Research on State Management Practices for the Rebalancing of State Long-Term Care Systems: Final Report

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Preface

In 2003, Congress directed the Centers for Medicare & Medicaid Services (CMS) to commission a study in up to 8 States to explore the various management techniques and programmatic features that States have put in place to rebalance their Medicaid long-term supportive services (LTSS systems and their investments in long-term support services towards community care. The States of Arkansas, Florida, Minnesota, New Mexico, Pennsylvania, Texas, Vermont, and Washington participated in the resulting 3-year collaborative study (hereafter called the Rebalancing Research). For the study, CMS defined rebalancing as achieving "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;" in an LTSS system that offers "a reasonable array of balanced options, particularly adequate choices of community and institutional options."

The study, which was extended 9 months from the original timelines, took place between October 2004 and June 2008, was a longitudinal study with qualitative and quantitative components that utilized a wide variety of methods. Among the many products generated are:

- 8 baseline case studies for each of the 8 states covering a period up to July 2005
- an 8-state update report, covering the period from August 2005 to July 2006
- 8 final cases studies for each of the 8 states, covering the period until December 2007
- 6 cross-cutting Topic Papers dealing with themes in Rebalancing
- 6 Quantitative Chartbooks

This final report has two purposes: 1) to summarize the methods, products and findings of this complex project, and provide a roadmap to its products; and 2) to suggest conclusions and recommendations that might be helpful to State officials, legislators, advocates, and providers and CMS on approaches to increase and improve long-term supports in the community for people with disabilities of all ages, enhance participant choice, and reduce reliance on institutions.

We are grateful to the liaisons to the study from the participating states: Herb Sanderson, Arkansas Division of Aging and Adult Services; Beth Kidder and Wendy Smith, Florida Agency for Health Care Administration; LaRhae Knatterud, Minnesota Department of Human Services; Deborah Armstrong, formerly New Mexico Department of Aging and Long-Term Services; Dale Laninga, formerly Pennsylvania Governor's Office on Health Care Reform and Mike Hall, Pennsylvania Assistant Secretary for Long-term Living; Marc Gold, Texas Department of Aging and Disability Services; Patrick Flood and later Joan Senecal, Vermont Department of Aging and Independent Living; and Kathy Leitch, Washington Aging and Disability Services Division: all were responsive, gracious, and thoughtful despite hectic schedules and multiple other demands on their time. We also thank the staff in each State who worked with us to provide State data and finder files to link with Medicaid data, and especially thank Glenn Mitchell of the Florida Policy Exchange Center, University of South Florida in Tampa for his special help with data analysis.

Many CMS officials have provided us with helpful critique and comment, including Melissa Hulbert, William Clark, Karen Armstrong, Ronald Hendler, and Susan Hill, and especially our three successive CMS project officers—Mary Beth Ribar, Dina Elani, and Kathryn King—who have been unfailingly facilitative and have provided us with many insightful comments and suggestions. All conclusions are those of the researchers and do not necessarily reflect the opinions of any officials at CMS or the participating States.

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Executive Summary

This final report reviews the goals and methods of a Congressionally mandated four-year qualitative and quantitative study of State strategies for their long-term supportive services (LTSS) undertaken to change the balance of utilization and expenditure in the State Medicaid programs for all populations to increase utilization of and expenditures on home and community based services and reduce utilization of and expenditures on institutions. The study activities took place between October 2004 and June 2008 in collaboration with eight participating States: Arkansas, Florida, Minnesota, New Mexico, Pennsylvania, Texas, Vermont, and Washington.

Findings in the products of the Rebalancing Research are discussed in Part I. These products include:

- State case studies conducted at three points in time, resulting in 18 separate reports, which are each summarized on pp. 12-26;
- 6 cross-cutting topic papers, which are each summarized on pp. 27-36; and
- 6 Chartbooks with special quantitative analyses, which are summarized on pages 37-46.

In general we conclude that it is possible for States to substantially alter the balance of their LTSS towards community without reducing the quality of overall services or dramatically increasing overall costs. States have different histories and circumstances, and no single management strategy will apply to all States. However, management strategies do make a difference in a State's ability to rebalance their LTSS systems.

Part 2 of this report provides conclusions related to management practices and recommendations.

Findings on Management Strategies

- Vision statements. States should develop a vision statement for LTSS that emphasizes choice and independence; the vision statement should be enunciated in one or more State statute and incorporated into the vision of relevant State agencies. Such vision statements are best to be prominent in all related print and electronic materials, and State employees need training on the meaning of the vision and how to make it operational.
- Operational consolidation. Consolidate operations related to all populations needing LTSS into a single State agency; consolidate functions such as budgeting & planning, operations, and quality assurance in a single State agency; the entity responsible for LTSS should control both the institutional and HCBS budgets.
- Expedited eligibility processes. Work towards expedited eligibility processes or even presumed eligibility; ensure the potential consumers get necessary information about choices at the right time.

- Eliminate waiting lists. Avoid wait lists for HCBS services, particularly if no wait is needed for institutional services; if wait list exist for waiver services, try to use State-funded services for seamless gap-filling.

- Array of services. Develop a varied array of services, beginning with a capacity for personal care and/or attendant services; build flexibility into the services themselves rather than require multiple services to fulfill particular tasks; redefine case management services to meet current system needs; include a wide variety of residentially-based services in the array; examine nurse practice acts to assure that nurses can perform teaching roles and delegate nursing tasks to unlicensed assistive personnel.

- Consumer-directed services. Consumer-directed services are an important building block in a rebalanced LTSS system and should be incorporated in both waivers and State Plan Personal Care Option Services. States have found it feasible for family members to serve as paid caregivers in such a system.

- Stakeholder roles. Develop and provided staff support for a stakeholder group, largely comprised of consumers, and encourage a visible role for this group; in addition, develop stakeholder groups for various programs and initiatives.

- Information infrastructure. Develop an information infrastructure to support HCBS services with an ability to track experiences of groups of participants with various needs and an ability to track the performance of service providers; develop reporting hotlines and incident reporting systems; make information on quality readily available to consumers; develop feedback on quality directly from consumer surveys or interviews with consumers.

- Role of managed care. Managed LTSS, often introduced as part of overall managed Medicaid services can be used to encourage community care and rebalancing if: the State is clear on incentives for community care; a mechanism is available to ensure that consumer choice of living situation is respected, and consumers are offered consumer-directed models; and assisted living settings are not over-utilized. Managed LTSS is more likely to carry incentives for HCBS if the providers are at financial risk for nursing-home care and/or incur penalties when nursing home residents dis-enroll.

- Numerical goals for nursing homes. Develop numerical goals for nursing home Medicaid expenditures, and, if possible, build them into budget forecasts; develop reimbursement incentives for nursing homes to downsize, close, and/or diversify into community services; for States with large ICF/MRs, develop incentives for them to close and perhaps become HCBS providers instead.

- Transition programs. Develop specific programs to assist those who wish to make transitions from institutions; fund and train a group of relocation specialists to work with transitioning individuals; build transition expenses, including relocation specialist services and expenses for deposits and furnishings into waivers or State-funded programs; ensure an unbiased outside source of information about community alternatives for persons living in institutions.

- Long-range strategies. While working on immediate issues that might result in better "rebalancing statistics," also consider long-range needs to sustain a system flexible and high-quality HCBS services are available. Examples include ways to build a high quality labor force for LTSS, efforts to develop livable communities (including transportation systems), and various efforts to increase the stock of affordable, accessible housing, and to make prosthetic equipment available. Such long-range planning may be undertaken as public-private partnerships.

Recommendations

General principles.

- Institutions, particularly nursing homes, should not be the standard against which other care is measured. Instead the primary thrust should be to keep people in the community, in their own homes if possible, but in a home in any event. Some degree of congregate living may be required to facilitate efficient delivery of services, but it should not come at the expense of depriving a person of a livable home.

- Infrastructure is needed. One level of infrastructure is administrative. Fragmentation impedes progress and efficiency. Some degree of programmatic coordination, ideally a centralized administration that controls funding and the full range of services for the full gamut of the LTC population should facilitate effective allocation of resources.

- Accountability is also central and extends beyond regulation to a more proactive approach that identifies goals and rewards their achievement at the individual and program level. Accountability for meeting individual consumer preferences would be part of the incentive system.

- Payments should be used to re-enforce established goals. The current approach of paying for services must be tempered towards paying for accomplishments, even accomplishments subjectively experienced by the consumer.

- Regulation has transformed the nursing home industry but at a cost. It has eliminated some (but certainly not all) woefully substandard care but it has failed to create a positive climate for improvement. We should not reinvent a heavy regulatory approach to LTSS based on nursing home regulations.

Recommendations for States Undertaking Rebalancing.

1. States should adopt a set of core values that might include the following:
    - Persons of all ages needing LTSS and their families are entitled to maximum feasible choice of and participation in selecting service providers and living settings;

    - Persons of all ages with disabilities have the right to choose and/direct a care plan involving "managed risk", in exchange for the advantages of personal freedom. Such

risk taking presumes access to good information about the benefits and risk implications of alternatives.

- The array of public service options and individual client choices may be bounded by reasonable considerations of costs.

- Quality of life is as important as quality of care.

2. States should work towards integrating services for all LTSS populations in the same agency, and towards achieving a unified budget for HCBS and institutional services.

3. A State LTSS system needs a fast, timely and standardized way to assess financial and functional eligibility.

4. A State LTSS system needs a high quality, accountable case-management system with capacity to provide information, assistance, and oversight for consumers.

5. A State LTSS system needs a fair rate setting and contracting process for providers.

6. A State LTSS system needs a process for assuring quality oversight throughout the system.

7. A State LTSS system needs a sophisticated group of consumers/families and providers who advocate for the LTSS system.

8. State lead agencies for LTSS should build a quality system by:
   - establishing programs in which substantial samples of individuals are surveyed to determine the outcomes of the institutional and community supports they receive;

   - analyzing those data to determine the settings and individuals for whom outcomes are relatively less well achieved;

   - reporting those outcomes publicly;

   - establishing quality improvement programs that address types of service, locations or groups of services recipients whose outcomes are less than should be achieved; and

   - instituting or proposing legislative policy and program changes in areas in which predictors of less favorable outcomes can be manipulated by policy.

9. The relevant State agency should review all regulatory language for any group residential settings to identify and remove requirements that force consumers to leave if they “need 24-hour nursing” or otherwise reach a certain level of disability.

Recommendations for State Legislatures: State legislatures should:

1. Set specific budget targets for decreased expenditures for institutional services and increased expenditures for home and community services with established incentives to meet/disincentives to miss those targets;

2. Create housing subsidies for individuals in the community for the cost of the housing subsidy if the cost of community supports needed to live in that housing and the subsidy are equal to or less than the cost of otherwise necessary institutional care.

3. Provide such subsidies at enrollment in Medicaid LTSS with simultaneous application for a HUD Section 8 housing voucher and maintain the state subsidies only until the individual(s) can claim a HUD Section 8 voucher or other federal subsidized housing.

Recommendations for consumer advocates. Consumer advocates should:

1. Monitor and publicize state performance in comparison to other states in key indicators of "rebalancing" (e.g., decreasing rates of institutionalization, relative balance of institutional vs. home and community services, relative balance and trends in state expenditures for institutional and home and community services, rates of competitive employment for persons with disabilities; independent housing rates for persons with disabilities; and so on.)

2. Obtain and publicize data or findings on variations in outcomes (choices, employment/earnings, community participation, etc.), satisfaction and expenditures for factors associated with rebalancing concretely and broadly framed (institutions vs. home and community supports, setting size, own home v. assisted living, consumer directed vs. traditional budgeting, care planning vs. person-centered planning).

3. Monitor the enforcement of the Olmstead decision in their States.

Recommendations for CMS and other Federal Agencies. CMS should consider:

1. Providing grants to states as incentive to consolidate of all their LTSS programs in one place in state government.

2. Providing a better Title 19 match for Home and Community Services as an incentive for states to provide this type of service.

3. Intervening in states that are making little or no progress in fulfilling the promises of Olmstead. Create potential benefits for progress (and potential detriments for continued lack of progress). For example, the FFP could be reduced by 1% per year for institutional services and increased by 1% per year for community supports for a period of time.

4. Engaging with HUD in a demonstration within targeted communities (ones in which the cost of housing exceeds what can be purchased with the standard SSI and SSDI cash

payment) of target housing subsidies linked to new Medicaid LTSS recipients and/or participants coming out of institutions.

5. Establishing partnerships with financial incentives for states to utilize a well-developed, standardized program of outcome assessment for substantial random samples of institution and community service recipients. In such a plan CMS not only contributes to states' obtaining state data for their own analysis purposes, but it integrates the data sets created to establish a multi-state means of studying the effects of various supports for persons of various characteristics living in various settings.

6. Encouraging States to expand state-plan coverage to include more HCBS services.

7. Encouraging the kind of federal statutory and regulatory changes needed so that a broad array of LTSS services could be available for all eligible Medicaid participants without regard to the artificiality of nursing-home certifiability. (This would include variants of the Vermont Choices for Community Care program).

8. Exploring the feasibility and desirability of and the needed statutory and regulatory changes for uncoupling room and board from services in nursing homes to level the playing field.

<u>Recommendations for States Undertaking Rebalancing.</u>

1. States should adopt a set of core values that might include the following:
   - Persons of all ages needing LTSS and their families are entitled to maximum feasible choice of and participation in selecting service providers and living settings;

   - Persons of all ages with disabilities have the right to choose and/direct a care plan involving "managed risk", in exchange for the advantages of personal freedom. Such risk taking presumes access to good information about the benefits and risk implications of alternatives.

   - The array of public service options and individual client choices may be bounded by reasonable considerations of costs.

   - A State LTSS system should incorporate the belief that quality of life is as important as quality of care.

2. In a State LTSS system no service should be viewed as more important than another; nursing homes are no more or less important than any other service even though they are mandated in Medicaid.

3. In a State LTSS system, States should work towards integrating services for all LTSS populations in the same agency, and towards achieving a unified budget for HCBS and institutional services.

4. A State LTSS system needs a fast, timely and standardized way to assess financial and functional eligibility.

5. A State LTSS system needs a high quality, accountable case management system with capacity to provide information, assistance, and oversight for consumers.

6. A State LTSS system needs a fair rate setting and contracting process for providers.

7. A State LTSS system needs a process for assuring quality oversight throughout the system.

8. A State LTSS system needs a sophisticated group of consumers/families and providers who advocate for the LTSS system.

9. State lead agencies for LTSS should build a quality system by:
   - establishing programs in which substantial samples of individuals are surveyed to determine the outcomes of the institutional and community supports they receive;
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   - reporting those outcomes publicly;
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   - instituting or proposing legislative policy and program changes in areas in which predictors of less favorable outcomes can be manipulated by policy.

10. The relevant State agency should review all regulatory language for any group residential settings where Medicaid waiver services are received to identify and remove requirements that require consumers to leave if they "need 24-hour nursing" or otherwise reach a certain level of disability.

<u>Recommendations for State Legislatures</u>: State legislatures should:

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2. Obtain and publicize data or findings on variations in outcomes (choices, employment/earnings, community participation, etc.), satisfaction and expenditures for factors associated with rebalancing concretely and broadly framed (institutions vs. home and community supports, setting size, own home v. assisted living, consumer directed vs. traditional budgeting, care planning vs. person-centered planning).

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3. Intervening in states that are making little or no progress in fulfilling the promises of Olmstead. Create potential benefits for progress (and potential detriments for continued lack of progress). For example, the FFP could be reduced by 1% per year for institutional services and increased by 1% per year for community supports for a period of time.

4. Engaging with HUD in a demonstration within targeted communities (ones in which the cost of housing exceeds what can be purchased with the standard SSI and SSDI cash payment) of target housing subsidies linked with a) new Medicaid LTSS recipients and/or b) persons coming out of institutions, so that new community HCBS recipients for whom the cost to the federal government for both subsidized housing and home/community supports would be less than the cost of an institutional placement would receive access to a HUD or HUD-liked Section 8 voucher simultaneous to the available of the community supports they need to live in their subsidized housing.

5. Establishing partnerships with financial incentives for states to utilize a well-developed, standardized program of outcome assessment for substantial random samples of institution and community service recipients. In such a plan CMS not only contributes to states' obtaining state data for their own analysis purposes, but it integrates the data sets created to establish a multi-state means of studying the effects of various supports for persons of various characteristics living in various settings.

6. Encouraging States to expand state-plan coverage to include more HCBS services.

7. Exploring the kind of federal statutory and regulatory changes needed so that a broad array of LTSS services could be available for all eligible Medicaid participants without regard to the artificiality of nursing-home certifiability. (This would include variants of the Vermont Choices for Community Care program).

8. Exploring the feasibility and desirability of and the needed statutory and regulatory changes for uncoupling room and board from services in nursing homes to level the playing field.

Research on State Management Practices for the Rebalancing of State Long-Term Care Systems: Final Report

Part I. Overview of the Study and its Products

Introduction

History and Goals of the Project

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 supportive services (LTSS) systems.[1] 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 and those used for community-based supports." The language of the Congressional request specified that the study should be both qualitative and quantitative in nature and should consider how States could meet the challenge of shifting the balance of their efforts away from institutional care and towards community care while ensuring quality in both the new community services and the remaining institutional services and avoiding a large increase in overall expenditures. A 3-year study was awarded to University of Minnesota and its collaborators (through a master contract held by the CNA Corporation) in October 2004 (hereafter called the Rebalancing Research Project) and, with a 9-month extension, was completed in June 2008.

The study progressed in parallel with many CMS activities and projects funded under the Real Choice System Change (RCSC) Grants that followed the 1999 Supreme Court Olmstead decision and the 2001 Presidential New Freedom Initiative. During the years following the

[1] Various States use different terms and acronyms for long-term supportive services and the populations served, and the predominant use of language has changed even over the last four years. For consistency in this final report, we use the term long-term supportive services (LTSS) rather than long-term care.

initiation of the Rebalancing Research, CMS further clarified that a balanced LTC system "offers individuals a reasonable array of balanced options, particularly adequate choices of community and institutional options" and emphasized the pivotal importance of incorporating person-centered planning and consumer-directed services into any rebalanced LTSS. Similarly, over our project period, CMS increasingly signaled to States an expectation that consumer stakeholders would have meaningful direct roles in program development, monitoring, and evaluation. e incorporated into our work plans and priorities an effort to discern management strategies that States use to achieve maximal consumer direction by participants in LTSS programs, and ongoing meaningful participation of consumer stakeholders at the policy and program levels.

