

# **Rebalancing Long-Term Care Systems in Arkansas**

**Long Version Report prepared by the Rebalancing Research Group**

**Submitted to the Centers for Medicare and Medicaid Services**

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The overall project was conducted through a Task Order under a CMS Master Contract between CMS and the CNA Corporation, Arlington, VA, and subcontracts and consultant agreements between CNAC and the various researchers. The 3-year study called for case studies of the experience of 8 states—other states in the study are: Arkansas, Florida, New Mexico, Pennsylvania, Texas, Vermont, and Washington. The baseline case study covers a period through July 31, 2005. An abbreviated version of this case study is also available at

[http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline\\_state\\_case\\_studies/Arkansas\\_abbreviated\\_baseline\\_case\\_study.pdf](http://www.hpm.umn.edu/ltcresourcecenter/research/rebalancing/attachments/baseline_state_case_studies/Arkansas_abbreviated_baseline_case_study.pdf)

The statements and opinions in the report are those of the writers and do not necessarily reflect the views of CMS or any of its staff, or the State liaisons to the project, or any other state staff or persons who spoke to us from participating states. We thank the Arkansas Liaison to the study, Herb Sanderson, Director, Arkansas Division of Aging and Adult Services..

## Rebalancing Long-Term Care Systems in Arkansas

Summary of Highlights.....	1
Section 1: Context for Rebalancing.....	4
Demographics and Economics.....	4
Geography.....	6
Rebalancing Status in Brief.....	7
Vision and Values for LTC.....	10
Leadership.....	11
State Government Organization for LTC.....	12
Organization of Long-Term Care at Local Levels.....	17
Advocacy Environment.....	17
Litigation Related to Rebalancing.....	19
Service Provider Environment.....	20
Historical Evolution of LTC.....	24
Programs and Services.....	26
Medicaid HCBS Waivers.....	26
Elder Choices.....	27
Alternatives for Adults with Physical Disabilities (APD). Authorized in 1997.....	28
Alternative Community Services (DDS ACS waiver).....	28
Living Choices/Assisted Living Waiver.....	29
Children’s Respite Waivers.....	29
State Plan Services.....	29
<b>Other Services</b> .....	30
Older American’s Act.....	30
Protective services and advocacy.....	30
First Connections Infant and Early Toddler Program.....	30
Section II. System Assessment.....	30
Access to Services.....	31
Array of Services.....	32
Quality Initiatives.....	33
Consumer Direction.....	34
Institutional Downsizing.....	35
Data Capacity.....	35
Mental Health Linkages.....	36
Acute Care Linkages.....	38
Housing Linkages.....	40
Section III: Featured Management Approaches.....	41
Independent Choices and Other Cash Options.....	41
Cash and Counseling Demonstration.....	41
Cash Allowances Post-Demonstration.....	44
Web-based Information Systems: SA-HELLO and AR-GetCare.....	45
Together We Can.....	45
Consumer Empowerment/Aging and Disability Leadership Academy.....	46
Consumer Directed Care Act/Nurse Delegation.....	47
Primary Care Case Management.....	48

Section IV. Quantitative Markers of Rebalancing.....	50
Markers of Change in Nursing Home Residents .....	50
Methods.....	51
Results.....	52
Relationships between HCBS and Institutional Care .....	55
Conclusions.....	58
General Conclusions .....	58
Issues for Future Observation.....	59

**List of Tables**

Table 1. Demographic Features Linked to LTC Needs in Arkansas .....	4
Table 2: Economic Characteristics in Arkansas and the United States .....	5
Table 3. Supply of Residential Services in Arkansas, 2000-2004.....	23
Table 4. Human Developmental Centers in Arkansas .....	24
Table 5. Selected LTC Milestones in the State of Arkansas through June 2005.....	26
Table 6. Overview of HCBS Waivers in Arkansas.....	27
Table 8. Change in NH Case Mix in Arkansas Three Months after Admission, 2002-2004 .....	54
Table 9: Utilization and Expenditures for Select Medicaid and Other Long-Term Care Services/Programs, Arkansas, 2000-2004 .....	56

**List of Figures**

Figure 1. County Map of Arkansas with Area Agency on Aging Regions .....	7
Figure 2. Arkansas Department of Human Services as of June 2005.....	13
Figure 3. Division of Aging and Adult Services as of June 2005.....	14
Figure 4. Organization of the Division of Developmental Disabilities as of June 2005 .....	15
Figure 5. Organization of the Division of Medical Services as of June 2005 .....	16
Figure 6. Clients Served in Selected Programs in Arkansas, 2000-2004 .....	55
Figure 7. Expenditures for Selected Arkansas Programs, 2000 to 2004 .....	57
Figure 8. Costs per Consumer Served in Selected Arkansas Programs, 2000-2004 .....	58

## **Preface**

The baseline case studies performed for this project were prepared in two forms: an abbreviated case study of approximately 15 pages, and a much longer report, of which this is an example.

Each longer report is organized in 4 sections: context; system assessment; management features, and quantitative markers of rebalancing. The first 2 sections use uniform headings for all reports. The Context section includes: demographics and economics, geography, rebalancing status in brief, political climate, vision and values for LTC, leadership, state government organization for LTC, local organization for LTC, litigation related to re-balancing, advocacy environment, service environment, and a historical and descriptive review of programs and Services. Maps, organizational charts, and statistical background tables are provided beyond the material in the abbreviated reports. The System Assessment categories found in most long reports are: access to services, array of services, consumer direction, quality initiatives, institutional downsizing, data capacity, links to acute care, and links to housing. The illustrative management approaches in Section III are presented in considerable detail. Section IV presents data on supply of services and quantitative comparisons of utilization and expenditures in home-and-community based long-term supports versus institutional long-term support services from 2000 to 2004.

In these baseline reports, we endeavored to trace the evolution of long-term supportive services in the State back to their post-Medicaid and post-Medicare beginnings, with particular emphasis on developments

## **Rebalancing Long-Term Care in Arkansas**

### **Summary of Highlights**

In 2004, Arkansas had an estimated population of 2.7 million people. Given the age, disability, income distribution and Medicaid participation rates in Arkansas, demand for publicly funded long-term care services is high, and the ability to generate revenue to meet the demand is limited. Nonetheless, Arkansas made substantial progress in the late 1980s and 1990s and continuing in the 21<sup>st</sup> century to increase use of home and community-based services (HCBS) for seniors and people with physical disabilities. The payoff has been success in rebalancing utilization towards HCBS; rebalancing nursing home expenditures has proven more elusive.

In contrast, Arkansas' historical track record from the 1990s forward in rebalancing services for persons with mental retardation and developmental disability (MR/DD) is weaker. In 1996, Arkansas was judged one of the most institutionally oriented states in the nation for MR/DD. Since then, a concerted effort has been underway to reverse that status; waiver slots for MR/DD have increased, small ICF MRs (e.g. with 6 or fewer beds) are becoming more prevalent than large ICF-MRs, and supportive housing and employment programs have been developed. Arkansas piloted an innovative community collaboration to enhance HCBS for children with MR/DD, which now operates in a 26 county area, as well as other programs to serve children in the community, some in tandem with the school systems. But Arkansas has closed none of its six (6) state Human Resource Centers, which in 2004 housed about 1200 people, although strategies are underway to overcome parental, professional, and public resistance to their downsizing.

With support of the Governor and the legislature, Arkansas articulated a strong vision of community integration and consumer choice. Arkansas pioneered in testing the National Cash and Counseling Demonstration, a 3-state randomized controlled trial of cashing out Medicaid

benefits. Arkansas then made this program, called Independent Choices, permanent; consumers may elect cash benefits rather than in-kind personal care services under the State Medicaid Plan. An HCBS waiver program for people with physical disabilities was designed with consumer-directed attendant care as its core service. The State is now exploring other applications of cash allowances, including the AOA family caregiver program and a Next Choices initiative, which would provide cash allowances for Medicaid nursing home residents who move to the community. In 2005, the legislature enacted the Consumer Directed Care Act, which exempted health maintenance services directed by a consumer or the consumer's agent from the strictures of the nurse practice act. The Governor's Integrated Services Task Force (GIST) is a focal point for Olmstead-related planning in Arkansas; its members represent a wide range of advocacy and provider representatives and high-level government agency heads participate actively with GIST. Intensive stakeholder involvement is the norm in all program initiatives. The Arkansas Aging and Disabilities Leadership Academy is an especially noteworthy state investment in developing more activated and informed consumer advocates.

Strengths facilitating rebalancing activities include consistent civil service leadership in the Divisions of Aging and Adult Services Division (DAAS), Developmental Disabilities Services (DDDS), and Medical Services (DMS); an innovative stance with openness to identifying, adapting, testing, and applying new approaches; and a wide array of partnerships with other government agencies and the private sector. Obstacles to rebalancing in Arkansas include: fiscal constraints; strong lobby groups for nursing homes and state institutions for MR/DD; and difficulty in creating a single-entry case-managed system given the historical evolution of the Area Agencies on Aging, home health agencies, and developmental disability organizations.

