

**Management Approaches to Rebalancing Long-Term Care Systems:
Experience in Eight States up to July 31, 2005**

Executive Summary

by

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The statements and opinions in the report are those of the writers and do not necessarily reflect the views of CMS or any of its staff, or the State liaisons to the project, or any other state staff or persons who spoke to us from participating states.

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Preface and Acknowledgments

This Executive Summary report encapsulates the comprehensive State case studies performed as a first year task in a 3-year study of state management practices in balancing long-term care systems. The studies were undertaken in and with the participation of 8 states. Separate abbreviated reports of 10-12 pages in length are also available for each State.

This work is performed by a large multi-organization team. From the University of Minnesota, the research team for this phase included: Rosalie A. Kane, PhD, Project Director; Robert L. Kane, MD, Co-Director; Reinhard Preister, JD, project coordinator; and Donna Spencer, MA all from the School of Public Health; K Charlie Lakin, PhD, from the Institute on Community Integration; and Terry Lum, PhD, from the School of Social Work. Linda Clark-Helms served as the CNAC project manager. Other collaborating researchers included : Robert Mollica, EdD, National Academy for State Health Policy, Portland, ME; Charlene Harrington, PhD, RN, and Martin Kitchener, PhD, from the Center for Personal Assistance Services, University of California at San Francisco; Charles Reed, Olympia, WA; and Dann Milne, Denver, Colorado, both consultants to the project.

Our aim in this Executive Summary was to cram as much information and analysis as possible into about 25 pages of narrative. Given that we developed a picture of each participating State's experience from the time that HCBS programs developed under Medicaid and Medicaid waivers (beginning at least in 1982, if not earlier), we necessarily needed to condense material from the longer case study narratives. Those seeking greater detail may consult the full-length report, which is comprised of an introductory chapter with fuller methods, and 8 long chapters of 60 pages or so for each of the State case studies. By the end of June, this long report will be available on request from Rosalie Kane, the project director or can be downloaded from her website (<http://www.hpm.umn.edu/LTCResourceCenter> or at <http://www.hcbs.org>.)

We thank our CMS project officers, MaryBeth Ribar and later, Dina Elani, as well as a group from CMS who periodically gave us input into the study's design and interpretations. In addition to the project officers, the latter group includes Melissa Hulbert, Ronald Hendler, and Bill Clark. Each participating State named one or more liaisons to the project, listed in Appendix B. We also are grateful to those State liaisons and to the numerous people in each State who provided information and insights and assisted us with acquiring data for quantitative analysis. The findings, conclusions, and interpretations, however, are the responsibility of the authors and do not reflect the opinions of CMS, any State officials, or any other informants from participating States.

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Executive Summary

Background

In 2003, Congress directed the Centers for Medicare & Medicaid Services (CMS) to commission a study in up to eight states to explore the effects of various management techniques and programmatic features that states have put in place to rebalance their Medicaid long-term care (LTC) systems and their investments in long-term support services. Congress realized that rebalancing efforts were taking place throughout the country, and sought information about how states reduced reliance on institutions, while managing aggregate costs and overall quality. In October 2004, CMS accordingly commissioned research to examine that topic. The report summarized here is the first product of a three-year project to study “rebalancing” from a qualitative and quantitative perspective.¹ See Appendix A for more detail on the background of the study and the origins of the Congressional request.

For the study, CMS defined rebalancing as reaching “a more equitable balance between the proportion of total Medicaid long-term support expenditures used for institutional services (i.e., Nursing Facilities [NF] and Intermediate Care Facilities for the Mentally Retarded [ICFs-MR]) and those used for community-based supports under its State Plan and waiver options.” CMS further clarified that a balanced LTC system “offers individuals a reasonable array of balanced options, particularly adequate choices of community and institutional options.” CMS made clear that it had no particular target goals for service supply or utilization across the array of services in order to label a system as appropriately balanced.

Research Approach

The study is not an evaluation of any State’s rebalancing efforts, nor is it based on any normative views on what constitutes the “correct” balance. (Rather, this study explored how various State leaders in the public and private sector, including consumers, themselves consider short-range and long-range goals related to rebalancing.) Further, the project is a collaborative endeavor with the participating States,² using both quantitative and qualitative approaches. This product presents a summary of baseline comprehensive studies of the experience in the 8 participating States. This is the first of 3 composite State case studies, covering a period through July 31, 2005. Subsequent Year 2 and Year 3 case study reports will describe, respectively, developments from August 1, 2005 to July 31, 2006, and from August 1, 2006 to July 31, 2007.

¹ This report is a shortened Executive Summary to accompany 8 abbreviated case studies, also on the CMS website; a longer series of case studies and a longer executive summary will be forthcoming on <http://www.hcbs.org> and the PI’s website at <http://www.hpm.umn.edu/LTCResourceCenter/>.

² See Appendix B for acknowledgment of individuals who serve as State Liaisons to the study.

Selection of States

We selected States in varying stages of rebalancing their LTC systems that also varied in context, LTC policies and service delivery, and management approaches. All invited States agreed to participate. They are: Arkansas, Florida, Minnesota, New Mexico, Pennsylvania, Texas, Vermont, and Washington. Information was gathered and reviewed from and about each State, including policy statements, legislation, reports, plans, program descriptions, and special research studies.

Site Visits

A team of 3 or more researchers made 3-day site visits to each State. These baseline site visits were concentrated in the state capital city, and entailed individual or group interviews with more than 30 contact people per state, including four different types of interviewees:

- State program officials in the major relevant agencies, ordinarily including the Departments of Human Services, Aging, Health, Mental Health, and Developmental Disabilities. We sometimes included representatives of Boards of Nursing, Housing Authorities, Labor Departments, Governor's staff, legislative staff, and key legislators. Our roster of interviewees tapped those involved in policy setting, rate setting, service allocation, and quality monitoring for long-term support for all populations, those overseeing nursing homes and state institutions, and leaders of selected special projects.
- Consumer stakeholders.
- Provider stakeholders, including nursing home, home care, and mental retardation trade associations, Area Agencies on Aging, and some direct service providers.
- Persons representing organizations implementing programs on a local level, which in instances when the local delivery system varied by target population entailed visiting 2 or more local access organizations

After the site visits, we conducted follow-up telephone contacts to round out information or to interview individuals who were not available during the site visits.

Products

The products of the 3-year overall study include, State case studies and topic papers.

State Case Studies

Baseline Case Studies

Abbreviated and full-length baseline case studies for each participating State cover each state's historical and present rebalancing of long-term services for all populations under Medicaid through the end of July 2005. The full baseline studies, about 60 pages each, are comprehensive and contain the following sections:

Context for rebalancing. This section includes demographic and economic conditions, geographical context, the State's vision related to rebalancing, political issues, leadership for LTC, state-level organization, local-level, organization, advocacy environment, supply of services, relevant litigation, historical milestones, and funding mechanisms and services covered under Medicaid State Plan, Medicaid HCBS waivers, and other relevant funding mechanisms.

System assessment. This section briefly characterizes the system in place in each State on the following topics related to rebalancing: access to services, array of services, consumer direction, quality initiatives, data capacity, links to acute care, links to housing, and links to mental health.

Featured Management Approaches. This section profiles management approaches of interest in the particular state. Management approaches includes re-organizations at the State level, approaches to developing local service delivery capability, and a wide range of other approaches related to access, services, quality monitoring, financing, and links to other services.

Quantitative Markers of Rebalancing. In the baseline study, we largely used aggregate data to make within-State comparison of service utilization, expenditures, and cost per participant served for a variety of institutional services, State-plan HCBS services, and HCBS waivers for the five years from 2000 through 2004. We also analyzed the nursing home Minimum Data Set (MDS) data over the same 5 year period to examine trend in acuity for those admitted to a nursing home and those who remained in a nursing home for more than 3 months.

Case Study Updates

Two sets of annual updates of each participating States' rebalancing efforts cover efforts covering August 2005 through July 2006, and August 2006 through July 2007.

Topic Papers

Eight special papers explore program management techniques used by several or all of the participating States and quantitative rebalancing activities. Topic choices sprang from the baseline State case studies.

Context

Making generalizations from one State to another always needs to be done cautiously. States have unique histories, philosophies, and structures that, along with current policy exigencies and operating philosophies, shape the way they will address LTC challenges and the routes they will take to rebalancing. At the same time, States can and do build on each other's experiences as they forge their particular solutions to achieving some common goals.

Specific State Contexts

Differences among the States relevant to rebalancing include geographic size and terrain, population size, population density, aging and disability patterns, ethnic diversity, degree of urbanicity, wealth and tax base for the state, poverty status of people with disabilities of all ages, and living arrangements. See Table 1 for the variation in selected demographic, geographic, and economic characteristics related to rebalancing services in the States.

