this page, illustrates several features which describe the states' service systems:

- Size of the MR/DD population residing in various living arrangements (e.g., PRFs, small CRFs, etc.)
- Definition of CBS
- Use of the ICF-MR program to finance CBS
- Use of the Section 2176 HCB Waiver and other Title XIX options
- Activity in supported employment and family support services
- Existence of a community-level MR/DD authority
- Extent of private sector involvement

These features are discussed throughout this chapter in relation to current MR/DD service systems, influences on the development of current systems, and goals for future CBS development.

1. How High-Low CBS-Emphasis States Differ

The three high-CBS emphasis states appear to share at least the following characteristics:

- A strong philosophical commitment to CBS, with an emphasis on maximum integration and independence for the MR/DD individual
- Broad-based support for the expansion of CBS
- Extensive CBS already developed
- Investment in CBS and depopulation of PRFs rather than major capital investments in PRF improvements

The low-CBS emphasis states generally illustrated the converse of these characteristics, as follows:

- Lack of coherent support for CBS
- Considerable investment in PRFs
- Strong and organized support for congregate care
- Relatively few CBS alternatives

Despite the presence of a community service network in two of the three low CBS states--both Texas and Virginia have a statewide system providing services at

the local level--their relative degree of CBS development and emphasis on CBS vs. large congregate care facilities is noticeably less than that found in the high-CBS emphasis states.

EXHIBIT II-1: State MR/DD Systems						
	Colorado	Michigan	Nebraska	Illinois	Texas	Virginia
Population	3.2 million	9 million	1.6 million	11 million	16.4 million	5.7 million
Population in PRFs	• Approximately 900 • 3 Regional Centers (one scheduled for closure) • ICF-MR certified	• 1,650 clients • 8 Centers for the Develop-mentally Disabled • ICF-MR certified	• 470 clients • Beatrice State Development Center only PRF • ICF-MR certified	• 4,500 clients • 9 PRFs • ICF-MR certified (or SNF)	• Approximately 9,000 clients • 13 State Schools for the Mentally Retarded • ICF-MR certified	• 3,000 • 5 State Training Centers (ICF-MR, SNF certified)
Population in CBS	• Approximately 2000 clients in community residential settings	• Approximately 4000 clients in community residential setting	• 2400 in all community programs (residential and non-residential)	• Approximately 3,000 clients in community residential settings (defined as <15/20 beds)	• Unclear	• 7,500 in all community programs
Definition of CBS	• Opportunities for participa-tion in the community, integration into normal settings • Ideally smaller than 6 or 8 bed facility • Some debate about the size issue	• Small residential settings (<6 beds) • Local direction and control • Opportunity for integration • Dispersed sites	• Individualized services • Small, least restrictive setting • Emphasis on local control	• State definition--anything that is not a PRF • Respondent's definitions focused on providing services in a small, homelike or home setting	• State definition--anything not operated by the state • Respondents' definitions focused on small size and opportunities for integration	• Small residential settings (<12 people) • Array of services in the community • Not state controlled, direction should could from local community
ICF-MR >15	• Total of 1,200 clients in large ICFs-MR • 3 Regional Centers (PRFs) • 6 privately operated ICFs-MR average 50-60 beds/350 clients • 900 clients in PRFs	• 1,650 in PRFs • No large private ICFs-MR	• Total of 840 clients in ICFs-MR 470 clients in one PRF • 370 clients in facilities >49 beds, operated by 3 private providers	• Total of 8,700 clients in large ICFs-MR • Approximately 4,200 in 46 private ICFs-MR • 4,500 in PRFs	• Total of 10,500 clients in large ICFs-MR • 31 facilities, most larger than 40-50 beds. Range as high as 160 beds • Approximately 2,500 clients in non-PRF large ICFs-MR	• Total of 3,060 clients in all large ICFs-MR • One privately operated, approximately 60 beds • PRF beds are all ICF-MR or SNF certiified
HCBC Waiver	• Has pursued waiver aggressively • Used to convert small ICFs-MR to waiver providers • Moving to Personal Care Alternative PCA model	• Applied Jan. 1987	• Approved in 1984, but not implemented • State concerns about cost, lack of control over local programs • May reapply	• Implemented in 1985 • Approved for 1,500 people, but only serving 658 • Provides: case manage-ment, resi-dential and habilitative services, and day training	• Approved in 1985 • Maximum of 450 clients • Will reapply in 1988	• Early application was turned down • Will submit new application this year

EXHIBIT II-1 (*continued*)						
	Colorado	**Michigan**	**Nebraska**	**Illinois**	**Texas**	**Virginia**
Other T19 Waiver	N/A	• Had 1915(b) waiver for Mental Health Clinic Services--now part of state Medicaid plan • Model waiver for medically fragile children	N/A	N/A	• Model waiver serving 27 clients (Katie Beckett waiver)	• Successful waiver for personal care services--some DD, but mostly aged/disabled • Developing waiver for adult day care and technology
Case Management T19 Coverage	No	• Applied for amendment • Providers can not be reimbursed under administrative costs	No	• Interested, but concerned about being required to offer freedom of choice of providers	• Tentative plans for this	No
Private Sector Involvement	• CCBs provide the bulk of community services directly • Varies throughout the state • Concern abut entry of multi-state, for profit chains	• All AIS homes privately owned, DMH holds lease • Extensive involvement of private non-profits	• Very limited • 3 private ICF-MR providers, and some private providers of group homes and non-residence services • Some degree of philosoph-ical opposi-tion to using private sector	• Extensive, both proprietary and non-profit • Mostly large ICFs-MR and nursing homes, but most day and community providers are private non-profit	• Very extensive in ICF-MR program • 2 large for-profit chains	• Limited • Varies throughout the state
Local MR/DD Authority	• Community Centered Boards (CCBs) • Private, 501 3(c)s • Independent, but central agency trying to assert more control	• Community Mental Health Boards (CMHBs) • Public, county-related • High level of autonomy, but state does have some considerable control and influence in setting priorities	• Regional Governing Boards for MH services • Public, county-related • Very high level of autonomy	• 3 possible mechanisms for county involvement: 337, 553, 708 Boards • Statewide, this is not significant • No tradition of local government involvement in human services	• Community MHMR Centers • Quasi-public • High level of independence	• Community Service Boards (CSBs) • Public, county-related • High level of autonomy
ICF-MR <16	• None • Converted under waiver	• Alternative Intermediate Services (AIS) • 1,800 beds	• None	• Approximately 400 clients in ICF-MR <15 • 400 new beds under construction; 200 awaiting CON approval • 25-30 facilities	• Approximately 120 facilities • 800 clients	• 12 facilities <16 beds • Total capacity 200 beds
Other CRF	• Approximately 2,000 clients in non-ICF-MR commun-ity facilities • Includes a variety of group homes, foster care, and personal care alternatives	• Approximately 3,600 clients in mental health system residential programs • Others in Dept. of Social Services System	• Approximately 1,200 clients live in other community residential facilities	• Approximately 2,000 clients in CRFs • Variety of settings ranging from individual placement to facilities for 20 or more	• Approximately 1,000 clients in non-ICF-MR residence	• Approximately 100 group homes for 12 or fewer people

EXHIBIT II-1 (*continued*)						
	Colorado	**Michigan**	**Nebraska**	**Illinois**	**Texas**	**Virginia**
Family Support	• Project which includes 50 famlies	• Family Support Subsidy adopted in 1983 • $8 million for 2,000 families • Cash payment to families • $4 million addition for other family support services	• Limited according to several responders • Some in-home support services, respite care	• Client and family support for approximately 7,000 clients	• Defined as a core service, requirement to provide	• 3 localized pilot projects
Supported Employment	• OSERS grant • Rocky Mountain Training Institute for supported employment providers	• OSERs grant • Began in 1986 with 4 sites • Plans to expand statewide by 1990	• Limited	• OSERs grant • Approximately 300 placements statewide	• Limited	• OSERS grant • In early stages, not extensive placement yet
94-142 Age Range	5 - 21	0 - 26	• Date of diagnosis through age 21	3 - 21	5 - 21	2 - 21
Abbreviations Used PRF: Public Residential Facility CRF: Community Residential Facility						

There were other factors which we had speculated were likely to differentiate the high and low states, but which did not appear to do so in our sample:

- **Strong employee unions**--Strong employee unions are not necessarily associated with resistance to CBS. For example, Michigan has closed three PRFs and significantly reduced its total PRF population, yet has highly organized and vocal state employee unions. In contrast, Texas and Virginia employee unions are not considered particularly strong.

- **Litigation**--Litigation apparently is not necessarily associated with strong CBS development. Texas has had major litigation regarding PRF conditions and the need for CBS alternatives, while Nebraska's was generally considered not to be a significant factor in its CBS growth. It seems more likely that the absence of litigation reflects the lack of strong advocacy for deinstitutionalization and CBS development, as in Illinois and Virginia.

- **Use of the ICF-MR program**--As can be seen in the exhibit on state MR/DD system characteristics, there are different patterns across the six states. (For example, Nebraska has not used the ICF-MR program for small CRFs at all, while Michigan has used it extensively.) In general, however, the low-CBS states use the ICF-MR program for larger facilities and place more overall reliance on the ICF-MR program than the high-CBS states.

- **Use of the HCB waiver**--Involvement in the HCB Waiver opportunities is not necessarily correlated with high interest in CBS. The waiver has not been used by Michigan and Nebraska, and has been used by Illinois and Texas.

Examples of specific state characteristics are highlighted in the following section.

2. State Characteristics

(1) MR/DD System Administration

The lead agency in each state's MR/DD system is considered to be the state MR/DD agency. In none of the six states is this agency a cabinet-level department. In four states, the MR/DD authority is part of a department encompassing mental health and mental retardation, with MR/DD programs administered by a separate entity within the department; in Colorado and Nebraska, the MR/DD program agency is located within a department of institutions. These configurations are typical of states nationwide.