Scope of Study

The contractor for this study was explicitly asked to take a broad view of the project and to consider all people of any age with disabilities of any type—physical, intellectual, psychological who are served under Medicaid and Medicaid waivers.

Initially we perceived that State management practices fell into at least four types:

- Strategies to improve access to services. At the outset, we understood that strategies to improve access could include provision of information to consumers, advocates, and decision advisors; speeding the process of both financial and functional eligibility; developing equitable and consistent availability of services across the entire state; improving the referral and assessment processes.

- Strategies to increase the array of services and their quality. At the outset we understood that these strategies included developmental efforts to create a service capacity; the encouragement of flexible options; ensuring labor force development for LTSS; developing information systems and Information Technology platforms to support decentralized community services; developing quality monitoring systems that would allow States to confidently increase investments in community care; and systematic ways to create incentives for institutional services providers to downsize and/or diversity their efforts. The service capacity might also depend on strategies for how to define and use Medicaid Home and Community Based Services (HCBS) waivers and structure optional state plan services.

- Strategies related to budgeting and payment. At the outset we understood that these strategies could include ways to manage State LTSS budgets so that money could be

moved from institutional to home and community based services (HCBS) programs; capitated managed care strategies; and reimbursement incentives.

- Strategies that involve linkages to other governmental and private sector programs. The study focused on Medicaid programs and on expenditures under Medicaid State Plans and under HCBS Medicaid waivers, but it also took into account how States effectively combined Medicaid funding with various federal funding streams for particular programs (e.g. for education, aging services, and rehabilitation services) and with State revenues. To maximize Medicaid's effectiveness as a vehicle for Rebalancing, States can use a variety of collaborative strategies. Potential collaborating entities varying according to various target populations and age groups but could include health care (both physical and behavioral); physical rehabilitation, vocational rehabilitation, and Centers for Independent Living programs; housing programs; Older Americans Act programs and the so called Aging Network of State Units on Aging and Area Agencies on Aging; manpower development programs; and educational programs at all levels (preschool, elementary and high school, college).

Although the major study focus was on HCBS programs, our purview also included activities related to meeting needs of, empowering, and ensuring high quality services to residents in institutions. Regardless of how an LTSS system is balanced between investments in HCBS and institutional services, States must meet quality goals for both sectors and will encounter tradeoffs in the use of State resources to manage all LTSS programs in the community and institutions on behalf of people with all kinds of disabilities and of all ages.

Selection of Participating States

Eight States participated in this collaborative project. They were: Arkansas, Florida, Minnesota, New Mexico, Pennsylvania, Texas, Vermont, and Washington

The selection of these 8 participating states followed an orderly process. The primary criteria established by CMS were that each selected state must be "in the process of rebalancing LTC systems towards community care" and that the states, collectively, must illustrate a range of management techniques across the whole spectrum of HCBS target populations and a range of state circumstances (e.g., larger or smaller, more or less populous, stronger or weaker county government structure, geographic variation, demographic variation, policy variation, service

structure variation. We excluded Alaska and Hawaii for practical reasons and because of their limited generalizability) and, at CMS request, Oregon and Wisconsin because they were the subject of recent or ongoing attention. We developed comparative information on the other States using easily available information and our own knowledge of policy directions for LTSS. With input from CMS, we narrowed the possible choices to 20 and grouped them to display what each would bring to the Rebalancing Research effort.

Collaborative Relationship with Participating States

With input from CMS, we issued invitations to 8 States; all invited States agreed to participate. We identified a liaison in each state (each a high level official in the state's governmental entity most responsible for LTSS) to be the project's primary contact. The 8 state liaisons formed the project's state steering committee to give collective input into the work. Later when we began collecting quantitative data from each State, we also identified one or more "point persons" to help us identify and understand the nature of each State's data collection systems and data repositories.

The Rebalancing Research was a collaborative effort with the participating States. It was not structured as a formal evaluation, nor was it based on examining the State's LTSS programs against any normative views on what constitutes the "correct" balance. Rather, the study was an endeavor with the participating states to gain insights on how and what kind of goals States set for LTSS, and what administrative arrangements, policy directions, service packages, and management activities had shown promise to them.

Overview of Methods

State Case Studies

State case studies were performed at three time periods, resulting in baseline, one-year follow-up and final case studies for each state. The case studies entailed both qualitative and quantitative analyses.

Baseline State Case Studies. The baseline case studies presented the current situation as of 2005 in the context of a presentation of the history of each State's development of LTSS from about 1970 forward. To prepare the baseline state-specific reports, we reviewed voluminous information on each state (including relevant state legislation and regulations, policy statements and manuals, assessment tools, relevant commission and task force recommendations, and special studies). We mapped the structure of state policy-making and operations related to LTSS, and prepared a historical timeline of major policy and programmatic milestones. In discussion with the State liaison we created lists of key consumer and provider stakeholders and identified who would best be able to provide us with quantitative data on supply, users, and costs of services. Members of the quantitative team conducted telephone interviews with the identified persons so that they could further understand the data available in that State. We created a standard context for each State's activities, drawing upon nationally available material on state demographics, manpower availability,

Site visit teams, including researchers for both the project's qualitative and quantitative components, then conducted 3-day site visits to each participating state in the spring of 2005. We developed a protocol for the site visits with specific questions and areas of inquiry for each category of respondent. During the site visit, the researchers met with representatives from four groups: state government officials; provider stakeholders; consumer and advocacy stakeholders;

and representatives from at least one local delivery sites. Site visits were focused on the State capital city. Three to four site visitors participated in each visit. 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.

We prepared summary tables to show changes in supply of various services each year from 2000 to 2005. We also prepared table shells to track participants and expenditures by program for the same years; programs tracked included the Medicaid waivers, Medicaid state-plan LTSS services, state-funded LTSS services, as well as programs funded through federal transfers such as Older Americans Act programs, and transfers from the Department of Education. The intent was to get as much comparable information as possible so that we could graph overall trends in utilization and expenditure and trends for different subgroup of participants. We also analyzed data from the Nursing Home Minimum Data Set in each of the 8 States for the years 2000 to 2004 to profile the functional and cognitive characteristics of all residents admitted and residents who were in the nursing homes in that State for at least 6 months.

Case Study Updates. For the second-year state update report covering the period from August 2005 to July 2006, we updated qualitative information through review of Web materials, and made telephone contacts with key informants in the States as needed, buttressed by in-person contacts at various national meetings. No site visits were performed for this update. Also we gathered an additional year of data from each State on expenditures and utilization of institutions, adding the year 2005 to our longitudinal profiling and to our MDS data on the acuity of nursing home residents. The focus of the 2006 update report was on change in context, organization, or services; on developments in the management approaches we were tracking; or on any new management approaches that the State had initiated.

Final State case studies. For the project's final state-specific reports, we again conducted site visits to each State; these occurred in November and December 2007 and each included at least two site visitors for a 2-day schedule. In addition to updating strategies we were following, these final site visits asked State officials to reflect on the goals, accomplishments, and management approaches over the entire period and next steps. The final case studies largely cover the period from August 2006 to December 2007.

Topic Papers

The Rebalancing Research included Topic Papers on cross-cutting themes relevant to rebalancing that drew on experience in the 8 States. After discussion with CMS, six topics for qualitative Topic Papers were selected, namely: State approaches to develop and sustain consumer advocacy; State organizational structures for rebalanced systems; the role of managed care in rebalanced LTSS systems; State approaches to enhance consumer decision-making about LTSS; the future of the nursing home in rebalanced LTSS systems; and community group residential settings in a rebalanced system and the extent to which States can ensure they are residential rather than institutional in nature.

Each Topic Paper employed data collecting strategies suited to the particular topic, but we used a consistent approach across all six. We relied heavily on information gathered for the state-specific case studies as a backdrop for the work, supplemented by reviews of the literature, state websites and other primary and secondary source materials, and by telephone or in-person interviews of selected government officials and stakeholder representatives. Each Topic Paper is briefly summarized in the section on products of the study.

Quantitative Analyses for Chartbooks

Research questions. Two remaining crosscutting topics were identified that required quantitative work: examination of total Medicaid costs for both LTSS and acute care for participants using HCBS services and participants using institutional services; and examination of case mix differences between participants using HCBS and institutional services. This work became expanded into what ultimately became the preparation of 6 Chartbooks.

Using a variety of data sources (state enrollment files, utilization data from Medicaid and Medicare, and individual client assessment data from states) we addressed several research questions. Because the focus is on rebalancing, the analyses look separately at program participants who are covered by Medicaid HCBS waivers and community services in the Medicaid State Plans and those covered by institutional services in the Medicaid State Plans.

The research questions were:

1. How do the utilization and cost of LTSS services (nursing facility, intermediate care facility [ICF], personal care, home health care and transportation) by Medicaid HCBS waiver participants and LTC state plan recipients differ across recipient groups and States?

2. How do the utilization and cost of medical services (hospital, emergency room, physician, physical therapy/occupational therapy/others, other practitioner, outpatient service, rehabilitation, hospice, other services, and pharmaceuticals) by Medicaid Home and Community-Based Services (HCBS) waiver participants, and state plan recipients receiving LTC services differ across recipient groups and States?

3. How do the utilization and Medicaid cost of these services differ for dual eligible HCBS recipients and recipients covered only by Medicaid?

4. How consistent is utilization of medical and LTC services across years?

5. How does utilization vary by participant characteristics?

Study population. Our study population consisted of all Medicaid LTC recipients in each state during 2001, 2002, and 2003. CMS collects Medicaid enrollment and utilization data from states through its Medicaid Statistical Information System (MSIS). This data collection has only

recently allowed for specific waiver participants to be identified. To perform comparable analyses for the 8 States, we asked States to provide a "finder file" including all individuals who were eligible for a HCBS waiver at least at one point during a year and including all individuals who received an LTC service under the State Medicaid plan during a year.

Specific waiver groups in each state were regrouped (based on their eligible population) into the following two waiver categories of interest: Aging and (Physical) Disability and Mental Retardation/Developmental Disability (MR/DD).[2] Our state plan groups of interest across eight states were limited to individuals who used nursing facility, intermediate care facility (ICF), home heath, and personal care services.

Our study population includes individuals who are enrolled in a relevant Medicaid waiver or LTC state plan service, including dual eligible recipients, or those enrolled in both Medicaid and Medicare as a result of age or disability. We excluded from our study population those individuals identified as having end stage renal disease, (ESRD). Although they represent a small portion of the population (less than 1% across the eight states), their high utilization of services could skew the results. Therefore, these individuals, identified through diagnoses associated with their claims data, were excluded from our study population.

Our analysis is limited to Medicaid enrollees (including dual eligible) in fee-for-service plans. Because reliable measures of utilization of services and their associated payment could not be obtained for Medicaid managed care enrollees, those covered by managed care were eliminated from this analysis. The number of person months in Medicaid managed care greatly

[2] By the end of the study period, we found that some States used the term Intellectual Disabilities/Mental Retardation (ID/MR) rather than the more familiar Mental Retardation/Developmental Disability (MR/DD). Minnesota uses the federal terminology Mental Retardation/Related Conditions (MR/RC). Waiver programs for participants with MR/DD use a variety of names and acronyms. In this report, for consistency, we refer to MR/DD waivers and MR/DD as general terms.

varied across states, ranging from virtually none in Arkansas, to over half for persons in nursing facilities in Minnesota.

Data sources. Cost data for medical and LTSS services were obtained from Medicare and MAX claims files, both created by CMS. Using the CMS Health Insurance Claim (HIC) number for Medicare and the Eligible Identifier Number obtained from the MAX PS file, we extracted all claims pertaining to the persons identified and linked with the state provided finder files. Medicare claims were extracted from the MedPar (finalized inpatient claims), Outpatient, Carrier, and Home Health files. Medicaid claims were extracted from the MAX utilization files (MAX IP: inpatient, MAX LT: long-term care, MAX OT: other services, MAX RX; and prescription drugs).

Participant characteristics. We analyzed both acute medical care services (including inpatient hospital, physician, physical therapy/occupational therapy/others, other practitioner, outpatient service, rehabilitation, hospice, other services, and prescription drugs) and LTSS services (including nursing facility, ICF, home health, personal care, and transportation). Our results look at each type of service separately.

Participant characteristics were measured using different methods and gathered from different sources. In one analysis we identified three states (Florida, Minnesota, and Washington) where assessment data was collected on person living in the community (also ICF/MR facilities) and were receiving long-term supportive services The assessments were conducted as part of the waiver eligibility determination process. These data were de-identified; we knew to which program the subject belonged, but no his/her specific identity. Thus, it was not feasible to link this information with other data on service utilization. We compared community dwelling participants with nursing home residents. Assessment data for nursing home residents included

MDS records. Each state uses different assessment tools and within states, some states use a different assessment instrument for aging populations compared to adult disable and MR/DD groups.

The second method of identifying participant characteristics used Medicaid and Medicare claims data and applied two established methods of case mix adjustment – CMS Hierarchical Condition Categories (CMS-HCC) score and the Chronic Disability Payment System (CDPS) score. The CMS-HCC model was originally developed by CMS to calculate beneficiary case-mix scores for adjusting Medicare payments and is currently used to adjust payments to Medicare Advantage plans. The CDPS model was originally developed specifically for Medicaid programs to make health-based capitation payments for TANF and disabled Medicaid beneficiaries. Both use diagnoses from service claims as well as some demographic data such as age and gender as well as program eligibility information such as reason for and length of eligibility. The CDPS predicts between 30 and 50 percent of the variance in health care costs in a population with disability. The HCC model can predict up to 40 of the potentially explainable variance in prospective health costs.

Case mix adjustment. To assess how much of the variation observed might be attributable to differences in case mix we used case mix adjustments based on modest adaptations of standardized adjustment systems in use for Medicaid and Medicare to address this issue.

To explore the effects of Rebalancing, we examined the composition of persons receiving LTSS from different venues. We sought to compare client composition across programs and, where feasible, between comparable community dwelling and institutional populations. For nursing home samples comparative data came from MDS records. For ICF/MR we had to rely on the same data bases used for community samples.

Summary of Products and Findings

Products fall in three categories: State Case Studies; Topic Papers; and Chartbooks on Medicaid (and in one set of analyses Medicare) costs and utilization.

State Case Studies

State-Specific case studies were performed at three time periods: baseline (which covered the period through July 2005, with an emphasis on 2000 to 2004 for the quantitative components of the case studies; 1-year update, covering the next year through July 2006; and final case studies, covering the next 18 months through December 2007. The baseline, state-specific case studies covered each state's historical and contemporary initiatives for rebalancing long-term services for all populations under Medicaid through the end of July 2005; these were prepared as long reports that included detailed contextual and program information, and as abbreviated reports, and were issued shortly after the projects first year. We also prepared an Executive Summary Report that summarized the voluminous material in the eight baseline case studies. The results of the annual update case studies were presented in a single update report with a section on each State; this report was issued shortly after the end of the projects second year. For the final year, we again issued individual state-specific updates, covering August 2006 through July 2007.

Below we identify and very briefly summarize the reports for each State (in alphabetical order) and then summarize the findings and cross-cutting themes from the Baseline Executive Summary Report and from the Update Report. Links to the full reports are provided.

Arkansas State Case Studies

- **Rebalancing Long-Term Care Systems in Arkansas: Experience up to July 31, 2005 (Abbreviated Report)**
  http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Arkansas_abbreviated_baseline_case_study.pdf
- **Rebalancing Long-Term Care Systems in Arkansas: Long Baseline Report.**
  http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Arkansas_long_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Arkansas: Case Study as of December 2007**
  http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/2007_case_studies/Arkansas_final_case_study_as_of_December_2007.pdf.

The Arkansas case studies emphasize effective ways that the State utilized federal and other grant programs to build its LTSS system, at times adapting experience from other States to Arkansas circumstances. The studies discuss Arkansas' development of consumer directed options, building on participation in the original Cash and Counseling Demonstration and moving into other areas, including a pilot program to cash out nursing home services. They discuss the development of assisted living rules, and deliberate strategies to strengthen consumer advocacy with a leadership training initiative.

At the end of the Rebalancing Research period, Arkansas was poised to implement a statewide Options Counseling Program (mandated by the legislature in 2006), and to implement a primary-care-based case management program. Rebalancing in Arkansas proceeded most effectively for seniors and persons with physical disabilities; the MD/DD programs are substantially institutionally based. Even with services to seniors, the proportion of Medicaid expenditures on nursing homes are high, partly due to favorable rates for empty beds. The State has been assisted in its efforts to develop community care for seniors and people with physical disabilities by strong continuity in leadership. Nursing homes are a strong interest group in Arkansas; although they have low occupancy, favorable reimbursement rates keep expenditures for nursing homes relatively high. Arkansas used a CMS System Transformation Grant to

develop many of its system elements and is now implementing Money Follows the Person demonstration.

Florida State Case Studies

- **Rebalancing Long-Term Care Systems in Florida: Experience up to July 31, 2005 (Abbreviated Report).** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Florida_abbreviated_baseline_case_study.pdf
- **Rebalancing Long-Term Care Systems in Florida: Case Study as of December 2007.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/2007_case_studies/Florida_final_case_study_as_of_December_2007.pdf

The Florida case studies emphasize the increase in HCBS services for persons with MR/DD, the use of managed care for LTSS for older people, the creation of a network of Aging Resource Centers, an exemplary program for Spinal Cord Injury, and the expansion of consumer-directed options.

The State of Florida favors developing partnerships between government, private philanthropy, and business on specific issues, and has done so effectively on matters such as increasing competitive employment for persons with disabilities, making assistive technology available, and creating livable communities for seniors. Florida has invested in improving its nursing homes, including increasing staffing standards, with the result that the balance of expenditures on nursing homes has increased over the study period. It has also invested in mandatory educational requirements for nursing homes and assisted living. Florida's progress towards greater HCBS has been hampered by a fragmented organization at the State level, a general stance opposing state taxation, and more recently, by a fiscal crisis that has slowed growth of all governmental programs.