From 2001 to 2004, Arkansas made excellent use federal and foundation grant funds to develop and test new programs before bringing them to scale. (From 2001-2004, Arkansas was

awarded \$5,219,706 in CMS Real Choice System Change Grants alone.) Strategically, state leaders prioritize improving access to information for consumers and providers. For example, Arkansas piloted a single entry point for services and a uniform assessment in Southwest Arkansas; including a state-wide Web-based system for both consumers and providers called SA-Hello, which was implemented statewide in a program called AR-GetCare. Other efforts underway are: developing affordable assisted living, beginning under the aegis of the Robert Wood Johnson Coming Home Program and including new initiatives; developing sites for the Program of All-Inclusive Care for the Elderly (PACE) to serve dually eligible individuals; and development of a primary care case management effort for chronic disease management modeled after an effective program developed in Georgia. The 2005 Legislative Assembly enacted legislation to move the Department of Health, as a Division, into the Department of Health and Human Services, to take effect in the fall of 2005. Planned for cost-saving, the reorganization was expected to prevention and chronic disease management initiatives for LTC consumers.

Future reports will follow the expansion of single-entry systems and improved assessment processes; housing initiatives, quality management and information technology initiatives; deinstitutionalization progress in MR/DD, and disease management for long-term care consumers. In October 2005 Arkansas was awarded a CMS Systems Transformation Grant, which should greatly facilitate these efforts. The body of the report details many of the initiatives summarized above, covering the period up to September 30, 2005.<sup>1</sup>

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<sup>1</sup> Note: The team site-visiting Arkansas on May 23-25, 2005 included Rosalie Kane and Robert Kane from University of Minnesota; Dann Milne, Colorado; Martin Kitchener, University of California at San Francisco; and MaryBeth Ribar, Centers for Medicare and Medical Services. This report is based on information gathered before, during, and after the site visit. In the baseline case study, we created a historical record and context for a period up to July 31, 2005, with the intent of up-dating the case study twice, as of July 31, 2006 and July 31, 2007. We thank our Arkansas study liaison, Herb Sanderson, director of the Division of Aging and Adult Services, and the many individuals in the public and private sector who provided us with insights for the report. The conclusions drawn are those of the authors and do not necessarily reflect any officials in Arkansas or at CMS.

## Section 1: Context for Rebalancing

### Demographics and Economics

As Table 1 shows, Arkansas is a state with fewer than 3 million people (32<sup>nd</sup> ranking in population in the nation) with a population that is aging somewhat faster than the national average and that has higher disability rates for all age groups including children, working age adults, and elderly people than is nationally reported. The population over age 85 and the population with a disability is more likely to live alone than the national average. About half the state's population lives outside urban areas. These circumstances create challenges for developing community care and improving long-term care overall.

**Table 1. Demographic Features Linked to LTC Needs in Arkansas**

Population Characteristic	Arkansas	United States
Total Population, 2004	2,752,629	293,655,404
Persons Age 65+, 2004	13.2%	12.1%
Persons Age 85+, 2004	1.3%	1.3%
Population Non-White,, 2003	20.3%	24.43%
Percent Population non-White or Hispanic	21.6%	32.7%
Urbanicity, 2003 (population in MSA).	50.0%	81.7%
Persons per square mile, 2000	51.3	79.6
Community Population age 5-20 with disability, 2004	9.0%	6.6%
Community Population, age 21-64 with a disability, 2004.	19.9%	12.0%
Community Population 65+ with a disability, 2004 <sup>a</sup>	49.1%	39.9%
Percent non-elderly persons with a disability, 2003	15.0%	10.9%
Men per 100 woman over age 85, 2002 <sup>b</sup>	42.6	47.9
Percent persons over 65 with Self-Care Difficulty, 2002	12.8%	9.2%
Percent persons over age 85 living alone, 2002.	54.8%	50.2%
Percent persons with disability living alone	40.9%	31.4%

Notes: These statistics come from the US Census Bureau, American Community Survey, which excludes people living institutions—e.g. nursing homes. A broad definition of disability is used, i.e., persons who report a disability in employment, mobility, and/or personal care. On web last visited 12/19/2005 at:

<http://www.census.gov/acs/www/Products/Ranking/index.htm> More detailed analyses regarding older people are found in the 2004 AARP cross-state report by Gibson et al.<sup>2</sup> We also utilized statistics available on the Website of UC San Francisco's Center for Personal Assistant Services, <http://www.pascenter.org/home/index.php>

<sup>2</sup> Mary Jo Gibson, Steven R. Gregory, Ari N. Houser and Wendy Fox-Grage (2004). Across the States: Profiles of Long Term Care. Sixth Edition. Washington, DC. AARP. Also on Web last visited 12/18/2005 at [http://www.aarp.org/research/reference/statistics/across\\_the\\_states\\_profiles\\_of\\_longterm\\_care\\_2004.html](http://www.aarp.org/research/reference/statistics/across_the_states_profiles_of_longterm_care_2004.html)

The average per capita income and the median household income in Arkansas are well below the national average, poverty rates and Medicaid participation rates are well above average, and the rate of those with no health insurance is slightly above the national average (Table 2). We calculated poverty figures multiple ways, and all calculations, Arkansas is challenged by higher than average poverty levels.

**Table 2: Economic Characteristics in Arkansas and the United States**

<b>Economic Characteristic</b>	<b>Arkansas</b>	<b>United States</b>
State Taxes Per Capita in 2004 <sup>1</sup>	\$2,027	\$2,025
Median household income, 2004	\$32,983	\$44,684
Mean personal income per capita (2004)	\$25,724	\$33,041
Percent of population in poverty (average 2002-2004)	17.9%	13.1%
Percent on labor force who are unemployed, 2004	5.2%	5.1 %
Persons without health insurance (3 year average, 2001-2003)	17.3%	15.1%
Households with cash public assistance, 2004.	1.8%	2.4%
Medicaid participation as % of population, 2003	22%	18%
Community dwelling persons age 65 in poverty, 2004.	12.8%	9.5%
Community dwelling persons age 5-17 with disability in poverty, 2004.	38.6%	27.0%
Community dwelling persons age 18-64 with disability in poverty, 2004	29.9%	24.5%
Community dwelling persons age 65 + with disability in poverty, 2004	19.9%	13.1%
Community dwelling persons age 65+ with care limitation in poverty, 2004	23.0%	15.7%
Community dwelling persons age 18-64 with disability up to 200% of poverty	56.6%	46.9%
Community dwelling persons age 65 + with disability up to 200% of poverty	52.9%	43.0%
Community dwelling persons age 5-17 with disability up to 300% of poverty	86.7%	68.1%
Community dwelling persons age 18-64 with disability up to 300% of poverty	74.2%	63.5%
Community dwelling persons age 65 + with disability up to 300% of poverty	72.1%	63.4%

**Sources:** State and local tax data come from the Rockefeller Institute and the National Association of State Budget Officers. <sup>3</sup> Health Insurance data are from Mills & Bhandari, 2003.<sup>4</sup> The numerator for Medicaid enrollment is from a special study funded by the Kaiser Family Foundation in 2003,<sup>5</sup> and the denominator from the American Population Survey, the later based on estimates of the community dwelling population. Various poverty rates are courtesy of Stephen Kaye, PhD, Institute of Health and Aging, University of California at San Francisco, who

<sup>3</sup> The Rockefeller Institute of Government in Albany, NY generates reports on state and local revenues and expenditures, most of which are on its website at: <http://rfs.rockinst.org/>. Also state summaries can be found on Websites maintained by the Bureau of Economic Analysis, US Department of Commerce, including: <http://www.bea.doc.gov/bea/regional/bearfacts/statebf.cfm>. Both last visited 12/19/2005. See also National Association of State Budget Officers (NASBO) (2005). The Fiscal Survey of States. (Submitted June 2005). Washington, D.C.: National Governors Association. On web, last visited 12/20/2005 at: <http://www.nasbo.org/Publications/fiscalsurvey/fsspring2005.pdf>

<sup>4</sup> Mills, R J & Bhandari, S (2003). Health Insurance Coverage in the United States, 2002. (Economics and Statistics Administration, U.S. Census Bureau, Current Population Reports, P60-22, pp. 1-23.. Washington, D.C. Department of Commerce. Website at: <http://www.census.gov/prod/2003pubs/p60-223.pdf> Last visited October 11, 2005.

<sup>5</sup> Ellis, ER , Smith, VK & Rousseau, DM (2004). Medicaid Enrollment in 50 States, June 2003 Update. (Health Management Associates, Lansing, MI and Kaiser Commission on Medicaid and the Uninsured, prepared for Kaiser Family Foundation, October 2004). On website: <http://www.kff.org/medicaid/upload/Medicaid-Enrollment-in-50-States-June-2003-Data-Update-Report.pdf> Last visited, December 1, 2005.

performed special cross-tabulations of disability status, age group, and poverty status from the American Community Survey, US Census data.

The mean per capita personal income in Arkansas of \$25,724 in 2004 was ranked 49<sup>th</sup> in the nation, the same relative ranking held in 1994 when average per capita personal income in Arkansas was \$17,350. In 2004, the bulk of Arkansas tax dollars came from general or special sales taxes (52.6%), followed by individual income tax (30.2%). Property tax accounted for 9.3% of state income and corporate income tax only 3.3%. Arkansas experienced a growth in Medicaid enrollment over the last few years. The state is one of just a few states with no budget stabilization fund. Its tax revenues were higher than estimated in 2004 (perhaps as a function of low estimations); in fact, both personal income tax revenues and corporate tax revenues have declined over the last few years.