The six states are similar to each other and to other states in the complex division of responsibility among various state and substate agencies for various components of the MR/DD system. For example, the Virginia system includes the following major actors:

- **Department of Mental Health and Mental Retardation (DMHMR)**
  Administration of the PRFs
  Planning, policy-setting, and budget development
  Funding and performance agreements with 40 local Community Services Boards (CSBs)
  Payment of non-Federal share of ICF-MR costs from its budget

- **Community Service Boards**
  - Provide six core services (emergency case, in- and outpatient services, residential care, day support, and prevention/intervention) to mentally ill, MR/DD, and substance abusing individuals
  - Provide minimum of 10 percent of program costs (primarily done through contributions of county and other local governments from local tax dollars)
  - Plan and design services to be operated directly or contracted Quality assurance
  - Other services/functions as locally determined

- **Department of Medical Assistance and Services (State Medicaid Agency)**
  Administration of the ICF-MR program
  Monitoring of the ICF-IMR program, including annual inspection of care and utilization review for each resident in each facility
  Authority to decertify individual clients and deny payment for services
  Training and technical assistance for DMHMR personnel and ICFMR operators

- **Department of Health**--Licenses and inspects the ICFs-MR

- **Department of Education and Local School Districts**
  - Operates special education programs for DD children ages 2-21 years
  - Developing new initiative for transition from special education to vocational programs

- **Department of Rehabilitative Services**
  Administers traditional vocational rehabilitation services program, including services to some MR/DD individuals
  Collaborating with DMHMR and a state university to demonstrate supported employment (an Office of Special Education and Rehabilitation Services (OSERS) grant)

- **Virginia Council on Development Disabilities**
  - Prepares state plan for services to the DD population, Federal DD definition
  - Stimulates development of program strategies

- **Department for Rights of the Disabled**
  Designated DD Protection and Advocacy agency
  Also advocates for needs of disabled citizens who do not meet Federal DD definition (e.g., people becoming disabled after age 22)
  Administrative agency where the Council on Developmental Disabilities is found

A chart illustrating the Virginia system follows this page as Exhibit II-2. At the state as well as the Federal level, it is clear that developing and maintaining a coherent community service system presents major challenges in philosophical and political leadership, blending disparate funding streams, and coordinating programs which cut across multiple authorities.

Decentralized Authority

Further contributing to the complexity is the role of substate MR/DD authorities in all of the states visited except for Illinois. The responsibilities for these local authorities are generally similar to those described above for the CSBs in Virginia. With the exception of Colorado's Community Centered Boards (CCBs), local authorities which are independent private 501C3 corporations, the substate authorities are related in varying degrees to local governments, usually counties. Members of the governing boards of local MR/DD authorities are usually appointed by county or other local government officials. In addition, local governments are frequently required to contribute to local program budgets.

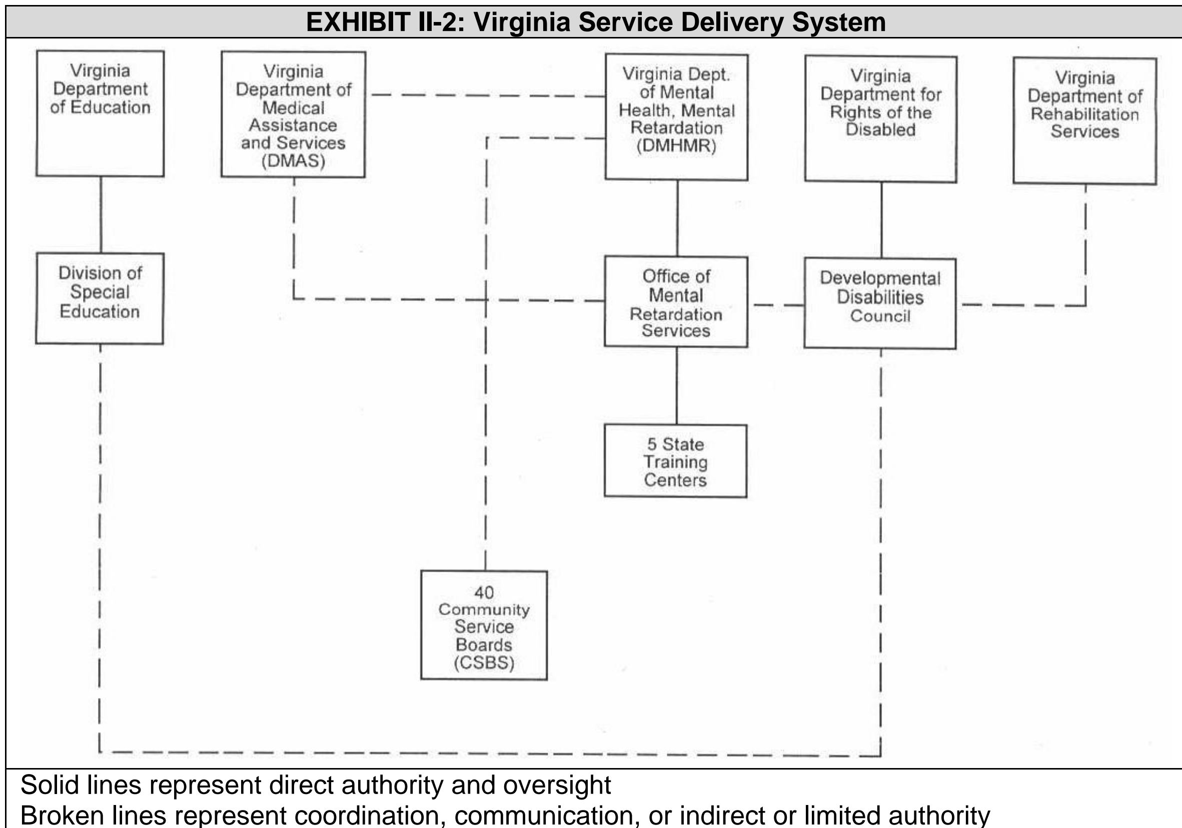


EXHIBIT II-2: Virginia Service Delivery System

Solid lines represent direct authority and oversight
Broken lines represent coordination, communication, or indirect or limited authority

In all five states with local authorities, it was agreed that there is tremendous variety among areas as to the array of available services, program priorities, clients served, local financial support, and program quality, even when statewide guidelines are in place. State MR/DD agencies in both Colorado and Michigan are attempting to exercise more control over local authorities, primarily through fiscal measures. Respondents in Nebraska, Texas, and Virginia did not report significant challenges to local authority. In all five, however, it is apparent that the state's ability to influence CBS development is limited by the degree of autonomy available to the local MR/DD authorities responsible for CBS programs.

Mental Retardation vs. MR/DD

Throughout this report, we have referred to the MR/DD population and service system--i.e., services to people with mental retardation and/or other developmental disabilities, with diagnoses such as autism, cerebral palsy, and epilepsy. Based on the current Federal definition of developmental disabilities, the MR/DD population also includes children with a wide array of conditions affecting their development such as ventilator- and other technology-dependent children, and children who have experienced head or spinal cord trauma. The central concept of the Federal definition is that it is based on the person's functional level rather than on his or her diagnosis:

> The term "developmental disability," as defined in the Developmental Disabilities Act (P.L.98-527), means a severe, chronic disability of a person which--

A. is attributable to a mental or physical impairment or combination of mental and physical impairments;

B. is manifested before the person attains age 22;

C. is likely to continue indefinitely;

D. results in substantial functional imitations in three or more of the following areas of major life activities:
   i. self-care,
   ii. receptive and expressive language,
   iii. learning,
   iv. mobility,
   v. self-direction,
   vi. capacity for independent living,
   vii. economic sufficiency; and

E. reflects the person's need for a combination and sequence of special, interdisciplinary, or generic care, treatment, or other services which of lifelong or extended duration and are individually planned and coordinated.

With the exception of the federally-funded state DD Councils and state DD Protection and Advocacy Programs, however, few state agencies use the Federal DD definition for service eligibility; in fact, none of the six states visited used the Federal definition. In four of the six states--Michigan, Nebraska, Texas, and Virginia--the lead state agency is specifically the mental retardation authority, and its responsibility does not extend to other developmental disabilities. Similar limits are in place at the community level in those states as well, with services to people with other developmental disabilities the exception rather than the rule--at least for services administered by the local MR authority (i.e., services that are available to people with other developmental disabilities are generally provided through special education, crippled children's services, Medical Assistance, etc.).

The implication of limiting service eligibility to those who are mentally retarded is that people who have other developmental disabilities may receive a less comprehensive range of services.

Definitions used for determining ICF-MR eligibility also differ from both the Federal DD definition governing state DD planning and the Protection and Advocacy requirements. Still other definitions are used in classifying the special education population and in determining eligibility for vocational rehabilitation programs. The key difference between the state and Federal levels, however, appears to be that of MR vs. MR/DD, as well as the common policy of states and local authorities to include in the service system mildly retarded people who would not necessarily meet the Federal DD definition, especially with its emphasis on severity.

It also is our understanding that such differences between Federal and state population eligibility are commonly found throughout the MR/DD system.

(2) Expenditures

The six states visited, like most states across the country, have increased their expenditures for MR/DD services and have increased the proportion of total MR/DD expenditures that support CBS as shown in Exhibit II-3 and Exhibit II-4. Nationwide, public expenditures (adjusted for inflation) rose 46 percent from 1977 to 1986, from $3.32 billion to $4.83 billion, not including local government funds. Expenditures for community services during this period rose 141 percent in constant dollars, while institutional expenditures rose only 14 percent. Although community expenditures in 1986 were still below 50 percent of total MR/DD expenditures, this percentage rose from 25 percent to over 41 percent between 1977 and 1986, despite the major expansion of the ICF-MR program for services in PRFs.