Table 1. Demographic and Economic Indicators in Eight States

	AR	FL	MN	NM	PA	TX	VT	WA	US
Total population 2004 (millions)	2.7	17.4	5.1	1.9	12.4	22.4	.6	6.2	293.7
% in community age 65+, 2004	13.8	16.8	12.1	12.1	15.3	9.9	13	11.3	12.4
% in community age 85+, 2004	1.7	2.2	1.9	1.4	2.3	1.1	1.8	1.7	1.7
% non-white &/or Hispanic, 2004	21.6	34.6	11.8	55.3	15.9	51.5	3.8	21.1	40.9
# of square miles	2,068	53,927	79,610	121,356	44,817	261,797	9,250	66,544	3,537,438
Persons per square mile, 2000	51	296	62	15	274	79.6	65	88	79.6
% in urban areas 2003	49.1	95.8	72.7	56.7	84.7	84.8	29.8	79.9	81.7
% age 5-20 with disability, 2004	9.0	6.1	5.7	6.4	7.2	6.1	9.1	6.4	6.5
% age 21-64 with a disability, 2004	17.6	12.1	9.2	14.5	12.4	11.0	13.6	12.8	12.0
% 65+ with a disability, 2004	50.5	35.7	34.8	45.8	37.8	42.5	38.3	38.6	40.2
% age 85+ living alone, 2002.	54.8	43.8	61.2	49.6	56.2	43.3	53.4	60.4	50.2
% with disability living alone, 2003	40.9	29.5	27.2	49.6	33.9	31.4	31.1	27.5	29.8
State taxes per capita 2005.	\$2,993	\$3,271	\$4,409	\$2,882	\$3,747	\$3,167	\$4,005	\$3,990	\$3,763
Median household income, 2004	\$33,948	\$40,171	\$55,914	\$35,587	\$44,286	\$41,275	\$45,692	\$48,688	\$43,527
Mean per capita personal income, 2005	\$28,443	\$35,368	\$41,158	\$29,137	\$38,586	\$33,907	\$36,050	\$39,768	\$37,167
% poverty, average 2002-2004	17.6	12.3	7.0	17.5	10.4	16.4	8.8	11.7	12.6
% unemployed in labor force, 2004	7.8	7.1	5.8	7.6	6.8	8.1	4.7	8.3	7.2
% with no health insurance (average 2001-2003)	17.3	17.6	8.2	21.3	10.7	24.6	9.9	14.3	15.1
% households with cash public assistance, 2004.	1.8	1.4	3.4	2.7	2.6	1.8	3.1	3.3	2.4
% Medicaid recipients, 2003	16.7	11.9	11.2	43.0	13.0	12.0	16.47	14.37	14.3
% age 5-17 with disability in poverty, 2004	38.6	23.5	16.0	35.2	28.5	26.3	32.4	26.9	27.0
% age 18-64 with disability in poverty, 2004	29.9	21.9	20.9	28.1	25.3	24.5	21.3	24.2	24.5
% age 65 + with disability in poverty, 2004	19.9	12.9	11.5	15.3	11.3	18.1	10.0	11.0	13.1
% 5-17 with disability up to 300% of poverty in 2004	86.7	70.0	60.4	80.9	74.3	67.4	70.0	57.6	68.1
% 18-64 with disability 300% of poverty in 2004	74.2	64.3	57.0	71.1	64.2	64.5	59.7	59.4	63.5
% 65 + with disability up to 300% of poverty in 2004	72.1	60.6	60.6	67.3	68.1	65.8	64.8	56.8	63.4

Notes:

--Census and geographic density data are from American Population Survey, US Census 2004, and refer only to people in the community. Tables and assumptions for data on web, last visited 2/12/2006 at: <http://www.census.gov/acs/www/Products/index.htm>. Data on seniors 65+ and 85+ from Gibson, MJ, Gregory, S, Houser, AN, & Fox-Grage, W (2004). Across the States: Profiles of Long-Term Care, 2004. Washington, DC: AARP. Web last visited 2/8/2006 a http://www.aarp.org/research/reference/statistics/across_the_states_profiles_of_longterm_care_2004.html.

--Statistics on rates of people with disability living alone are from the Center for Personal Assistance Services, UC San Francisco, last visited on web 2/12/2006 at: http://www.pascenter.org/state_based_stats/index.php.

-- Tax and personal income figures from 2005 are compiled by the Retirement Living Information Center based on the Tax and the a and the Bureau Economic Analysis, last visited 2/8/2006 on web at <http://www.retirementliving.com/RLtaxburdens.html>.

--Health insurance data are from De-Navas-Walt, C, Proctor, BD, & Mills, RJ (2005). Income, Poverty, and Health Insurance in United States, 2004. US Census Bureau.

--The numbers of people on Medicaid as of June 2003 by state were drawn from Ellis, ER, Smith VK, & Rousseau, DM (2004). enrollment in 50 States, June 2003 Update, Kaiser Foundation Commission on Medicaid and the Uninsured, on web last visited at <http://www.kff.org/medicaid/7237.cfm>

--Poverty and near poverty status for people of various ages with disability were calculated for us from American Population Survey using age breakdowns more consistent with labor force (5-17, 18-64, and 65+) than those usually reports, courtesy of Stephen Kaye, UC San Francisco.

The range in population is enormous, from Vermont with about 600,000 people to Texas with 22.4 million people. At 15 people per square mile, New Mexico contends with remote rural areas, whereas Pennsylvania and Florida are more densely populated. Florida has the largest proportion of its population over 65, but Pennsylvania has a slightly greater proportion over age 85. Disability rates for people of all ages, including children, are highest in Arkansas. Texas and New Mexico are more ethnically diverse than the other States. The proportion without health insurance is in single digits in Minnesota and Vermont but exceeds 20% in Texas and New Mexico. Age-specific rates of disability, poverty and near poverty among people with disability vary. Arkansas and New Mexico have high poverty rates; residents of Minnesota, Vermont, and Washington have higher incomes. Despite having the lowest poverty rate in the general population, Washington also had the highest unemployment rate at 8.3%, compared to 4.7% in Vermont and 5.8% in Minnesota. Moreover, considerable regional variation can be found within States on many of these parameters. Taking all elements together, New Mexico and Arkansas face high public demand and limited resources. Florida, Pennsylvania, and Texas face added challenges because of the scale and complexity of the state. In general, the 8 States were aware of and used such statistics in planning. Other relevant contextual variations include the frequency, structure and length of legislative sessions, and the legislative and executive budgeting and auditing processes in place.

Common Context

Despite their differences, certain challenges and issues were common across the 8 States:

- Budget shortfalls and perceived need to rein in the costs of Medicaid.
- Involvement in one or more law suits to reduce institutional use and HCBS waiting lists and improve the quality of care.³
- Active engagement with consumer and provider stakeholders to consider how to change long-term support.
- Successful receipt of external funding to support design and infrastructure for rebalancing efforts, including CMS Real Choice System Change grants, other CMS grants, funding from other government agencies, and funding from private foundations.
- Active, and often bipartisan, engagement of their Legislatures in LTC issues, including expansion of community care, re-design of State agencies or creation of new ones, study of long-term care options, and monitoring effects of policies.
- Continuity of leadership and depth of experience within State administration leaders, which was particularly reflected among state officials responsible for operating key agencies related to LTC. Tenures of 20 to 30 years in related leadership positions in the State were not uncommon.

³ We refer here to suits under the Americans with Disability Act (ADA) in general or Olmstead-related actions, and to litigation over quality of services pre-dating the 1991 ADA. Private litigation against nursing homes and other providers has been a policy issue, particularly in Florida and Texas, leading to tort reform efforts and/or increased expenditures in nursing homes to raise quality, which could have an indirect effect on re-balancing.

Management Approaches

State Organization

The 8 participating States have actively considered how to organize State governments for long-term support across functional lines, and whether and how to integrate planning, budget management, operations, quality monitoring, and consumer protection. These considerations of merger (or at least coordination) include two distinct kinds of integration: 1) across institutional and HCBS services, and 2) across target populations, including wide age ranges from children to centenarians and widely varying types of disabilities (see Table 2 for a summary of each state's organizational structure).⁴ Many of the States had undergone re-organizations within the last decade, some more extensive than others.

The most dramatic re-organization was in Texas, where a massive consolidation and re-alignment of State agencies began in 2003. In Vermont, the Department of Aging and Disability became the renamed Department of Aging and Independent Living and incorporated developmental disability services. In Washington, the process of consolidation and integration of what became the Division of Aging and Adult Services (DAAS) culminated in the incorporation of a previously separate Division of Developmental Services into DAAS.

Other States moved in the opposite direction, splitting off components such as Aging or Developmental Disability into higher-level agencies. For example, in 2002, the New Mexico legislature created a Cabinet-level Department for Aging and Long-Term Services. In a period of decades, Florida has moved towards greater differentiation of State agencies providing LTC. The State Unit on Aging, formerly in a large umbrella agency, the Florida Department of Health and Rehabilitative Services (HRS), obtained its own Cabinet-level status as the Department of Elder Affairs in 1991. In 1997, HRS was split into two Departments: Health; and Children and Families (DCF). In 2004, a distinct Agency for Persons with Disability (APD) was spun off from DCF for persons with developmental disabilities. Department status gives more visibility to specific constituencies, but when key organizations in LTC are separate, arguably more attention must be given to vehicles for communication and collaboration.

In Pennsylvania, a Governor's Task Force for Health Care Reform became the fulcrum for change, drawing on staff from various agencies as needed. In New Mexico, interagency collaboration was mandated across at least 3 Cabinet agencies (Aging, Health, and Human Services), including joint financing and management of capitated programs.

⁴ Table 2 does not incorporate the level of detail found in multiple organizational charts in the Full Case Studies.

Table 2. State-Level Organization for Long-Term Care in 8 States as of July 31, 2005