## **Geography**

Arkansas is the 29<sup>th</sup> largest land mass of the 50 states, covering a bit more than 53,000 square miles. Almost square shaped, Arkansas is 260 miles long and 240 miles wide. Little Rock, the capital and by far the largest city (with about 184,000 people) is located almost in the dead center of the state in Pulaski County, the metropolitan area with a population of about 366,000 people. No other cities in Arkansas exceed 85,000 in population; Fayetteville, Jonesboro, Pine Bluff, Fort Smith, and North Little Rock (a separately incorporated city adjacent to the capital), exceed 50,000 people. Fort Smith, AR, population about 80,000, on the Oklahoma border is the corporate headquarters of Beverly Enterprises, the well-known nursing-home chain. West Memphis, AR on the other side of the state, population 27, 666, is part of metropolitan Memphis, Tennessee. Arkansas is divided into 75 roughly equally sized counties, each with a county judge who serves as chief executive officer of the county. Figure 1 shows a county map, with the jurisdictions of the 8 Area Agencies on Aging.



**Figure 1. County Map of Arkansas with Area Agency on Aging Regions**

**Rebalancing Status in Brief**

Arkansas made substantial progress in rebalancing utilization of services for older people in the 1990s. This early progress was reflected in the findings of two comparative state studies looking at aging services only using 1992 and 1995 data. The 1992 study found Arkansas in the top 10 states for rebalancing based on its relative strength in commitment to growth of HCBS services and its control of nursing home expenditures. The 1995 data still found Arkansas performing well in overall commitment to community expenditures and utilization, though it was

only performing at the average in terms of controlling nursing home expenditures. Both years, Arkansas showed very high demand for publicly funded long-term care for older people, based on disability and income data.<sup>6</sup>

Data on Arkansas' progress in moving towards community care in the MR/DD sector during the same period show an opposite picture. In 1996, Arkansas' community services expenditures for MR/DD were 27% below the national average, and its institutional expenditures (state institutions and ICF/MRs) were 65% above the national average. At that time Arkansas used nursing homes for people with MR/DD more than any other state. Moreover, Arkansas was the only state that increased the number of residents in its state between 1996 and 1992.<sup>7</sup> More recent figures show the tide is turning, however. According to Arkansas records, the numbers of Medicaid recipients in nursing homes and ICF/MRs have declined each year since 1998. As we discuss in Section IV, the following reductions in utilization occurred between 2000 and 2004: from 1290 to 1207 residents in state MR/DD facilities; 1,839 to 1,766 in ICF/MRs, and 20,482 to 19,759 Medicaid nursing home residents, though aggregate expenditures in all 3 of these institutional settings increased. Expenditures on Medicaid HCBS waivers and in-home services under the Medicaid state plan increased markedly during the same 5 year period, though the elderly and disabled waiver lost participants in the last few years, perhaps because of the growth of personal care and cash options. Indeed expenditures on personal care under the Medicaid state plan increased markedly as did the MR/DD waiver.

### **Political Climate**

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<sup>6</sup> Ladd, RC, Kane, RL & Kane, RA (1999). State LTC Profiles Report, 1996 (Report submitted to US Office for Assistant Secretary for Planning and Evaluation, HHS, April 1999). Minneapolis, MN: National Long-Term Care Mentoring Program, School of Public Health, University of Minnesota; and Ladd, RC, Kane, RL, Kane, RA, & Nielsen, WJ (1995). State LTC Profiles Report. (Report prepared under a grant from Administration on Aging,) November 1995). Minneapolis, MN: National LTC Mentoring Program, School of Public Health, University of Minnesota.

<sup>7</sup> Braddock, D, Hemp, R, Parish, S, & Westrich, J (1998). The State of the States in Developmental Disabilities. Washington, DC, American Association on Mental Retardation, pp. 117-124,

Arkansas' Governor, Republican Mike Huckabee, a former pastor and former lieutenant governor, became one of the youngest state governors when he took office in 1996 upon the Governor's resignation. Subsequently twice elected to four-year terms, he has used his political popularity to advance programs in education, health care, state parks, highways, and technology development. Building publicly on his own personal experience with chronic illness (Type 11 diabetes), he made health care and healthy living a priority in the State of Arkansas, and he chose a Healthy America initiative as his theme for his term as Chair of the Association of State Governor's, which began in July 2005. Governor Huckabee led the ballot initiative in the year 2000 that the entire state tobacco settlement to health programs. A fiscal conservative in a fiscally conservative state, he presides over a political climate that favors holding the line on property taxes. Nonetheless, he fought successfully in 1999 for a sales tax add-on to benefit parks and fisheries, and in 2000 for a bond drive for Arkansas highway infrastructure. He also called a special legislative session in 2003 to develop new taxes to avoid Medicaid cutbacks.

The Arkansas legislature is a strictly term-limited volunteer body that meets for 60 days in each odd-numbered year unless special sessions are called. At present, the majority is in the Democratic Party, but bipartisan agreement seems to have been achieved around objectives related to quality management of Medicaid programs, and the health and long-term care agenda pursued by the executive agencies. Given term limits and short sessions, the legislature is much guided by strategic plans developed at intervals by and for the various sub-cabinet agencies. Goals related to community care and to quality management of Medicaid programs have garnered consistent bi-partisan agreement; the 2005 Session enacted a large number of bills related to health care in its short term, including a Consumer Directed Care Act (Act 1440), which exempted care directed by the consumer or the consumer's agent from the strictures of the

nurse practice act.<sup>8</sup> Over the years, legislators have been willing to vote for the extension of waiver slots in the MR/DD waiver. Although the legislature is generally supportive of HCBS, the political realities also include legislators from time to time who are nursing home owners and wield influence with their colleagues.

### **Vision and Values for LTC**

After much deliberation, the Governor's Integrated Services Taskforce (GIST), comprised of consumers and providers, and adopted a resolution in the spring of 2005 to promote HCBS services in Arkansas. It reads, in part: "it is the policy of the State of Arkansas to promote and maximize the use of home and community-based services, so older people and persons with disabilities can be integrated in their communities." This resolution carries particular conviction because it was negotiated with provider representatives in the group. Earlier, the Division of Aging and Adult Services participated in an exercise of Belief-Based Performance Management, initiated by its umbrella agency, the Department of Human Services. The Division's general belief that "every person matters," was further articulated into 5 more specific beliefs, including:

1. Adults should choose where they live and how they receive services.
2. Adults should age well.
3. Adults should be safe.
4. Access to information enhances LTC choices,
5. An aging society requires innovation and change.

Outcomes associated with Belief 1 were that Arkansas would create a balanced LTC system, that Arkansas long-term care consumers would live in the least restrictive environment, and that consumers would have the option of directing their own care. Quantitative goals and timetables

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<sup>8</sup> Legislation from the most recent session is summarized on the legislature's Website, last visited on 12/19/2005 at: <http://www.arkleg.state.ar.us/2005/data/2005GeneralSummary.pdf>

were established for each outcome. The Division of Developmental Disabilities Services (DDS) enunciates 6 planks in its mission: 3 of these statements support participant choice and community integration:<sup>9</sup>

- Protecting the constitutional rights of individuals with disabilities and their rights to personal dignity, respect and freedom from harm.
- Encouraging family, parent/guardian, individual, and public/community involvement in program development, delivery, and evaluation.
- Engaging in statewide planning that ensures optimal and innovative growth of the Arkansas service system to meet the needs of persons with developmental disabilities and to assist such persons to achieve independence, productivity, and integration into the community.

Further DDS enunciates:

To accomplish its mission, DDS, the DDS Board, and its providers are committed to the principle and practices of: normalization; least restrictive alternatives; affirmation of individuals' constitutional rights; provision of quality services; the interdisciplinary service delivery model; and the positive management of challenging behaviors.

## **Leadership**

Leadership for community integration and re-balancing is found at many levels. As already stated, the Governor and legislative leaders exert leadership in this direction. At the state agency level, sustained leadership has been exercised by division heads with long experience as career civil servants in Arkansas state government. These include Herb Sanderson, director of the Division of Aging and Adult Services since 1984, before which he served as Executive Director of a 2-county Area Agency on Aging centered in Jonesboro, AR. Mr. Sanderson is active nationally and has brought ideas for adaptation to Arkansas based on experiences in other parts of the country. The Medicaid Director, Roy Jeffus, has been with the Arkansas Department of Human Services since 1977 and has been either Assistant Director or Director of Medical

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<sup>9</sup> The DDS Mission is found on its Website, last visited 12/19/2005 at:  
<http://www.arkansas.gov/dhhs/ddds/NewWebsite/DDS%20Mission%20Statement.html>