EXHIBIT II-3: National and Selected State MR/DD Expenditures: 1977-1986[1,2]

	Total Expenditures ($ in millions)			Institutional Expenditures[3] ($ in millions)			Community Expenditures ($ in millions)			Community Expenditures: % of Total ($ in millions)		
	1977	1986	% Change	1977	1986	% Change	1977	1986	% Change	1977	1986	% Change
U.S. Total	3,320.00	4,830.00	45.48	2,490.00	2,830.00	13.65	830.00	2,000.00	140.96	25.00	41.41	65.63
Colorado	43.75	51.00	16.57	25.00	25.00	0.00	18.75	26.00	38.67	42.86	50.98	18.95
Nebraska	27.47	30.42	10.74	14.15	15.00	6.01	13.32	15.42	15.77	48.49	50.69	4.54
Michigan	139.50	207.00	48.39	117.00	60.00	-48.72	22.50	147.00	553.33	16.13	71.01	340.29
Illinois	180.00	197.50	9.72	137.50	122.50	-10.91	42.50	75.00	76.47	23.61	37.97	60.83
Texas	160.0	184.50	15.31	135.00	152.00	12.59	25.00	32.50	30.00	15.63	17.62	12.74
Virginia	66.00	81.25	23.11	56.00	63.75	13.84	10.00	17.50	75.00	15.15	21.54	42.15

SOURCE: Braddock, D.; Hemp, R.; and Fujiura, G. Public Expenditures for Mental Retardation and Developmental Disabilities in the United States: State Profiles. Public Policy Monograph Series No. 29. Chicago: University of Illinois at Chicago, 1986.

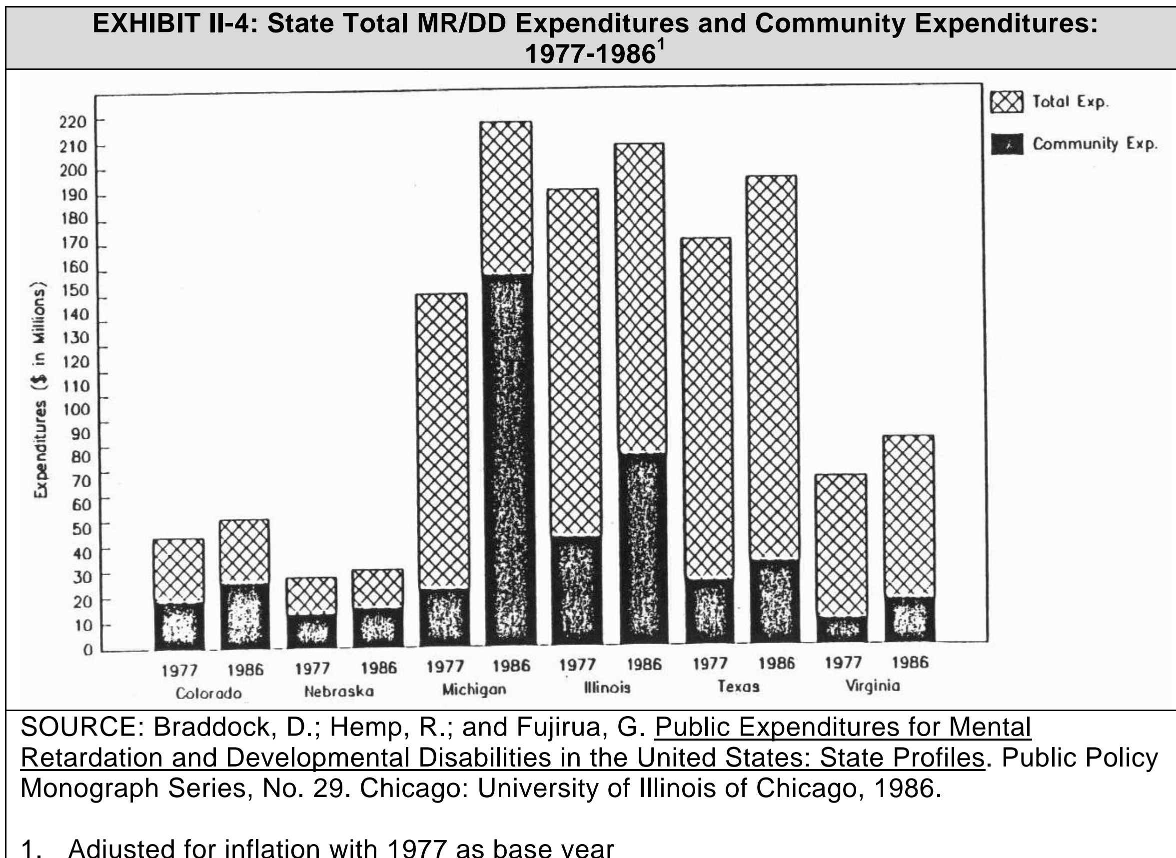
Adjusted for inflation with 1977 as the base year.
State expenditures do not include local expenditures.
Includes all ICFs-MR with more than 15 beds.

Expenditures in the six states illustrate the differences in MR/DID funding patterns between high CBS and low CBS states, as shown in Exhibit II-3 and Exhibit II-4 preceding this page. Although the three low states have increased CBS expenditures significantly from 1977-1986, as well as increasing the proportion of total MR/DD expenditures used to support community services, this proportion in all three was still below the national average of 41.4 percent: Illinois with 38.0 percent of expenditures going to CBS; Virginia - 21.5 percent, and Texas - 17.6 percent. In contrast, more than 50 percent of the public MR/DD expenditures in all three of the high-CBS emphasis states were for community services.

It should be noted that these totals generally do not include local government and other community-level expenditures as noted in Braddock (1986) from which these exhibits are adapted. (Such data are not routinely collected and reported by state MR/DD agencies.) Estimates from knowledgeable informants in Colorado were that CCBs, local governments, and other local funds provide 27 percent of the: resources for community services. Extensive local support is not necessarily correlated with high-CBS emphasis. For example, counties and other local governments in Virginia provide a minimum of 10 percent and as much as 50 percent of

local CSB budgets for MR and other community mental health services. County governments in Nebraska and Michigan also are responsible for a portion of the costs of services to county residents in PRFs, although this is not common throughout the nation. Concerns about any potential increases in local government contributions for MR/DD services were raised by several informants because of the recent loss of the General Revenue Sharing program.

EXHIBIT II-4: State Total MR/DD Expenditures and Community Expenditures: 1977-1986[1]



SOURCE: Braddock, D.; Hemp, R.; and Fujirua, G. Public Expenditures for Mental Retardation and Developmental Disabilities in the United States: State Profiles. Public Policy Monograph Series, No. 29. Chicago: University of Illinois of Chicago, 1986.

1. Adjusted for inflation with 1977 as base year

Trends in per capita MR/DD expenditures further illustrate differences between high- and low-CBS emphasis states, as shown in Exhibit II-5. Although all six states have increased per capita expenditures for community services, the three low-CBS emphasis states were well below the national community per capita expenditure average of $8.34, $6.50 (Illinois), $3.07 (Virginia), and $1.98 (Texas), while only one of the three high-emphasis states, Colorado, is below the national average at $8.05--possibly reflecting the additional 30 percent provided by CCBs and other local sources not included in the total.

EXHIBIT II-5: National and State Per Capita MR/DD Expenditures: 1977-1982[1]									
	Total Per Capita Expenditures			Institutional Per Capita Expenditures			Community Per Capita Expenditures		
	1977[2]	1982	% Change	1977[2]	1982	% Change	1977[2]	1982	% Change
U.S. Total	14.66	20.11	+38.0	10.99	11.85	7.8	3.67	8.34	+12.76
Colorado	15.14	15.79	+4.3	8.60	7.74	(10.0)	6.54	8.05	+23.0
Nebraska	17.50	18.89	+7.9	9.01	9.32	+3.4	8.49	9.57	+12.7
Michigan	15.07	22.77	+51.0	12.64	6.60	(48.0)	2.43	16.17	+565.0
Illinois	15.76	17.11	+8.6	12.04	10.61	(11.9)	3.72	6.50	+74.7
Texas	11.25	11.27	+0.18	9.49	9.29	(2.1)	1.76	1.98	+12.5
Virginia	12.35	14.23	+15.29	10.47	11.16	+6.6	1.88	3.07	+63.3

1. Adjusted for inflation with 1977 as the base year.
2. Based on 1980 census figures.

The ICF-MR Program

All six states participate in the ICF-MR program, as do nearly all states nationwide. The significant differences between the high- and low-CBS emphasis states are in their use of the ICF-MR program for medium and large (more than 15 beds) and small (15 beds or less) facilities, as illustrated in Exhibit II-6. Neither Colorado nor Nebraska uses the 15-bed or less ICF-MR program because policymakers in these two states feel that the ICF-MR model, even in a small setting, is too institutional. Michigan has used the program extensively for its AISMR residences, but plans to convert many to non-ICF-MR residences under the HCB waiver program. Michigan's use of the Alternative Intermediate Services (AIS)-MR model has been targeted to seriously disabled MR individuals. The three low-CBS states have not used the small ICF-MR program extensively; unlike the Colorado and Nebraska examples, the relative lack of small ICFs-MR in Texas, Virginia, and Illinois does not reflect the development of non-ICF-MR community residences or philosophical opposition to the "medical" model. However, officials in these three states indicated that the 15-bed or less ICF-MR program will probably be the area of fastest growth in community residential programs in the immediate future.

EXHIBIT II-6: State MR/DD Population in ICFs-MR Per 100,000 General Population							
State	State Population[1]	Residents of ICFs-MR >15 beds[2,3]	Residents of IFC-MR >15 per 100,000 General Population	Residents of ICF-MR <15 beds[3]	ICF-MR <15 per 100,000	Total ICF-MR	Total ICF-MR per 100,000
Colorado	3.2 million	1,250	39.06	0	--	1,250	39.06
Michigan	9.0 million	1,650	18.33	1,800	20.00	3,450	38.33
Nebraska	1.6 million	840	52.50	0	--	840	52.50
Illinois	11.5 million	8,700[4]	75.65	400	3.47	9,100	79.12
Texas	16.4 million	10,500	64.02	800	4.87	11,300	68.90
Virginia	5.7 million	3,060	53.68	200	3.50	3,260	57.19

1. 1987 population estimates from Kakin, et al, 1986.
2. Includes PRFs
3. Data supplied by state MR/DD agencies.
4. Does not include approximately 2,000 MR/DD people in nursing homes.