	General State Organization
AR	Responsibility for HCBS is in an umbrella agency, the Department of Human Services (DHS). One arm of DHS conducts the traditional child welfare and social services programs; the other, under a deputy director, includes the main agencies working on LTC, including the Division of Aging and Adult Services (DAAS), which administers most HCBS waivers, the State Unit on Aging, and adult consumer protection and consumer education programs; the Division of Disability Services (DDS); and the Division of Health Services, housing the Medicaid agency and a unit responsible for survey and certification of health facilities. The Division of County Operations (which manages the eligibility process) and the Division of Behavioral Health, both in the same arm of DHS, are closely related to LTC. The Department of Health merged into DHS late in 2005.
FL	The “Health Cabinet” is comprised of multiple agencies responsible to the Governor, including: the Agency for Health Care Administration (AHCA), which houses the state Medicaid director and Health Care Quality field operations; the Department of Health; the Department of Elder Affairs (initiated in 1991); the Department of Children and Families, and the Agency for People with Disabilities, carved out of Children and Families in 2004. Responsibility for HCBS waivers and State programs are divided among these agencies. Older Americans Act functions and state-funded Community Care for the Elderly programs are in Elder Affairs.
MN	An umbrella cabinet agency, the Department of Human Services (DHS), is divided into 4 major Administrations: Continuing Care, Health Care, Chemical and Mental Health Services, and Children and Family Services. The Medicaid Director and the DHS licensing unit operate as DHS agency-wide functions. Continuing Care, the main unit for LTC, contains Adult and Aging Services, which runs HCBS waivers and state plans for seniors, Older Americans Act services, and protective services and consumer advocacy for seniors; Disability Services, which runs 4 HCBS waivers and licenses and monitors quality for MR/DD providers; and Nursing Facility Rates and Policy. State-operated mental health centers and DD programs fall under the Mental Health Services Administration in DHS. Policies and rate setting for managed care (even when LTC is involved) fall to the Health Care Administration of DHS. Licensing and certification of health agencies are in the Department of Health.
NM	Since the creation of the Department of Aging and Adult Services (DAAS) in 2002, three closely cooperating cabinet-level departments share responsibilities for long-term support: DAAS, which administers the Disabled and Elderly Waiver, the personal care state plan option, Older American’s Act services, consumer and elderly rights programs, and adult protective services; the Department of Health, which is responsible for survey and certification, behavioral health, and several HCBS waivers, including the large developmental disability waiver; and the Department of Human Services, which manages income eligibility.
PA	Three Cabinet level agencies are involved in LTC: the Department of Health, which houses survey and certification; the Department of Aging, which operates Older American’s Act programs, state-funded LTC, and the aging waiver; and the Department of Public Welfare (DPW). DPW includes the Office of Medical Assistance, where the Medicaid agency is housed, the Office of Mental Retardation, the Office of Income Maintenance (where eligibility is determined), and the Office of Social Programs (which houses a variety of LTC programs for adults). Responsibility for HCBS waivers are scattered throughout these 3 Departments and their subunits. The Governor’s Office of Health Care Reform) OHCR was created in 2003, as a Cabinet level agency able to draw staff from the other agencies, and with overall responsibility for planning. Much of the current impetus for change is spurred by the OHCR.
TX	Texas undertook massive reorganization of its State government, reducing the number of agencies and moving units within the umbrella Health and Human Services Commission (HHSC). After the changes, the Executive Commissioner of HHSC operated 4 major Departments, each headed by a Commissioner: Aging and Disability Services (DADS), Health Services, Family and Protective Services, and Assistive and Rehabilitative Services (DARS). DADS is the focal point for all LTC, both institutional and community based and for all target populations. Within DADS, 3 cross-cutting Centers (Policy & Innovation, Program Coordination, and Consumer and External Affairs) were formed and 4 major operational units (a COO, responsible for functions like contracting, legal services, consumer rights, and IT; an Asst Commissioner for Access & Intake; an Asst Commissioner for Provider Services; and an Asst Commissioner for Regulatory Services. Within these units, the functions are carried out for all target populations and settings.
VT	An umbrella Agency for Human Services has 4 departments: Dept of Aging, Disability, and Independent Living (DAIL), Office of Vermont Health Access (the Medicaid Agency), Health, Children and Families, and Corrections. DAIL, the major organization for LTC, has 4 Divisions: Licensing and Protection, Disability and Aging Services, Blind and Visually Impaired, and Vocational Rehabilitation. MR/DD programs are in DAIL and Mental Health programs are in Department of Health.
WA	The Aging and Disability Services Administration (ADSA), located within umbrella Department of Social and Health Services, has consolidated responsibility for policy, financing, service operations, regulation, and quality of LTC for all populations in all service settings. ADSA operates through 4 Divisions: Home and Community Services, Residential Care, Developmental Disability, and Management Services.

Specific organizational variations were noted, including:

- the placement of the State Unit on Aging and the related State and local organization of Administration on Aging programs, including Title III services, the long-term care ombudsman program, the family caregiver program, and benefits counseling;
- the placement of protective services such as guardianship, advocacy and protection, and legal services;
- the location and visibility of physical and vocational rehabilitation programs;
- the placement of mental health/behavioral health/substance abuse services, which fit uneasily somewhere between the purview of Departments of Health and the purview of Departments of Human Services;
- the location and responsibilities of the Nursing Home and ICF/MR Survey and Certification Agency;
- the location and practices of the organization that certifies Medicaid eligibility for LTC;
- the development of visible units with the organization responsible for LTC to work with and facilitate the work of stakeholder groups.

Many State leaders cited advantages in administratively consolidating policy, financing, service delivery, and quality assurance functions, and in particular the advantages of being able to manage budgets for institutional services and HCBS services in the same agency. The cross-fertilization of personnel experienced with different target groups also was perceived to be useful in bringing together the strengths of various groups: for example, combining the advocacy and commitment to community care and consumer direction often found in agencies serving people with mental retardation with the cost-consciousness often found in state organizations serving older people. In general, re-organizations across functional lines, such as occurred in Texas, offers an opportunity for creative, “out-of-the-box” thinking. Some states have combined data bases and information systems, notably Washington, and others are working to that end.

The jury may still be out on the optimal State organization to promote rebalancing, and indeed it seems unlikely that one “best model” will emerge. It appears that effective LTC management can occur in a division within an umbrella agency as readily as within a Cabinet-level agency dedicated to LTC, if functions are thoughtfully consolidated in one place within State government.

Local Organization and Access

Access to long-term supports begins at the local level, where applications for services, assessment of eligibility and need, and actual service delivery take place. In structuring their systems, States must consider their own unique geography and their structures of state-county relationships. Essentially, the choices are some mix of: regional State offices, State contracts with county governments, State contracts with various lead private-sector (either non-profit

and/or for-nonprofit) organizations, and centralized entry systems relying on Internet, telephone and mail.

Although States have taken advantage of new communication technology over the past decade and have implemented on-line applications and centralized review functions (e.g., New Mexico's approach that utilizes a managed care organization in Albuquerque to process functional eligibility), none of the States entirely eliminated face-to-face contacts. Rather, the States were developing multiple approaches to achieve timely and equitable access.

States vary in the extent to which they utilize single assessments and/or single lead organizations across multiple disability and age groups. The Area Agencies on Aging sometimes are a focal point for most local services, sometimes play a major role for older people and or people with physical disabilities, and sometimes play no role at all. At the local level, separate Mental Retardation authorities tend to control access to developmental services, but this pattern also varied. Intra-State variation can be found as well, either because of State pilot initiatives (some grant-funded) or because of local initiatives. For example, a Consolidated Waiver Program (CWP) is being piloted in San Antonio Texas; Hennepin County in Minnesota (location of Minneapolis) has recently merged its Mental Retardation services with its other services; and Pennsylvania conducted a major "Fast-Track" project in selected counties.

States are conscious that the level of awareness and acceptance of the State's policy strategy among local authorities will largely dictate the options made available to the consumers. Even Vermont, a small State in both land mass and population has put great energy into state-local communication and collaboration. See Table 3 for a summary of local organization for long-term entry systems.

Consumers experience two general reasons for delays in getting services r within these systems: 1) waits for financial and/or functional eligibility to be determined, care plans developed, and services initiated, and 2) waits until slots for particular waiver funding becomes available. If HCBS services are philosophically meant to divert people from entering institutions when they choose HCBS, the first reason for waiting must be eliminated. Some states have achieved speedy processing, and are willing to presume eligibility, backing up their judgments with state funding if the consumer proves ineligible; Washington illustrates this strategy. Others states are working to achieve rapid processing, sometimes encountering a barrier of eligibility offices that are concerned about making access to the programs too easy. Pennsylvania demonstrated that it could dramatically cut the time from first application to actual receipt of services in pilot counties, and at the end of this case study period, the Governor's Commission for Health Care Reform was attempting to expand the processes statewide. Some States cite difficulties in acquiring a physician's signature as a barrier to rapid establishment of functional eligibility. Requiring a physician's signature is due to State rather than federal policies; some State agencies mistakenly believe they are fulfilling federal law to require the signature, whereas others philosophically hold that a physician should attest to "medical necessity." Inter-agency dialogue within a State is usually needed to streamline application procedures and make decisions about physician signatures, presumptive eligibility, and the like.

Table 3. Local Organization for Long-Term Care in 8 States, as of July 2005

General Organization at the Local Level and Related Issues	
AR 75 counties	Local entities of the Office of State Services certifies Medicaid eligibility; regional nurses employed by Aging and Adult Services certify functional eligibility; and case management is provided through 8 Area Agencies on Aging. A separate MR/DD local system is accessed through 6 multi-county Area Program Managers and case management is provided by licensed developmental disability providers. Physician signature needed for level of care. The State is developing a pilot of fast track to eligibility, which now takes at least 45 days.
FL 67 counties	The Department of Children & Families (DCF) does financial eligibility from 14 Regional offices. Nurse-social worker State-employed CARES teams in 11 regions (18 offices) assess eligibility for NH and all but MR/DD programs. 11 Area Agencies on Aging manage selected waivers and a State-funded programs through 52 contracted "lead agencies." Applications for MR/DD waivers or State-funded services are made through 14 Agency for Person with Disability (APD) regions; APD contracts with independent "support coordinators" for case management. Financial eligibility for most programs takes at least 45 days; total eligibility about 90 days; physician sign-offs needed for Level of Care.
MN 87 counties	Counties are autonomous entities contracted by the State. Financial and functional eligibility consolidated in nurse-social worker teams from county departments of human services and/or health. County-administered LTC consultation has replaced more top-down case management concept. Mental retardation lead agencies operate in a separate system. Equity of resource allocation across counties and programs is a concern. Managed Care Organizations and Tribal entities also lead agencies in some circumstances. Multi-county Area Agencies on Aging for Older Americans Act programs.
NM 33 counties	Access and functional eligibility organized centrally (through state contract with MCO and in-person assessments by network of nurses contracted by HMO) Case management delivered through a network of contracting case management providers (separate but overlapping lists are used for Disabled and Elderly and for Developmental Disabilities). Financial eligibility is determined by the Income Support Division (ISD) of the Human Services Office, which maintains 39 regional field offices (1 or more per county). 6 Areas Agencies on Aging and 5 Adult Protective Services Regions. Physician level of care certification required.
PA 67 counties	Financial eligibility for all waivers, state plan services and income supports is through County Assistance Offices. Aging Services entry is through 52 Area Agencies on Aging; services of the Office of Mental Retardation (OMR) is accessed through 46 county OMR Offices; Community Services for Persons with Physical Disabilities is accessed through just 2 agencies, both Centers for Independent Living (of which the State has 17); the process takes about 90 days except in a 10-county area where "Community Choices," a Fast Track capability has been created that completes assessment and instates services within days,. Through the pilot, PA determined physician signature are not needed for level-of-care determinations.
TX 254 counties	3 front doors to system. Local Division of Aging & Disability Services (DADS) offices for eligibility through 11 DADS regions and offices in almost all counties.. Multi-county Area Agencies on Aging and multi-county Mental Retardation Authorities under contract with DADS have care management responsibilities. Texas is attempting to develop a more efficient way for consumers to access services based on internet, phone, and mail as well as in-person. Long" interest list" are managed by regions.
VT 14 counties	Vermont is divided into 10 regions for waiver applications for seniors or disabled with either an Area Agency on Aging or a designated home health agency as lead; 10 regions each with a Designated Agency for Developmental Services. Applications for attendant programs begin with designated lead agency but the process is managed through Committees of Consumers. The state has 5 AAAs--some AAAs serve as lead LTC agencies and all lead for Older Americans Act Services.
WA 39 counties	Maintains large state regional staff in for eligibility for waivers. Area Agencies on Aging and Mental Retardation authorities have built-in roles for ongoing case management. Modularized, computerized assessment and care planning system brings coherence to local entry. Heavy emphasis on case management in system. Fast track and presumptive eligibility built in. Physician signatures are not required.