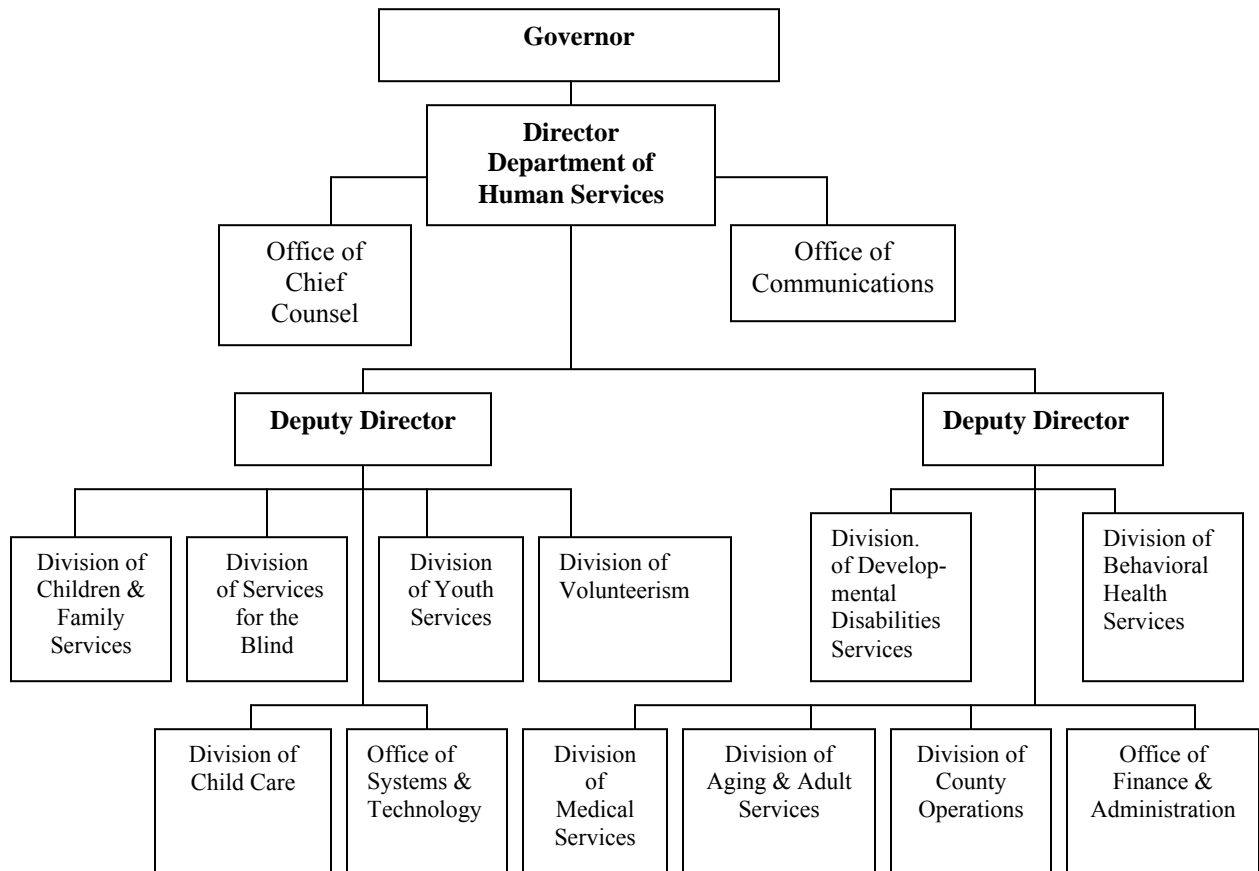
Services since 1995. James Charles Green, the Director of the Division of Developmental Disability since 2003 was before then the Superintendent of one of Arkansas' state human development centers; he holds a PhD in special education. Joni Jones, the director of the Division of County Operations had occupied leadership positions in the Department of Human Services for 23 years when appointed to her position in 2001.

### **State Government Organization for LTC**

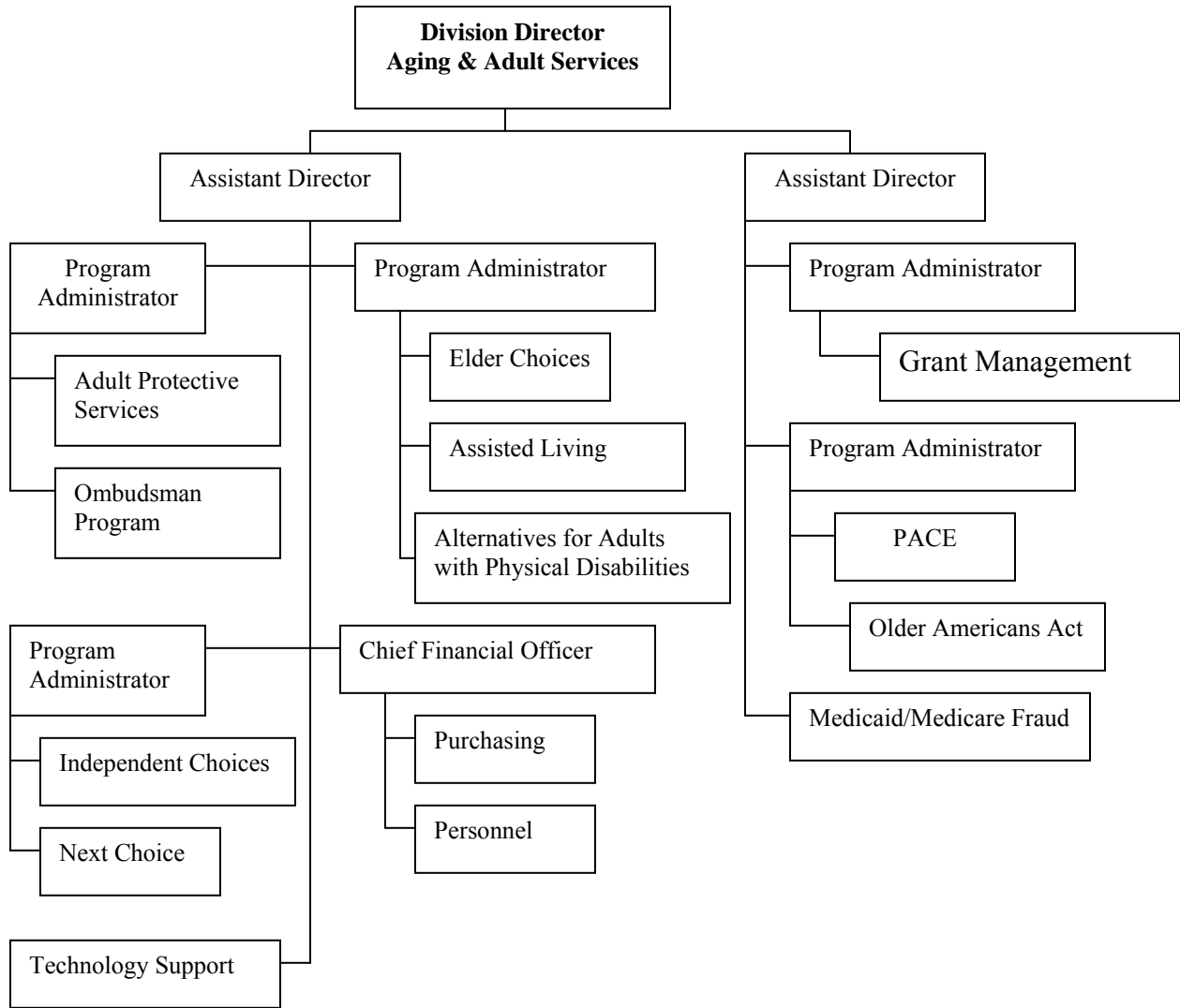
Responsibility for community long-term care is housed in an umbrella agency, the Department of Human Services (DHS); one major arm of the agency under a deputy director conducts the traditional child welfare and social services programs. The other arm, under a deputy director, includes the main organizations working on long-term care: the Division of Aging and Adult Services (DAAS); the Division of Disability Services (DDS); and the Division of Health Services, which is the single-state Medicaid agency. The Division of County Operations and the Division of Behavioral Health in the same also in the same arm of DHS are also closely related to long-term care issues. See Figure 2 for the general organization of the Department of Human Services at the time covered by this case study. Preparations were then underway for a merger of the Department of Human Services and the Department of Health in the fall of 2005, which will result in an even larger umbrella organization.

Figure 3 details the organization of the DAAS. As the figure shows, the Division manages the ombudsman program, adult protective services, three HCBS Medicaid Waivers for Seniors (Elder Choices), Adults with Physical Disabilities (Alternatives), and Assisted Living, DAAS also administers all Older American's Act programs with its director, Herb Sanderson, serving as the State Unit on Aging Director. Independent Choices, the Cash and Counseling program, and Next Choices, a cashing of nursing home care under development, are housed in DAAS, as is the PACE program and most of the Real Choice System Change grant activity. The MR/DD waiver

is housed in the DDS and two respite waivers for children are managed directly by the Division of Medical Services.