The use of the ICF-MR program for larger facilities also varies between the high- and low-CBS states, with placements averaging 36.6 per 100,000 in Colorado, Michigan, and Nebraska vs. an average of 64.5 per 100,000 in Illinois,

Texas, and Virginia. The greater use of the ICF-MR program for large facilities in the low-CBS states also is reflected in the higher per 100,000 population averages in the ICF-MR program overall, with an average of 43.3 ICF-MR residents per 100,000 in the high-CBS states vs. 68.4 per 100,000 average in the low-CBS states. It should be noted that these data do not include MR/DD people in non-ICF-MR Medicaid-certified nursing homes, a significant factor in states like Illinois where 3,000 such people have been identified.

(3) Services

A comprehensive array of services to MR/DD individuals cuts across many agencies and responsibilities. The six states we visited, although varying considerably with each other and within the states themselves as to the degree of CBS development and availability, all included the following services.

- **Residential**
  - Large congregate care institutions
  - Small-medium congregate care facilities
  - Small family-sized CRFs
  - Semi-independent living units (i.e., some supervision provided)
  - Mix of public and private ownership, and mix of for-profit and not-for-profit among the private providers

- **Habilitation Programs**
  - As part of residential services (daytime, evening, or both)
  - Offsite day programs for people living in residential facilities or in their own homes
  - Prevocational programs (May be considered part of vocational or educational services)
  - Adult activity programs (May be considered part of vocational or educational services)
  - Offsite programs generally provided by public or private not-for-profit agencies

- **Vocational Services**
  - Assessment and counseling (through state Vocational Rehabilitation (VR) services or MR/DD)
  - Vocational training (general preparation or specific) preparation for competitive employment
  - Sheltered employment--All but moderately/mildly disabled persons are still likely to be limited to sheltered workshops and work activity programs, even in more progressive states
  - Various models of supported employment
  - Mix of public and private not-for-profit providers, mostly private

- **Education**
  - Special education services for various age ranges and with mixed levels of integration of more severely involved students
  - Relatively limited adult education
  - Widespread use of early intervention/infant stimulation in most states, either through education or local MR/DD service system

- **Supports to Families**
  - Home training for family members/parents
  - Respite care (limited availability)
  - Some subsidies available
  - Information and referral
  - Most commonly provided by local MR/DD authorities or their contract agencies

- **Case Management**
  - Available to both families and individual clients
  - Generally a mandated service or nearly so
  - Usually the responsibility of the local MR/DD authority
  - May also be some additional case management by individual providers

- **Other**
  - Medicaid coverage (general health care, acute care, ICF-MR, and other long-term care services)
  - State SSI supplement (40 states)
  - Advocacy

The tremendous growth in MR/DD services, especially at the community level, has been associated with families' abilities to work with local and state officials to develop opportunities for MR/DD young people. In many cases, families initiated community programs to provide alternatives to placement in state institutions. Since most MR/DD individuals never were placed in state facilities, however, the real impact of CBS growth has been in the promotion of the development of each individual's potential for independence.

How Service Configurations Vary Among States

Services in the three high-CBS states are different from those found in the low-CBS states as follows:

Issue	High CBS Emphasis (CO, MI, NE)	Low-CBS Emphasis (IL, TX, VA)
Availability	More CBS available across the board/more served	Less CBS available/fewer served
Size/Type of Residential Services	Higher percentage of small and noncongregate options	More reliance on large and medium congregate care facilities, even in community
Client Disability	More CBS available to severely and multiply disabled clients/relatively less difference between CBS and PRF populations	Major gaps in CBS especially for severely and multiply disabled/CBS population generally much less disabled than PRF population
Deinstitutionalization	Early commitment to reduce PRF population	Relatively late in efforts to reduce PRF population

The emphasis on CBS in-service programs is illustrated by Colorado's plans to expand options that are considered even more likely to promote individual development than the present system. The community residential system serves approximately 2,000 people in a variety of settings: follow-along supervision, minimum and moderate supervision group homes, intensive developmental group homes, social/emotional group homes, and behavior management group homes. Under the HCB Waiver, Colorado is adding Personal Care Alternatives (PCAs) to this repertoire. The objective of the PCA program is to allow the DD individuals to establish a home in the community rather than having to move as they "progress" through a series of facilities. Three models are being used, with staffing and support varied to meet individual needs. The host home model employs a family to have a DD person live in their home. In the peer companion and independent apartment models, the client lives with a disabled or nondisabled person and receives the necessary degree of support services. The PCA program is available to clients with a wide range of disability levels, including the severely and multiply handicapped. Simultaneously, the state Division of Developmental Disabilities is working with other agencies and the local MR/DD authorities for significant expansion of supported employment programs. In contrast, the low-CBS states are still thinking primarily in terms of large (8-15 person) group homes as the way to meet CBS objectives, although Texas has implemented policies limiting ICF-MR development to six-bed facilities.

High-CBS states also differ from low-CBS states in their use of the Medicaid program for CBS overall; Nebraska has chosen not to use Medicaid for CBS, while Michigan has used It extensively to expand community services, and Colorado has used the waiver to maintain growth in its CBS. In contrast, the low-CBS states have primarily used the ICF-MR program, and have focused on funding larger congregate facilities as illustrated in Exhibit II-1 above.

Other service system characteristics, however, are found to a varying degree among the six states regardless of CBS emphasis. All are placing increased emphasis on supports to families and supported employment initiatives. There also is no general

correlation between CBS emphasis and private sector involvement, with the exception of the influence of large congregate care providers in the low-CBS states.

Major Service Caps

There also was considerable uniformity across the six states in their identification of gaps in the MR/DD service system. The major gaps mentioned include the following:

- Services for youth requiring special education, especially day programs/ supported employment
- Services in rural areas
- Services for more challenging clients (even where some are available, more are needed)
- Programs to enable technology-dependent children to remain in their own homes (model waiver not sufficient to meet demand)
- Age-appropriate programs for elderly DD people
- In the four MR (i.e., not MR/DD) states; services for people with other developmental disabilities

The primary difference between high- and low-CBS states was that most informants in Illinois, Texas, and Virginia described across-the-board gaps in community services, as well as gaps in relation to particular population subgroups.

(4) Quality Assurance

Responsibilities for quality assurance in the state MR/DD system are typically divided among several agencies, reflecting the diverse responsibilities for the administration of service programs. For example, in Texas, quality assurance responsibilities involve the following actors:

- **Texas Department of Mental Health and Mental Retardation (TDMHMR)**
  - Oversight of local community MH/MR program
  - Monitoring and quality assurance in the state schools and community programs
  - Monitoring of non-ICF-MR residential facilities

- **Community Mental Health and Mental Retardation Centers**
  - Oversight of service provided at the local level based on performance contract with TDMHMR
  - Governance provided by Center Boards of Directors
  - Monitoring of individual client programs by case managers (also provided by case managers in state PRF outreach programs in areas without a center)

- **Department of Human Services**
  - Promulgating regulations for the ICF-MR program
  - Application of financial sanctions against ICF-MR providers

- **Texas Department of Health**
  - Certification of state PRFs and licensing of all non-PRF ICFs-MR
  - Inspections of care for residents of PRFs/all ICFs-MR

- **Texas Planning Council for Developmental Disabilities**--Service Evaluation

- **Texas Rehabilitation Commission**
  - Oversight of vocational rehabilitation services
  - Quality controls in administration of the Supplemental Security Income (SSI) and Social Security Disability Income (SSDI) programs

- **Texas Education Agency**--Oversight of special education services provided by the Independent School Districts

- **Early Childhood Intervention Program**--Oversight is provided by a parent representative and representatives from four state agencies: TDMHMR, Department of Health, Texas Education Agency, and Department of Human Services

- **Advocacy, Inc. (Designated DD Protection and Advocacy Agency)**
  - Legal and protective advocacy services for individuals
  - System advocacy

Additional oversight is provided by the judicial system in ongoing monitoring of the implementation of the consent decree of the Lelsz V. Kavanaugh suit mandating deinstitutionalization of three Texas PRFs; Association of Retarded Citizens (ARC)-Texas has been involved actively in the litigation, and attempts to monitor Its compliance as well as to call the state's attention to other quality issues.

The Texas quality assurance profile is fairly typical of states in general as well as the six states visited, although states vary in specific divisions of responsibility among agencies and in mechanisms for monitoring non-ICF-MR community residences, with relatively few states having a comprehensive system of formal licensure of non-ICF-MR group homes. In many states, some DD people also live in "foster homes"--more accurately described as board and care homes, usually operating on a proprietary basis and housing several mentally disabled individuals--which are licensed and monitored by the public social services agency. As required by the Keyes Amendment, states specifically must provide assurances of systematic monitoring of board and care homes with more than one SSI recipient who have designated the operator/proprietor as representative payee.

The Case Management Debate

In Texas and two other states, issues were raised regarding the effectiveness of case management in quality assurance. Typically, a case manager's responsibilities include the monitoring of program services to be sure that: the individual client is receiving needed services as have been arranged (and presumably tailored to meet individual program goals); services are meeting basic standards of quality; and changes in providers are made as appropriate to respond to changing needs of the individual, or when It appears that a current provider is unable to meet those needs. The issue that has arisen is the question of <u>conflict of interest</u> when the case management is provided by the same local MR/DD authority that provides or administers the services. Informants in Texas, Nebraska, and Colorado noted pressure on the state to <u>separate</u> case management functions from the local CBS agencies, based on the premise that client interests cannot be adequately protected by case managers who work for and with the providers whose interests may conflict with the client's--for example, retaining a higher functioning person in a more sheltered setting than necessary because he/she is easier to work with (and therefore also less costly) than more disabled clients. Illinois officials indicated that they plan to move to an independent case management system, rather than continuing to contract for case management with providers of other services. Advocates for the present system, however, argue that case management responsibilities to the individual are kept paramount and that their being part of the overall agency benefits the clients by having better case manager access to and influence on program services. The resolution of this issue was noted as a factor likely to affect future CBS development by several respondents.