The second reason for waiting—i.e., waiting for funded service slots—is common, particularly for developmental disability services waivers. Managing wait lists for waivers and applying priorities for services across a State is difficult, especially given that counties or regions usually maintain the wait lists. Further, most states have no ready capability of knowing whether individuals on wait lists are actually receiving services in the interim; States are confident that many persons do receive services for which they are eligible while waiting for waiver services, and they realize that some school-age children are on wait lists prior to their anticipated actual needs. Thus, a wait list is not necessarily a no-service list. A variety of management techniques are being used to reduce wait lists. Florida has recently been vigorously working to reduce its waiting list for developmental services waivers; the process of contacts made to persons on the waiting list is transparent and well document on the Agency for Persons with Disability website. Texas maintains the longest “interest lists,” a term used to connote that assessment has not yet occurred, but there, too, recent appropriations have been made to reduce the interest lists.

Values and Vision

Each of the eight States has enunciated mission and value statements and/or principles that support rebalancing. Such statements emphasize choice, dignity, community integration, consumer direction, inclusion, full employment, and civic engagement. (See Table 4 for a sampling of language.). Value statements are often embodied in statutes and consistently promulgated in multiple State agency vision statements, reports, and websites, with slight variants in focus from agency to agency. Some of the selected statements date back to the 1980’s. A 1995 State of Washington statute is quoted at length because it explicitly links government consolidation to achieving rebalancing, comprehensively includes mental health and education departments, and enunciates consumer stakeholder involvement in planning.

Some vision statements incorporate protection and safety for consumers (which may somewhat vitiate the vision of choice and independence) and statements on good quality of services. Some States also incorporate within their vision statements the expectation of government accountability and efficiency, and they may even hold out the view that community choices will save the state money—Texas, Minnesota, Florida, New Mexico, and Washington include accountability and efficiency language, and Pennsylvania is perhaps best illustrates language that incorporates a vision cost savings directly attributable to community care. Consumer planning groups or advisory groups for special projects such as those undertaken by Real Choice System Change Grants typically enunciate value statements as well, and ordinarily make stronger statements than do State agencies without tempering goals of consumer choice and community care with goals of safety at the individual level or cost savings and accountability at the collective level.

Taken together, the dozens of mission and values statements enunciated in the eight States illustrate substantial incorporation of the ideals of community care in state law and executive agency missions. In the 1980s, Richard C. Ladd, a major architect of Oregon’s LTC program argued for the power of embodying strong vision statements in statute and executive agency missions as a way of keeping focus on rebalancing and related goals in the face of opposition. In 2005, we found that such powerful statements were deeply embedded in State documents (and more ephemeral State websites) in a way that affords an aura of inevitability and “business as usual” to goals and missions that might have been considered revolutionary at the time Medicaid was enacted. In our view, the power of these value statements is substantial.

Table 4. Value and Mission Statements in 8 States, as of July 31, 2005

	Selected Value and Mission Statements
AR	“ . . . it is the policy of the State of Arkansas to promote and maximize the use of home and community-based services, so older people and persons with disabilities can be integrated in their communities.” Source: Governor’s Integrated Services Task Force, prepared 5/20/2005 for legislative adoption.
FL	“ . . . to create an environment that provides choices, promotes independence and enables older Floridians to remain in their communities for a lifetime.” Source: Florida Department of Elder Affairs, Mission Statement, on web, last visited February 15, 2005 at http://elderaffairs.state.fl.us/english/mission.html .
MN	“ . . . Expand consumer-directed services, an option that gives consumers control to make life choices and to exert control over their own lives, including dollars spent for services and staff who provide them.” Source: Priority Statement of Minnesota Division of Disability Services.” Listed on website, last visited February 15, 2005 at http://www.dhs.state.mn.us/main/groups/disabilities/documents/pub/dhs_id_004608.hcsp
NM	“ . . . to achieve the highest quality of life for older adults, persons with disabilities, and their families by enhancing autonomy, health, economic well-being, community involvement and personal responsibility.” Source: Mission statement of the New Mexico Aging and Adult Services Department found on website, last visited May 29, 2005 at: http://www.nmaging.state.nm.us/Aging_Long-Term_Services_Department.html .
PA	“ . . . recipients of attendant care have the right to make decisions about, direct the provision of, and control their attendant care services. This includes, but is not limited to, decisions about hiring, training, managing, paying and firing of an attendant. . . .” Source: Attendant Services Act of 1984.
	“We are committed to an aggressive effort to rebalance our long-term care system, providing opportunities so that people of all ages and all disabilities may live independently in the community. . . Redesigning the system in this way is a double win. First, it likely will save taxpayers millions of dollars. It will give us the opportunity to redirect money to other programs providing health care. And, more important, it will allow Pennsylvanians to receive services in the setting they prefer. Overwhelmingly, that is at home.” Source: <i>Needed changes in long-term care: PA is trying some out now, in Phila. and elsewhere</i> . Op Ed Article by Greco and Torregrossa (Director and Associate Director, Governor’s Office of Health Care Reform), <i>Philadelphia Inquirer</i> , April 8, 2004.
TX	“ . . . Preserve, enhance, and maintain independence – enable the aging and people with disabilities, including those with mental retardation and other developmental disabilities, to live as independently as possible for as long as possible through an effective, individualized system of service provision in community and institutional settings.” Source: the Health and Human Services Strategic Plan for DADS, 2005-2009.
VT	“It is the policy of the state of Vermont that all older Vermonters and Vermonters with disabilities should be able to live as independently as they choose and as their personal circumstances permit; be able to receive services and benefits which they need and to which they are entitled by law; be able to be full and active participants in the life of their communities, including competitive employment consistent with their abilities and interests; and be protected against unlawful and unnecessary restriction. . . .” “The laws pertaining to the department of aging and disabilities and its programs shall be construed liberally to carry out the policies stated in this section.” Source: Vermont Statue Title 33 (Human Services), Chapter 5 (Aging and Disabilities), Section 501. (Last sentence part of 1989 update.)
WA	<ul style="list-style-type: none"> --Ensure that services are provided in the most independent living situation consistent with individual needs; --Ensure that long-term care service options shall be developed and made available that enable functionally disabled persons to continue to live in their homes or other community residential facilities while in the care of their families or other volunteer support persons; --Ensure that long-term care services are coordinated in a way that minimizes administrative cost, eliminates unnecessarily complex organization, minimizes program and service duplication, and maximizes the use of financial resources in directly meeting the needs of persons with functional limitations; --Develop a systematic plan for the coordination, planning, budgeting, and administration of long-term care services now fragmented between the division of developmental disabilities, division of mental health, aging and adult services administration, division of children and family services, division of vocational rehabilitation, office on AIDS, division of health, and bureau of alcohol and substance abuse; --Encourage the development of a statewide long-term care case management system that effectively coordinates the plan of care and services provided to eligible consumers; --Ensure that individuals and organizations affected by or interested in long-term care programs have an opportunity to participate in identification of needs and priorities, policy development, planning, and development, implementation, and monitoring of state supported long-term care programs.” --Support educational institutions in Washington state to assist in the procurement of federal support for expanded research and training in long-term care; and --Facilitate the development of a coordinated system of long-term care education that is clearly articulated between all levels of higher education and reflective of both in-home care needs and institutional care needs of functionally disabled persons.” Source: State of Washington House Bill 1908 enacted 1995.

For the most part, however, States had not explicitly enunciated long-range or interim numerical goals for the balance of their services structure, though by endorsing HCBS they implicitly suggest a balance shift. As exceptions, Washington's biannual strategic plan goals are explicit about how much shift from institutions is expected for the next 2 years, and Vermont has enunciated exceptionally explicit rebalancing goals.

Service Array and Funding Strategies

States foster the development of an array of services through licensing rules (or their absence) and through decisions about what to fund and who to make eligible for funding. The Medicaid state program and the Medicaid waivers are center-pieces for public funding of long-term supports. This project's abbreviated and full state case studies detail the variation in funding programs (including the number of HCBS waivers) and the ways services are defined and enumerated under those waivers. Considerable variation is found in how those building blocks are used, including:

- the balance of and articulation between State Plan services, on the one hand, and HCBS waiver services, on the other
- the proliferation of specialized HCBS waivers versus the consolidation of programs into fewer waivers;
- the development of separate waivers for services provided in group residential services such as assisted living versus the incorporation of assisted living and similar services into waivers;
- the extent to which personal care services under the State Plan are identical for all participants or vary by age;
- how state-funded or block-grant funds are used to further rebalancing. Reasonably, States prefer to use funding streams eligible for federal match when possible, but most are retaining the capacity to use some State-only programs to fill particular gaps;
- whether HCBS waivers and State Plan or state-funded programs have a consumer-directed option;
- whether some waver services are provided through managed care programs.