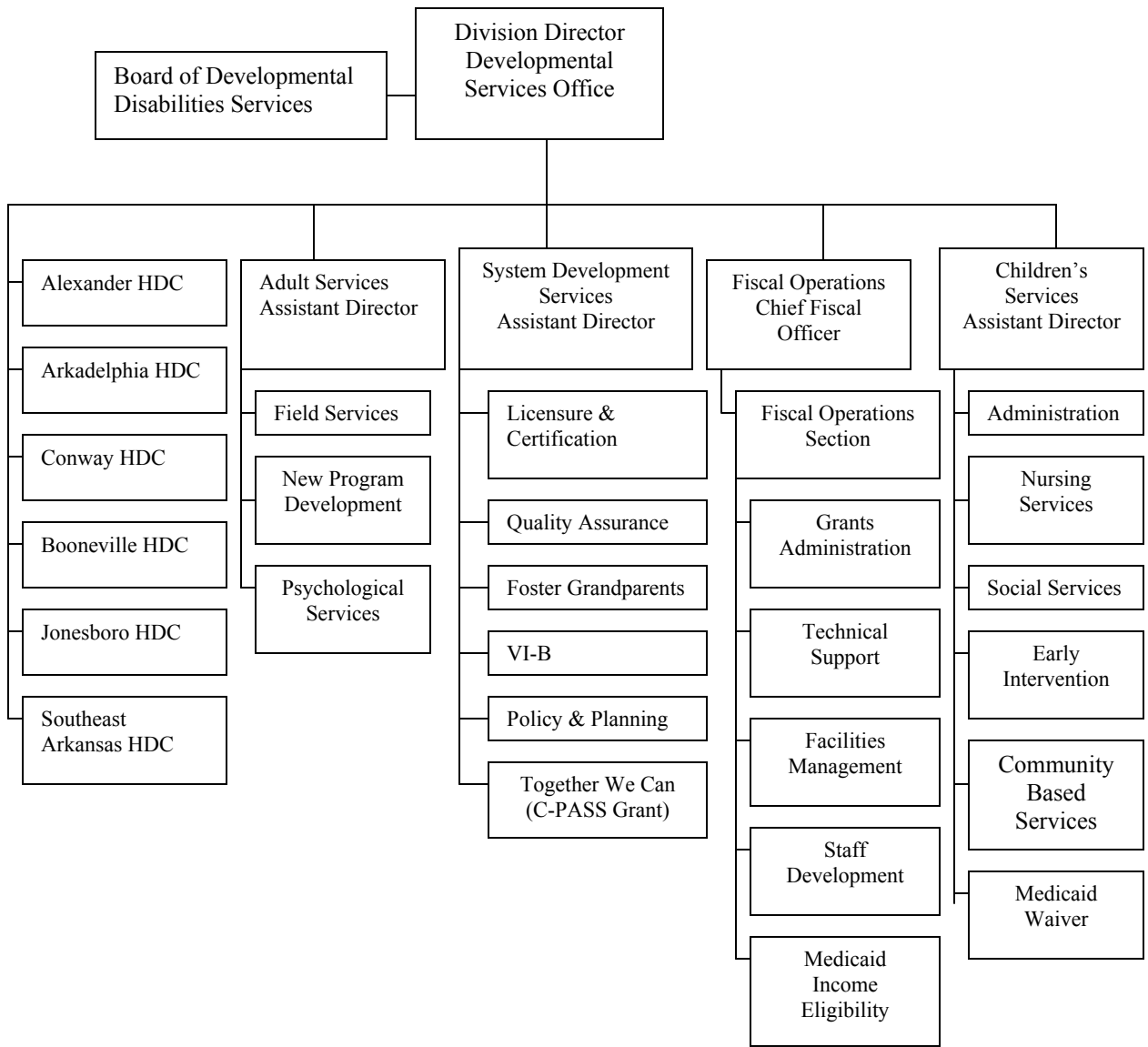


**Figure 2. Arkansas Department of Human Services as of June 2005**



**Figure 3. Division of Aging and Adult Services as of June 2005**

Figure 4 describes the organization of the Division of Developmental Services (DSS). The far left part of the chart displays the 6 state institutions for MR-DD, called Human Development Centers. Together these settings house about 1200 residents. The organizational structure permits management of community programs—the growth areas—in tandem with managing institutional care.

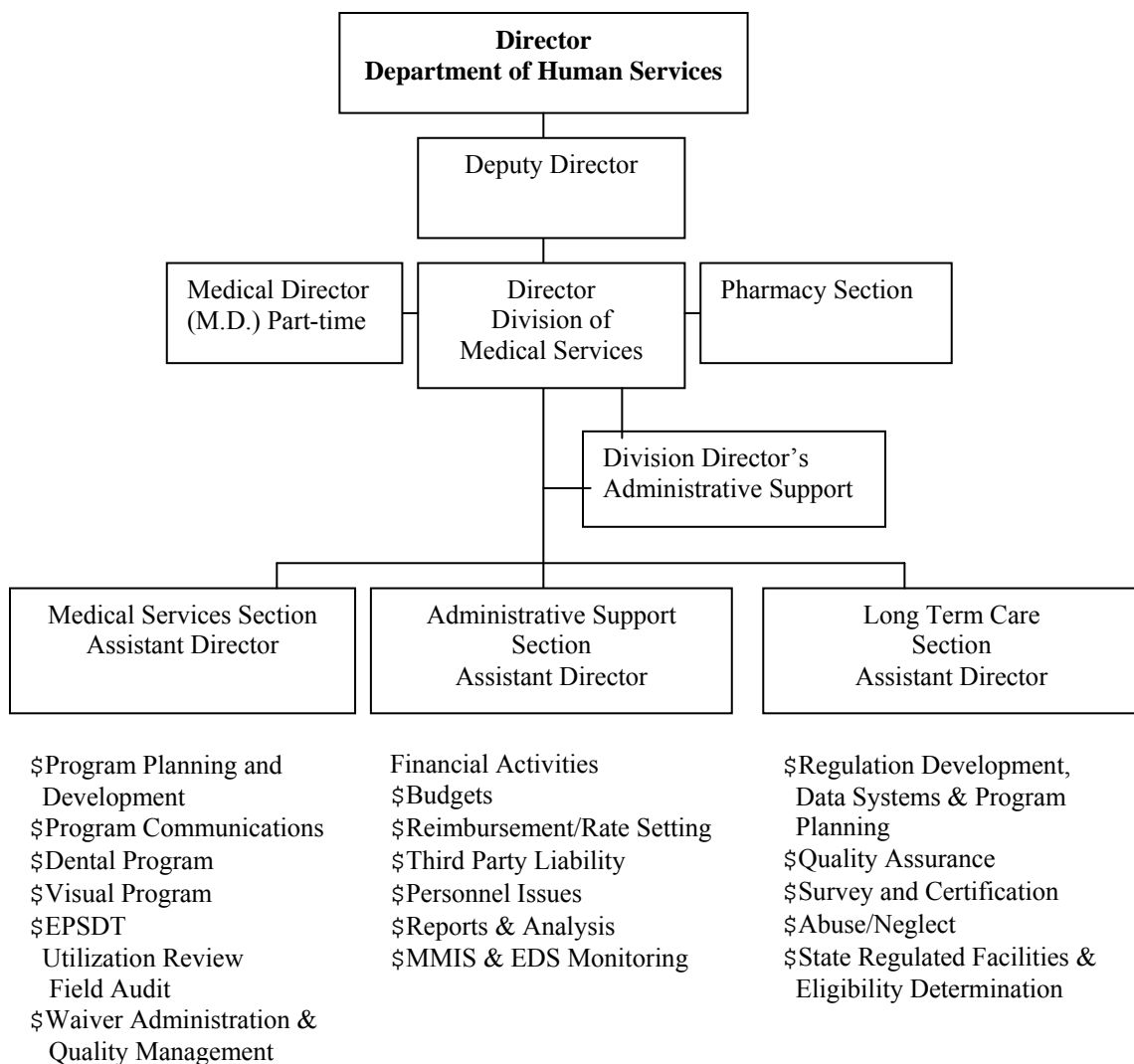


**Figure 4. Organization of the Division of Developmental Disabilities as of June 2005**

The waiver programs shown in Figure 4 include the major HCBS waiver for MR/DD and two children’s respite waivers initiated in 2001; the state opted not to renew either when they expired in 2005, but identified other funding for those services. DSS is the recipient of a CMS grant for Personal Assistance Services and Supports (C-PASS) and through that mechanism administers an innovative program of resource development and collaboration in 26 counties, on the chart labeled “Together We Can.” The DDS website is explicit that the goal of Together We Can is to “Explore

new delivery models to update Arkansas' outdated system.” The intent of DDS is to maintain high quality programs for all age groups but to move rapidly towards greater community integration and family and consumer control. Note that DSS licenses providers and conducts quality assurance activities.

Finally, Figure 5 shows the Division of Medical Services. In addition to all the functions of the Medicaid operations, this Division includes a Long Term Care Section, responsible for Survey and Certification activities.



**Figure 5. Organization of the Division of Medical Services as of June 2005**

## **Organization of Long-Term Care at Local Levels**

The Aging Network in Arkansas is comprised of 8 Area Agencies on Aging (AAAs), which was shown on the map in Figure 1. AAAs are the focal point for assessment for need for care for persons age 60 and above, and are the gateway to a wide array of services funded by the Older Americans Act and state funds and through the Elder Choices waiver. Area Agencies on Aging in Arkansas have had an unusual evolution, and most provide home care services directly. Community services to adults with DD, including Medicaid Waiver Services, are accessed through Area Program Managers; the state is divided into 6 multi-county areas for this purpose. Financial eligibility and formal application for income support and all Medicaid services, including Medicaid waivers, are managed through the Division of County Operation, and its 6 Service Areas: 1 area is comprised of Pulaski County alone, and the others divide the state somewhat equally. Each county has at least one field office—Pulaski County where Little Rock is located has four offices. The county field offices, the Area Agencies on aging, and the 6 County Service Regions all have different boundaries. Mental health services are coordinated through 15 multi-county community mental health centers; again the mental health regions overlap other jurisdictions.