Minnesota State Case Studies

- **Rebalancing Long-Term Care Systems in Minnesota: Experience up to July 31, 2005** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Minnesota_long_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Minnesota: Long Baseline Report.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Minnesota_long_baseline_case_study.pdf
- **Rebalancing Long-Term Care Systems in Minnesota: Case Study as of December 2007.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/2007_case_studies/Minnesota_final_case_study_as_of_December_2007.pdf

The Minnesota case studies describe a bifurcated system for older persons and all other persons with disabilities. For the former, strategies have included a planning approach, evolution of a housing-with-services form of assisted living, a switch to mandatory managed LTSS in 2005, and development of a county-based long-term care consultation program to replace a more traditional case management program. For the younger populations, strategies have included efforts to rationalize assessment and individual budgeting across all waivers, and an innovative quality assurance approach.

For all populations, Minnesota has developed a consumer directed community support system. However, it has been somewhat difficult to ensure that Consumer Directed supports are offered to seniors who receive LTSS through managed care. Minnesota has invested heavily in HCBS for all populations. The lead agency, the Division of Continuing Care within the umbrella Department of Human Services, takes the stance that the State has a strong interest in and responsibility to improve the ability of privately paying consumers to be well-informed and to have access to affordable community-based LTSS.

New Mexico State Case Studies

- **Rebalancing Long-Term Care Systems in New Mexico: Experience up to July 31, 2005 Abbreviated Report.:** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/New_Mexico_abbreviated_baseline_case_study.pdf
- **Rebalancing Long-Term Care Systems in New Mexico: Long Baseline Report:** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/New_Mexico_long_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in New Mexico Case Study as of December 2007** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/2007_case_studies/New_Mexico_final_case_study_as_of_December_2007.pdf.

The case studies in New Mexico highlight the implementation of a Personal Care Option Program, which included both self-directed as well as agency-delivered services, offered a living wage to direct caregivers, permitted family members to be paid as caregivers, and helped catapult New Mexico into becoming the 2nd highest rated State in balancing Medicaid expenditures towards HCBS in 2005 ; the Mi Via waiver program for consumer-directed services; a managed behavioral health program developed as a consortium effort of multiple State agencies; and incorporating adult protective service screening into the ADRC's mandate. Organizationally, three collaborating cabinet level agencies—the Department of Aging and Long-Term Services, the Department of Health, and the Department of Social Services—had responsibility for LTSS, and worked closely together. New Mexico illustrates the challenges inherent in a large state with remote areas, and the need to develop an access system that worked under those circumstances. New Mexico is planning towards a managed care program for dually eligible older people.

Pennsylvania State Case Studies

- **Rebalancing Long-Term Care Systems in Pennsylvania: Experience up to July 31, 2005 (Abbreviated Report):** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Pennsylvania_abbreviated_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Pennsylvania: Long Baseline Report.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Pennsylvania_long_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Pennsylvania: Case Study as of December 2007.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/2007_case_studies/Pennsylvania_final_case_study_as_of_December_2007.pdf.

The Pennsylvania case studies describe efforts to systematically downsize nursing homes, testing of presumed eligibility for HCBS in selected counties, and nursing home transition programs. Pennsylvania's system of LTSS is fragmented across State organizations and multiple waiver programs. To address the fragmentation, the Governor create an Office of Long-Term Living, first as part of the Governors Office of Health Care Reform, and later as an agency run by a Deputy Secretary who reports to both the Secretary of Public Welfare and the Secretary of Aging. The Governor strongly endorsed HCBS and by the end of the Rebalancing Research numerical goals for nursing home reduction had been established; part of the enthusiasm for community-based LTSS was the expectations of financial savings for a troubled economy in the State. Building blocks for the new HCBS emphasis included developing quality monitoring processes for its case management programs; nursing home downsizing initiatives especially for county homes, development of waiver coverage for assisted living and creation of assisted living rules, steps delayed in part because of quality issues in Pennsylvania's Personal Care Homes (providers holding themselves out as doing assisted living simply needed a personal care home license up to this point); and encouragement of a network of PACE programs (called LIFE programs), ideally collated with senior housing. Consumer directed services was not an easily developed option for older people in a system that was very oriented to case management

through a network of AAA-associated county-based Corporations on Aging. The State's replication of the Cash and Counseling program was not operational in Spring of 2008 because HCBS waiver renewals needed to be processed first. Pennsylvania is participating in the Money Follows the Person demonstration and, to that end, AAAs and Independent Living Centers are embarked on a systematic program to identify persons who want to leave nursing homes and assisted with transitions. The final case study notes that State officials expanded efforts to encourage nursing homes to downsize or diversify, using individually tailored reimbursement packages as an incentive and providing technical assistance to the industry.

Texas State Case Studies

- **Rebalancing Long-Term Care Systems in Texas: Experience up to July 31, 2005: Abbreviated Report.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Texas_abbreviated_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Texas: Long Baseline Report.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Texas_long_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Texas: Case Study as of December 2007** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/2007_case_studies/Texas_final_case_study_as_of_December_2007.pdf.

Texas pioneered the development of a Money Follows the Person initiative through legislatively enacted riders, beginning in 2001, that permitted persons leaving nursing homes to receive HCBS services through waivers without going on a waiting list or taking someone else's slot; instead he or she used resources transferred from the nursing home budget. Other initiatives developed in Texas to facilitate this direction included transition specialists; use of MDS data to identify people wanting to leave nursing homes; development of a Service Responsibility Option in its large State-plan Personal Care Options program; and expansion of the managed LTSS and Medicaid acute care initiative, Star + Plus from the Houston area to other parts of the State. Overall rebalancing expenditure statistics in Texas show achievement in shifting the balance for

older people and people with physical disabilities but a strong tilt to institutional care in the D/DD area.

By the end of the Rebalancing Research more than 20,000 Texans had made transitions from nursing homes, the majority of them elderly. Texas also introduced a pilot to assist with transitions from State schools and large ICF-MRs, and a process through which residents in these institutions or their legally responsible surrogates receive options counseling annually from a contracted outside entity. Texas has many challenges in developing its system, including the huge geographical expanse of the State, a high degree of local control, and historically high waiting lists (called interest lists) for waivers. In tackling these challenges, Texas has taken the highly successful strategy of government reorganization so that almost all matters associated with LTSS for any populations of any age or disability and in any location from their own homes to institutions are managed by the Department of Aging and Disability Services, which is organized along functional lines (e.g., Intake and Access, Regulatory Services, Provider Services). Texas also was early in creating a stakeholder entity, the Promoting Independence Advisory Committee, to monitor progress against benchmarks in achieving choices for community care. Over the past 5 years, the intake systems have become more streamlined, interest lists are reduced (although still long), and the DADS structure has brought clarity and arguably enhanced success with legislative requests. Texas' plans to participate in the national Money Follows the Person demonstration included developing some enhanced services for people with mental health challenges and incentives for closure of ICF-MRs with 9 or more residents.

Vermont State Case Studies

- **Rebalancing Long-Term Care Systems in Vermont: Experience up to July 31, 2005 (Abbreviated Report).** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Vermont_abbreviated_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Vermont: Long Baseline Report.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Vermont_long_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Vermont: Case Study as of December 2007.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/2007_case_studies/Vermont_final_case_study_as_of_December_2007.pdf.

The Vermont case studies highlight the development of Choices for Community Care, an innovative 1115 waiver program that uncouples the link between nursing home eligibility and Medicaid waiver services by developing tiers of eligibility for LTSS with only the highest need level deemed to have an entitlement to either nursing home or community care. Vermont is also characterized by a high degree of consumer direction (including family provided care), complete closure of state institutions and large ICF/MRs and a highly integrated model of services for persons with MR/DD. Housing initiatives and mental health initiatives were underway at the end of the Rebalancing Research period, and the State is actively considering how it might evolve to small community nursing homes in the future. The structure of State governmental for LTSS has enhanced Vermont's ability to plan and develop services; almost all LTSS programs are consolidated in the Department of Aging and Independent Living (DAIL), which is organized along functional lines.

Washington State Case Studies

- **Rebalancing Long-Term Care Systems in Washington Experience up to July 31, 2005 (Abbreviated Report).** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Washington_abbreviated_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Washington: Long Baseline Report.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_case_studies/Washington_abbreviated_baseline_case_study.pdf.
- **Rebalancing Long-Term Care Systems in Washington: Case Study as of December 2007.** http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/2007_case_studies/Washington_final_case_study_as_of_December_2007.pdf.

The case studies for the State of Washington feature: the development of an Independent Provider (IP) model of service delivery and the functioning of the Home Care Quality Authority in relationship to that model; the structure and use of an automated modular assessment and quality management tool called CARE (Comprehensive Assessment and Review Evaluation) to manage the system; a forecasting system used for prospective budgeting; and quality initiatives in the entire service structure. The strong union presence in the IP program has presented challenges and required State agencies to develop a competence in labor relations.

Washington has been successful in shifting the balance to HCBS, particularly for older people and people with physical disabilities. Washington officials in part attribute this success to the structure established at the State level with consolidation of LTSS planning, budgeting, service delivery, and quality monitoring for all populations and ages consolidated in the Aging and Adult Services Administration in the umbrella Department of Human Services.

Baseline Executive Summary Report

Rosalie A. Kane, Reinhard Priester, Robert L. Kane, & Robert L. Mollica. Management Approaches to Rebalancing Long-Term Care Systems: Experience in Eight States up to July 31, 2005, Executive Summary (Submitted to CMS on May 26, 2006).
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/Executive_Summary_Baseline.pdf

This Executive Summary Report issued in May 2006 summarized conclusions and themes from the case studies to that point. It first noted that each State's strategies to encourage rebalancing or to create more community care needed to be seen in the specific context of that Sates. Differences among the rebalancing project's 8 states relevant to rebalancing included geographic size and terrain, and degree of urbanity; and population patterns regarding aging and disability, ethnic diversity, wealth and tax base for the state, and poverty status of people with disabilities. Despite 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 lawsuits to reduce institutional use and HCBS waiting lists and improve the quality of care; 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; active, and often bipartisan, engagement of their Legislatures in LTC issues; and continuity of leadership and depth of experience within State administration leaders.

Management approaches and general themes in the Baseline Executive Summary are summarized below.

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. Many of the States had undergone re-organizations within the last decade, none more extensive than Texas, where a massive consolidation and re-alignment of State agencies began in

2003. Other states, such as Florida, moved in the opposite direction, splitting off components such as Aging or Developmental Disability into higher-level agencies.

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 general, re-organizations across functional lines, such as occurred in Texas, Vermont, and Washington offers an opportunity for creative, "out-of-the-box" thinking, allows for cross-fertilization of the best practices from the various disability groups, and generates clarity in presenting LTSS to State legislators.

Local organization and access. Access to long-term supports begins at the local level. The Area Agencies on Aging sometimes are a focal point for local services for all populations, sometimes for all populations except consumers with MR/DD, sometimes for seniors only, and sometimes play no role at all in access to LTSS. Local mental retardation, Centers for Independent Living, or local offices of State authorities may also be built into the local access system. Sometimes multiple access systems co-exist at the local level and the system can be quite complex for consumers to navigate.

States have taken advantage of new communication technology over the past decade and have implemented on-line applications and centralized review functions, as an adjunct or even a substitute for face-to-face contact. States vary in the extent to which they utilize single assessments and/or single lead organizations across multiple disability and age groups.

Consumers experience two general reasons for delays in getting services within LTC 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. To mitigate the first kind of access problem, States have worked on providing information, developing fast-track or presumed eligibility, and eliminating specific roadblocks such as delays occasioned by waiting for physician signatures; some States have eliminated the physician signature for authorizing medical necessity. The second reason for waiting—e.g., insufficient services or waiver 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 often maintain the wait lists.

Values and vision. Each of the eight States has enunciated mission and value statements and/or principles that support rebalancing, usually emphasizing choice, dignity, community integration, consumer direction, inclusion, full employment, and civic engagement. Taken together, the statements and principles illustrate substantial incorporation of the ideals of community care in state law and executive agency missions. 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. 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 in all states. However, considerable variation was found, for example, in:

- the balance of 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; and

- whether some waver services are provided through managed care programs.

States also were undertaking systematic effort to identify gaps in the array of services, such as transportation, or assistive devices.

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 to gather consumer input. States also involved provider stakeholders (including providers of institutional care) in planning and feedback.

Consumer direction. Consumer direction (or person centered planning in the language used more often in MR/DD services) was explicitly incorporated into service programs under Medicaid waivers or Medicaid state plans, and/or included in separate programs (e.g. in a separate HCBS waiver for consumer directed services). 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. Some States devoted efforts to developing the infrastructure to support consumer-direction, especially the fiscal intermediary services, provision of information, and development of employer skills among consumers.

Real Choice System Change & other grant funding. The eight States have strategically utilized a wide range of grant funding to build their HCBS systems to their current state. Real Choice System Change Grants from CMS have been among the most important resources. Other grants from CMS (such as the Medicaid Infrastructure Grants) grants from the Administration on Aging (e.g., Alzheimer's grants, and grants for Aging and Disability Resource Centers, the latter a joint initiative with CMS), and grants from the Health Resources Services Administration all played a role, as well as grants from Foundations such as the Robert Wood Johnson Foundation (RWJF), which supported affordable assisted living initiatives and Cash and Counseling expansions, the Better Jobs, Better Care initiative for improving the LTSS workforce, and affordable assisted living, among other things. Two (2) of the States, Arkansas and Florida, were among the original Cash and Counseling demonstration States, and 5 of the remaining 6 States received grants to replicate Cash and Counseling. Pennsylvania and Vermont were among the

5 States funded for State-wide demonstrations of workforce improvement under Better Jobs, Better Care.

Quality initiatives. Quality Initiatives have been directed at improving institutional services and designing approached to proactive management of the quality of HCBS services. Examples of approaches to nursing home quality are:

- Data-driven approached to improving quality
- Payment mechanisms to give incentives for quality
- Legislated higher staffing standards for nursing homes
- State support of culture change efforts for nursing homes.

On the HCBS side, examples include:

- Incorporation of consumer into establishing definitions of quality and quality monitoring approaches;
- Direct interviews with consumers to elicit their experience with services;
- 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

Better information for consumers. Strategies for improving consumer information permeate the work of these eight States, including:

- Web-sites with extensive cross-referencing among government agencies and comprehensive indexes to more readily clarify programs;
- 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;
- State-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, such as:

- Certificate of Need or moratoriums to limit the supply of nursing homes;

- Reimbursement incentives to encourage nursing homes to downsize and/or diversify.

- Mandates that consumers in state institutions for developmental disabilities be offered systematic and regular information about the possibility of leaving;

- Funding for transition services in HCBS waivers, state plans, or both;

- Money-Follows-the-Person Initiatives as vehicles for helping consumers leave institutions

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. 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) and have worked on housing and labor force issues.

Quantitative markers of rebalancing. The analyses of relative utilization and expenditures on HCBS versus institutional services showed that all 8 states had achieved some measurable progress in terms of moving the ratio of service investment towards community care, and in serving more participants in the community. Noteworthy baseline findings include:

- Some states have made substantial progress in deinstitutionalize of consumers with mental retardation and developmental disability but a few States still struggle with large proportions of consumers in state-operated institutions or face stakeholders expressing opposition to planned closures

- Utilization and expenditures for nursing homes and HCBS waivers for elderly persons from 2002 to 2004 were relatively steady across all states, except for significant increases in waiver expenditures and the number of clients in Minnesota, New Mexico, and Pennsylvania and a significant decrease in the both metrics in Florida

- Contrary to expectations that growth in waiver activity would be associated with an increase in case mix acuity in nursing home residents, the case mix levels in nursing homes was found to be essentially unchanged between 2002 and 2004.

- Some States made greater use of personal care under the Medicaid State Plans than of waivers. The ratio of personal care to waiver expenditures was 4:1 in Texas and 2:1 in New Mexico. Only New Mexico spends more per case on personal care than waivers.

- Substantial variation across the states in the expenditure per client served in 2004 for various types of LTC services. Generally, per client ICF-MR expenses are far larger than those for nursing homes. Likewise the DD waivers expenses greatly exceed those for aging.

- In comparing expenditures for MR/DD and aging, total institutional spending is higher for aging, but the costs per participant are much greater for MR/DD.

Update Case Study Report

Rosalie A. Kane, Reinhard Priester, Robert L. Kane, & Donna Spencer. A Year in State Management Practices for Rebalancing Long-Term Care Systems: Update of Activities in 8 States, July 2005 to July, 2006. (Submitted to CMS, April 2, 2007).

http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/State_Case_Study_Updates_as_of_December_2006.pdf

This report updated initiatives that we had begun following in the baseline report and identified new initiatives. It also added one more year to the quantitative analyses. Some findings are summarized below.

All 8 States made steady progress with most of the initiatives and activities described in the base-line case studies. As a group, they experienced considerable stability in executive leadership related to long-term support services (LTSS). No state showed a change in goals or direction from the proceeding year.

Overall health reform continued to be an issue for State governors. Florida and Vermont both implemented Medicaid reform, taking advantage of the possibility of block grants to the State to manage a fixed Medicaid budget. Some States, particularly, Florida, Texas, and Arkansas, experienced additional costs related to hurricane recovery that needed to be factored into their considerations.

State-specific management approaches include:

- Arkansas worked on creating quicker and more equitable access to LTC, using its System Transformation Grant to establish a virtual single-entry system and to integrate MR/DD and behavioral health into that access system.

- Florida expanded its community care and its employment programs for persons with MR/DD, using savings achieved by prior utilization review and supplemental legislative appropriations to cut down the waiting lists. Related to older people, the State received Federal approval for a combined 1915 (b/c) waiver to implement an integrated managed care initiative, Florida Senior Care, as a pilot project in 2 areas of the state.

- Minnesota continued its broad-scale planning for the aging of the baby-boomers. Efforts to create a universal assessment for four of the States HCBS waivers continued, and the State initiated a county-by-country review of quality in its lead agencies for LTC. By November of 2006, all the State's managed care organizations (MCOs) were constituted as Special Needs Plans (SNPs) under Minnesota Senior Health Options (MSHO), which was reorganized into MSHO SNPs for the Medicare component of the integrated capitation. Seniors in the Elderly Waiver and Medicaid program chose or were passively enrolled into MSHO and arrangements were made on a county by county basis for the interaction between the MSHO SNPs and the counties. Consumer-directed community support programs also expanded and the State continued to downsize its nursing-home sector.