See Table 5 for a summary of structural elements in the construction of programs.

Table 5. Summary of LTC Programs in 8 States as of July 31, 2005

	AR	FL	MN	NM	PA	TX	VT	WA
Number HCBS waivers	6	10	5	4	11	7	5	8
Assisted Living incorporated as a waiver service			[[[[
Assisted living as a separate waiver for 1 populations	[[[[
One or more waivers covering only children	[[[
Personal care &/or attendant service in State Medicaid Plan	[[[[[[
Personal care in state plan covers all target populations			[[[
State funded services supplement waivers and state plan.	[[[[[[[[
Consumer directed services developed as separate waiver.	[[[
Consumer directed service built into existing waivers.			[[[
Consumer directed options in State Medicaid Plan	[[[
Consumer directed options in State or AOA programs	[[
Spinal injury state program (e.g., via motor vehicle fines).		[[
Some HCBS waivers run by MCOs (excluding PACE)		[[[
PACE programs under development	[[[[[[[

Notes: The Washington Waiver count includes a large MR/DD waiver that was phased out during 2004 and the 4 waivers being phased in to replace it. The Arkansas waiver count includes the Independent Choices which uses an additional 1115 waiver authority to provide cash in lieu of in-kind benefits without jeopardizing other benefit statuses. Otherwise we have not included 1115 waivers in the count. Consumer directed waivers under development but not authorized as of July 31, 2005 are also not counted.

Stakeholder and Advocacy Involvement

Consumer involvement in shaping and monitoring services is both a vehicle to rebalancing and an end in itself based on commitment to values of inclusion and building programs that most meet the expressed needs of the participants who use the services. States have employed a variety of strategies to elicit stakeholder involvement and provide vehicles for expression, ranging from creation of special or standing Task Forces and Committees to conducting statewide hearings and speak-outs. Typically, States pursue more than one approach. Often they designate key personnel and visible offices within the State hierarchy to maintaining communication with stakeholders. Some official advisory or oversight committees that are appointed by governors or cabinet secretaries mandate by law that certain constituencies be represented and/or that a percentage of members be persons with disabilities and/or their responsible family members.

States also show much evidence of involving provider stakeholders in planning and feedback. Each State needed to determine whether to utilize separate or joint advisory groups for the 2 types of stakeholders, and most did both. Sometimes, a particular organization casts itself or is de facto cast in the role of both consumer and provider stakeholder—for example, various aging and mental retardation organizations have defined advocacy roles for a constituency but also provide service. Providers of institutional care are also important stakeholders who are incorporated into standing committees and task forces.

Consumer Direction

Consumer direction is explicitly incorporated into service programs under state plans, and/or is included in separate programs. Table 6 illustrates the explicit attention to consumer direction that was found in the 8 States.

Table 6. Consumer Direction in 8 States as of July 31, 2005

	Evidence of Consumer Direction (Including Cash Options)
AR	<p>--Independent Choices program tested Cash and Counseling in state person care plan in a randomized controlled trial and made operational after demonstration period.</p> <p>--Consumer Directed Attendant Care is a core service in HCBS Alternatives Waiver for Persons with Physical Disability</p> <p>--a personal attendant component is being built into developmental disabilities services under Arkansas C-PASS grant, and consumer direction is being infused in Elder Choices HCBS waiver.</p> <p>--cash allowances are being used in the Administration on Aging family caregiver respite program.</p> <p>--a Next Choices program is being considered, which would cash out services for consumers who leave nursing homes.</p>
FL	<p>-- longstanding Home Care for the Elderly Program under state funding, provides cash options</p> <p>-- tested Cash and Counseling in a randomized controlled trial of adults and children in 3 HCBS waivers</p> <p>--consumer direction now built into HCBS waivers after piloting in Developmental Services</p>
MN	<p>--consumer directed community supports (CDCS) have been developed, along with related materials and manuals</p> <p>--in 2004 MN modified all its HCBS waivers to include CDCS as a service</p> <p>--in 2005, MN completed readiness reviews for and established a system of state-wide fiscal intermediaries for CDCS, incorporating 3 levels of activity for the fiscal intermediaries from fiscal conduit to agency with choice.</p> <p>--consumer direction incorporated into Older Americans Act family caregiver programs</p> <p>--managed care organizations delivering waiver services under capitated program are required to include the consumer-directed option.</p> <p>--piloting a Cash and Counseling Program in first wave of replications</p>
NM	<p>--consumer direction is embedded as a choice in state Medicaid plan personal care option</p> <p>--Consumer Directed Care Act of 2003 specifies inclusion of consumer direction in personal care, defined the concept, and mandates annual report to the legislature on take-up of consumer direction compared to more traditional models</p> <p>--New Mexico is preparing a self-directed waiver, Mia Via, to which those in or applying for existing HCBS waivers may enter. The Self-Directed Waiver Advisory Group meets regularly and is considering highly specific issues such as how to define quality in the context of self direction.</p>
PA	<p>--Grant from National Association of State Units on Aging used to assess consumer, potential consumer, and provider perspectives on consumer direction documented high receptivity , but considerable confusion about the concept.</p> <p>-- piloting a Cash and Counseling Program in first wave of replications</p>
TX	<p>--Consumer direction is directly incorporated into large Primary Home Care program (i.e. state option personal care) and HCBS waivers</p> <p>--a Service Responsibility Option has been developed within Primary Home Care that permits the consumer to direct services (including selection, supervision, and dismissal of providers within a framework where a provider agency pays bills and acts as fiscal agent.</p>
VT	<p>--HCBS waiver participants (elderly and disabled and persons receiving developmental services may choose between consumer directed and agency care, with the former being direction by oneself or a surrogate. In 2005 about ½ chose consumer directed model.</p> <p>--“Participant-directed attendant program,” a longstanding state-funded service is consumer-directed and also utilized panels of consumers to establish basis for allocation of funds to each plan.</p>
WA	<p>--Revised Code of Washington defined term “self-directed care” as meaning that an adult living in his or her own home recruits, training, supervises, and directs the paid personal aide.</p> <p>--in March 2005 an unduplicated count of 799 consumers, mostly under age 65, were receiving self-directed care under HCBS waivers,</p> <p>--piloting a Cash and Counseling Program in first wave of replications.</p>

Consumer-direction is on the increase, moving from an unfamiliar term 20 years ago to a concept that is embedded in state policy and programming to some extent in all the states in this study. Its application has spread from younger people with physical disabilities to all populations. Cash options are also appearing within the Medicaid program. States are beginning to incorporate consumer-direction numbers into their statistical presentations, sometimes under legislative mandate. With the proliferation of consumer direction, task forces are working on details, such as how quality will be defined when the consumer is in charge of services, and how consumer direction might be reconciled with managed care organizations holding capitation for long-term care. Texas, New Mexico, and Arkansas have explicitly infused consumer direction into their State Plan Personal Care Option, with New Mexico standing out with a piece of 2003 legislation actually named the “Consumer Directed Care Act.”

Real Choice System Change & Other Grant Funding

The eight States have utilized a wide range of grant funding to build their HCBS systems to their current state. Real Choice System Change Grants (RCSC) have been important resources. Between 2001-2004, 6 of the States were awarded System Change Grants, 6 were awarded Quality Assurance/Quality Improvement Grants, and 5 were awarded Aging and Disability Resource Center Grants, 4 were awarded Nursing Facility Transition Grants (not counting 2 earlier CMS grants for nursing home transitions prior to the RCSC funding), and 3 were awarded each of Integrating Housing with Services, Community-Integrated Personal Attendant and Supportive Services, and Money Follows the Person Grants. Other sizable RCSC grants in that period included a Comprehensive Systems grant to Vermont and an Independence Plus grant to Florida. Besides this CMS support, 2 of the States were among the 3 original states who received Robert Wood Johnson Foundation (RWJF) and OASPE support for piloting Cash and Counseling and 3 others are working on cash and counseling grants in the current replication phase. Other CMS, AOA, and HRSA grants, plus RWJF grants (some of the latter centered around Labor Force Development or Managed Care, have also helped prime the pump and add focus to rebalancing efforts.

Quality Initiatives

Quality Initiatives have been directed at improving institutional services (including nursing homes and remaining state developmental disability institutions), and designing approaches to proactive management of the quality of HCBS services. Among the approaches to nursing home quality, we note:

- Programs of consultation services designed in parallel to more traditional regulatory approaches (especially in Washington and Texas)
- Data-driven approaches to improving quality (notable in Texas)
- Payment mechanisms to give incentives for quality (especially in Minnesota)
- Legislated higher staffing standards for nursing homes (especially in Florida)
- State support of culture change efforts for nursing homes.
- An innovative “risk management” approach to improve NH quality in Florida
- Structural changes in survey and certification that bring nursing homes and HCBS programs under the same organizational structure

On the HCBS side, we have noted the following approaches to quality monitoring:

- Development of data capacity to monitor quality in real time. (These efforts are largely in the development stage.)

- Incorporation of consumer into establishing definitions of quality and quality monitoring approaches.
- Consumer feedback through in-person and web-based satisfaction surveys.
- Efforts to develop “critical incident” approaches to quality monitoring and improvement, especially in the developmental services area.
- Monitoring the quality of the allocation and case management process, particularly notable in Washington State.

In addition, Florida has emphasized standards for training (e.g. on Alzheimer’s Care) that cross all service providers.

Better Information for Consumers

The strategy of improving consumer information permeates the work of these eight States. The following developments have been noted in one or more of the States:

- Web-sites with extensive cross-referencing among government agencies and comprehensive indexes to more readily clarify programs (found in all 8 States).
- Web-based approaches for consumers to include their own circumstances and geographic location and emerge with tailored information about likely eligibility for programs and actual links to relevant providers in their own area.
- Searchable data bases for personal care attendants and other providers.
- Registries of affordable housing to improve the capacity for consumers and case managers to search housing data bases for real-time vacancies.
- State efforts to become an authoritative source of information about health conditions and chronic disease management.
- Out-reach across cultures and disability groups through web and printed materials in multiple languages, and in alternative formats for people with visual impairments.
- Innovative approaches such as system navigators and long-term care consultants to bring personal contact to and shape help for consumers making decisions.
- States-developed training manuals and training programs for consumers on how to direct their own services.