A related issue in quality assurance through case management is the ability to control provider reimbursement. Case managers have relatively little ability to determine reimbursements in the states visited or in states in general, especially in systems where the local case manager is not defined as the single point of entry to publicly supported services. For example, in most of the states visited, individual families can place DD relatives in private Medicaid facilities (generally large congregate care facilities) without going through the local assessment and case management system. In three of the states visited there were tensions between administrators of these facilities and the local MR/DD authority as to oversight responsibilities, with the large facilities tending to recognize only the traditional Medicaid quality assurance mechanism.

3. Major Influences on Community Service System Development

Informants in all six states described an array of factors which had influenced CBS development--both incentives and barriers--in their respective states. There also were extensive consensus within individual states as to which factors had been significant and what their influence had been. For example, although many of the key informants in Nebraska placed themselves at the forefront of the move to develop

community services beginning in the late 1960s, there was strong consensus that the following factors contributed to Nebraska's leadership in CBS development:

- Involvement of parents and community members in the early stages of CBS development
- A strong, well-organized Association for Retarded Citizens
- Leaders in the field of community services, both theory and practice, who are involved in Nebraska
- Support from elected officials on both the state and local levels
- Ability to articulate a value-based statement of what mental retardation services should be
- Structural factors:
  - Small state population
  - Simple political system (unicameral legislature)
  - Small financial investment in the institutional system
- Availability of funding for CBS development
  - Title XX funds
  - State funding of startup costs
- Strong and widespread philosophical commitment to CBS

A lawsuit filed in the early 1970s was considered to have made some contribution to CBS development, but informants noted that the litigation came after Nebraska had made a commitment to CBS and had developed a framework for financing and delivering those services through the 1969 inter-local Agreement Act. The only major factor identified as a barrier to CBS expansion was the state's recent economic difficulties. Despite these problems, however, support for CBS is strong enough that the mental retardation services budget received a slight increase in the last legislative session even as budgets for nearly all other state services were cut.

Not surprisingly, informants' descriptions of major influences in low-CBS emphasis states tended to focus more on inhibiting factors along with incentives. Although resource constraints were identified as an issue, many of the factors cited by informants as having inhibited CBS development had more to do with philosophical commitment and the state's political environment. For example, there was general consensus among the Texas informants that the following factors had been barriers to significant growth in CBS services:

- The legislature has been reluctant to fund human services and for MR/DD services; available resources have not been adequate to fund both institutional and community services.

- Several respondents cited the conservative political ideology which emphasizes independence, family privacy, and limited government as a major barrier to community services.

- The low level of public awareness has been an obstacle. Because there is little experience with community services In Texas, the public and many members of the legislature do not believe community services will work.

- Opposition from state school superintendents who have influence with the legislature and from Parents Associated for the Retarded of Texas (PART), the pro-institution parent group.

- Fears that reducing the size of state schools will mean lost jobs for state employees, with severe economic consequences in areas where the state school is a major employer.

- Several respondents commented that the institutional bias of the ICF-MR program continues to encourage Texas to emphasize institutional services.

- The absence of a reliable Federal funding stream for community-based, nonresidential programs.

Federal Program And Policy Influences

Nearly all informants described Federal programs and policies, along with other factors, as important influences in the development of the state's MR/DD system. The Medicaid program, particularly the ICF-MR component, was the most frequently mentioned influence, reflecting the extensive use of the program to support residential and related services. The significant variety in the ways the six states have used the Medicaid program to finance MR/DD services reflects the individual state's approach to MR/DD services and the Medicaid program in general, rather than program designs dictated at the Federal level. Differing rates of use for large facilities illustrate this trend. It also should be noted that although the Federal financial participation (FFP) in Medicaid is attractive to states, and candidly cited by several informants as a major factor in program design, states have not chosen to take advantage of all the Medicaid funding that is already available, such as funding for small community residences or for day programs under the clinic services option. A few informants specifically noted concerns about the Medicaid program's open-ended feature in relation to expanded obligation of state resources for the non-Federal share.

The major influences of the ICF-MR program included the following:

- Program requirements for PRFs forced states to raise standards, lower staffing ratios, and improve physical plants. High-CBS states tended to use depopulation and CBS development as part of these initiatives, while low-CBS states were likely to have focused more on PRF improvements.

- Existing private facilities were converted to ICFs-MR, especially large congregate care facilities in the low-CBS states of Illinois and Texas. (Although some smaller CRFs were converted in Michigan, Illinois, and Texas, this was not done on a major scale as has occurred in a few other states, most notably New York and Pennsylvania).

- Recent influence of the "look behinds" appeared to refocus attention on the need to maintain standards or risk loss of FFP. Even though the "look behinds" were sometimes painful for state officials, and led to some concern that required investments in PRFs and other large facilities would divert resources from CBS expansion, nearly all key informants described them as a positive influence.

The Section 2176 HCB Waiver was considered to have been a major influence in three of the six states, cutting across the CBS continuum. In Colorado, the Waiver was credited with having preserved the CBS expansion momentum at a point when the state's economy was in recession; as noted above, Colorado has used the Waiver to develop its PCAs model and to convert small ICFs-MR to non-ICF-MR CRFs. (Michigan plans to use its proposed Waiver similarly.) Illinois and Texas officials indicated that despite their inability to implement the Waiver at the full level approved, it has been instrumental in stimulating CBS development and in demonstrating the effectiveness of CBS. It should be noted that the three remaining states all plan to use the Waiver in the future, specifically to expand CBS availability.

Only one of the states has used other options of the Medicaid program extensively in its CBS system. Michigan covers some offsite day programs under the clinic services option, is developing coverage for case management as a discrete service, and has worked with the community mental health services system to ensure that these local MR/DD authorities are certified as Medicaid providers (all but one of the 55 local authorities are so certified). Michigan, along with Texas, also has obtained a model, or "Katie Beckett" waiver for services to severely disabled children; however, this was not considered a major influence.

The availability of client SSI funds was not mentioned frequently, but was identified by some informants in high-CBS states as a factor in CBS development. This was particularly the case in the high-CBS states, where SSI contributions from clients have been used in combination with Section 8 rental subsidies to finance non-ICF-MR alternatives. The Title XX/Social Services Block Grant (SSBG) program was a major .influence on the development of the Nebraska CBS system

because of the availability of financing that could be used flexibly to meet needs defined at the local (Regional Governing Board) level. Title XX/SSBG also was used in Illinois and Texas (low-CBS states) to expand CBS in the late 1970s early 1980s. For example, Illinois spent an average of over $25 million in SSBG funds per year on MR/DD community services for the three years 1979-1981. Currently, however, all three states have reduced their use of Title XX/SSBG, and its influence is minimal.

The Developmental Disabilities Act

All six states have active Councils on Developmental Disabilities, funded through the Federal DD Act grant program. Informants reported varying degrees of involvement of the Councils in promoting CBS and advocating for more integrated and individualized services. Requirements for inter-agency cooperation in DD planning were noted in providing information on the strengths of Council activities, but not singled out as having had a major influence. It was clear that the Federal DD definition requirements for the Council and State Protection and Advocacy Agency had not been a major influence in the four states which focus on mental retardation rather than MR/DD. Some DD Council representatives in low-CBS states noted the political-reality limitations on their ability to push for major changes such as the reforms contained in the community and Family Living Amendments (CFLA). An informant in one state reported that the DD Council's endorsement of the CFLA proposed in the 98th Congress was deeply resented by a major private provider of MR/DD congregate care services who opposed CFLA and was able to generate thousands of letters to the governor protesting the Council's action.

Programs Not Administered By HHS

Informants in all six states noted the impact of P.L. 94-142, the Education for All Handicapped Children Act, in the expansion of community services. Although implementation of P.L. 94-142 has not always meant the degree of integration or "mainstreaming" that some had envisioned, there was general consensus that the program has led to expanded opportunities for MR/DD children and young adults, as well as preventing institutionalization. There also was consensus across the states that the success of P.L. 94-142 was placing major strains on the adult MR/DD service system, as young adults "age out" of special education and find no programs available. Waiting lists of "aging out" students were noted as a major issue in all six states.

There was lack of consensus on the influence of federally supported VR programs in CBS development. VR agency representatives tended to describe programs as reaching significant numbers of MR/DD people in the community, while most other informants indicated that VR programs seldom served more severely handicapped MR/DD clients (one VR agency representative presented this perspective in consonance with other informants in the state). The influence of the Independent Living program was noted by officials in only two states, perhaps because it was seen as serving the non-MR disabled population in systems where the primary focus is on mental retardation.

The Federal supported employment initiative was noted by several informants in each state. Four of the six states--two of three in each category--have grants from OSERS to develop supported employment services, as noted in Exhibit II-1 on state characteristics. Interest in supported employment was also expressed in Nebraska and Texas, the two states without OSERS grants, especially by representatives of the Association for Retarded citizens. Federal leadership from the Administration on Developmental Disabilities and OSERS in promoting supported employment seemed to be helpful to states in developing initiatives at the state level. On the other hand, some informants, and other MR/DD system representatives, expressed considerable skepticism regarding the feasibility of supported employment as a major vocational service objective despite its attractiveness. The major questions involved responsibility for long-term costs, recruitment of employers in rural areas or areas of high unemployment and declining economy, and program effectiveness for severely and multiply disabled individuals.

Other Influences On State MR/DD System

The primary influence on the development of CBS cited by informants in the high-CBS states was the broad-based support and philosophical commitment to community services. Virtually all informants in the three states believed this support and commitment to have resulted in state legislative appropriations for CBS, significant depopulation of PRFs, pro-CBS litigation, and widespread CBS development that was generally supported the community level. Informants in all three high-CBS states identified an informal coalition of parents, advocacy organizations, political leaders, and CBS providers who, along with policymakers in the state MR/DD agency, had helped shape the MR/DD system.