## **Advocacy Environment**

Arkansas state officials invested substantial efforts to engage consumers and advocates in considering the delivery system and approaches to achieving expanded HCBS. The Governor's Integrated Services Taskforce (GIST) was founded in July 2001 to implement post Olmstead planning. GIST appointees include major consumer advocacy and self-advocacy groups as well as providers and relevant state agency heads. With regular almost monthly meetings and a sub-committee structure, the GIST takes its mission seriously, studying the issues, conducting hearings around the state, and seeking organized feedback on its draft positions. Its 2003 Olmstead plan contains 114 recommendations, the most important organized in priority order. The document is

backed by detailed information on services and expenditures.<sup>10</sup> At the time the Plan was submitted, GIST was chaired by the director of an Independent Living Center and its membership included representation of the National Alliance for the Mentally Ill, the Mental Health Council of Arkansas, the ARC of Arkansas, AARP, Arkansas Easter Seals, and a large number of consumers or family members of consumers. At the time of our site visit, the GIST chair was a family member consumer and founder of the Arkansas Autism Society, who was also employed as a special education expert in the Arkansas Department of Education; to keep her role as a consumer representative clear, she literally took leave from her state job whenever she acted as a GIST member. Over the years, GIST has grappled with the difficulty of enhancing communication and collaboration across disability and age groups. GIST leaders comment that they often need to return to separate programmatic thrusts to get to specificity in GIST or subcommittee work, but that the effort to work across “silos” is helpful.

Consumer and other stakeholders are involved in advisory councils for other Arkansas Initiatives such as a Housing Workgroup, a QA/QI Task Force, a Medicaid Infrastructure Grant Steering Committee, a DDS (Developmental Disability) Grants Advisory Council, a DDS Family Support Advisory Group, and a Bridging the Gap Alzheimer’s Disease and Developmental Disabilities Task Force. In these and other examples, some the stakeholder bodies have some representation of GIST members, but new consumer voices are also included, and, like GIST, provider stakeholders and government officials also serve on the various groups.

Strategically DAAS and DDS take the position that HCBS development will be enhanced by strengthening grass roots consumer agencies. Though the full panoply of disability advocacy and

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<sup>10</sup> Governor’s Integrated Services Task Force (2003). The Olmstead Plan: A Catalyst for Collaboration and Change. (Submitted by Arkansas Department of Human Services to Governor Mike Huckabee, March 31, 2003). Little Rock: State Department of Human Services. On website, last visited 12/21/2005 at <http://www.arkansas.gov/dhhs/aging/OlmsteadReportVer6.doc>

self-advocacy groups are found in Arkansas, some consumer advocates believe that consumer organizations themselves are not as powerful as they might be in the state; as in many states, seniors are often represented by paid advocates rather than seniors themselves. Section III profiles the Arkansas Aging and Disabilities Academy, an education program initiated by DAAS to strengthen advocacy leadership statewide. In its role as State Unit on Aging, DAAS also provides support for Biennial meetings of the Silver Haired Legislature.

### **Litigation Related to Rebalancing<sup>11</sup>**

Legal challenges advancing HCBS in Arkansas involve access issues and waiting lists. In June 2003 Tessa G filed a lawsuit challenging Arkansas practice of placing individuals seeking home- or community-based services on a “request list” rather than allowing them to submit an application. The district court dismissed the suit after the state conceded that Federal law required that individuals be allowed to apply for HCB services and to have their application acted on promptly. The state also agreed to offer waiver services to individuals on the request list (up to its CMS-approved cap). (*Tessa G. v. Arkansas Department of Human Services et al.*)

In a related matter, *Porter and Norman V. Knickrehm et al.*, two residents of one Arkansas state institution for persons with DD challenged the states admission and discharge procedures because the state does not provide judicial review of continued placement at such facilities. In November 2004, the court ruled that although Arkansas’ admission policies met due process tests the state must provide post-admission judicial reviews to ensure that institutionalized individuals would not be unnecessarily confined when they have been determined to benefit from community placement.

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<sup>11</sup> The cases discussed here are not necessarily inclusive of all Arkansas law suits in this arena. More details regarding these cases are at: Smith G.A. “Status Report: Litigation Concerning Home and Community Services for People with Disabilities.” Human Services Research Institute. 2005. [www.hsri.org/index.asp?id=news](http://www.hsri.org/index.asp?id=news) and, Kitchener, M. Willmott, M. and Harrington, C. “Home and Community Based Services: Olmstead and Olmstead-Related Lawsuits”. UCSF National Center for Personal Assistance Services. 2005. <http://www.pascenter.org/olmstead/>

In November 2001, three families and three EPSDT (Early and Periodic Screening, Diagnostic, and Treatment) providers brought suit to prevent the state from instituting cuts in EPSDT services that were planned due to budget shortfalls (*Pediatric Specialty Care, Inc., et al. v. Arkansas Department of Human Services*). The court ruled that EPSDT services are mandated by Federal requirements and prevented the state from removing these services from the state Medicaid plan. The Arkansas Department of Human Services appealed. The 8<sup>th</sup> Circuit Court of Appeals held that although the state need not specifically list EPSDT services in its state plan, it must provide them when they are ordered by a physician. A 4<sup>th</sup> amended complaint filed by plaintiffs in this suit in July 2004 alleged that the state's prior authorization system for EPSDT services was operated to arbitrarily deny necessary services in order to reduce state expenditures. After additional challenges by the state, the court allowed this complaint to proceed to trial in 2005 to determine whether the prior authorization system resulted in the impermissible denial of services. The case remains open.

### **Service Provider Environment**

The Office of Long-Term Care in the Division of Medical Services licenses nursing homes, ICF-MRs, residential care facilities, adult day care and day health facilities, Alzheimer's special care units, and the state's single post-acute head injury unit. In 2004 the state had 242 nursing facilities, housing with about 25, 800 beds, and 40 ICF MRs. Arkansas is somewhat higher in its nursing home bed supply than the national average; in 2003 it had 66 beds per 1000 people over 65 compared to 49 in the US as a whole. Almost 80% of the nursing facilities were dually certified for Medicare and Medicaid and 80% were for-profit entities; of the remainder 16% are private nonprofit and 4% government-owned. The supply seems to be sufficient; according to 2003 data, Arkansas occupancy rates were 73% compared to 85.5% in the United States, a decline of 7% over a 5 year period.

Arkansas licenses residential care facilities, which are any group residential setting serving 3 or more residents. None of the residents may require nursing home level of care. Since 2003, the state has licensed assisted living, which in Arkansas must be apartment-style maximizing dignity and privacy. DAAS has worked to increase the supply. Level I and Level II Assisted Living differ only in staffing requirements and levels of acuity permitted among the residents. The discharge criteria promulgated in 2003 are rather stringent even for the higher Level II settings. Level I residents must not need nursing care, except for 60 days with one 30-day extension allowed. Level II residents may require nursing care, but must not need 24-hour care, or be bedridden. Oddly, regulatory language states that they may not have a terminal condition unless a physician or “advanced practice nurse” states that the care will be safe. If Assisted Living is to be a vehicle for community integration these rules may need re-examination. State authorities are also interested in developing adult foster care, but since 2000, none were operating in the state. Group homes for MR/DD are separately licensed by the DDS. Supportive living apartments do not require licensure because they are construed as the participant’s own home, though the licensed DD providers offer the specific services. See Table 3 for information on the supply of residential services.

Arkansas does not have a Certificate of Need process for new facilities, per se, but it does use a planning model to authorize expansion of facilities and some home care programs, through a the Arkansas Health Services Permit Agency, governed by a 9-member appointed board, the of Health Services Permit Commission.<sup>12</sup> The Permit Agency has responsibility for Nursing Facilities, Residential Care Facilities, Assisted Living, Home Health and Hospice Agencies, Psychiatric Residential Care Facilities, and ICF/MRs. The methodology for approving new programs and expansion of existing programs used a mixture of establishing a supply target for

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<sup>12</sup> The Health Services Permit Agency and Commission are described on a website last visited 12/20/2005 at <http://www.arhspa.org/>.

population size and taking into account historical quality of the organizations. Some of the rules seem to favor expansion of existing providers above introducing new providers.<sup>13</sup> The Arkansas Hospital Association, representing about 100 general and specialty hospitals throughout the state, many of which operate nursing home swing beds and home health agencies, is a particularly strong organization; its President is a former state legislator and a former lobbyist for both the hospital association and the home care and hospice association.

In Arkansas, two classes of home care agencies are licensed: Class A, which are Medicare-certified home health agencies; and Class B, which provide home health care but are not Medicare-certified. Both types of agencies are licensed by the Office of LTC in the Division of Medical Services and both may be vendors of personal care under Medicaid waiver programs. Other agencies may also become authorized vendors of person care, including private care agencies (which are licensed by the Department of Labor and must demonstrate \$1 million or more in liability insurance to be authorized for payment under the Elder Choices waiver); Residential Care Facilities (which may provide and bill for personal care, but only to those living in the residential care setting); DD Service Providers/ Education Service Cooperatives (which are limited to DD settings such as day habilitation programs, or school-based programs. Only Class A and B home health agencies are allowed to provide personal care in all locations, and Residential Care Facilities and DD Service Providers/Education Service Cooperatives are explicitly prohibited from providing personal care to consumers in their own homes. Agencies providing targeted case management providers, which in the Arkansas system may bill the Medicaid state plan for case management services to help waiver consumers gain access to health services, may also elect to provide personal care or home care services directly. Also noteworthy is that in Arkansas all but one of the Area

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<sup>13</sup> See the Services Permit Agency manual on the web, last visited 12/20/2005 at: [http://www.arhspa.org/rules\\_regs/rulebook\\_october\\_2005v2.pdf](http://www.arhspa.org/rules_regs/rulebook_october_2005v2.pdf)

Agencies on Aging delivers some level of direct home care services. Finally, fiscal intermediary agencies are those providers created to provide employer-related services (check writing, withholding) and counseling under the Independent Choices program, established through the Cash and Counseling demonstration.