Reducing Institutions and Transition Programs

Besides applying initiatives to increase HSCB services and render them more flexible, States have undertaken strategies to down-size their nursing homes and other institutions.

- States typically are using Certificate of Need or moratoriums to limit the supply of nursing homes.
- States have mandated that consumers in state institutions for developmental disabilities be offered systematic and regular (e.g. annual) information about the possibility of leaving.
- Minnesota and Pennsylvania have built incentives for nursing homes to close or downsize; Minnesota includes financial incentives for nursing homes to create private rooms.
- States have worked actively with Housing Authorities to make Section 8 vouchers available for individuals leaving nursing homes.
- States have incorporated funding for transition services in HCBS waivers, state plans, or both.
- States have engaged Centers for Independent Living in the transition efforts, especially Texas and Minnesota.
- Money-Follows-the-Person Initiatives, already in place in Texas, are being explored by several States as vehicles for helping consumers leave institutions.
- Texas has also made good use of MDS-based information on the number of consumers in each nursing home who want to leave (on an aggregate basis and individual names to relocation specialists working under State contract) to provide more effective targeting of relocation assistance.

Major System Changes

Amid the important but narrower strategies deployed by the States as building blocks, all of these eight States could be said to be engaged in some major thrust towards rebalancing. Table 7 summarizes the over-arching strategies in each state. It is notable that the emphasis is related to each State's accomplishments so far and, therefore, what they perceive as the next need and opportunity. All States have put more funding into HCBS waivers, tried to reduce waiting lists in the MR/DD side (except in Vermont where no such waiting lists exist), have worked on housing, labor force, and quality assurance efforts to some extent, and have engaged consumers in the efforts.

Table 7. Over-Arching Rebalancing Strategies in 8 States as of July 31, 2005

	Over-Arching Strategies
AR	--Consumer direction and cash options.
FL	--Managed care, incorporating HCBS and consumer direction. --Expansion of developmental disability services while tackling efficiency issues in the use of resources for DD --Quality initiatives and training requirements for Nursing Homes and other licensed providers.
MN	--Managed Care, incorporating HCBS and consumer direction. --Improving information. --Moving towards more equity across state and across target populations (except Aging) --Long-range planning.
NM	--Building capacity through the personal care option program. --Consumer direction --Improving wages of direct caregivers.
PA	--Development of fast track capacity --Governors Office of Health Care Reform as a vehicle for change.
TX	--Money Follows the Person. --Relocation Assistance --Consumer Direction
VT	--1115 waiver to uncouple nursing-home certifiability and HCBS services for people with high levels of need.
WA	--Independent Provider models, buttressed by State Home Care Authority --Major investment in data systems to manage resource allocation and quality.

Quantitative Markers of Rebalancing

How well are States achieving their rebalancing goals? Certainly the eight states in this study have introduced a plethora of new funding streams and services on the ground. They have involved advocates in designing the systems, and have endeavored to make service options more available. All have achieved some measurable progress in terms of moving the ratio of service investment towards community care, and in serving more participants in the community. Some states have made very substantial progress in deinstitutionalize of consumers with mental retardation and developmental disability (notably, Minnesota, New Mexico, and Vermont). A few States still struggle with large proportions of consumers in state-operated developmental centers (especially Arkansas) and/or in large ICF-MRs (especially Texas for the latter). Washington State made considerable progress in closing State Mental Hospitals but reached a recent barrier with about 1000 participants still in state regional centers and various stakeholders expressing opposition to planned closures.

Quantitative Markers

We have examined quantitative markers of rebalancing in several ways using aggregate data from the Minimum Data Set (MDS) on Nursing Homes to approximate acuity in nursing homes, and aggregate data provided by states to describe utilization and expenditures in various State Plan programs for Medicaid (institutional services and HCBS services) and Medicaid waiver programs. Below we present some summary charts. Appendix C provides two tables with more detailed absolute figures on utilization and expenditures by program by state and with MDS data by state.

Figure 1 compares the changes in utilization and expenditures for nursing homes and HCBS waivers for elderly persons from 2002 to 2004, and examines the acuity in nursing homes for the same period. (The time periods were chosen because the MDS became universally available in 2002). Because the institutional comparison here is for nursing homes, developmental disability waivers and waivers limited to people under age 65 are excluded from the analysis, though mixed aging and disability waivers are included). Nursing home spending and clients served are shown in the first two bars. Elderly waiver participants and spending are shown in the next two bars. The last two bars show the changes in ability to perform activities of daily living (ADL scores) and cognitive performance scores (both derived from the MDS) in nursing home residents at three months after admission (to eliminate the effect of short stay residents). One might have expected that growth in waiver activity would be associated with an increase in case mix acuity in nursing home residents, but we found essentially no change in the case mix levels. Several States show substantial increases in aging waiver activity over this period (Minnesota, New Mexico, and Pennsylvania; two show modest increases (Washington and Vermont). None show an increase in case mix. None show reductions in nursing home spending. Only Minnesota, Pennsylvania, and Washington show any decrease in numbers of persons in nursing homes.

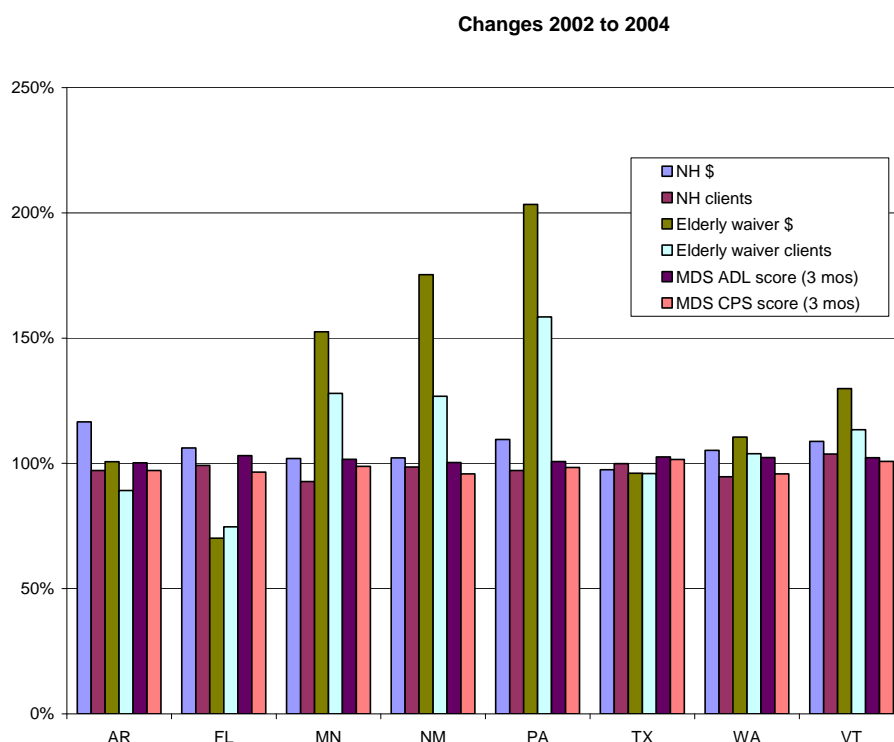


Figure 1: Utilization and Expenditures on Nursing Homes and HCBS and Acuity in HCBS from 2002 to 2004

Some States made greater use of personal care under the Medicaid State Plans than of waivers. The relative use of these two HCBS approaches is described in Figure 2, which compares the use of waivers to personal care under the State plans in 2004. Texas makes the greatest use of personal care. New Mexico spends the next most proportion of money on personal care, but Washington serves relatively more people. Only New Mexico spends more per case on personal care than waivers. Pennsylvania is omitted from the analysis because it does not cover personal care under its State Plan.

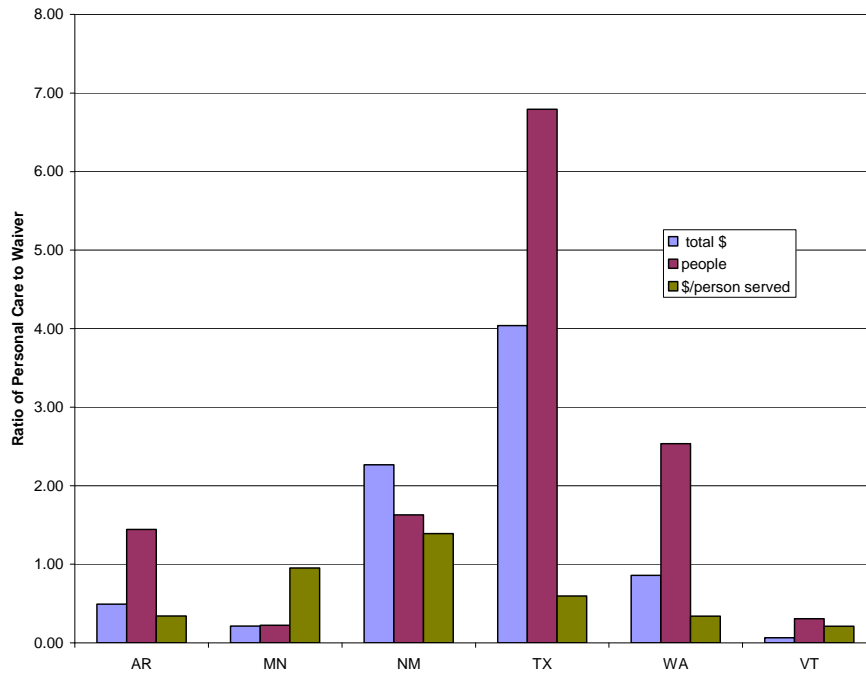


Figure 2: Ratio of State Plan Personal Care to Waivers, 2004

Figure 3 shows the differences across states in the expenditure per client served in 2004 for various types of LTC services. The ICF-MR expenses are far larger than those for nursing homes. Likewise the DD waivers expenses greatly exceed those for aging. Nonetheless there is substantial variation across the States.