- New Mexico continued to support consumer directed care options in its State Personal Care Option program and *Mi Via*, a 1115 waiver plan. The New Mexico legislature enacted Money Follows the Person legislation, and the state explored expanding its managed long-term care initiatives.

- Pennsylvania created a Long-Term Living Council to continue rebalancing initiatives begun by the Governor's Commission for Health Care Reform. Early priorities included nursing home transition efforts, a program of quality assurance and monitoring of the case management system, a workforce initiative, and conscious state planning to develop a network of PACE (Program of All-Inclusive Care for the Elderly) programs.

- Texas established into state law its Money Follows the Person (MFP) program, initiated under Riders to the Appropriation process. It also conducted a pilot program to move MFP to ICF-MRs, and strengthened its transition counseling capacity State-wide. Texas planned to expand its Star+Plus integrated care waiver from Houston to 3 other multi-county areas in the State, conditioned on Federal approval.

- Vermont implemented its 1115 waiver Choices for Care program for seniors and persons with physical disabilities, achieving a smooth start-up. The State established an initial milestone of at least 40% of program enrollees residing in home or community settings in all regions, and was close to achieving it.

- Washington continued its initiatives for independent provider and consumer-directed care and its concerted effort to assist individuals with mental illness, including establishing a congregate housing setting for that group. The State also undertook a long-range Governor-commissioned planning initiative for LTC.

- Three of the 8 states (Arkansas, Texas, and Washington) were in the first round of the Money Follows the Person demonstration.[3]

[3] Pennsylvania was funded in the 2nd round, receiving notification in 2007. Florida, Minnesota, and New Mexico had applied for the 1st round but for various reasons, discussed in the final case studies, each State decided not to pursue a revised application.

- All the States are working on refining information systems and effective ways of accessing LTSS, and all are intent on increasing their ability to monitor quality.

Quantitative markers suggest continued progress in all 8 states towards rebalancing goals, but with variation within and across states. The patterns of change in utilization and expenditures between HCBS and institutional care vary across states and for target populations within States. Highlights from the comparisons between 2000 and 2005 include:

- Despite the substantial growth in HCBS participants in most of the states, little change is found in the acuity of nursing-home residents from 2000 to 2005.

- The number of participants in nursing homes in 2005 exceeded those in elderly and disabled waivers in all States except Washington, but the number of participants in MR/DD waivers consistently outpaced the participants in institutions.

- Arkansas and Florida show a slight decrease in aging and disability waiver participants, Texas and Washington show slight increased, and the others show substantial increases. The number of participants in nursing home declined in 5 States (Arkansas, Minnesota, New Mexico, Washington, and Vermont).

- Taken as a cross-sectional for 2005 as a whole, nursing home expenditures are highest, followed by expenditures on MR/DD waivers. In Texas and Washington, elderly and disabled waiver expenditures exceed expenditures on MR/DD waivers. Over the 5 year period, the growth of expenditures on waivers exceeded that on institutions, with the exception of Florida, where expenditures on elderly and disabled waivers grew less than expenditures on nursing homes (in part due to a large increase in nursing home reimbursement the proceeding year to accommodate a mandates staff ratio increase). Expenditures on ICF/MRs decreased in Minnesota, Texas and Vermont.

Topic Papers

We released a series of six (6) cross-cutting Topic Papers. Each Topic Paper highlights an issue of importance in State rebalancing efforts and draw from the experiences of some or all of the 8 states in the Rebalancing Research. The Topic Papers also tended to conceptualize a particular area related to Rebalancing so as to encourage discussion at Federal and State levels.

Topic Paper Number 1. Reinhard Priester, Amy Hewitt, & Rosalie Kane. State Strategies to Build and Sustain Consumer Advocacy**.** (Final version submitted to CMS**,** September, 2006**).**

http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/topicpapers/Topic_1_Building_and_Sustaining_Consumer_Advocacy.pdf.

Topic Paper Number 1 considered all 8 States, and emphasized strategies undertaken by State governments either to develop a strong consumer advocacy capacity or to incorporate consumer advocacy into its operations. Highlights of findings are below.

Topic Paper Number 1. Consumer Advocacy. All 8 States in the Rebalancing Study have consciously used mechanisms to involve consumers in long-term care policy-making. States have engendered an effective consumer advocacy presence by 1) taking stock of existing advocacy capabilities; 2) ensuring that all disability constituencies, representing people of all ages, are included: 3) seeking the views of consumers early in the process of program or policy development; 4) involving advocates who are direct consumers of services; 5) institutionalizing in statute processes for consumer involvement; and 6) engaging in a multi-faceted strategy including representation on policy and advisory committees, education and self-education efforts, and public hearings. Direct consumers are particularly effective advocates, especially for legislative advocacy, but may need training and support. Direct State funding to advocacy groups proved helpful, as did State staffing for advocacy efforts. Considerable fragmentation was found across disability groups and between advocacy efforts by aging versus other disability groups. Noteworthy state activities included:

- Arkansas' Governor's Integrated Services Taskforce, a broadly based stakeholder group, to oversee the state's response to the Olmstead decision

- Florida's Family Care Councils, established by statute, comprised only of consumers, and funded by the state.

- New Mexico's large and open-membership stakeholder work groups who provide input around specific policy initiatives to the Aging and Long-Term Services Department.

- Texas' Promoting Independence Advisory Committee whose consumer and provider members are required by law to submit annual reports with their opinions and recommendations.

- Vermont's array of structural mechanisms to incorporate consumers and other stakeholders into nearly every aspect of planning for community long-term care and support services.

- Washington's consumer-dominated Home Care Quality Authority which has rule-making authority to ensure the quality of in-home care

Suggestions for States wishing to channel the energies of consumer advocates to support the rebalancing agenda and to ensure that their policies and programs reflect consumer needs include:

- Take stock of and build on existing advocacy capabilities and groups within the State

- Ensure that all types of disabilities and age groups are heard, by high level government officials

- Seek the views of consumers early, before crucial decisions have been made.

- Involving advocates who are direct consumers of services

- Institutionalize in statute processes for involving consumers in the policy process

- Adopt a multi-faceted strategy for consumer involvement; a single strategy is unlikely to be sufficient.

Topic Paper Number 2. Rosalie Kane, Robert Kane, Martin Kitchener, Reinhard Priester, & Charlene Harrington. State Long-Term Care Systems: Organizing for Rebalancing Topics in Rebalancing State Long-Term Care Systems. (Final version submitted to CMS, December, 2006)**.**
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/topicpapers/Topic_2_State_Organizational_Structure_for_Rebalancing.pdf.

This Topic Paper compares approaches to organizing LTC at the State level, with emphasis on 2 organizational features: integration and centralization. Integration (versus fragmentation) is defined in 3 ways: integration of key functions for LTC; integration of programs within Medicaid and of Medicaid with other state programs; and integration of functions and programs for all LTC consumers. Centralization (versus decentralization) refers to the extent to which discretion and decision-making occurs at State versus local levels. Among the markers of centralization are uniform assessment protocols and procedures, use of State personnel in local areas for assessment and care-planning functions, and number of LTC entry points at the local level. Key findings are described below.

Topic Paper Number 2, State Organization**.** The level of integration and centralization for LTC varies across the 8 states. Washington has the highest level of integration, with all LTC functions and programs for all populations (except an AIDS/HIV waiver) unified in a single accountable department within an umbrella agency. Across most states, the trend seems to be towards:

- Bringing LTC functions together in the same agency
- Developing greater articulation among Medicaid LTC programs and between Medicaid LTC programs and other state-operated or state-funded LTC programs
- Integrating programs across multiple groups of consumers
- Creating more centralization of long-term care functions across a State

Tentative conclusions are:

- We find considerable support for merging organizations that manage institutional care and HCBS into a single state entity in order to maintain a focus on rebalancing, to pinpoint accountability for outcomes, and to render budgetary allocation and reallocation more flexible. We found no reason to favor a separate cabinet-level agency over a unit within an umbrella agency
- The most effective budgetary arrangement is for the same entity responsible for operations to both develop the forecasting or fiscal analysis on which the budget

allocations are based and have the ability to move money (e.g., between institutional and HCBS budgets and across programs and consumer groups).

- Functional eligibility determination should be integrated with other functions in long-term care planning, delivery, and oversight.

- Important collaboration and communication between LTC authorities and other governmental organizations is enhanced if the LTC authorities are consolidated.

- Although strong local leadership is needed to make community care and consumer choice possible within the constraints of local conditions and resources, some state-level centralization is important for establishing equitable systems statewide. A uniform assessment tool and state-wide training are indicated.

This Topic Paper concludes that integration will be positively associated with rebalancing success, and urges further work to operationally define elements of integration and examine their relative importance. Rebalancing will also be enhanced by some centralization, but optimal amounts of local discretion have not been well established.

Topic Paper Number 3. Reinhard Priester, Rosalie Kane, & Dann Milne. Managed Long-Term Care and the Rebalancing of State Long Term Support Systems. (Final version submitted to CMS, December, 2007).
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/topicpapers/Topic_3_Implications_of_Managed_Long_Term_Care_for_Rebalancing.pdf.
Many States are encouraging or mandating managed LTSS services for various populations, sometimes in conjunction with management of all Medicaid services, both acute and LTSS. The reasons for advocating managed care may be unrelated to LTSS itself. This Topic Paper considers whether managed care facilitates, impedes, or is irrelevant to increasing HCBS services and consumer direction within HCBS services. The Paper briefly considers all 8 States but concentrates on experiences in Florida, Minnesota, and Texas, as well as planning for New Mexico.

Topic Paper Number 3, Managed Care. Although in some ways managed LTSS may seem at odds with the new emphasis on consumer direction, arguably if a managed care organization is provided with clear policy goals and flexibility, possibly Medicaid Managed Long-Term Care (MMLTC) could operate outside preconceptions about where frail elders and persons with disabilities are best served and develop innovative ways to deliver an array of community services. Conclusions of the Topic Paper are summarized below:

- States were active partners in all managed long-term care programs involving Medicaid.

- As November 2007, Florida, Minnesota and Texas were in the vanguard of state MMLTC initiatives while New Mexico and Vermont had proposals to implement statewide MMLTC programs. State MMLTC programs differed on fundamental characteristics such as who is eligible, whether participation is mandatory or voluntary, the geographic area covered, the degree of integration of Medicaid and Medicare, the degree of integration of acute and long-term care for non-dual populations, and the type of organizations the state contracts with to provide services.

- Several States have maintained an active involvement as a partner in MMLTC efforts not only to establish and monitor contracts with Managed Care Organizations (MCOs) and set rates, but also to ensure that the long-term support services are consistent with the State's community care values and emphasis on choice, consumer direction, and community integration.

- Most of the cost savings to date come from more aggressive approaches to primary care and care coordination leading to reductions in hospital costs.

- State expectations for MMLTC to better coordinate care and services, reduce fragmentation, and improve health and social outcomes have been high. Among officials in the 8 States, Florida is most explicit that MMLTC is a means towards rebalancing LTC systems.

- Evidence of MMLTC's impact on consumer outcomes has been inconclusive and at times contradictory.

- The interface between consumer direction and choice, on the one hand, and managed care, on the other hand, remains to be fully determined.

- So far, managed care has been used more extensively with older persons than younger persons with disabilities.

- Managed care plans have varied widely in the extent to which they contract with aging network services or other publicly funded service networks.

- The extent to which MMLTC is likely to emphasize community over institutional care will depend on the costs of services in each arena, the amount of financial risk the plans bear for nursing homes or other institutions, the rules and financial arrangements surrounding disenrollment, and program administration.

Topic Paper Number 4. Rosalie Kane, Reinhard Priester, & Robert Kane. State Long Term Support Systems to Promote Informed Consumer Decisions: Information Provision, Decisions Tools, and Options Counseling (Final version submitted to CMS December, 2007). http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/topicpapers/Topic_4_State_Strategies_to_Promote_Consumer_Decisions.pdf.

This Topic Paper reviewed State approaches to promoting informed consumer decisions at junctures when a specific decision about type and place of care must be made. The Paper looked conceptually at criteria for an informed decision, and reviewed strategies in various States to enhance informed decision-making through information provision, options counseling, or new forms of case management. Key findings are discussed below.

Topic Paper Number 4, Informed Decision-Making. An informed decision can be said to have been made when the consumer decides among two or more viable options, makes the choice freely and without coercion, has the cognitive capacity to make the decision, has accurate and complete information about choices and their risks and benefits, and decides after examining options in the light of personal values and preferences.

For States to enhance informed decision-making, they need systems that offer culturally competent communication, build in formal periods of decision-making and reviews of earlier decisions, reduce delays in program eligibility to minimize precipitous decisions, and provide access to neutral, informed face-to-face options counselors. When States have highly developed person-centered planning and/or consumer-directed service systems, the values of individualized consumer choice should become enshrined in the system. Even so, the ability of consumers in such systems to make informed decisions cannot be assumed unless that consumer has access to accurate information and (as needed) assistance to clarify risks and benefits and weigh the pros and cons and risks of each alternative in the light of personal values.

Through Aging and Disability Resource Center funding and other mechanisms, States have developed extensive web and print resources to inform consumers about options, and have made efforts to brand their materials and make them visible. Taking advantage of information technology, several States have developed self-assessment tools that enable the consumers

themselves to introduce personal information and get ideas about care plans and local resources. Special attention is being given providing information to persons living in institutions. Some States perceive aim to offer information on choices to privately paying as well as publicly funded consumers, perceived as a strategy that will ultimately positively affect the public costs of care.

Case management, a function for screening, assessment, care planning, and monitoring, is in the process of re-invention. Terms such as long-term care consultant and systems navigators are being used for parts of or all of the function. This new terminology reflects a strong presumption of the importance of consumer choice and sees case management as a consultative rather than prescriptive activity.

The extent to which informed decision-making that meets the criteria actually takes place is not known. Evaluation tends to be restricted so far to measuring the use of information sources. No data are available at present to evaluate informed decisions by asking the decision-makers about the choices they were considering, whether they felt adequately and accurately informed, whether they were rushed in decision-making, and the logic that brought them to the decision they made.

Topic Paper Number 5. Rosalie Kane, Reinhard Priester, & Robert Kane**.** The Future of the Nursing Home in a Rebalanced Long-Term Supportive Services (LTSS) System (Submitted to CMS May 2008).
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/topicpapers/Topic_5_Future_of_the_Nursing_Home_in_a_Rebalanced_System.pdf.

Using the 8 States as a laboratory, this topic paper examines the extent to which States have made explicit plans for the future of the nursing home in their rebalanced LTSS systems, including plans for the size of the industry and plans for its nature. The paper considers the kinds of policy levers used by States or potentially available to States for shaping nursing homes of the future.

Topic Paper Number 5, Future of the Nursing Home. The 8 States vary in their supply of nursing homes, the ownership structure of the nursing home industry, and their quality of care

records. All show a gradual reduction in acuity of the population in nursing homes (a phenomenon observed nationally), which does raise the possibility that alternative settings are feasible. Major findings and conclusions were:

- All the states continue to see a need for the licensed and certified nursing home in the foreseeable future, although Vermont saw a role only if nursing homes were to become more consumer oriented and offer care in "a home-like environment that honors the resident's preferences, customs, and individual histories."

- Four (4) of the 8 states (Minnesota, Pennsylvania, Vermont, and Washington) created specific projections and/or goals for how LTSS should be allocated between institutional and community care in the next decade or so.

- Minnesota, Pennsylvania and Vermont have all developed policies and incentives to encourage nursing homes to downsize, Minnesota downsizing policies also work towards changing the qualitative nature of the nursing home by containing incentives for increasing single-occupancy rooms. Pennsylvania's approach encourages facilities to diversify into housing and other community services in lieu of providing nursing home care.

- States are moving in various ways to encourage a higher quality of life in nursing homes, including: supporting culture change endeavors; providing reimbursement or certificate-of-need exceptions for facilities that renovate to develop physical plants that support a better quality of life; developing training towards more individualized care; and creating a demand for better quality of life among potential residents and payers by report card systems and web-based public information.

- A trend was also noticed towards greater enforcement of nursing home regulations and creation of monitoring systems (apart from the survey and certification process) that help nursing homes come into or remain in compliance with existing federal regulations. Such programs may well create facilities with fewer care problems, but they do not necessarily alter the fundamental model of institutional service, which critics find over-medical and insufficiently conducive to resident autonomy, choice in daily life, community integration, and quality of life.

- Transforming nursing homes will undoubtedly have financial implications. Funding will be needed to encourage the transition from the current large institutions to new living designs that allow consumers a more normal life. Some models are already under development, but much more can be done to build on the experience of the MR/DD community.

- Transforming nursing homes is complicated by their dual role in delivering post-acute care and long-term care, the former largely funded by Medicare and not in State control.

- Particular management strategies described in this Topic Paper include:
    - Supply controls through moratoriums and certificate-of-need programs in all states;
    - Nursing home down-sizing initiatives in Minnesota, Pennsylvania, and Vermont;
    - Incentives for and encouragement of nursing home culture change in all States;
    - Development of specialized regulatory standards for Green House style nursing homes in Arkansas;
    - Reimbursement incentives for nursing homes undertaking major innovation for culture change in Minnesota.
    - A report card system in Minnesota that includes quality of life.
    - New approaches to quality monitoring (apart from survey and certification reviews) in Florida, Texas, and Washington.

Topic Paper Number 6. Rosalie A. Kane & Lois J. Culter. Community-Based Residential Care Settings as Rebalancing Vehicles: State Strategies to Make Them More like Home than like Institutions (Submitted to CMS June 2008).

http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/topicpapers/Topic_6_Community_Group_Residential_Settings_as_Rebalancing_Vehicles.pdf.

This topic paper developed 5 criteria that, taken together, would make a group residential setting less or more institutional in nature. It then considered the extent to which the programs in the 8 States minimized the likelihood that group residential settings would develop an institutional nature. It also examined the extent to which States had mechanisms to be informed about the nature of its group residential settings.