In contrast, the lack of such coalitions or their relative weakness was noted by informants in the three low-CBS states as a major factor in the relative lack of CBS development. At the same time, informants in these states reported that there continues to be strong political support for large MR/DD institutions, both PRFs and large private facilities. In Texas, for example, several of the PRFs, or "State Schools," are located in rural areas where they are a primary source of employment and support for the local economy; state legislators representing these areas understandably resist efforts that could lead to PRF closure. Private providers have also wielded considerable influence. For example, private providers and the nursing home lobby in Texas were successful in persuading the legislature to pass a law mandating that HCB rates be limited to a rate that is less than the average reimbursement rate for community ICF-MR providers; some informants felt this had hampered implementation of the Waiver.

Informants across all six states cited the states' economy as a major factor in shaping their MR/DD systems. Five of the six states--all but Virginia--reported significant economic problems which have increased the difficulties of financing CBS development. Informants noted various ways that this influence is felt, including

pressures to obtain maximum FFP, (conversely) to limit FFP in order to avoid state match demands, to defer new initiatives, and to avoid demonstration program grants which are seen by some as likely to leave the state with an obligation to continue the support when the demonstration funds cease. The negative effect of the state's economic difficulties on CBS development was clearly stronger in the low-CBS states, where political strength is still developing, and less influential in the high-CBS states. As noted above, despite extreme problems in the economy, Nebraska's appropriations for CBS have continued to increase even as most other programs have been cut back.

The availability of resources for new service development was cited as a significant factor in most states. Some high-CBS states found ways to help substate MR/DD authorities and local providers develop services, for example, by appropriating special funds to cover startup costs (Nebraska), or by making additional funds available to local authorities. Texas has developed a major capacity-building initiative through its "Prospective Payment System" which makes $55.60 per day available to the local mental retardation authority for each client who returns to the area from a state PRF. Overall, however, the lack of startup funds was more frequently reported as a barrier, especially in low-CBS states. Several informants expressed concerns regarding their state's ability to maintain quality care in PRFs while simultaneously developing major expansions in community services.

The relationship between the state Medicaid and MR/DD agency was noted as a factor in all six states as well. Information in the three high-CBS states reported generally good working relationships and an overall consensus on Medicaid program objectives in relation to MR/DD individuals. For example, respondents in Michigan reported that the Department of Mental Health (the lead state MR agency) and the state Medicaid agency have worked together effectively on developing Medicaid-financed MR services. Moreover, views in the two agencies about appropriate goals for MR/DD services appeared to be compatible. Similar relations and a growing consensus had reportedly developed recently in one of the three low-CBS states. Informants identified this as having contributed to such activities as small ICF-MR development and effective use of waivers to expand CBS. In the other two low-CBS states, informants noted disagreements between the MR/DD and Medicaid agencies regarding areas such as target population, degree of medical orientation, and use of the Waiver. For example, in one state, the ICF-MR target population considered appropriate by the Medicaid agency was MR/DD individuals with significant health care needs, while several other Informants saw the need to serve a wide range of MR/DD individuals in the ICF-MR program, emphasizing habilitation rather than medical care.

Finally, informants in all six states reported several examples of intrastate variety that Influences their respective MR/DD systems. Many informants noted that rural areas have particular difficulties in meeting CBS development objectives, even when support is not the issue, due to lack of financial and programmatic resources. In contrast, community services in metropolitan areas and/or

around universities were reported to be much more extensive and progressive, in both high- and low-CBS states. All states reported major differences in the availability of financial support from local governments and other local sources; where minimum local match is required, political support and commitment has meant contributions well above the minimum in some areas, and correspondingly better services.

In all but Illinois the considerable autonomy of local MR/DD authorities also has contributed to significant variation within states regarding CBS design and availability. Not surprisingly, several informants reported tensions between states and local MR/DD authorities, and in some cases with local governments, regarding state control vs. local autonomy. Another local autonomy issue cited as a factor in two of the three low-CBS states was local zoning authority. Several informants in these states reported that in the absence of legislation at the state level that restricts local zoning practices which discriminate against CRFs, community opposition was strong enough to use restrictive zoning rules to keep CRFs out.

4. MR/DD System Goals

There was general consensus within individual states and across the six states on goals for their MR/DD systems, regardless of where they are currently:

- Expanded development of community services, especially in integrated, normalizing settings
- Significant increases in supports to families and avoidance of out-of-home placement
- Continued reduction of PRF populations
- Development of supported employment programs
- Improvements in quality assurance efforts

The objectives for implementation of these goals varied, however, in relation to the state's efforts to date. Informants in high-CBS states tended to identify objectives such as closure of state PRFs and total or nearly-total PRF depopulation; small noninstitutional community alternatives for severely and multiply-handicapped MR/DD individuals or people with "challenging behaviors;" preference for non-ICF-MR models for community residences, such as Colorado's PCAs; and supported employment as a significant alternative to sheltered employment. Informants in the low-CBS states, especially Illinois and Texas, were more apt to describe such objectives as expanded group home and small ICF-MR development, gradual PRF depopulation, and meeting widespread needs for vocational and day programs. Although some informants in these states advocate the same kinds of objectives as those described in the high-CBS states, these views tended to be in the minority, with the exception of supported employment. There also was a greater tendency in low-CBS states for informants to see congregate care as a desirable alternative for more severely disabled individuals, with the more integrated services

targeted primarily to individuals with mild or moderate disabilities. In addition, informants in high-CBS states were more apt to focus on client-based service development, while informants in low-CBS states tended to identify facility development needs.

There was considerable emphasis in all six states on cost-effectiveness as a major objective in MR/DD services. From the state perspective, this sometimes included pressures to seek FFP to support services, in particular through the Medicaid program. Several informants, however, including state officials, expressed the hope that states could work with the Federal Government to use the Medicaid program cost effectively to tailor services to meet individual needs and to avoid expensive out-of-home placements. Representatives in all six' states noted that state MR/DD budgets are scrutinized in detail by both the executive agencies and the legislature for cost containment strategies.

There also was a sense of optimism in three low-CBS states regarding their CBS development goals. State agency representatives and other informants in these states described an assessment of the current situation as "the time being ripe" for support to develop an expanded CBS system. These assessments were generally based on such factors as support from the governor, improvements in relations among involved agencies, and a sense that it is MR/DD's "turn" for attention and support in the legislature.

It should be noted that there were a range of opinions in all six states as to the appropriate MR/DD system goals and the strategies by which goals should be implemented. Each of the six states has an association of pro-PRF parents and advocates who object to plans that would include total PRF depopulation. Each state has some large facility private providers who advocate continued support for congregate care and sheltered workshop providers who feel threatened by pressure to convert services to supported employment. Tensions between advocates for noninstitutional, integrated services for MR/DD individuals and those who see a major continuing need for institutions and other traditional service models were expected to continue in all the states visited. The primary difference between the high- vs. low-CBS states was the relative strength of the two perspectives.

III. FEDERAL POLICY PERSPECTIVES

Most of the informants had perspectives to offer on Federal policy. Their comments focused on two areas: (1) how Federal policy influences or has influenced their state's MR/DD system; and (2) what changes in Federal policy would be helpful to the state in expanding CBS development. In this chapter, a summary of these perspectives are followed by a brief analysis of how states might be expected to respond to changes in Federal policy of the kind being considered by the Working Group.

1. State Perspectives on Federal Policy Influences

Federal policies were seen by state informants as one of several influences on MR/DD systems. This section presents a summary of views on Federal policy influence in promoting an overall orientation toward community MR/DD services, and influence on the system's administration, client eligibility, services, financing, and quality assurance.

(1) Influence On CBS Orientation

To date, Federal policy appears to have had minimal influence in promoting an emphasis on community services. The notable exception has been the Medicaid HCB Waiver program, which was cited by several states as significant in their CBS development and expansion efforts. The small ICF-MR program had been a major factor in support of CBS development in three of the states. However, two of the three, both high-CBS states, are in the process of reducing the use of the program through the Waiver, Colorado has in fact completed its conversion of small ICFs-MR to non-Medicaid facilities. The influence of the Developmental Disabilities Act and other Federal programs in promoting greater emphasis on CBS is unclear. Although several examples of pro-CBS activities of DD Councils were cited, it was not clear to what extent these activities had been shaped by Federal program requirements or in turn had been a major influence on state MR/DD systems, as DD Council influence was not cited as a factor in CBS development by the informants.

Several aspects of the ICF-MR program and the availability of FFP were primarily perceived to have discouraged CBS. For example:

- The original ICF-MR standards and the more recent "look-behind" effort encouraged large investments in capital improvements in PRFs and subsequent pressure to continue using PRFs.

- Pressure to maximize FFP encourages use of ICFs-MR even if other residential programs would be more appropriate for clients when the alternatives would require 100 percent state financing.

- ICF-MR regulations promote the use of large facilities because of economics of scale--some physical plant and staffing requirements make small ICFs-MR economically infeasible.

The Individual context of each state, however, appears to have been a major factor in determining response to FFP. For example, all three of the high-CBS states chose to depopulate PRFs and develop CBS as a major strategy for meeting ICF-MR standards and retaining FFP for their PRFs; the three low-CBS states, given the same options, chose to emphasize investments in PRFs.

Federal policies In special education, in particular the implementation of P.L. 94-142, also were seen as having promoted CBS orientation, although several informants noted differences in the degree to which MR/DD students, especially those with multiple handicaps, were Integrated with their nondisabled peers. There also were noticeable differences among the states regarding age ranges covered through the education system and services provided, given the latitude provided to the states in designing their approach to P.L. 94-142 implementation. The primary impact cited across the six states was the growing pressure to expand community services to meet the needs of special education students leaving school, and the increased activism of parents whose expectations have been raised regarding alternatives to institutionalization or total dependency on family members for activities and assistance.

The Supported Employment initiative was seen as promoting CBS development as well. The demonstration, training, and technical assistance opportunities were generally regarded as helpful in enhancing CBS orientation. It should be noted, however, that interest in supported employment was tempered in most of the states by observers who questioned its feasibility on a large scale.

(2) Influence On Service Organization And Administration

Federal policy was not considered a significant influence on the states' service organization and administration. Two exceptions noted were in the restriction of program responsibilities to the designated state Medicaid agency, and the difficulties in some states in developing consensus between the MR/DD and Medicaid agencies on how the Medicaid program can best be used for services to MR/DD individuals.