**Table 3. Supply of Residential Services in Arkansas, 2000-2004**

Setting	2000		2001		2002		2003		2004	
	Fac.	Res.	Fac.	Res.	Fac.	Res.	Fac.	Res.	Fac.	Res.
<b>Institutional Settings</b>										
Nursing Facilities	241	25,492	239	25,248	255	26,984	265	28,361	242	25,812
ICFs-MR	40	1,672	40	1,672	40	1,672	40	1,672	41	1,687
State Operated Human Development (MR/DD) Centers	6	1,290	6	1,304	6	1,263	6	1,245	6	1,207
<b>Residential Settings</b>										
Residential Care Facilities	152	5,647			122	4,647			111	4,3694
Adult Foster Homes	1		1	After 2000 no adult foster care home were licensed.						
Assisted Living I	Assisted Living I not licensed until 2004								1	54
Assisted Living II	Assisted Living II not licensed until 2004								5	221
<b>Community</b>										
Home health agencies	107		100		95		88		99	
Adult day care	48		50		50		52		56	
Targeted case mgmt	298		268		231		126		100	
Fiscal intermediaries (Independent Choices)	5		4		4		4		5	
Licensed Developmental Disability Providers in 2004										96
MR/DD Early Intervention Voucher Providers in 2004										46

Notes: Data were largely provided by staff at Arkansas Department of Human Services, Division of Medical Services and are for state fiscal years. Residential care data were provided by Mollica & Johnson-LaMarche.<sup>14</sup>

Arkansas still maintains its 6 state Human Development Centers (HDCs), which opened between 1959 and 1978. Described in Table 4, each is operating near its regulated capacity. All but 2 (Conway and Jonesboro) are located in communities under 12,000 people: Warren has a population of about 6500, Booneville about 4000, and Alexandria a population of only 614; it is reasonable to think that some of the smaller economies depend on the HDCs. Most of the HDCs maintain that much of their population is either severely intellectually impaired, dually diagnosed with mental illnesses, or both. Although most HDCs still use some dormitory-style

<sup>14</sup> Mollica, R & LaMarche- Johnson, H (2005). *Residential Care and Assisted Living Compendium 2004.* (Under grant from OASPE to Research Triangle, Inc, Submitted to ASSPE Marhc 2005). Portland, ME: National Academy for State Health Policy.

accommodations, the current management strategy includes developing smaller housing units on the campus, emphasizing work programs both on and off campus, increasing involvement with the local communities, and trying to promote discharges to the community whenever feasible. With the exception of Warren (which is entirely comprised of private rooms), the HDCs largely use multi-bedded sleeping rooms for residents, even when organized into apartments and group home arrangements. Staff based in the HDCs also provides substantial amounts of therapeutic services to people living in the surrounding communities.

**Table 4. Human Developmental Centers in Arkansas**

Name/Location	Census 6/ 2005	Consumer Characteristics	Programs and notes
Alexander (licensed for 125)	115	Men, 18-64; 85% dual diagnosis of MR/DD & mental illness	In former TB sanatorium, Cooperative job venture with Arkansas Parks & Tourism.
Arkadelphia (licensed for 134)	120	18-64; 65% have dual diagnosis of MR/DD & mental illness	Emphasizes job participation & community transition; 1 home ownership arranged.
Booneville (licensed for 159)	149	18-68; 81% dually diagnosed; need to be ambulatory	On-campus and off-campus work programs; some apartments
Conway (licensed for 539)	513	Age 8-69; 36 school age children; 116 medically fragile; 95% profoundly or severely retarded	Founded 1959; 32 miles from Little Rock; wide range of therapeutic capabilities and programs
Jonesboro (licensed for 128)	113	Age 18-51	Oriented to community involvement; 50% are in labor force;
Warren (licensed for 72)	72	Adults, range of cognitive abilities; no medically fragile residents.	Emphasizes habilitation and social skills; 25% in supported employment. 4 single-family homes (15 residents in each), and 3 group homes; all private rooms.

Source: Much of this information is found on the DDS home page on Web, last visited 12/21/05 at <http://www.arkansas.gov/dhhs/ddds/NewWebsite/index.html>. We supplemented it as needed with phone calls to the Human Resource Centers.

Summarizing this information, Arkansas has an array of services, including services that may be used flexibly for consumer centered services, and is working towards further refining its capacity for flexible service delivery. The recently enacted modifications of the nurse practice act, discussed in Section III, assist in that effort.

**Historical Evolution of LTC**

Table 5 shows major milestones in the evolution of HCBS services in Arkansas.

The cash and counseling project, Independent Choices, initiated in 1998, was an important event in the development of consumer-direction and HCBS infrastructure in Arkansas; Independent Choices operates through the state plan personal care option rather than the waiver program and is open to all target populations. Particularly noteworthy in the historical evolution is the large number of grants received by the Arkansas Department of Human Services to advance HCBS. Funding from the Real Choice Systems Change Initiative alone (including the Aging and Disability Resource Center, which is a partnership with the Administration on Aging [AOA]) amounted to \$5, 219, 706 excluding the large award made in FY 2005 just after the period covered in the case study; this last award brings Arkansas' resources from RCSC to more than \$8 million. During the same period, Arkansas received many other awards, including from different units in CMS, from AOA, and the Robert Wood Johnson Foundation) to advance its programs. Such an excellent track record of garnering developmental funds reflects the ability of the state to put forward a coherent vision and set of strategies to reach the vision; it also reflects an investment in a unit of personnel to write the grant applications and manage the resultant programs.

**Table 5. Selected LTC Milestones in the State of Arkansas through June 2005**

<b>Year</b>	<b>Policy or Programmatic Development</b>
1991	<ul style="list-style-type: none"> <li>Elder Choices (1915 waiver) approved</li> </ul>
1997	<ul style="list-style-type: none"> <li>Alternatives (1915 waiver) approved for adults with physical disabilities</li> </ul>
1998	<ul style="list-style-type: none"> <li>Cash and Counseling Demonstration project (1115 waiver) approved</li> <li>Independent Choices program (Cash &amp; Counseling) established</li> </ul>
2000	<ul style="list-style-type: none"> <li>Alternative Community Services, DDS ACS (1915 waiver) approved for persons with DD</li> <li>Ballot Initiative approved to earmark all tobacco settlement funds for health care, including expanding financial eligibility for elderly waiver above SSI level</li> </ul>
2001	<ul style="list-style-type: none"> <li>Respite care for children (1915 waivers) approved</li> <li>Governor’s Integrated Services Task Force (GIST) established to guide planning for HCBS</li> <li>RCSC System Change grant awarded to DAAS</li> <li>RCSC C-PASS grant awarded to DDS</li> <li>RWJF Coming Home Project grant to DAAS for affordable assisted living</li> <li>Act 1230 created Assisted Living in Arkansas</li> </ul>
2002	<ul style="list-style-type: none"> <li>Assisted Living (1915 waiver) approved</li> <li>Assisted Living Regulations enacted</li> <li>RCSC NF Transitions grant to DAAS</li> <li>RCSC Children’s respite Grant to DDS</li> <li>Developed ombudsman for HCBS waiver services</li> <li>Legislature provided additional funding to reduce waiting lists for waivers</li> </ul>
2003	<ul style="list-style-type: none"> <li>GIST <i>Olmstead</i> plan released</li> <li>RCSC Respite for Children grant</li> </ul>
2004	<ul style="list-style-type: none"> <li>RCSC QA/QI grant to DAAS</li> <li>RCSC Aging and Disability Resource Center grant to DAAS</li> <li>RCSC Integrating Long-Term Supports with Affordable Housing grant to DAAS</li> <li>AOA Alzheimer’s Demonstration grant to DAAS</li> <li>CMS Demonstration to Improve Direct Service Community Workforce to DAAS</li> <li>US DHHS OASPE planning grant to develop a 1115 waiver plan for the Next Choice program, which would provide cash allowances for those leaving nursing homes</li> <li>\$1.50 an hour increased approved for personal care and in-home waiver services</li> </ul>
2005	<ul style="list-style-type: none"> <li>CMS awarded DAAS a Medicaid Infrastructure Grant to increase employment of people with Disabilities.</li> <li>Consumer Directed Care Act enables nurse delegation, the culmination of collaborative activity between DAAS and Board of Nursing</li> <li>Division of Medical Services created the Waiver Quality Management Unit to oversee quality in all waivers &amp; contracted with MedStat to develop tools and operations</li> <li>DDS began participating in National Core Indicator program for quality outcomes.</li> <li>State Plan Personal Care Option was amended to allow services outside the home.</li> <li>In 9/05 Arkansas was notified of receipt of a CMS RCSC System Transformation Grant award for about \$3 million dollars for 2005-2009.</li> </ul>

**Programs and Services**

Medicaid HCBS Waivers

Arkansas operates six HCBS (1915 c) waivers, described in Table 6. Except for the MR/DD waiver, none have waiting lists.