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Topic Paper Number Six. Community Residential Settings. When rebalancing is measured nationally, group residential settings such as assisted living, group homes, and adult family homes are usually placed in the community column in contrast to nursing homes, ICF-MRs, State Schools for persons with MR/DD, or long-stay hospitals. But some advocates perceive many residential settings to mirror institutions. Conclusions of this topic paper include:

- Five criteria were identified that make a residential setting more or less institutional in nature: namely: residential scale and characteristics; privacy; autonomy, choice, and control within the residential setting; integration of residents in the setting with the greater community; and resident control over moving to, remaining in, or leaving the setting.

- State levers to influence the nature of community residential settings and avoid institutional characteristics include regulatory standards for settings; vendor standards; quality assurance programs; eliciting of self-reported experience of consumers and their agents and developing a data base with this information and other objective measures of community integration; training initiatives on privacy, autonomy, choices, and community integration for state staff, surveyors , ombudspersons, case managers, providers, and others; making information available to help them make comparative selection of residential settings initially and to move to new settings; and attention to fair housing issues.

- States varied in the kinds of standards they develop for residential settings. Standards developed for physical settings, for characteristics of consumers permitted to be served in the setting (sometimes called admission and retention standards), and standards for staffing and programming can each be used to accentuate either community or institutional characteristics of the setting.

- Residential services to persons with developmental disabilities were more often provided by licensed providers rather than in licensed facilities. This model may offer more flexibility for integration into the community.

- States had regulatory barriers that interfered with community living in group residential settings. These were less prominent in Minnesota (where no case-mix limits were established for assisted living) and perhaps least prominent in Vermont.

Often community residential settings, even small group homes, were licensed, partly because reimbursement was tied to the setting rather than the person. Uncoupling that tie might be helpful.

- Many of the States promulgated information about the quality of the community residential settings, and Texas in particular included information about resident's rights. This would seem a promising avenue to enhance residential features.

- For residential criteria such as those suggested here were to be accepted, widespread education would be needed for service providers, case managers, regulators, and even the general public. States could lead in that effort.

- States tended to lack systematic information about whether their community residential settings were adhering to residential criteria. Some features and policies of the settings could be incorporated into a data base as could data from surveys and complaint investigations, but systematic direct reports from samples of consumers and their agents would be the only source of information on some criteria.

- Most of the States had made efforts to improve the quality of their institutions, increase the residential nature of the settings and the privacy, and individualize care to a greater extent. Nonetheless we did not really identify substantial numbers of nursing homes or ICF-MRs (except perhaps those with 6 or fewer residents) that met residential criteria. It would probably be easier to build up the service capacity in community residential settings while guarding against them becoming institutional than to transform those already licensed and functioning as institutions.

Quantitative Chartbooks

Originally, the Rebalancing research called for 8 cross-cutting Topic Papers. In early planning with CMS, the decision was made to conduct quantitative analyses in lieu of two of the Topic Papers. In general, the goals were to 1) compare all Medicaid costs (acute-care and long-term care) for persons receiving LTSS in the community and those receiving LTSS in institutions; and 2) to relate expenditures to characteristics of participants in HCBS settings and in institutions in States with data that allowed such analyses. Most of the analyses relied on national Medicaid data, linked to the participants via a finder file sent by each participating State. For one set of analyses we also incorporated data in assessment files from Florida, Minnesota, and Washington. Ultimately, we produced six separate Chartbook-style reports.

Chartbook Number 1. Robert L. Kane, Patricia Homyak, Donna, Spencer, Shriram Parashuram, Jin Lee, W. Mark Woodhouse. Analysis of Medicaid Expenditure Data for Long-Term Care Participants in HCBS Services and in Institutions in 2001 (Submitted to CMS, January 29, 2008).
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/chartbooks/Chartbook_1_Medicaid_LTC_Expenditures_2001.pdf

This report is the first in a series of reports using MAX data, which is a refined data set built (under a contract with MPR) from the Medicaid claims data submitted by each state as part of its Medicaid Statistical Information System (MSIS). The data presented here are restricted to Medicaid fee-for-service (FFS) payments.

Chartbook Number 1. Medicaid expenditure data in 2001. Finder files were created by each state based on persons enrolled in each relevant waiver program or who had used state plan LTC services. Person month is the unit of analysis. Specific waiver groups in each state were regrouped (based on their eligible population) into the following two waiver categories of

interest: Aging and (Physical) Disability and Mental Retardation/Developmental Disability (MR/DD). State plan groups of interest across eight states were limited to individuals who used nursing facility, intermediate care facility (ICF), home heath, and personal care services. Our analysis is limited to Medicaid enrollees (including dual eligible) in FFS plans. Because reliable measures of utilization of services and their associated payment could not be obtained for Medicaid managed care enrollees, those covered by managed care were eliminated from this analysis.

The number of person months in Medicaid managed care greatly varied across states, ranging from virtually none in Arkansas, to over half for persons in nursing facilities in Minnesota. We analyzed both medical care services (including inpatient hospital, physician, physical therapy/occupational therapy/others, other practitioner, outpatient service, rehabilitation, hospice, other services, and prescription drugs) and LTC services (including nursing facility, ICF, home health, personal care, and transportation). Our results look at each type of service separately.

Although this initial report is based on data drawn from the period early in the study, before many rebalancing activities were actively underway, it offers two sets of potential lessons. Even this level of aggregated data generates a number of policy implications, which can be summarized as follows:

- There is substantial variation in the use of different types of health care services within and across states and among waiver groups and state plan recipients. For example, recipients of home health state plan services have much higher inpatient utilization rates than waiver groups. New Mexico is frequently higher than the other seven states in terms of inpatient hospital utilization. More work is needed to understand how much of this difference is explained by differences in case mix (personal factors such as age, gender, and existing diagnoses or medical conditions). This will be the subject of subsequent reports. State differences will likely remain due to other factors, such as the cost of labor across states.

- The amount spent on medical care (including acute care services) and on LTC per client also varies across participants and states. For example, inpatient hospital expenditures for

waiver clients are generally lower than other beneficiaries, whereas expenditures for home health clients are higher. For example, expenditures for acute care for home health state plan recipients range across states from $450 per person month in Vermont to over $4,000 in Washington. The average cost of nursing home care is lower than for ICFs. If the differences in spending are not matched by differences in outcomes, issues of efficiency should be explored.

- There is some correspondence between waiver and state plan spending by target group (i.e., MR/DD and ICF); medical care for younger persons generally costs less than for older beneficiaries. The difference in payments for inpatient hospital care is more pronounced, but the pattern continues for ambulatory care and prescription drug payments with MR/DD and ICF groups being lower than aging and disabled and nursing facility groups.

- Medical costs constitute a substantial Medicaid cost for persons receiving home and community based LTSS services, particularly home care services in a number of states. One possible reason for this may be a higher acuity level of those individuals receiving home care services. These higher medical expenditures may represent an area where savings in medical costs could be used to support more LTSS

- Contrary to expectations, the utilization of dual eligible participants, regardless of waiver group or state plan service group was often lower than the non duals. This finding suggests that the dual eligible population may not be as frail as previously reported.

Additionally, the work generated some technical lessons about the challenges of using MAX data to compare States.[4]

Chartbook Number 2. Robert L. Kane, Patricia Homyak, Donna, Spencer, Shriram Parashuram, Jin Lee, W. Mark Woodhouse. Analysis of Medicaid Expenditure Data for Long-Term Care Participants in HCBS Services and in Institutions in 2002 (Submitted to CMS January 29, 2008.)
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/chartbooks/Chartbook_2_Medicaid_LTC_Expenditures_2002.pdf.

This report is the second in a series of reports using MAX data, a refined data set of information originally gathered by each state as part of its claims data and submitted to CMS through its Medicaid Statistical Information System (MSIS). The data presented here are restricted to Medicaid fee-for-service (FFS) payments.

[4] Among the limitations in using the MAX data, Medicaid data collected by states and reported through the MSIS reflect individual state differences. Medicaid eligibility and coverage vary by state. In addition, eligibility and coverage within states can change over time. Coding of services and procedures were modified to meet specific state needs rather than to follow a uniform system. The data set thereby may overlook or misreport unique state differences.

Chartbook Number 2, Medicaid expenditure data in 2002. Generally, we found consistency in results observed between 2001 and 2002. Major findings are highlighted below;

- Substantial variation was found in the use of different types of health care services within states between waiver groups and state plan recipients as well as across states. For example, recipients of home health state plan services have much higher inpatient utilization rates than waiver groups and other state plan services. With home health care recipients, hospital utilization in Arkansas, New Mexico, and Washington is over 25% whereas hospital utilization in Pennsylvania and Vermont was just over 5%. More work is needed to understand how much of this difference is explained by differences in case mix (personal factors such as age, gender, and existing diagnoses or medical conditions).

- The amount spent on medical care including acute care services and on LTSS per client also varies across participants and states. For example, inpatient hospital expenditures for waiver clients are generally lower, whereas expenditures for home health clients are higher. For example, expenditures for acute care for home health state plan recipients range across states from $450 in Vermont to over $4,000 in Washington. State differences in payments may be a result of other factors, such as cost of labor across states. If the differences in spending across groups are not matched by differences in outcomes, issues of efficiency should be explored.

- We found some correspondence between waiver and state plan spending by target group (i.e. MR/DD and ICF); younger persons generally cost less than for older beneficiaries. The difference in payments for inpatient hospital care is more pronounced, but the pattern continues for ambulatory care and prescription drug payments with IDDD and ICF/MR groups being slightly lower than aging and disabled and nursing facility groups.

- Medical costs constitute a substantial Medicaid cost for persons receiving home and community-based LTC services, particularly home care services in a number of states. One possible reason for this may be a higher acuity level of those individuals receiving home care services. Savings in medical costs could potentially be used to support more LTSS.

Chartbook Number 3. Patricia Homyak, Robert L. Kane, Shriram Parashuram, Jin Lee, W. Mark Woodhouse. Analysis of Changes in Medicaid Expenditures from 2001 to 2003 for Long-Term Care Participants in HCBS and Institutional Settings (Draft submitted to CMS March 26, 2008)
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/chartbooks/Chartbook_3_Changes_in_Medicaid_LTC_Expenditures_2001_2003.pdf.

This report is the third in a series of reports using MAX data, a refined data set of information originally gathered by each state as part of its claims data and submitted to CMS through its Medicaid Statistical Information System (MSIS). The data are restricted to Medicaid fee-for-service (FFS) payments. The report compares 2001 and 2003.

Chartbook Number 3, Medicaid expenditure changes from 2001 to 2003. Some general trends in utilization and payment for medical and LTSS services between 2001 and 2003 were noted:

- Payments for acute inpatient stays and ambulatory care services were steady between 2001 and 2003.
- Payments for nursing home stays and prescription drugs increased between 2001 and 2003.
- Little difference was found in the payment trends for medical or LTSS services across types of services between Medicaid only and dual eligible enrollees.
- Little difference was found in the payment trends for medical or LTC services across types of services comparing across waiver and state plan analytic groups.

Chartbook Number 4. Robert L. Kane, Patricia Homyak, Shriram Parashuram, Jin Lee, W. Mark Woodhouse. Analysis of Expenditures for Dually Eligible Participants in HCBS and Institutional Settings Using Both Medicaid and Medicare Data. (Draft submitted to CMS March 26, 2008)
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/chartbooks/Chartbook_4_Medicaid_Medicare_Expenditures_Dually_Eligible_LTC_Consumers.pdf.

This report presents analyses for dual eligible beneficiaries using combined Medicare and Medicaid claims data of payments for LTSS and medical care services in the eight states participating in the study. The data presented here are restricted to Medicare and Medicaid fee-for-service (FFS) payments for the dual eligible population. This chartbook focuses on describing 1) the demographics of the dual eligible population; 2) the relative use of Medicare covered services across waiver and state plan participants; as well as 3) the role/ impact of the two funding sources, Medicare and Medicaid, on overall payment for LTSS and medical care services.

Chartbook Number 4. Medicare and Medicaid expenditure data. The highlights of findings are summarized below:

- We found variation in the use of different types of health care services within and across states and among waiver groups and state plan recipients. For example, recipients of home health state plan services have much higher inpatient Medicare payment rates than waiver and other state plan groups. Pennsylvania tends to have higher Medicare payment rates for most types of services whereas Vermont tends to have lower payment rates. This pattern is generally consistent across analytic groups.
- Medical care for younger persons generally costs less than for older beneficiaries.

- The ratio of payments for medical care to payments for LTC increases after adding Medicare payments consistent with Medicare coverage. The increase, however, is not as high as might be anticipated given the population, suggesting that Medicaid payments overall and payments for LTC services in particular continue to be substantial in the dual eligible population. The exception is for home health state plan recipients.

Chartbook Number 5. Robert L. Kane, Patricia Homyak, Shriram Parashuram, Jin Lee, W. Mark Woodhouse. Analysis of the Effect of Case Mix Adjustment Data on Medicaid Expenditure Data for 2002. (Draft submitted to CMS March 8, 2008; Final version June 2008).
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/chartbooks/Chartbook_5_Case_Mix_Adjustment_of_Medicaid_Expenditure_Data.pdf

Previous analyses in this series traced the expenditure patterns of LTC users under waiver and state plans. Questions were raised about how much of the observed variation might be attributable to differences in case mix. The analysis in this report uses case mix adjustments based on adaptations of standardized adjustment systems in use for Medicaid and Medicare to address this issue. It asks several questions: 1) Does the pattern of case mix vary across states and populations?; 2) Is the case mix for dually eligible (i.e., Medicare and Medicaid) clients higher than that for Medicaid only clients?

Chartbook Number 5, Effects of Case Mix Adjustment on Medicaid Expenditures. This study adapts case mix models developed for the Medicare and Medicaid programs that use administrative data (e.g., age, living situation, diagnoses) to create case mix indexes. Because the two programs serve different clienteles and have different elements in their respective data bases, the two case mix calculation systems are different. Individual case mix scores for beneficiaries were estimated using a prospective model, which used individual demographic information and diagnoses available in the Medicaid and Medicare claims from the year 2001. Cost data for medical and LTC services were obtained from Medicare and MAX claims files, both created by CMS. Using the CMS Health Insurance Claim (HIC) number for Medicare and the Eligible Identifier Number obtained from the MAX PS file, we extracted all claims pertaining to the persons identified and linked with the state provided finder files. Medicare claims were extracted from the MedPar (finalized inpatient claims), Outpatient, Carrier, and Home Health files.

Medicaid claims were extracted from the MAX utilization files (MAX IP: inpatient, MAX LT: long-term care, MAX OT: other services, MAX RX: prescription drugs).

Our study population for this specific chart book includes individuals who are enrolled in a relevant Medicaid waiver or LTC state plan service in 2001 and 2002. They were either dual eligible recipients -- enrolled in both Medicaid and Medicare as a result of age or disability -- or non-dual eligible recipients, enrolled only in Medicaid. Among the dual-eligible recipients, only those who were identified in the state finder files, were linked to Medicaid MAX data and were eligible for Medicare were included in our analyses. We excluded from our study population those individuals identified as having end stage renal disease, (ESRD). Although they represent a small portion of the population (less than 1% across the eight states), their high utilization of services could skew the results.

To address questions about how much of the observed variation in analyses of expenditures on LTC and acute care might be attributable to differences in case mix, we calculated case mix using slight modifications of the techniques already adopted for Medicare and Medicaid. The Chronic Disability Payment System (CDPS) was developed specifically for Medicaid programs to make health-based capitation payments for TANF and disabled Medicaid beneficiaries. The CMS Hierarchical Condition Categories (HCC) model was developed to predict Medicare payments, and is currently used to adjust payments to Medicare advantage plans. Results are summarized below.

- Using the usual CDPS scores the case mix for MA only MR/DD waivers and ICF/MR residents is higher than that for duals. However, when the revised score is used the difference is reversed. (The revised score affects only the duals.) Among participants in the Aging and Disability waivers, the dually eligible participants were more impaired than those not dually eligible using both scoring systems, but the revisited score widens the gap.

- Among nursing home residents the usual scoring shows slightly more impairment among the MA only, whereas the revised score shows a large difference in favor of more impairment among the duals.

- In general, the patterns of relative relationships among the states seen with unadjusted analyses are maintained when case mix is applied. However, the size of the effects is often greatly influenced by case mix adjustment.

- The general observation that dually eligible clients have a much higher case mix is not seen when all clients are eligible for LTC. In that case, the differences often depend on how the case mix is calculated. When the usual approaches are used there appears to be an undercount of diagnoses. When this undercount is corrected the patterns change to suggest that the duals are more impaired. However, the undercount, by definition, applies only to the dually eligible consumers.

In interpreting data about LTC expenditures and related medical costs, it is important to recognize the role case mix adjustment can play. It is more difficult to decide whether to consider case mix and if so, how.

Chartbook Number 6. Robert L. Kane, Patricia Homyak, Donna, Spencer, Shriram Parashuram, Jin Lee, W. Mark Woodhouse. Rebalancing Assessment Data on HCBS Recipients and Nursing Home Residents in 3 States. (Draft submitted to CMS March 8, 2008; Final version June 2.)
http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/chartbooks/Chartbook_6_Case_Mix_Patterns_LTC_Consumers_3_States.pdf
This report compares the composition of long-term care users across programs (both state plan and waiver) and across sites of care using data from three States in the Rebalancing Project: Florida, Minnesota and Washington.

Chartbook Number 6, Assessment Data from Three States. The initial goal of this report was compare the composition of long-term care users across programs (both state plan and waiver) and across sites of care. We used data from three states in the Rebalancing Project (Florida, Minnesota and Washington). Each state brought a different perspective. The CARE system in Washington permitted comparisons between the MR/DD and the aging and disabled clientele because the same assessment form was use for both groups, but this was not possible in the other

two states. As a result, the comparisons are largely restricted to the aging and disabled population.

In Florida, data were available for the aging waiver and aging disabled group as well as those from a specific nursing home diversion waiver, and from nursing home residents. The nursing home sample was more disabled that either the aging or disabled waiver group. The nursing home diversion waiver group more closely approximated the nursing home residents.

In Minnesota, the ICF sample was older and tended to require a little more assistance with various tasks than the MR/DD population, but the two groups were generally comparable. Nursing home residents were much more disabled than those in the Elderly Waiver Almost 20% of the EW group had no ADL impairments.