It should be noted that there are no Federal policies with extensive requirements for MR/DD service organizations and administration comparable to, for example, requirements in the Older Americans Act for both State Units on Aging (SUAs) and area agencies in aging (AAAs). The DD Act requirements for state DD Council composition and related state plan requirements, however, are somewhat

analogous to the policies governing SUAs. As noted above, however, the Council's influence on the state system as a result of these policies is unclear.

(3) Influence On Client Eligibility

The primary Federal policy on client eligibility that was cited repeatedly was the requirement under the Medicaid program that limits eligibility to people in institutions, either because of parent-deemed income provisions or because needed services could only be reimbursed by Medicaid if provided as part of an ICF-MR program. Informants in all six states noted that families who wanted to keep even severely disabled relatives at home were frequently unable to do so because of the lack of resources and the ineligibility for Medicaid. It should be remembered that only two of the states have used the Medicaid Clinic services option to support habilitation services, with MR/DD adults in the other four states therefore having essentially no access to Medicaid services other than covered physical health care, unless they live in an ICF-MR or are served under the HCB Waiver.

The Federal DD definition appears to have had little effect on client eligibility. The primary service system in four of the six states is a mental retardation rather than a MR/DD system. In addition, it was clear from discussions with state informants that many of the mentally retarded people--primarily adults--who are already in the service system are mildly retarded individuals who may or may not meet the Federal DD definition.

Eligibility issues were raised by some informants regarding the interpretation of "need for active treatment" and of criteria for the SSI and the SSDI programs. The questions raised were generally focused on consistency in interpretation and the need to understand the relevant Federal policies rather than the impact of the policies themselves. Informants indicated that it was still too early to see if eligibility problems in the disability review process have been addressed with the recent changes. Finally, it should be noted that states have different eligibility criteria for different components of their MR/DD systems, with some components being more strongly influenced by Federal policy than others. For example, despite some differences among state agencies' administration of the Federal SSI and SSDI disability review programs, the eligibility for these programs is strongly influenced by Federal policy. In contrast, there are many MR/DD programs run by state agencies with little or no FFP, in which states set eligibility criteria virtually without Federal policy influence. The overall MR/DD service system includes many components with minimal Federal funding or regulation, such as the Michigan Family Support subsidy program. Even where Federal eligibility criteria exist, latitude in their interpretation frequently contributes to differences among, and even within, states as to who is served.

(4) Influence On Services

The ICF-MR program is the primary influence on the services being provided to MR/DD individuals. The emphasis on active treatment and the definitions of covered

services were given mixed reviews by the states. On the positive side, most informants felt the concept of active treatment (as opposed to custodial care) was helpful in designing services, as is the emphasis on individual program planning. Restrictions against coverage of educational and vocational program services, especially when narrowly interpreted, were seen as having a negative effect on services design. Several respondents also noted the current confusion over the definition of active treatment. The policies permitting optional standards for ICFs-MR under 16 beds were not mentioned as significant in shaping services.

The Federal policy Influence on who provides services appears to be minimal. Although Medicaid requires freedom of choice and that providers meet various standards to be certified, current policies do not seem to have affected the mix of public and private providers, for-profit and not-for-profit providers, or the level of competition; the extent and nature of private sector involvement has been shaped primarily by the individual state's policies and regulatory environment. For example, in three of the states, concerns were expressed that the state Medicaid agency's certification of large for-profit congregate care facilities was in conflict with goals for integrated community services.

(5) Influence On Financing

The primary Federal policy influence on financing has been the availability of FFP. It was clear that FFP is a factor in how states finance their MR/DD system, but clearly not the only factor or even necessarily the major factor. Even when Federal income maintenance funds provided to individuals are included, Federal funds represented less than 54 percent of MR/DD public expenditures--not including special education--in four of the six states. When SSI and SSDI are excluded, all six states fall below 50 percent use of FFP for their MR/DD system.

The Federal policy influence in rate-setting methodologies, primarily relevant to the Medicaid programs, was not explored. Concern was raised in general that some Medicaid policies increase program costs, as noted above. The HCB and model waivers were generally seen as more cost effective ways to finance services, although some informants noted financing constraints within the waiver regarding the interpretation of cost comparison formulas.

(6) Influence On Quality

Federal policy was widely considered to have a strong influence on program quality in the ICF-MR program, especially with the "look-behind" surveys. State ICF-MR review processes also influenced quality. However, the "look-behinds" also were a source of tension in some states over interpretations of Federal policy. Other Medicaid quality assurance efforts were mentioned by some informants such as the activities of the Regional Office (Region V) in reviews of skilled nursing facilities (SNFs) and Intermediate Care Facilities (ICFs) in Illinois which led to the identification of 2,800 to 3,000 inappropriately placed DD nursing home residents.

Other Federal policy influences on program quality and quality assurance mechanisms were not identified, although undoubtedly the DD Protection and Advocacy program, Section 504, P.L. 94-142, and other civil rights protections are a factor. States vary in the divisions of responsibility for quality assurance seemingly without regard to Federal policy requirements, with the exceptions of the state Medicaid agency designation.

2. Implications for Federal Policy

The analysis of state perspectives on the factors which influence their MR/DD systems and their implementation of CBS development objectives revealed various implications for Federal policy. Informants in all six states were forthcoming in their discussions of Federal policy influences, changes in Federal policy that were considered helpful to CBS development, and policies that they thought would inhibit such development. There was considerable consensus on these perspectives within individual states and across the six states. Although the description of the potential state responses to changes in Federal policy is, of necessity, speculative in nature, the relative degree of consensus on policy perspectives may indicate that the projected responses summarized at the end of this section are on target.

(1) Federal Policy Perspectives

Informants across the six states, including advocates for institutional and congregate care within the services continuum, were interested in Federal policy changes that would help their state expand its community services system. Most informants were particularly interested in policies that would promote the following: services which emphasize natural homes or homelike residences well integrated into the community; supports to families; and a full range of habilitation, education, developmental, and vocational services. There was widespread support for the following principles:

- **Increased flexibility to states** in the ways Medicaid can be used to support community services
  - In-home services to severely disabled children that would not be dependent on model waiver procedures
  - Coverage of appropriate educational and vocational program services (e.g., supported employment)
  - HCB Waiver either continued indefinitely or made a regular optional program (although some informants were concerned that fiscally conservative policymakers would be less likely to pursue the HCB approach If It was for an optional program)

- **Maintain or expand FFP**

- Expand FFP availability for low-CBS states needing to develop services, at least over a short-term transitional period
- Stabilize FFP/increase state's ability to predict how much FFP will be available
- Some support for Medicaid "cap" in exchange for significant Increases in flexibility, despite opposition from advocacy groups to loss of entitlement and open-ended funding
- Some support for lower FFP rates for PRFs and other large facilities, support not limited to CBS advocacy groups, especially in low CBS states, as a necessary Incentive to shift emphasis to CBS

- **Federal leadership**
  - Clarification/strengthening of support for CBS, especially in the Medicaid program
  - Articulation of CBS goals and philosophy across Federal programs
  - Clarification throughout the Federal-state Medicaid partnership network regarding the ICF-MR program and ways in which it differs from other long-term care services under Medicaid
  - Shift from facility basis to client basis
  - Reduction of conflicting program requirements/eligibility criteria between such programs as SSI/SSDI, vocational rehabilitation, special education, and Medicaid
  - Support for services through the VR program that are more responsive to the needs of MR/DD individuals
  - Continuing strong Federal presence in quality assurance
  - Consistency among Regional Offices in program monitoring and interpretation of Federal policy
  - Administrative consolidation within HCFA for MR/DD programs and policies

- **Greater emphasis on cost-effective support to families that help avoid unnecessary institutionalization**

- **Technical assistance**
  - "State-of-the-art" services
  - Manpower training in new technologies
  - Training for surveyors and quality assurance program administrators

The Federal policy features accorded the strongest support and broadest consensus were increased flexibility and support for noninstitutional community alternatives, increased emphasis on help to families, strong Federal leadership, and maintenance/expansion of FFP.

Policies That Could Inhibit CBS Development

Informants in both high- and low-CBS states were generally optimistic that the kinds of Federal policy changes under consideration could be helpful in promoting CBS goals. Informants cited changes, however, which they considered likely to have a negative effect on CBS expansion. These included the following:

- **Capped FFP**--Although some informants expressed willingness to consider a cap in exchange for greater flexibility, others expressed concern that capped FFP for MR/DD programs could result in declining FFP over time, as has happened with Title XX/Social Services Block Grant funding.

- **Reduced FFP**--Informants in all six states expressed concern that FFP for MR/DD services should not be reduced, especially given the precarious position of the state economies.

- **Elimination Of The HCB Waiver**--All six states are in support of the kinds of flexibility offered by the HCB Waiver and are concerned that its elimination would impede further CBS development.

- **Increased Fragmentation**--Some informants recommended that policies which target services to specific population subgroups be avoided.

- **Condemnation Of Congregate Care**--Informants in low-CBS states, where large congregate care providers and/or PRFs have considerable political support, were concerned that policies which seem to condemn large MR/DD facilities would increase resistance to CBS development. Others in these states, however, indicated that the evidence on the merits of community services in smaller integrated settings required policy approaches that clearly favor this approach.

The Informants' primary concern was that trends toward increased flexibility and Individualized programming be continued without loss of Federal support.

(2) How States May Be Expected To Respond To Changes In Federal Policy

The analysis of state perspectives, in particular of the observations of informants in the low-CBS states, provided some indication as to how states may respond to changes in Federal policies affecting MR/DD service systems. Perhaps the most significant point emerging from the review of state perspectives is the following:

> There was a strong general consensus that merely "tinkering" with Federal MR/DD policies will have little effect on states' ability to expand community-based services and to promote models that emphasize integration, productivity, and independence.

State responses to the kinds of changes in Federal policy under consideration by the Working Group that were further suggested by the analysis are summarized in the following.