Figure 4 directly contrasts the expenditures for DD and aging in terms of overall costs and per clients served. Total institutional spending is higher for aging, but the costs per participant are much greater for DD. For waiver dollars, only two States spend less on DD: Washington and Texas. For the other states, the total spending is several times higher for DD. Waiver spending per client served is consistently higher for DD. Figure 5 shows the same data in a different way, allowing a clear contrast of spending patterns within each State. Once again Figure 4 and 5 were calculated to maximize the comparison between developmental services and aging services, and, therefore, waivers limited to people with physical disabilities under age 65 did not figure in these analyses.

In subsequent analyses for Year 2 and Year 3, we will explore the utility of making other kinds of within-state comparisons of utilization and expenditures for a variety of programs and target populations. The graphs presented here illustrate a way of presenting data to highlight rebalancing challenges and accomplishments.

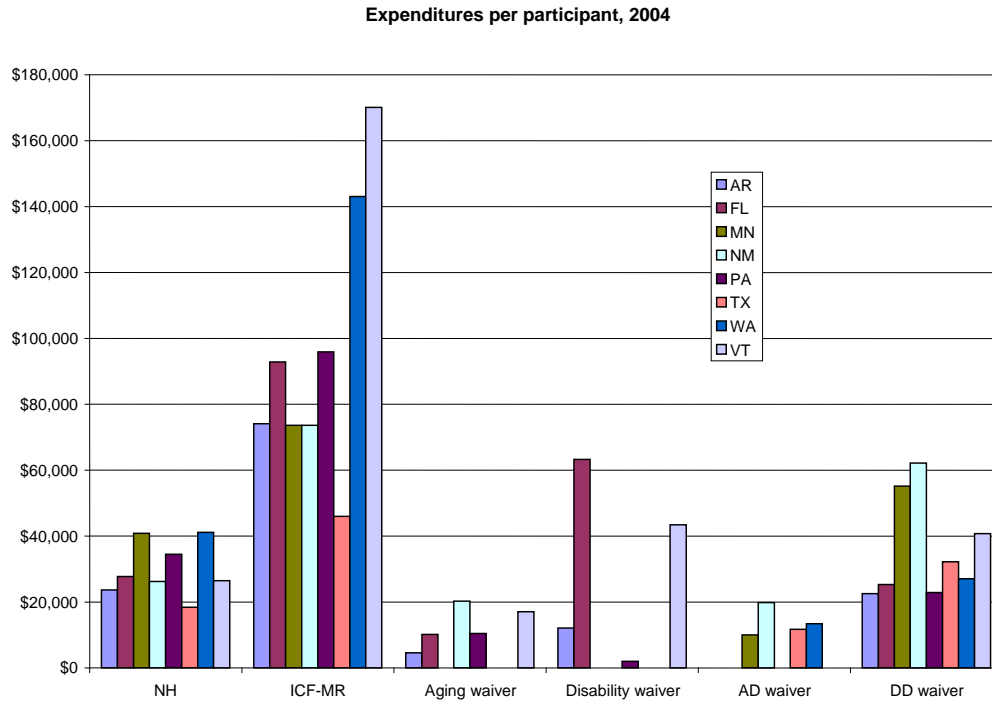


Figure 3: Expenditures per Participant by Waiver or Institutional Service, 2004

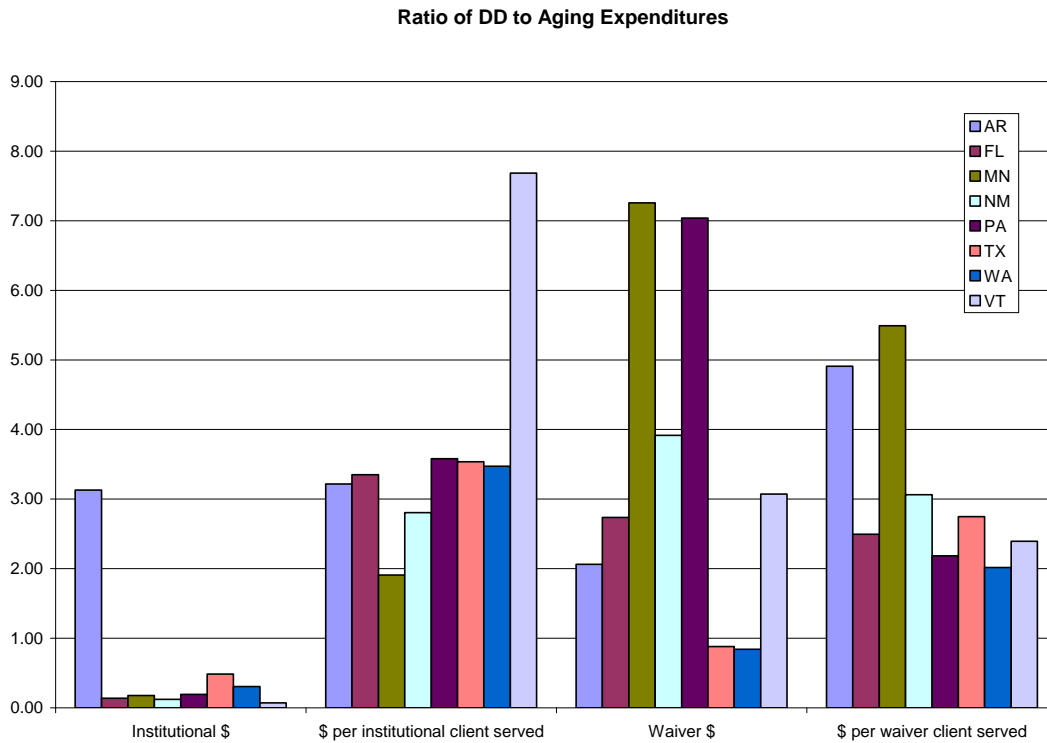


Figure 4: Ratio of DD to Aging Expenditures in Waivers versus Institutions, 2004

Ratio of DD to Aging Expenditures, 2004

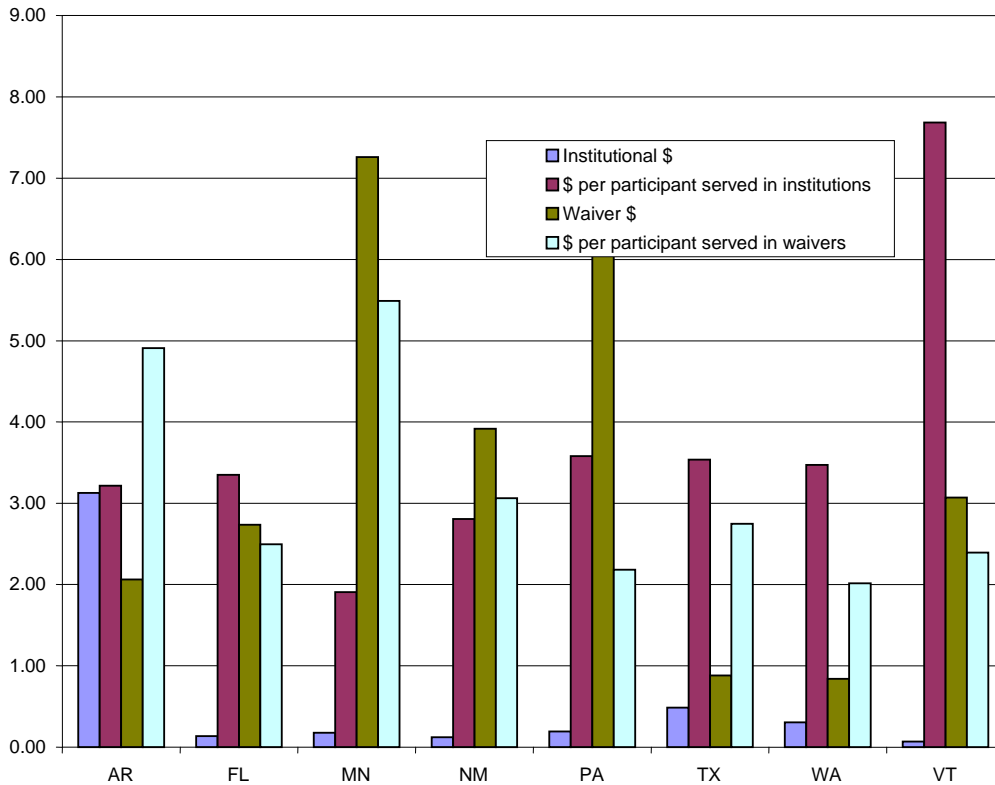


Figure 5: Ratios of State Developmental Disability to Aging Expenditures 2004

Moving Forward

Accomplishments

Please note that this is the first of 3 in a series of annual reports and presents the baseline findings of the study. The States in this Rebalancing Study have been committed to changing LTC. Some made substantial progress before the Year 2000, either in services to people with mental retardation and developmental disability, services to aged people and people with physical disabilities, or both. All have expanded options in the last 5 years, and the momentum seems to be present to push further in the next decade.

The States in our study took the post-Olmstead decision expectations seriously, and subscribed to the goals of the New Freedom Initiative. All but one had created Task Forces of stakeholders and high-ranking government officials to plan for and monitor progress towards community integration (Minnesota already had mechanisms in place to comply with post-Olmstead planning). Additionally, all the States tended to take comprehensive approaches to thinking about LTC and long-term support services. First, they necessarily put LTC in perspective of all the issues and concerns confronting state government—for example, economic development, tax policy, educational policy, and health policy broadly construed. Second and interesting from the perspective of State management approaches for

rebalancing of long-term support, States tended view the problems and potential solutions broadly. Not uncommonly, task forces assembled to address the general state policies or particular sub-issues included labor departments, transportation departments, education departments (particularly pertinent to issues related to HCBS for children), and housing authorities, in addition to the obvious involvement of the relevant agencies responsible for Medicaid, Aging, Health Services, Developmental Disability, and Mental Health.