In Washington the Aging and Disabled (AD) recipients had lower rates of severe continence problems than either nursing home residents or persons in the MR/DD waiver. Nursing home residents had greater ADL disabilities than either waiver group, but the disability patterns in the AD and DD groups were quite similar. By contrast participants in the MR/DD waiver showed poorer cognitive function than either participants in the AD waiver group or nursing home residents, who are more cognitively impaired than the participants in the AD group.

This analysis illustrates the lack of data to facilitate careful comparisons among client groups. Community client assessments are inconsistently and incompletely recorded. Comparisons across waiver groups are likewise impeded by the use of different instruments. Nonetheless, some conclusions can be drawn. In Florida and Minnesota elderly persons living in the community and covered by waivers seem considerably less disabled that those in nursing homes. In contrast, the disability level in Washington nursing homes is on a par with that of

elderly people in adult foster homes. Older people living at home or in assisted living seem less disabled than those in nursing hopes.

General Conclusions from Special Quantitative Studies.

In general, overall Medicaid expenditures for participants who received LTSS in the community were less than for those who received LTSS in institutions. This information helps counteract the concerns expressed by nursing homes that there would be hidden costs in higher acute-care under Medicaid if the States expanded HCBS services. In general, also, the need levels (case mix) were higher for in institutions than in the community, though State variation is high and those findings are somewhat difficult to interpret. Below are some of the other summary conclusions drawn from the work that comprised all six Chartbooks; these illustrate the kinds of observations we were able to generate using these methods.

- Variation in the use of different types of health care services among participants in different waivers and between waiver participants and users of State plan LTSS services was substantial within a given State; additionally we noted substantial variation among States. For example, recipients of home health state plan services have much higher inpatient utilization rates than waiver groups and other state plan services. With home health care recipients, hospital utilization in Arkansas, New Mexico, and Washington is over 25% whereas hospital utilization in Pennsylvania and Vermont was just over 5%. More work is needed to understand how much of this difference is explained by differences in case mix (personal factors such as age, gender, and existing diagnoses or medical conditions).

- The amount spent on medical care including acute care services and on LTSS per participant also varies across participants and states. For example, inpatient hospital expenditures for waiver clients are generally lower, whereas expenditures for home health clients are higher. For example, expenditures for acute care for home health state plan recipients range across states from $450 in Vermont to over $4,000 in Washington. State differences in payments may be a result of other factors, such as cost of labor across states. If the differences in spending across groups are not matched by differences in outcomes, issues of efficiency should be explored.

- We found some correspondence between waiver and state plan spending by target group (i.e. MR/DD and ICF); younger persons generally accounted for less spending than older beneficiaries. The difference in payments expenditures is most pronounced for inpatient hospital care, but the pattern continues for ambulatory care and prescription drug, where

payments for participants in MR/DD waivers and ICF were being slightly lower than those for consumers in aging and disabled waivers or in nursing facilities.

- Medical costs constitute a substantial Medicaid cost for persons receiving home and community-based LTSS services, particularly home care services in a number of states. One possible reason for this may be a higher acuity level of those individuals receiving home care services. Savings in medical costs could potentially be used to support more LTSS.

- Contrary to expectations, the utilization of dual eligible participants regardless of waiver group or state plan service group. This suggests that the dual eligible population may not be as frail as previous reported.

- Payments for acute inpatient stays and ambulatory care services were steady between 2001 and 2003.

- Payments for nursing home stays and prescription drugs increased between 2001 and 2003.

- Little difference was found in the payment trends for medical or LTC services across types of services between Medicaid only and dual eligible enrollees.

- Little difference was found in the payment trends for medical or LTC services across types of services comparing across waiver and state plan analytic groups.

- The variation in the use of different types of health care services within and across states and among waiver groups and state plan recipients found in analyzing Medicaid data persists when looking at Medicare data for the dually eligible. For example, recipients of home health state plan services have much higher inpatient Medicare payment rates than waiver and other state plan groups. Pennsylvania tends to have higher Medicare payment rates for most types of services whereas Vermont tends to have lower payment rates. This pattern is generally consistent across analytic groups.

- Medical care for younger persons generally costs less than for older beneficiaries.

- The ratio of payments for medical care to payments for LTC increases after adding Medicare payments consistent with Medicare coverage. The increase, however, is not as high as might be anticipated given the population, suggesting that Medicaid payments overall and payments for LTC services in particular continue to be substantial in the dual eligible population. The exception is for home health state plan recipients.

- The level of disability is hard to compare across states because each state uses different measures.

- In Florida and Minnesota elderly persons living in the community and covered by waivers seem considerably less disabled that those in nursing homes. In contrast, in

Washington, the disability level of elderly participants in nursing homes is on a par with that of elderly people in adult foster homes. Older people living at home or in assisted living seem less disabled than those in nursing homes.

- Because this data is cross-sectional, care must be taken in drawing etiological conclusion. The nursing home residents could be more disabled because community care is picking up the less disabled persons, or the two sites could simply be serving different populations.

- Case mix adjustment does not explain a great deal of the differences in usage patterns across recipient groups and across states

- Dually eligible beneficiaries do not have substantially higher risk scores than Medicaid only recipients; neither their adjusted nor their unadjusted expenditures are substantially higher despite the often cited observation that they are disproportionately high users of services. When the nature of their LTSS is controlled, that difference disappears. The observation may be based on the fact that dually eligible participants are often found in nursing homes.

Part II. Conclusions and Recommendations

Conclusions

Evidence of Rebalancing

The growth in HCBS is a result of both redistribution of effort and absolute expansion of HCBS. Patterns vary across states and time.

All of the states showed some evidence of rebalancing but the extent of the shift and the way they achieved it varied widely. The patterns were substantially different for rebalancing services for older people compared to rebalancing services for participants with MR/DD. Waivers were much more heavily used by the latter group in almost every state, though for two States (Florida and Pennsylvania), the waivers covered only intellectual disability (i.e. mental retardation) rather than including developmental disability. In 3 States (Vermont, New Mexico, and Minnesota), institutional care for persons with MR/DD was virtually eliminated. Under such circumstances, the remaining challenges for advocates for persons with MR/DD are to retain the advances already made and continue to maximize opportunities for community integration and a good quality of life.

Figure 1 summarizes the shifts in clients and expenditures in the 8 States from 2000-2005. Although there are some offsets, where institutional clients decrease and community clients increase, the growth in the latter well outstrips the decline in the former. In only three states did the number of NH residents decline (AR, MN, WA); in only one of those (MN) was there a corresponding increase in HCBS waiver clients. By contrast PA had substantial growth in both nursing home residents and HCBS waiver clients. Hence, rebalancing was largely achieved by adding new clients.

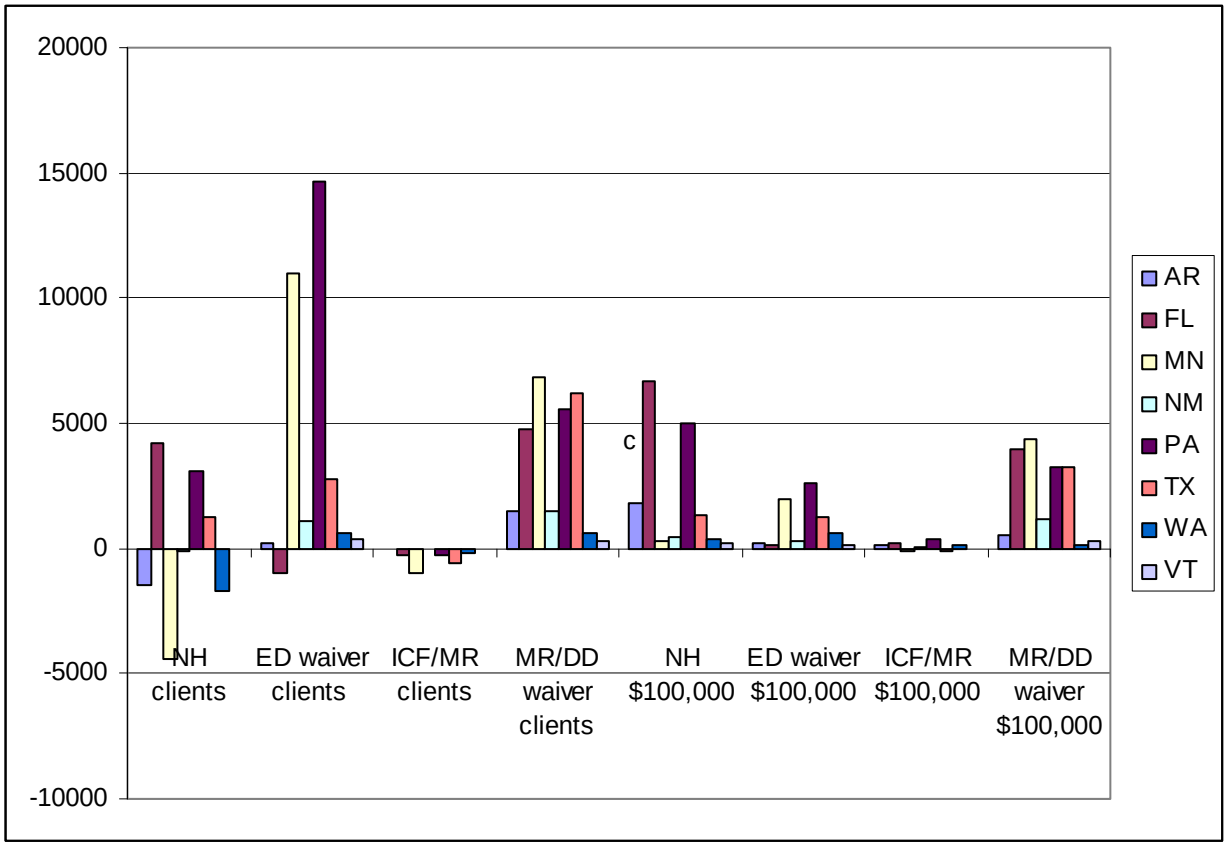

Figure 1: Absolute Changes in Clients and Expenditures by State and program, 2000 to 2005

Washington had begun its change in the balance between institutional and community services for older people and people with physical disabilities well before the beginning of our periods of observation in 2000. Its progress, therefore, was more in terms of consolidation, and in introducing service refinements. Other States, including Vermont and New Mexico made major shifts in their programs, Vermont by undoing the prevalent link between waiver care and nursing home eligibility. In effect, Vermont established levels of need and assured that persons in the most severe categories would be served regardless of location (i.e. by entitlement), whereas others with lesser need would be served if possible.

States achieved rebalancing in two basic ways: 1) by reallocating resources from institutions to community care and 2) by adding additional resources to community care. In

general, the first strategy was used more often for MR/DD clients, where there was strong enthusiasm for moving clients out of institutions.

Some states embarked on deliberate campaigns to reduce their use of nursing homes. Washington actively used case management to redirect clients into the community. Minnesota and Pennsylvania created incentives to downsize the nursing home sector; and Florida instituted managed care programs that substituted assisted living for nursing homes.

In most instances, the shift away from using nursing homes did not dramatically reduce expenditures in that category. Even when the capacity was reduced the overall spending remained high and often increased. It appears that legislators are loath to threaten nursing home funding; it is still seen as the last refuge for the frail elderly client. This phenomenon was particularly noted in Arkansas. In Florida expenditures in the nursing-home sector went up despite the increase in community care; this was not due to an increase in residents but to the implementation of new mandatory staffing standards to improve nursing-home quality.

In terms of expenditures, the figure also shows that the increase in nursing home expenditures exceed that for community waivers in all but a few states (WA, MN). The NM picture is complicated because its major growth in personal care was through the state plan. By contrast, waiver expenditures for MR/DD grew much than MR/ICF payments.

Patterns of Expenditures

Medical care costs are equal or greater than LTSS costs for many HCBS clients. Plans for funding HCBS should go beyond simply redistributing LTSS. _Savings on the acute care side could represent a potential_source of funds to expand HCBS efforts.

Although a great deal of Medicaid expenditure for LTSS recipients goes LTSS services, often Medicaid expenditures for their acute care are substantial as well. The debate over funding LTSS services better is often couched solely as a question of targeting and increasing efficiency. However there are also opportunities to use savings from reduced acute care expenditures to improve LTC. Better coordination of acute and LTC might create such savings. Figures 2 a and 2b illustrate the ratio of acute expenditures to long-term care expenditures for both wavered services and state plan services, respectively, for those clients who are not dually eligible (i.e., where Medicaid must cover medical costs). In a number of instances the ratio is greater than 1 (shown by the bold horizontal line), indicating that acute care expenditures exceed those for LTSS. For MRDD waiver clients medical expenditures exceeded LTC expenditures in MN, PA, TX, and WA. For aged and disabled clients only two states show this pattern (TX and WA), but PA is at parity and several states come close (MN and VT). Among state plan clients, those receiving home care in every state except AR had medical expenses that exceed LTC expenses; and in two states (TX and WA) the same was true for PCA clients.

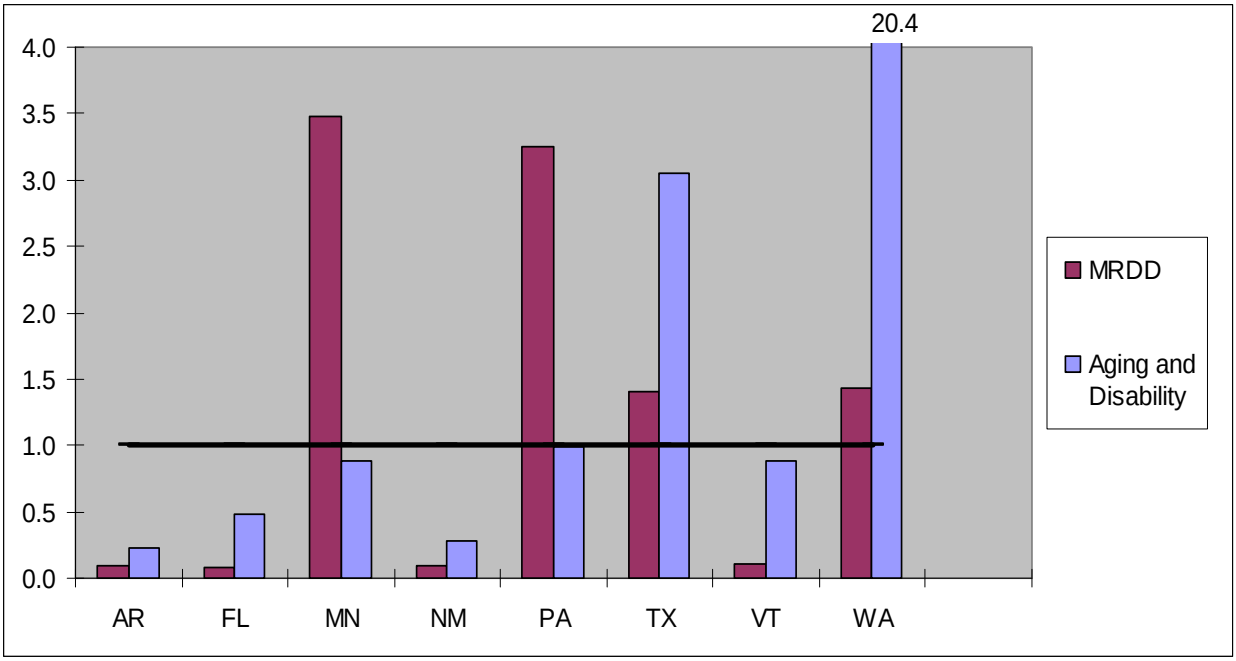

Figure 2a: Ratio of Medical Care to LTSS Medicaid Payment per Person Month in Waiver Groups in 2002 for non-dual eligible Fee-for-Service Enrollees

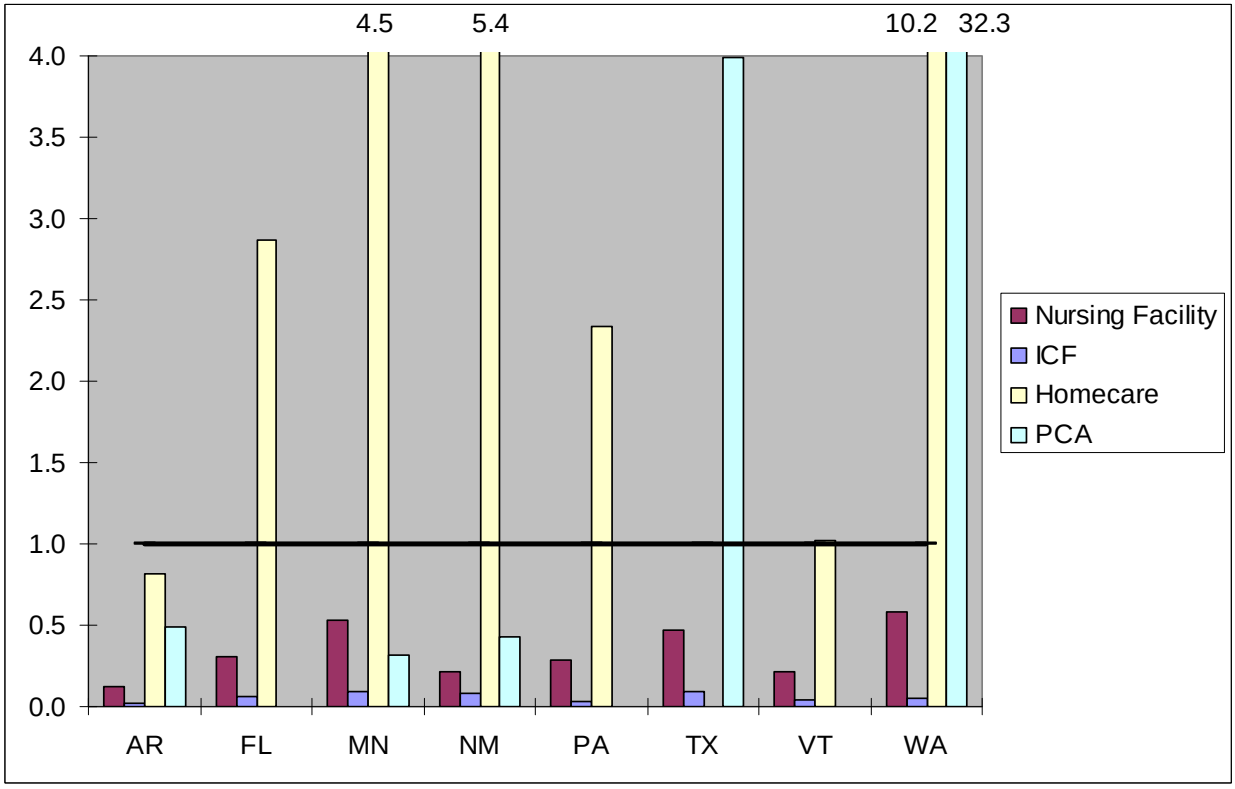

Figure 2b: Ratio of Medical Care to LTSS Medicaid Payment per Person Month in State Plan Group 2002 for non-dual eligible Fee-for-Service Enrollees

Management Strategies

Vision and goal setting. To some extent all 8 States enunciated a vision for LTSS that at least included participant choice and community integration. These aspects of the vision statement area particularly strongly articulated in New Mexico, Texas, Vermont, and Washington. States usually also incorporate ideas of high quality services and protections for seniors and persons with disabilities into their vision, and enunciated principles for major State agencies responsible for LTSS may also include principles such as effective stewardship of resources, or support of family care. States usually do not explicitly include reduction of institutions in their vision statements but may include a vision that participants live where they choose. It is not accidental that the word "choice" or "option" or "independence" has been attached to numerous recent LTSS programs in these States. Texas' initiative for post-Olmstead planning is called the Promoting Independence Initiative, Vermont's breakthrough 1115 waive program is called Choices for Community Care, and Arkansas has recently branded all its major programs with the word Choice in their titles. Key informants in the States recommended that visions statements emphasizing choice, dignity, and independence and other values be incorporated into statute as well as the mission of key agencies. Once such values are enshrined in Statute they become visible to the legislature and the public as a point of reference and efforts to shift attitudes, including the fixed attitudes of long-time providers of human services or health care, can be more focused.