- **Overall emphasis on community services**
  - States will welcome Federal actions that facilitate expanded CBS with state policymakers, including philosophical direction, FFP, and technical assistance.
  - Low-CBS states in particular would be able to use Federal leadership in promoting CBS growth by:
    - Giving CBS supporters more "ammunition" (Federal standards, Federal policy statements, FFP that was available for CBS, etc.)
    - Direct assistance in CBS development (demonstrations, technical assistance, fiscal incentives, support for CBS system development, etc.)
  - It is not clear, however, if even radical changes in Federal policy would "turn around" a state which was determined to cling to large PRFs and other large congregate facilities (i.e., more determined than the low-CBS states visited for this study).

- **Administration**
  - Effects on MR/DD system administration--overall division of responsibility and centralization vs. decentralization--are likely to be minimal unless new policies prescribed particular structures. Since there is considerable variety among states, as well as considerable history, prescriptive requirements would not be well received.
  - States would generally support increased discretion in the governor's ability to delegate authority for some MR/DD aspects of the state's Medicaid program. This option would be particularly helpful to states in which the Medicaid long-term care program is .predominantly oriented to the needs of the frail elderly.
  - States would welcome changes that brought more consistency in goals, target population, and specific requirements across such Federal programs as Medicaid, SSI and SSDI, Developmental Disabilities, Vocational Rehabilitation, Special Education, and Adult Basic Education. These efforts could be useful to states and communities In planning and monitoring their CBS systems and in developing more cost-effective service strategies.

- **Client Eligibility**
  - The effect of Federal policy changes on client eligibility would depend on the use of mandatory client populations as well as the particular criteria selected. In states which do not generally include services to people with developmentally disabilities other than mental retardation, at least through the primary MR system, Federal mandates to include the full range of developmental disabilities would present significant problems in financing and system development.

- States are currently serving many mentally retarded people in their service systems, primarily adults, who may not meet DD definitions that focus on severity and/or inability to achieve gainful employment. If such clients were no longer eligible for services supported by FFP, many states could be expected to raise objections. This would be a particular problem in low-CBS states in which most of the people currently in their CBS system are higher functioning individuals; a major cutback in available FFP for these clients would mean other state resources would have to be used for this population rather than for new services for the moderately and severely disabled clients still in the PRFs.
- Most states also are already providing some services to families, including parent training, infant stimulation, respite care, Information and referral, and subsidy payments. Although some FFP Is being used, primarily through the HCB Waiver and P.L. 94-142 programs, most of these efforts are supported by state and local funds. A change in Federal program eligibility would therefore have more effect on the financing of services to DD people in their own homes, rather than change the overall scope of the population being served.

- **Expenditures**
  - State's expenditures on their MR/DD systems are likely to be much more influenced by the state's economy than by Federal policy.
  - Even if considerable new FFP were available, It Is unreasonable to assume that states will automatically increase their overall MR/DD expenditures or necessarily jump at FFP (although a few might be expected to do so). Most states are concerned about match requirements, open-ended obligations, and building up constituency expectations beyond what the state can afford in a period of economic difficulty. This is borne out by the observation that many states have not used Medicaid options for MR/DD services that are already available.
  - Low-CBS states, especially those with troubled economies, may be unable to expand CBS and maintain quality PRF services simultaneously without short-term transitional assistance.
  - Demonstration project funding may be helpful in supporting CBS innovations that can then be used as models throughout the MR/DD systems. Low-CBS states in particular may benefit from programs that validate community service models, such as small CRFs and vocational programs that integrate severely disabled adults into the community.
  - Short-term demonstration project funding may be unattractive to some states if policymakers fear it establishes a level of support that the state will be unable to maintain after the demonstration funding is over. Demonstration funds that can be used for capacity building and system development might be useful to low-CBS states where key officials object to the usual kinds of demonstration grants.
  - Many states are likely to use the HCB Waiver to expand CBS and alternatives to ICFs-MR. Changes in the HCB Waiver program, such as

simplification of procedures and time-limited short-term developmental cost increases, would make the waiver even more useful, especially to low-CBS states.

- State SSI supplements are a major component of state-expenditures for CBS, especially in states which use non-Medicaid alternatives for community residences. States may be expected to raise this issue in response to policies which would pressure states to shift to non-Medicaid CRFs.
- State reactions to cost-sharing requirements will probably be mixed. Many states provide nearly all MR/DD services at no cost to participants, including family members, regardless of ability to pay.[1] This is particularly true for families of adult MR/DD individuals whose freedom from financial responsibility for PRF and other service costs has been won in several states through the courts and hard-fought lobbying efforts. If cost-sharing were optional, states might be faced with difficult political battles with parents and other advocates. Mandatory cost-sharing provisions might be implemented with less political difficulty at the state level; however, the mechanics of cost-sharing and its monitoring would be seen as extremely difficult administratively in most states. Nevertheless, there is some state interest in cost-sharing as an appropriate strategy in financing community services.

- **Services**
  - States could be influenced to raise the portion of MR/DD resources devoted to community services, especially if Federal policy changes are significant in shifting emphasis and support to CBS. Low-CBS states will probably require additional resources during the transition period to accomplish this, however, as they generally lack the CBS "infrastructure" to build on.
  - Reductions in PRF population can be accelerated somewhat in low-CBS states, especially through combination of CBS growth and PRF depopulation incentives and help with system development. Some low-CBS states, however, are likely to continue their focus on expanded CBS for those who have never been in the institutions, especially in the absence of litigation on other strong pressures to deinstitutionalize.
  - Services to families are likely to continue to expand, with or without major Federal policy changes. Federal policy will be significant in the extent to which states are able to expand family support more rapidly, and in their ability to capture FFP for these programs.
  - States will be more likely to develop small non-ICF-MR CRFs if provisions like those currently found in the HCB Waiver are in place.
  - Significant growth in the availability of vocational services and adult education programs is likely if reimbursement for these services under

[1] This is unlike the public mental health system , which frequently charges for services based on ability to pay, but which serves primarily a low-income population without access to the private sector. The public MR/DD system in most states is the primary service system to people of all but the highest income levels.

Medicaid extends beyond those covered by the COBRA amendments. Implementation also may present states with major turf battles as the MR/DD, Medicaid, VR, and education agencies sort out fiscal and administrative responsibilities.
  - Increased emphasis/FFP availability could result in more providers being Involved and more choices available to consumers and payors. Because of the differences among states in their regulatory environment and degree of public vs. private dominance of the MR/DD system, however, the effects on provider makeup can be expected to vary considerably from state to state.
  - States will welcome increased flexibility in the use of FFP, and can be expected to use this flexibility for more cost-effective services. At the same time, increased state flexibility could mean that some states will pursue goals other than those preferred by Federal policymakers.

- **Quality assurance**
  - Most states can be expected to welcome strong Federal leadership in community services policy and to use it to gain support for CBS initiatives.
  - States generally can be expected to support a continuing strong Federal presence in quality control, as in the "look-behinds," provided that quality assurance standards are clearly defined and communicated throughout the system on a timely basis.
  - Major increases in state oversight requirements (for example, mandatory licensing of all providers receiving FFP under an HCB-like approach) would require extensive changes in many state systems, and also could increase costs significantly.
  - Requirements that permitted only a single quality assurance (QA) organizational structure would cause difficulties in states with other models. For example, a mandatory separation of case management from service provision and administration would require extensive changes in states that currently require local MR/DD authorities to provide case management. At the same time, recognition of the issue of separation of oversight from services responsibilities might be useful to states in meeting appropriate goals for quality assurance, for example, if states were required to include independent program monitoring as a part of their QA system.

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Based on our analysis of influences on state MR/DD systems, it is clear that no single Federal policy approach will automatically lead to implementation of policy objectives for optimal productivity, independence, and integration of developmentally disabled people in their respective communities. States with relatively little CBS emphasis to date and with strong support for congregate care in large MR/DD facilities are likely to need considerable assistance--Federal leadership in the articulation of policy goals, FFP incentives for community services expansion, and technology transfer of cost-effective CBS program design--if their MR/DD systems are to progress

significantly toward CBS policy goals. Federal policy also is one of several factors influencing state MR/DD systems. Although its influence can be considerable, it will continue to be limited in relation to the states' overall policymaking context. It also is unlikely that current Federal policy approaches emphasizing devolution of authority to the states will be reversed in favor of prescriptive requirements for MR/DD service systems. Finally, it should be noted that state MR/DD policies are not implemented uniformly across the respective states; the influence of Federal policy on MR/DD services is further limited by the constraints on state-level control of its system at the community level, especially in states with decentralized MR/DD authority. Within these recognized limitations, however, Federal policy and programs can make a major contribution in CBS development. The six states reviewed in this analysis of MR/DD perspectives were clearly supportive of Federal leadership in MR/DD policy, and of an improved Federal-state partnership in cost-effective service systems. Their appreciation of being consulted by the Working Group through the activities of this study was indicative of the potential for a collaborative approach to implementation of MR/DD Federal policy goals.

IV. GLOSSARY

CBS	-	Community-Based Services
CRF	-	Community Residential Facility
DD	-	Developmental Disability/Developmentally Disabled
FFP	-	Federal Financial Participation
HCB	-	Home and Community Based Care Waiver
HCFA	-	Health Care Financing Administration
HHS	-	Department of Health and Human Services
OSERS	-	Office of Special Education and Rehabilitation Services
ICF	-	Intermediate Care Facility
ICF-MR	-	Intermediate Care Facility for the Mentally Retarded
MR	-	Mental Retardation/Mentally Retarded
PRF	-	Public Residential Facility
SNF	-	Skilled Nursing Facility
SSI	-	Supplemental Security Income
SSDI	-	Social Security Disability Insurance
Title XIX	-	Title XIX of the Social Security Act--Medicaid
QA	-	Quality Assurance
CFLAs	-	Community and Family Living Amendments
CCBs	-	Community Centered Boards
ARC	-	Associated for Retarded Citizens
ASAs	-	Approved Service Agencies
PCAs	-	Personal Care Alternatives