Likely Challenges

New challenges may arise that will influence rebalancing positively or negatively. Among the ones that States indicate they are watching are:

- Stresses or opportunities created by changes or reductions in federal Medicare policy and federal or State Medicaid policy.
- Quality developments in both institutional care (which may demand more money for that sector) or in HCBS services.
- The possible re-alignment of provider stakeholders to include new stakeholders in HCBS policy and programs such as unions of direct care attendants and/or managed care organizations providing LTC.
- More explicit conceptual struggle with how to plan for nursing homes in the next decades in terms of supply and nature of the service.

Directions for Future Tracking

Some of the areas where we expect further developments, based in part on directions the eight States have already taken and in part based on systems gaps that they have identified, include:

- Refinement of approaches to HCBS for people with serious mental health problems, with predatory behavior, and with Alzheimer's disease.
- More emphasis on adaptive technology.
- More emphasis on transportation.
- More emphasis on housing and refinement of housing with services models, including the role of Fair Housing in enabling breaking down rules about who may live in assisted living.
- More technology for quality monitoring and quality improvement applied to HCBS.
- More struggle with wage incentives for personal care workers and the tension between improving these wages and expanding public funding of services.
- New approaches to chronic disease management, medication management, and nurse practice.

Finally, we are flagging several "big picture" conceptual issues related to HCBS waivers managed care, and equity across populations.

- Waivers were initially introduced as means of expanding Medicaid efforts to provide HCBS. Introduced with great caution and concerns about inducing new demands, waivers have gradually transformed into mainline efforts. Why then would states pursue waivers over incorporating services directly into their state plans? Waivers allow states to control risks by limiting the implementation geographically and establishing waiting lists. The fact that states still rely on these strategies suggests that they do not yet believe that persons with disabilities can be cared for in the community instead of in institutions or that they fear the demand will always outstrip the affordable supply. States like Vermont have begun to demonstrate other approaches to confronting these concerns.
- States are actively pursuing managed care to meet several ends. Managed care's greatest advantage is offering more predictable costs. Some believe that managed care can save money, but ultimately those savings will depend on the capitation rates established; thus far few managed care companies will work in situations where they do not see the rates as favorable. A less discussed advantage of managed care is the protection it affords by distancing those publicly accountable from any denial or restriction of services; in effect, managed care provides a buffer. For some, managed care offers a way to integrate and consolidate services that has not been directly addressed within government.
- States tend to offer different options to younger rather than older consumers, and nursing home transition programs are often more vigorous for or targeted at persons under 65 as a top priority. The most costly service plans tend to be in the developmental services area--here both seniors and people with physical disabilities are disadvantaged. Some of these differences may be due to different needs and preferences by age and type of disability, but they probably also stem from differing advocacy traditions and different understandings among providers, families, and the persons with disabilities themselves about what is appropriate and feasible. Moreover, in the quest for equitable handling of consumers across age groups and programs (and for holding down the costs of individual plans to what is "necessary" in order to serve more consumers, states are grappling with what kind costs differences adhere to a habilitative versus supportive service plan. Cost effectiveness calculations for specific services have been hard to apply in the developmental disability area given the weight of individual preferences. We do not see that kind of attention to individual preferences of seniors, and there seems to be much more acceptance that many seniors need to be in institutions to be safe.

Appendix A. Background on Authorization of the Rebalancing Study

In 2003, Congress directed the Centers for Medicare & Medicaid Services (CMS) to commission a study to explore the effects of various management techniques and programmatic features that states have put in place to rebalance their Medicaid LTC and long-term support investments. The specific Congressional request (included in summary of S. 1356, the 2004 appropriations bill for the Departments of Labor, HHS and Education) read as follows:

The Committee [Senate Committee on Appropriations, 2003] understands that States are working to rebalance their long term care systems, but information on the techniques and aggregate costs is lacking. Therefore, the Committee expects CMS to work with three to eight States and research the program management techniques used by these States to provide adequate services while effectively managing aggregate costs as States rebalance their long term care systems to reduce reliance on institutional services and increase community based services. CMS should also work with these States to gather and report on the changes in aggregate costs and per person expenditure to the Medicaid program and the numbers of individuals receiving institutional care and community based care. CMS should give preference to States implementing statewide initiatives.⁵

In October 2004, CMS's Advocacy and Special Initiatives Division awarded a contract to perform this work in collaboration with eight states that are in the process of rebalancing LTC services.⁶

In its Request for Proposals, CMS defined rebalancing to mean “adjusting the state’s Medicaid programs and services to achieve a more equitable balance between the proportion of total Medicaid long-term support expenditures used for institutional services (Nursing Facilities [NF] and Intermediate Care Facilities for the Mentally Retarded [ICFs-MR]) and those used for community-based supports under its State Plan and waiver options.” Further, CMS stated that a balanced long-term support system “offers individuals a reasonable array of balanced options, particularly adequate choices of community and institutional options.”⁷ Thus, rebalancing does not imply a particular target ratio of LTC expenditures between institutional and community care. Rather, the term reflects the goal of state reform efforts to provide all persons in need of LTC and supports with choices among an array of options to assure that they receive care and supports in the most appropriate, integrated, and cost-effective setting relative to their needs.

⁵ Transcript for 108th Congress, Senate, 1st Session 108-81, Departments Of Labor, Health And Human Services, And Education, And Related Agencies Appropriation Bill, 2004 on web at:

[http://thomas.loc.gov/cgi-bin/cpquery/?&dbname=cp108&maxdocs=100&report=sr081.108&sel=TOC_613120&/a>](http://thomas.loc.gov/cgi-bin/cpquery/?&dbname=cp108&maxdocs=100&report=sr081.108&sel=TOC_613120&/)

⁶ The project was awarded to the CNAC Corporation, Arlington, Virginia in October 2004. The Institute for Health Services Research at the School of Public Health of the University of Minnesota provided the Principal Investigators for the project under a subcontract to CNAC (Master Contract No.: 500-00-0053 , Task Order # CMS-04-0014). The CNAC project manager is Linda Clark-Helms, and the PIs from University of Minnesota are Rosalie A. Kane and Robert L. Kane. This work also entailed subcontracts to the National Academy for State Health Policy (Robert Mollica) and the University of California at San Francisco (Charlene Harrington), and consultant agreements with Charles Reed and Dann Milne, who previously had directed operational state long-term care programs in the States of Washington and Colorado, respectively.

⁷ Request for Task Order Proposal CMS-04-0014 for “Research of Program Management Techniques Taken by States to Rebalance Their Long-Term Care System”, Attachment A, Statement of Work, p. 3 of 13.

Appendix B: State Liaisons for Rebalancing Study

Arkansas

Herb Sanderson
Director
Division of Aging and Adult
Services
Department of Human Services
Little Rock, Arkansas.

Florida

Beth Kidder
Chief
Bureau of Medicaid Services
Agency for Health Care
Administration
Tallahassee, Florida 32308

Minnesota

LaRhae Knatterud
Director
Aging Transformation
Continung Care Administration
Department of Human Services
St. Paul, Minnesota

New Mexico

Deborah Armstrong
Secretary
Department of Aging and Long
Term
Services
Santa Fe, New Mexico

Pennsylvania

Dale Laninga
Co-Director
Long Term Care Reform Project
Governors Office of Health Care
Reform
Harrisburg, Pennsylvania

Texas

Tom Phillips
Project Manager
Department. of Aging & Disability
Services
Austin, Texas

Vermont

Patrick Flood
Commissioner
Department of Aging and
Independent
Living
Waterbury, Vermont

Washington

Kathy Leitch
Assistant Secretary
Aging and Disability Services
Administration
Department of Social & Health
Services
Olympia, Washington

Note: The chart lists study State liaisons during the first year of the study, the period reflected by this report.

Appendix C. Detailed Tables

Table C.1. Comparisons of Client Load and Expenditures across States in 2004

	AR		MN		NM		PA		TX		WA		VT	
	# Clients	\$ millions	# Clients	\$ millions	# Clients	\$ millions	# Clients	\$ millions	# Clients	\$ millions	# Clients	\$ millions	# Clients	\$ millions
State MR Institutions	1,207	\$96	2,139	\$167			1,502	\$257	5,119	\$484	1033	\$152		
Nursing Facilities	19,759	\$468	22,848	\$935	6,429	\$169	76,678	\$2,645	94,772	\$1,745	12,447	\$513	3,631	\$96
ICFs-MR	1,766	\$131	2,039	\$150	281	\$21	2,586	\$248	7,901	\$364	59	\$4	6	\$1
MR facilities	2,973	\$227					4,088	505	13,020	\$848	1,092	\$156		
State Plan Home Care/Personal Care	16,957	59	13,665	\$258	9,676	\$182			33,860	\$3,365	10,730	\$125		
Home Health Services	6,515	\$12							208,516	\$2,627			3,595	\$8
Elderly/Disabled waivers	8724	\$51	10,994	\$111	2,606	\$53	18,307	\$162	37,747	\$443	23,318	\$314	1,729	\$29
MR/DD waivers	3,034	\$69	14,532	\$802	3,335	\$207	47,544	\$109	12107	\$390	9,726	\$264	1,961	\$9
Supported Living/Group Residential Housing			14,162	\$87							3,607	\$180	256	\$5

Table C.2. Change in Nursing Home Case Mix Three Months after Admission

	Arkansas		Florida		Minnesota		New Mexico		Pennsylvania		Texas		Vermont		Washington	
	2002	2004	2002	2004	2002	2004	2002	2004	2002	2004	2002	2004	2002	2004	2002	2004
3 Months																
Mean ADL score	12.34	12.30	13.98	14.41	12.44	12.21	11.06	11.99	15.27	15.60	12.77	13.28	13.18	13.48	13.99	14.32
Change 2002-2004		-0.04		0.43		-0.23		0.93		0.33		0.51		0.3		0.33
Mean CPS score	2.56	2.44	2.57	2.48	2.34	2.27	2.36	2.28	2.43	2.40	2.53	2.64	2.43	2.45	2.63	2.52
Change 2002-2004		-0.04		0.43		-0.23		0.93		0.33		0.51		0.3		0.33