Rebalancing management strategy: develop a vision statement for LTSS emphasizing choice and independence; work to enunciate the vision in one or more State statutes; incorporate it into the vision of relevant State agencies; make the vision prominent in related print and electronic materials; and train State employees on the vision and how to make it operational.

State Organization and Structure**.** Although there is no single configuration of stage agencies to assure more effective rebalancing, the observations across the eight states studied suggest that

a more integrated approach is preferable. The level of integration extends along two axes: target populations and functions.

When aging and disabled services are housed in the same agency as services for people with MR/DD or physical disabilities, there is greater opportunity for the programs to be administered along common rules. More egalitarian treatment is likely to follow. Three of the 8 States (Texas, Vermont, and Washington) have so far been able to bring about substantial integration of programs in State government for all disability groups and all ages into a single State agency, which is organized along functional lines across disabilities. Officials in these States attest to great benefits as a result of this reorganization, including greater cross-sector innovation and greater clarity for legislatures. (Only Washington thus far applies the same assessment protocol to people of all ages and disabilities, a further form of integration.). Initially, particular programs such as State Units on Aging, may feel they have lost their identity and focus for advocacy with such an organizational structure, although ultimately key informants say that they can achieve their goals better from within an agency organized along functional lines. The two States with separate cabinet level departments for aging (Florida and Pennsylvania) had the least cohesive organizational structure.

Another form of integration is between budgeting and planning and operations, and yet another is between the institutional and the HCBS sectors. Again, Texas, Vermont, and Washington show the greatest consolidation of functions in a single agency. We would argue that LTSS programs are more effectively delivered and are more likely to be able to

Rebalancing management strategies: consolidate operations related to all populations needing LTSS into a single State agency; consolidate functions such as budgeting & planning, operations, and quality assurance in a single State agency; the entity responsible for LTSS should control both the institutional and HCBS budgets.

implement rebalancing when the operating agency has direct control over the total Medicaid LTSS budget. Even though Medicaid is an open-ended program, it is easier to develop and implement re-distributional plans when the implementing agency has direct control over the funding. A separate Medicaid agency may find itself conflicted by other demands for the same funds from non-LTC, quarters. Likewise, it is easier to redistribute savings in acute care for the target population into LTSS if the operating agency has its hands on the purse.

Lead State agencies for LTSS typically bear a name that at least signifies its unified nature, such as the Department of Aging and Disability Services (DADS) in Texas, the Department of Aging and Long-Term Services in New Mexico, and the Division of Aging and Adult Services in Washington. The lead agency in Vermont, formerly re-named the Department of Aging and Disability (DAD) made a further name change during the study period, and is now the Department of Aging and Independent Living, with part of the mission enshrined in the agency title. In Minnesota the agency with the primary responsibility is called the Division of Continuing Care, and the recently developed entity in Pennsylvania is called the Office of Long-Term Living, a name that connotes something more upbeat than Long-term Care. (Notably, however, the Office of Long-Term Living does not at present enjoy the unified authority strategically recommended and answers in part to a cabinet-level Pennsylvania Department of Aging. In all the other examples of strategically named lead agencies, no independent department on aging exists.

Access to services.

Rebalancing management strategies: work towards expedited eligibility processes or even presumed eligibility; ensure the potential consumers get necessary information about choices at the right time.

Rebalancing in more difficult if consumers are presumed eligible for nursing home services yet incur long delays in establishing eligibility

for HCBS. These delays may concern establishing financial eligibility or functional eligibility (i.e., nursing-home-certifiability, or both). Requirements for physician signatures to establish "medical necessity" also introduces delay. Among the 8 States, Washington had established the most efficient eligibility process, and during the Rebalancing Research period, Texas had improved its speed of eligibility and Pennsylvania demonstrated that it could develop an expedited process in 10 counties that led to assessment and service initiation within days. Also related to improving access, States found it helpful to get a neutral source of information about choices to consumers when they were leaving hospitals or leaving a rehabilitation setting.

Rebalancing management strategy: avoid wait lists for HCBS services, particularly if no wait is needed for institutional services; if wait list exist for waiver services; try to use State-funded services for seamless gap-filling. .

Another aspect of access is having an availability of services so that consumers need not go on a waiting list, or at least that they receive some services while on a waiting list for more extensive services, such as might be found with a waiver slot. Many States developed strategic use of State-funded programs to fill gaps. Some States that were faced with long wait lists for waivers, reconfigured their MR/DD waivers to create additional waivers with less rich service mixes, a strategy typically resisted by consumers and some consumer advocates; for example, Washington the large major waiver and substituting four waivers of graduated intensity of service. Similarly, Florida initiated a new MR/DD waiver with less intensive services than in its original large Developmental Services (DS) waiver. The dilemma is whether it is better to serve more participants at a less-then-ideal service level and eliminate a wait list, or whether it is better to allow a wait list to increase and use that to persuade legislators that more funds are needed. In Texas where interest lists for the MR/DD waiver are long, advocates for

persons with MR/DD still prefer not to participate in managed care programs such as Star + Plus, even though as enrollees they would then have not wait for services.

Array of services. Creating a rebalanced LTC system requires having available a variety of supportive services to meet the range of individual needs and preferences. Personal care and attendant services are the bedrock of the services array. The services needed vary according to the participant's physical, emotional, and intellectual needs and life circumstances. Generally speaking, practical services that assist the participant's functioning are particularly important—these may include assistive devices (their purchase and repair), transportation, interpretation, escort, and the like. Arguably, if an attendant is permitted to perform a flexible range of services within and outside the participant's home, then a single attendant services embraces what is provided by a larger number of specialized services (e.g. homemaker services, meal services, escort services, and the like), assuming also sufficient hours of that attendant's help. Some services do not seem capable of providing a meaningful community alternative. For example, day care may offer some respite for family caregivers, but without substantial additional services it is not able to displace institutional care.

Rebalancing management strategies: develop a varied array of services, beginning with a capacity for personal care and/or attendant services; build flexibility into the services themselves rather than require multiple services to fulfill particular tasks; redefine case management services to meet current system needs; include a wide variety of residentially-based services in the array; examine nurse practice acts to assure that nurses can perform teaching roles and delegate nursing tasks to unlicensed assistive personnel.

The value of case management or care coordination as a service has been widely debated. Part of the confusion can be traced to the multiple roles case management has played, and the fact that it has been heavily used as a basis for determining eligibility for care or for specific services. It has likewise been employed as way to encourage clients to adhere more closely to their therapeutic regimens. In still other contexts, it is a bridge between social

and medical care. Although many policy makers seem to view case management as essential to services, it has not been empirically shown to be useful in many instances. Part of the problem may be due to a lack of definition; part may be traced to variable implementation. Some of the 8 States in the Rebalancing Research project perceive advantages in particular variants of case management services such as system navigators (in Texas), long-term care consultants (in Minnesota) or options counselors (in Arkansas) or transition counselors (now in many of these States). Certainly job coaches and life coaches have played important roles in MR/DD services.

Services tailored to an array of living settings are important. In some instances, the classification of a service as community or institutional may appear arbitrary. Some variations of assisted living, for example, seem to offer little better by way of independence and control, than what is available in nursing homes. Some MR/ICFs closely resemble small group homes while others are much lager and more institutional. But in general, the array of services needs to be adaptable to creating and sustaining a variety of living arrangements, including those likely to be more workable in rural areas.

Several States concluded that they would be better able to produce an array of flexible services at an affordable price if modified or clarified nurse practice rules to permit registered nurses to delegate nursing tasks to unlicensed assistive personnel. Washington and Arkansas particularly developed nurse delegation policies and educational programs.

Consumer-directed services. Development of consumer-directed service models is desirable both for the increased autonomy they provide to program participants or their agents, and the added flexibility associated services tailored by and to the consumer.

Rebalancing management strategy: consumer-directed services are an important building block in a rebalanced LTSS system and should be considered in both waivers and State Plan Personal Care Option Services; States have found it feasible for family members to serve as paid caregivers in such a system.

Strong consumer-directed options were developed in Arkansas, Minnesota, New Mexico, Texas, Vermont, and to a lesser extent, Florida. In Washington, an independent provider model predominates and offers considerable flexibility to consumers. In most of these consumer-directed programs and in the Washington Independent Provider model, family members may be selected and paid as caregivers; Minnesota is an exception in that it has more constraints on paying family members. Consumer-directed programs are found in waivers and State Plan personal care options programs, and several of the 8 States are developing consumer-directed programs for Administration on Aging-funded gap- filling programs. States have had challenges in developing reliable fiscal intermediary services, and both Arkansas and Florida needed to make major changes in the way they handled the fiscal intermediary function. Despite complications, we found widespread enthusiasm for developing and expanding consumer-directed services. Not only can they provide more value for the dollar, but, as it was discovered in Arkansas, consumers or their agents can sometimes utilize cash allowances to piece together assistance when agencies cannot hire help and deliver services.

Rebalancing management strategy: develop and provided staff support for a stakeholder group, largely comprised of consumers, and encourage a visible, substantive, and ongoing role for this group; in addition, develop stakeholder groups for various

Consumer stake-holder groups. Several States have developed a cross-disability over-arching stakeholder group charged with overseeing the implementation of a post-Olmstead plan. In Texas this group is the Promoting Independence Advisory Committee (PIAC), established almost a decade ago. In Arkansas it is the Governor's Integrated Services Task Force (GIST). Consumers participate on these groups along with high State officials from the relevant agencies. The PIAC is a particularly impressive example; it monitors achievements against the plan and issues regular reports; the PIAC's effectiveness is

partly due to the policy sophistication of many consumer advocates in Texas, but is also attributable to State actions in establishing and supporting the PIAC. In contrast, the GIST in Arkansas, where consumer activism was under-developed, became a vehicle for building consumer participation, skills, experiences, and solidarity. For such consumer groups to function effectively, the State needs to provide staff support. It is helpful if additional consumer and stakeholder groups (sometimes with membership overlapping other groups) are attached to specific projects and programs. The structure of DADS in Texas, for example, calls for an Advisory Council for each of the three major subdivisions that area headed by a Deputy Commissioner.

Rebalancing management strategies: develop an information infrastructure to support HCBS services with an ability to track experiences of groups of participants with various needs and an ability to track the performance of service providers; develop reporting hotlines and incident reporting systems; make information on quality readily available to consumers; develop feedback on quality directly from consumer surveys or interviews with consumers.

Quality of services. When States aspire to develop an array of services, it is also understood that they seek to develop services of reasonable quality. Most States are concerned about fulfilling their responsibilities to protect vulnerable citizens, and States feel a responsibility for services when they foot the bill. In rebalancing their LTSS systems, States have perceived a need to develop information systems to identify problems in a timely way, critical incident reporting structures, and an information technology platform to support a decentralized system of services. States with consolidated organizational structures have been better positioned to develop unified, comprehensive, and transparent approaches to quality management. It has also proved important that States not define quality as adherence to a strict set of input regulations, but rather that they elicit the consumer voice in describing the quality of their experiences. Finally some States, notably

Texas in this group, have taken steps to help home-care providers understand that program participants do have the right to take risks and to live in the community with less service than the agency might consider optimal or safe.

Quality of services tends to be perceived quite differently with reference to nursing homes compared to community care for seniors, and again differently for HCBS for older people and HCBS for participants with MR/DD. For several reasons, including ease of access and public pressure, a standardized data system has been imposed on nursing homes and a regular inspection system (known as the nursing home survey) is in place. Moreover, all nursing homes are subject to life safety code requirements. Quality in the context of nursing home care has been addressed across the now familiar spectrum of structure, process and quality. Structural standards have been established for such elements as staffing, organizational structure, and physical plants. Process standards include the use of medications, and the performance of nursing tasks. Outcomes include rates of negative events (e.g., percentage of new bedsores developed, or urinary catheters, or unsought weight loss) and clinical trajectories (e.g., rates of decline in physical functioning, rates of depression). Most of the information for assessing nursing home quality comes from the mandated MDS (Minimal Data Set); some comes from on-site inspections. Until recently virtually all the quality concerns were focused on elements of quality of care with much more minimal and recent attention to measures of quality of life.

The situation in community care for seniors is quite different. Often no standardized data base exists beyond periodic assessments by case managers, largely undertaken to determine service eligibility and the intensity of the services plan. The emphasis around quality concerns has been on 1) whether services are provided as ordered, 2) preventing or quickly detecting abuse or neglects; 3) and consumer satisfaction. Some States (Arkansas in this group) use a

variant of the MDS/HC (MDS Home Care) for HCBS services and several of the States including Minnesota and Washington, have taken steps to enable cross-walking between MDS data and assessments used in CBS, but HCBS assessments are not as frequent or as detailed as the nursing home assessments. A few States have implemented more systematic ways to track assessment and quality information using computer systems that create indexes and allow officials to look across individual participants or specific care providers to see patterns (Washington is a good example of this), but no state has defined a customer base for a provider and systematically assessed that cluster in a manner comparable to the approach used to develop quality indicators in nursing homes. Further, age-appropriate outcome markers such as competitive employment, living in independent community housing, or school attainment would need to be incorporated into a quality system with appropriate case mix adjustors.

Quality systems for services for persons with MR/DD are often managed by a different operational unit than are the services for older people and people with physical disabilities. Even quality inspections for ICF-MRs are typically performed by the State agency responsible for developmental services. On the HCBS side, much more attention has been given to the roles of consumers (including parents) in quality assurance than for corresponding programs for seniors and persons with physical disabilities. Because person-centered planning, choice, and community integration have been widely accepted in developmental disability services, quality measures have emphasized whether preferences are met and whether the services provided are sufficient and highly rated and many States participate in the Core Indicator program or the Participant Experience Survey or both in order to acquire such data. Actual evidence of benefit in terms of improved function or increased autonomy is not generally addressed.

In Washington a new structural element has been added to quality activities through a Home Care Quality Authority (HCQA). With effective political advocacy on the part of the Service Employees International Union (SEIU), which represents all independent providers in a closed shop, quality standards have been enunciated related to wages, benefits, and working conditions for Independent Providers. The HCQA, an independent government agency almost completely comprised of members who themselves have disabilities and use services, provides resources to facilitate the effectiveness of Washington's independent provider system for consumer-employers and unionized workers, the latter often family members.

To summarize, quality paradigms are changing in systems working towards rebalancing. Some efforts are being made to change the quality approach in nursing homes to one that emphasizes participant empowerment and quality of life outcomes, and much effort is being made to develop information systems and quality monitoring systems for States to confidently oversee their emerging community LTSS systems. Building in surveys of consumer experience is an important element of the quality program. So too is the provision of information for consumers about the quality record of all providers, including HCBS providers. Such information is particularly readily available on websites in Texas.

Payment strategies are consciously used to create incentives for providers. Nursing home and ICF/MR payments differ from all LTSS services because they include room and board. In HCBS, the allocations per capita tend to be much lower for waiver programs for seniors and persons with physical disabilities than for persons with MR/DD.

Financing and payment strategies.

As part of the State case studies and also the Topic Papers on the future of the nursing home (#5) and on community group residential care settings (#6), we explored the way rates were set, service and budget levels allocated, and payment made for various LTSS

services. Differences can be seen from institutions to HCBS, and between MR/DD programs and other HCBS programs.

Generally, the nursing home carries forward the hospital model of merging room and board with services. (Were this practice stopped and the room and board components of nursing homes separated from the service components for reimbursement and consumer billing, the nursing home would have difficulty competing on the price and nature of its the living spaces.) Some payment systems use a case mix adjustment, whereby more is paid for presumably more complex or difficult cases. Such an approach creates the perverse incentive that making clients less dependent may lower the payment rate for them. Some preliminary efforts have been launched to create incentives for better care. This so-called pay-for-performance pays higher a rate if providers achieve specified quality measures, which can be based on structure, process or outcome measures.

Setting the payment rate for a community service under Medicaid or Medicaid waivers can be challenging. Ideally a waiver is supposed to deliver the service to eligible clients at a cost equal to or lower than that charged by the covered institutional service. Advocates for persons with disabilities (especially for persons with MR/DD) have used that argument to insist that community clients should get services at least up the cost of institutional care, which was quite expensive. Among elderly participants community care is often considerably cheaper than nursing home care (even when room and board is factored in) and it is thus feasible to serve more clients, but controlling eligibility is a problem because the concept of nursing home certifiable is imprecise. Hence, some waiver programs have fixed the number of slots available to control costs and have instituted waiting lists. But having clients spend long periods on waiting lists raises problematic questions about the need for the services in the first place.

In general aging and disability services are assigned based on some measure of a client's disability profile. The greater the level of need, the more is allowed. Historically, with MR/DD programs, need profiles were seldom created and waiver services were allocated on the basis what is believed the client can use. In essence, need is then defined in terms of the absence of services. In some of the States, notably in Minnesota, considerable effort has been devoted to developing an equitable system of developing participant budgets across four major waivers (the elderly waiver was excluded, largely because much of its services are delivered by capitated managed care entities.) Payment incentives build into managed care are discussed in the next section.

Managed care. Several states have been attracted to managed care for LTSS. The appeal is predicated on several potential advantages:

- The payment is fixed and hence predictable (and thus budgetable).
- It is presumed to save money (The price is advertised as a discount over what it would otherwise cost, but trey actual price may vary dependent on just who enrolls.)
- It may allow states to accomplish something they could not do directly (e.g., ration services, push for a cheaper mode of care, and avoid bureaucratic conflicts).
- The State may already be invested in Medicaid managed care for acute care or behavioral health and perceive clinical advantages for seniors and people with disabilities if acute care and LTSS could be integrated in a single capitated delivery system.

Rebalancing management strategy: Managed LTSS, often introduced as part of overall managed Medicaid services can be used to encourage community care and rebalancing if: the State is clear on incentives for community care; a mechanism is available to ensure that consumer choice of living situation is respected, and consumers are offered consumer-directed models; and assisted living settings are not over-utilized. Managed LTSS is more likely to carry incentives for HCBS if the providers are at financial risk for nursing-home care and/or incur penalties when nursing home residents disenroll.

Some of the states that have used managed care have done so through the overall Medicaid program (Texas, Florida, and Minnesota). Some have also developed managed care programs specifically aimed at LTC clients; Florida has tried a waiver program specifically designed to divert nursing home eligible clients into other types of care, which turned out to result in a heavy use of assisted living facilities. The diversion has succeeded, but the cost savings are still being disputed. Minnesota has superimposed on a mandatory managed care program for Medicaid recipients (including those receiving elderly waivers but not covering most nursing home residents) a major program for the full gamut of dually eligible seniors in its MSHO (Minnesota Senior Health Organization). Its effects were not dramatic during the initial evaluation period. Its impact on costs has yet to be established. In its expansion to mandatory LTSS coverage for dually eligible seniors, Minnesota is struggling with how to ensure that seniors receive choices (for example, choices of consumer-directed options) while allowing managed care entities to actually manage.

Managed care has more often been mandated for older LTSS participants than for participants with physical or intellectual disabilities. In many instances, consumer pressure has prevented the imposition of compulsory managed LTSS on younger groups of people with disabilities. In Florida, however, pressure by advocates for seniors prevented Florida Senior Care from being implemented as a mandatory program during its demonstration phase.

Minnesota has demonstrated a model for managed care for dually eligible persons with physical disabilities called the Minnesota Disability Organization (MnDO) where the enrollees with disabilities and their advocates exert substantial control over the nature of the services.

Some States have identified advantages with the PACE model of full-risk managed acute-care and LTSS for dually eligible seniors. Recognizing that PACE typically reaches just a small number of participants and serves as a choice in some geographic areas rather than a major system plank, Pennsylvania is trying to bring PACE replication projects to scale and to encourage a network of these programs, co-located with senior housing, when possible throughout the State. PACE carries the theoretical advantage that PACE providers are at financial risk forever for nursing home care of its enrollees. (The Florida Diversion program has only limited financial risk for nursing home residents, and recently, responding to high levels of disenrollment when participants disenrolled, Florida introduced penalties to the MCO when consumers reverted to fee-for-service.)

Downsizing and changing nursing homes. The expansion of community care has put pressure on nursing homes. The availability of alternative forms of care creates competition and a heightened awareness of other ways to meet LTC needs. Perhaps the most direct competition has come from the burgeoning area of assisted living, which combines housing with services. This has led to a situation in many States where nursing homes are less than fully occupied; this is particularly true in States with historically high bed supply (such as Minnesota) compared to those with low bed supply (such as Florida).

Even if there is not one-for-one displacement of HCBS for nursing homes, the availability of more community options has generated a re-evaluation of the role of nursing homes. Opinions run the gamut with some commentators. Some maintain that there should no longer be nursing

Rebalancing management strategies: develop numerical goals for nursing home Medicaid expenditures, and, if possible, build them into budget forecasts; develop reimbursement incentives for nursing homes to downsize, close, and/or diversify into community services; for States with large ICF/MRs, develop incentives for them to close and perhaps become HCBS providers instead.

homes; others argue that there will always be at least a residual need for some institutional care. To the extent that parallels hold, some states have totally closed the institutions that previously houses participants with MR/DD. Although it is not always reasonable to assume that the same factors apply to older persons and persons with MR/DD, the lessons learned from the latter should be studied when planning for the former. Even severely impaired persons are now treated in the community. The argument for the need for residual nursing home beds may eventually lose credibility. At present none of the States have called for eliminating nursing homes, but Minnesota, Pennsylvania, Vermont, and Washington have set numerical goals for reductions. Other States prefer, such as Texas, prefer not to articulate goals for nursing home use but rather to create alternatives and emphasize goal of consumer choice.

There is general agreement that fewer nursing home places are needed and that facilities should be modified to offer privacy, individualized services, and even consumer-directed services. The presence of alternatives has stimulated discussion about what such a facility should look like, and the nursing home industry itself has responded with considerable enthusiasm towards culture change.

Some States in the Rebalancing Research have introduced incentives for nursing homes to close, downsize, or diversify into community care (Minnesota and Pennsylvania) and also to develop single rooms. Pennsylvania has taken the added step of developing internal expertise in nursing home management and is able to provide consultation to downsizing facilities on how to

deal with cash flow problems. These strategies are very effective for rebalancing in the sense of reducing expenditures in the nursing home sector. (In contrast some States, particularly Florida have developed expensive improvements to nursing homes through mandated staffing ratios and other mechanisms, which increased the unit cost of nursing home care and the expenditure balance in Medicaid without changing nursing home utilization.) Texas has embarked on a process of creating incentives for ICF-MRs with 9 or more beds to close.

Because the nursing home has developed in response to various external pressures and incentives, it is a crude amalgam, trying to serve multiple constituencies. Some suggest that allowing the same facility to provide post-acute care and LTC is a mistake because different skills are needed for each and the blend lowers the results for both. Moreover, the merger encourages clients to stay in these facilities after their rehabilitation is complete.

Transition programs. Rebalancing efforts are a mixture of diversion programs (which require targeted attention and priority services to persons likely to enter nursing homes or other institutions), and transition programs, which help participants leave nursing homes. Especially in States with high institution use, structured transition programs are needed. These programs combine specific opportunities for persons living in intuitions to learn about community options from an unbiased advisor, and funding of services related to transitions (e.g., rent and utility deposits, furnishings and household goods, and the counseling assistance or relocation specialists' services needed to plan for moving to the community). Some States have given their Area Agencies on Aging, their Centers for

Rebalancing management strategies: develop specific programs to assist those who wish to make transitions from institutions; fund and train a group of relocation specialists to work with transitioning individuals; build transition expenses, including relocation specialist services and expenses for deposits and furnishings into waivers or State-funded programs; ensure an unbiased outside source of information about community alternatives for persons living in institutions.

Independent Living or both structured roles in this effort. Some have expected the nursing home ombudsman to help. Pennsylvania followed Texas' lead and utilized MDS responses on question Q to identify individuals who expressed a wish to leave nursing homes. Arkansas has commissioned data analysis to identify those most likely to be assisted to leave nursing homes. Furthermore, States have made clear to nursing homes that the relocation specialists must be welcomed to the facility and, as agents of the State, they are not to be considered as solicitors.

Obstacles to rebalancing. Movement toward community care has not progressed evenly across the states; as a corollary, one might surmise that states have encountered different obstacles. One obstacle cited by all States is financial resources for rebalancing. State budgets have been tight and new funding is hard to come by. It is easier to make changes when they are incremental additions rather than substitutive displacements. On the other hand, the State of Pennsylvania has used tight budgets as part of the reason for the necessity to move to community services. Most states have responded to some or all of various incentive packages put forth by CMS to encourage developing more HCBS, but that strategy is often more reactive than proactive, and also does not deal with funding once a developmental grant has ended. .

In the preceding sections we have already discussed a variety of obstacles to rebalancing, related to access, array or services, and organizational structure. Lobbies play a strong and recognized role in shaping State policies; usually lobbies for institutional or other providers and for professional groups are stronger than lobbies for consumer groups. Home health organizations and associations of Area Agencies on Aging, for example, sometimes present obstacles to consumer-directed services. Another obstacle to rebalancing is posed by consumer constituents who have family members who have been long-stay residents in institutions. This phenomenon was found among family members of residents of State-run institutions in

Washington, Arkansas, and Texas, where common cause is made with employee associations or employee unions in these institutions..

A more subtle obstacle is beliefs about how individuals needing LTSS should be served and protected. Key staff at State levels and even more so in local governments and non-governmental organizations may hold strong beliefs about what is feasible or even right for community care. Those who are heavily invested in past programs may be reluctant (even to the point of sabotage) to embrace new developments. Some States use the vehicle of negotiated risk agreements to encourage providers to allow participants to accept risks. Texas took specific steps to clarify to home care agencies that they were not responsible for the consumer's safety 24 hours a day and that consumers have the right to take risks. A key factor in shifting resources from institutions to community care was the role of consumer lobbies. The success on behalf of persons with MR/DD was not matched in the aging world for several reasons. Institutional care for the former was largely provided by state institutions which did not have the organized lobbying strength seen with nursing homes. Conversely, in most states elderly advocates have not been strong enough to offset the nursing home lobby. The question is usually framed as protecting the most vulnerable. As a result, even when nursing home supply is reduced the net funding level increases to "protect" those residents still there. In some rural areas, the problem is confounded because the nursing home is a major employer; state legislators are reluctant to lose jobs for their constituents.

Finally, we found some evidence that State officials worry about accelerating costs if large numbers of seniors now served in nursing homes were cared for in the community. Some also worry about the woodwork effect of poorly targeted diversion programs. These concerns were expressed in Florida.

Long-term strategies. The conclusions drawn from the Rebalancing Research discussed so far are relatively short-term as were the strategies States undertook to improve their "rebalancing statistics"—i.e. the proportion of expenditures on HCBS as opposed to institutions. The States also undertook some long-range efforts to build the capability of the HCBS system, including labor force development projects, projects to develop low-cost and accessible housing, transportation initiatives, or projects to develop disability-friendly communities. Minnesota is particularly given to long-range planning and its stance has been to develop systems of LTSS for all citizens, not just those who are eligible for Medicaid or Medicaid waivers. Florida developed several long-term public-private partnerships around prosthetic equipment and livable communities. Arkansas worked to develop and implement accessibility standards and universal design in all housing and to make low- and moderate-income accessible housing available. Pennsylvania and Vermont emphasized labor force development and retention.

Recommendations

General principles. We begin this section of recommendations with some general principles before offering more specific recommendations. The next major step in the evolution of LTC will need to rely on some fundamental principles.

1. The basic tenet of publically funded LTSS needs re-examination. Institutions, particularly nursing homes, should not be the standard against which other care is measured. Instead the primary thrust of policy should be to enable people to be in the community, in their own homes if possible, but in a home in any event. Some degree of congregate living may be required to facilitate efficient delivery of services, but it should not come at the expense of depriving a person of a livable home.

2. Infrastructure is needed. One level of infrastructure is administrative. Fragmentation impedes progress and efficiency. Some degree of programmatic coordination, ideally a centralized administration that controls funding and the full range of services for the full gamut of the LTC population should facilitate effective allocation of resources.

3. Accountability is also central. In this context accountability extends beyond regulation to a more proactive approach that identifies goals and rewards their

achievement. It can begin at the individual level and sum to the programmatic level. Such an approach implies that individual preferences are central.

4. Payments should be used to re-enforce established goals. The current approach of paying for services must be tempered towards paying for accomplishment, even when that accomplishment is subjective.

5. The Medicaid program should look to the full range of its coverage and not segregate LTSS and medical care. Savings in the latter can be used to bolster the former. Ideally this pooling of resources would extend to Medicare as well for dually eligible participants, but the only venue for achieving this end has been managed care.

6. Unfortunately, the savings accrued by managed care are enjoyed by the MCO not the Medicaid program. The likelihood of recouping these savings through lower premiums seems remote, although such approaches should be fostered. The experience of Arizona's ALTCS program may be instructive in this regard. They have set rates each year based on assumptions of greater savings. The Family Care program in Wisconsin may offer another model by relying on public corporations rather than private enterprises. The former may be more amenable to sharing the benefits of consolidation.

7. Paradoxically, while encouraging commingling of funds, it is also important to move away from the current system of nursing home care that seeks to serve a heterogeneous population through a single product. Post-acute care requires quite different skills and attitudes than does LTC. Moreover, using the same institutions for both can lead to perpetual nursing home stays.

8. Regulation has transformed the nursing home industry but at a cost. It has eliminated some (but certainly not all) woefully substandard care but it has failed to create a positive climate for improvement. We should not reinvent a heavy regulatory approach to LTSS based on nursing home regulations.

<u>Recommendations for States Undertaking Rebalancing.</u>

1. States should adopt a set of core values that might include the following

   - Persons of all ages needing LTSS and their families are entitled to maximum feasible choice of and participation in selecting service providers and living settings;

   - Persons of all ages with disabilities have the right to choose and/direct a care plan involving "managed risk", in exchange for the advantages of personal freedom. Such risk taking presumes access to good information about the benefits and risk implications of alternatives.

   - The array of public service options and individual client choices may be bounded by reasonable considerations of costs.

- State LTSS systems should incorporate the belief that quality of life is as important as quality of care.

2. A State LTSS system needs a fast, timely and standardized way to assess financial and functional eligibility.

3. In a State LTSS system, States should work towards integrating services for all LTSS populations in the same agency, and towards achieving a unified budget for HCBS and institutional services.

4. A State LTSS system needs a high quality, accountable case management system with capacity to provide information, assistance, and oversight for consumers.

5. A State LTSS system needs a fair rate setting and contracting process for providers.

6. A State LTSS system needs a process for assuring quality oversight throughout the system.

7. A State LTSS system needs a sophisticated group of consumers/families and providers who advocate for the LTSS system.

8. State lead agencies for LTSS should build a quality system by:
   - establishing programs in which substantial samples of individuals are surveyed to determine the outcomes of the institutional and community supports they receive;

   - analyzing those data to determine the settings and individuals for whom outcomes are relatively less well achieved;

   - reporting those outcomes publicly;

   - establishing quality improvement programs that address types of service, locations or groups of services recipients whose outcomes are less than should be achieve;

   - instituting or proposing legislative policy and program changes in areas in which predictors of less favorable outcomes can be manipulated by policy.

9. The relevant State Agency should review all regulatory language for any group residential settings where Medicaid waiver services are received to identify and remove requirements that force consumers to leave if they “need 24-hour nursing” or otherwise reach a certain level of disability.

<u>Recommendations for State Legislatures:</u> State legislatures should:

1. Set specific budget targets for decreased expenditures for institutional services and increased expenditures for home and community services with established incentives to meet/disincentives to miss those targets;

2. Create housing subsidies for individuals for home the cost of the housing subsidy plus the cost of community supports needed to live in that housing are equal to or less than the cost of the otherwise necessary institutional care.

3. Provide such subsidies at enrollment in Medicaid LTSS with simultaneous application for a HUD Section 8 housing voucher and maintain the state subsidies only until the individual(s) can claim a HUD Section 8 voucher or other federal subsidized housing.

Recommendations for consumer advocates. Consumer advocates should:

1. Monitor and publicize state performance in comparison to other states in key indicators of "rebalancing" (e.g., decreasing rates of institutionalization, relative balance of institutional vs. home and community services, relative balance and trends in state expenditures for institutional and home and community services, rates of competitive employment for persons with disabilities; independent housing rates for persons with disabilities, and so on);

2. Obtain and publicize data or findings on variations in outcomes (choices, employment/earnings, community participation, etc.), satisfaction and expenditures for factors associated with rebalancing concretely and broadly framed (institutions vs. home and community supports, setting size, own home v. assisted living, consumer directed vs. traditional budgeting, care planning vs. person-centered planning).

Monitor the enforcement of the Olmstead decision in their States.

Recommendations for CMS and other Federal Agencies. CMS should consider:

1. Providing grants to states as incentive to consolidate of all their LTSS programs in one place in state government.

2. Providing a better Title 19 match for Home and Community Services as an incentive for states to provide this type of service.

3. Intervening in states that are making little or no progress in fulfilling the promises of Olmstead. Create potential benefits for progress (and potential detriments for continued lack of progress). For example, the FFP could be reduced by 1% per year for institutional services and increased by 1% per year for community supports for a period of time.

4. Engaging with HUD in a demonstration within targeted communities (ones in which the cost of housing exceeds what can be purchased with the standard SSI and SSDI cash payment) of target housing subsidies linked with a) new Medicaid LTSS recipients and/or b) participants coming out of institutions.. In such a program new community HCBS recipients for whom the cost to the federal government for both subsidized housing and home/community

supports would be less than the cost of an institutional placement might receive access to a HUD or HUD-liked Section 8 voucher simultaneous to the available of the community supports they need to live in their subsidized housing.

5. Establishing partnerships with financial incentives for states to utilize a well-developed, standardized program of outcome assessment for substantial random samples of institution and community service recipients. In such a plan CMS not only contributes to states' obtaining state data for their own analysis purposes, but it integrates the data sets created to establish a multi-state means of studying the effects of various supports for persons of various characteristics living in various settings.

6. Encouraging States to expand state-plan coverage to include more HCBS services.

7. Exploring the kind of federal statutory and regulatory changes needed so that a broad array of LTSS services could be available for all eligible Medicaid participants without regard to the artificiality of nursing-home certifiability. (This would include variants of the Vermont Choices for Community Care program).

8. Exploring the feasibility and desirability of and the needed statutory and regulatory changes for uncoupling room and board from services in nursing homes to level the playing field.