**Table 6. Overview of HCBS Waivers in Arkansas**

Waiver	Year begun	Participants, 2004	Expenditures in 2004	Eligibility	Major Services
Elder Choices	1991	7,223	\$33,227,062	Age 65+ who need nursing facility but request community care	.Adult day care, adult foster care, chore and homemaker services, home delivered meals, emergency response, and respite care.
Alternative Community Services (DDS ACS waiver)	1997	3,034	\$68,528,531	Age 21-64 with a developmental disability. Need ICF/MR level of care but request community care	Crisis abatement/ respite, care services, integrated supports services, supported employment, physical adaptation services, specialized medical supplies, case management, consultation services, crisis center intervention services
Alternatives for Adults with Physical Disabilities (APD)	2000	1,501	\$18,153,903	Age 21-64 with physical disabilities who need ICF level of nursing home but request community care; costs of HCBS services do not exceed cost of nursing facility placement, monthly income no higher than 300% of SSI income limit	Attendant care, environmental accessibility, adaptations/adaptive equipment
Living Choices/ Assisted Living	2002	75	\$619,683	Age 21 or older; needs ICF level of nursing home but chooses to remain in the community in a congregate setting.	24-hour supervision and limited nursing services
Children's Respite Services, MR/DD  Children's Respite Services	2001	275 across both of these Respite Waivers	N.A.	Children as home under age 19 with MR/DD who meet the ICF/MR level of care	Respite care for families to enhance existing supports and the EPSDT services

Elder Choices. Established in 1991, Elder Choices is the oldest of Arkansas' HCBS waivers. It offers homemaking services, respite care, adult day care, emergency response, home-delivered meals, and respite services. Personal care is not offered under the waiver, but a consumer may simultaneously receive waiver services and State Plan personal care. Adult foster care services are

covered under the waiver, but as an earlier section suggested, the supply of adult foster care is not yet developed. Targeted case management is available under the state plan, usually received from the Area Agency on Aging. At the time of this report, 7,223 seniors were enrolled in the program and the expenditures for 2004 were \$33,227,062. Based on the recommendation of the GIST, in 2004 DHS added spousal resource protection to the ElderChoices waiver, and added retroactive eligibility to ElderChoices and the ACS waiver for supported living, which allows for provider reimbursement by Medicaid for services rendered while the ElderChoices application is pending.

Alternatives for Adults with Physical Disabilities (APD). Authorized in 1997 and operated by DAAS, this waiver serves nursing-home certifiable consumers aged 18-64 with physical disabilities. Its main service is attendant care; environmental modification and adaptive equipment are also included to permit living at home and integration into the community. From the outset it was designed to be a consumer directed service. Consumers may receive up to 8 hours a day of attendant care, 7 days a week. Consumers recruit, hire, supervise and approve payment for attendants, who may be a family member though not a spouse or legally responsible person (e.g. a guardian). The design of the APD waiver reflects principles similar to the Cash and Counseling program, which was being implemented on a demonstration basis in Arkansas at the same time. Starting with about 200 participants, this waiver served about 1500 people in 2004 with expenditures in 2004 of \$18,153,903.

Alternative Community Services (DDS ACS waiver). Operated by DDS, this waiver serves consumers of all ages with a qualifying diagnosis of mental retardation and/or developmental disability and a need for the nursing home level of care. A wide range of habilitative and therapeutic services are available, including adaptive equipment, environmental modification, personal care, transportation, crisis abatement, specialized medical supplies, consultation, day habilitation, supportive employment, crisis management, consultative services, specialized

equipment and adaptive services. Integrated support services are also covered: this is a package which includes habilitation, supportive living and alternative living. Case management is provided through the waiver. Of the 92 licensed MR/DD providers, 50 offer both case management and waiver services, and another 14 offer waiver services without the case management. ACS is the most expensive of the waivers in absolute and per capita terms, serving 3, 034 consumers in 2004 with aggregate expenditures of \$68,528,531. ACS is the only waiver with a waiting list, but because of a concerted effort to reduce that list, including appropriations of the legislature for that purpose, the list was down to about 300 people in June of 2005.

Living Choices/Assisted Living Waiver. Operated by DAAS, this is the newest, covering services in Type 11 Assisted Living settings. With just 23 participants in 2003 and an increase to 75 in 2004, it is growing in tandem with the increase in assisted living settings.

Children's Respite Waivers. These two waivers were initiated in 2001 to provide additional support to children under age 19 with high levels of physical and/or cognitive needs who are living at home. They were meant to add to the services in the ESPDT services and Children's Health programs when additional respite supports to family would enable community living.

State Plan Services. With reference to long-term care, the Arkansas Medicaid State plan covers personal care, home health care, private duty nursing (for persons using respirators only), emergency and non-emergency medical transportation, medical equipment, and targeted transportation. The consumers may opt to receive personal care through Independent Choices, a program that offers a cash allowance slightly discounted from the value of the in-kind agency services with or without payroll management services (most consumers opt for the payroll services). In May of 2005, 1,413 consumers were enrolled in Independent Choices, and the program expenditures totaled \$4,781,538.

## **Other Services**

Older American's Act. The typical array of services are provided under the Older Americans Act, including services in a network of largely rural senior centers, information and referral programs, congregate and home-delivered meal programs, transportation, benefits counseling, and so on. The Family Caregiver program developed by the Aging Network offers the option of cash allowances. A special Alzheimer's Program is being piloted in one of Area Agencies on Aging.<sup>15</sup>

Protective services and advocacy. Adult protective services, and ombudsman services, are based in each Area Agency on Aging. Under one of the RCSC grants, Arkansas has also established an ombudsman for HCBS waivers.

First Connections Infant and Early Toddler Program. Funded through the Individuals with Disabilities Education Act, this program assists the families of infants and toddlers (birth to age 3) with developmental delays or diagnosis of developmental disability to access services. Case coordination for this program is performed by state employed specialists only; 11 Developmental Specialists and 2 Developmental Specialists managers conduct the assessment and provide the monitoring and service access.

Early Childhood Program. This program provides services to about 2500 children aged 3 to 6 with developmental delay or a diagnosis of developmental disability, including center-based rehabilitation for children aged 3-5. It is similarly managed by developmental specialists. Children may receive therapeutic and habilitation services in their own home or at centers.

## **Section II. System Assessment**

In this section, we briefly profile selected system functions, using identical headings to those in each state-specific case study. Section III, which follows, highlights selected New Mexico

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<sup>15</sup> Arkansas State Plan on Aging: Federal Fiscal Years 2003-2006  
<http://www.arkansas.gov/dhhs/aging/ARStatePlanOnAging-FY03-06.pdf>

programs or initiatives that are especially noteworthy and innovative management approaches for rebalancing.

### **Access to Services**

Access to services for the MR/DD population is managed within a separate system from access for seniors and people with physical disabilities; the former through Area Agencies on Aging and the latter through developmental disability providers. In both instances, the financial eligibility for Medicaid services is determined through the Office of County Programs, which has a local presence in each county. Financial and functional eligibility for Medicaid or Medicaid waivers can take 45 days in Arkansas, a lag time that state officials view as a problem and are moving to address in current demonstrations and planning. The Aging and Disability Resource Center piloted in one region is expected to be a model for a state-wide system. Similarly, Arkansas plans to refine a state-wide web-based assessment tool that would assist with equitable and prompt access to services. The State believes strongly that access to information is the first step in access to service and has invested heavily in developing web-based tools to enhance information to all participants in the system.

Arkansas officials recognize that the State presently lacks a unified system of care, and that its various programs operate separately. County-level human services staff, who are responsible for eligibility for all income maintenance and in-kind benefit programs as well as Medicaid and Medicaid waiver programs can sometimes be confused about the various programs, a problem compounded by turnover among these personnel and the lack of information in the minds of potential consumers. Similarly, no mechanisms are established currently to divert consumers from institutional care or help them move between programs. If an adult child presently asks for a nursing home application from a local DHS office, he or she may well receive it with no information about HCBS options.

Through its Aging and Disability Resource Center grant, DHS.DAAS is piloting a one-stop shopping system that would serve both seniors and people with physical or developmental disabilities in a 12-county region. The ADC is co-located with a senior center, a developmental disability adult day program, transportation services, a HUD Section 8 Rental Assistance Program, and AAA case managers. A toll-free regional telephone answering service is available during weekday working hours, staffed by personnel familiar with the use of Case workers use of the SA-HELLO resource described above. The ADRC goes a step further by using a recently developed automated Consumer Assessment, Referral, and Evaluation Tool (CARETool) to allow multiple agencies to enroll consumers and record service information.

### **Array of Services**

Arkansas has a wide array of in-home providers of home care and personal care services, and developmental disability services. The State is developing a capacity for independent providers as personal care workers and attendants, and the fiscal intermediary system needed to manage such services when the State is paying. (The Service Employees International Workers has already noted the potential in Arkansas, and is recruiting to establish itself in the State; unlike Washington State, providers in Arkansas are not required to be union members but according to the website for the Arkansas local, 100 personal care workers have joined the Arkansas local at this time.)<sup>16</sup> Finally, Arkansas is investing in the development of assisted living and other housing with services models for older people that combine a service capacity with a desirable living environment. Its strategy here includes establishing a regulatory framework for assisted living at a time when no assisted living existed in the state.

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<sup>16</sup> SEIU Local 100 Arkansas, website, last visited, December 22, 2005, at <http://www.seiu100.org/index.php?id=393>

## **Quality Initiatives**

The Division of Medical Services (DMS) has overall responsibility for quality under Medicaid, but various divisions have responsibilities in their own areas of operation. Quality management for DDS has been particularly separately developed. To create a quality management strategy for their HCBS waivers based on the CMS framework, the DAAS and DDS collaborated on a proposal for a Quality Assurance/Quality Improvement (QA/QI) Systems Change grant, which was awarded in 2004. The goals and objectives of the QA/QI grant included an assessment of the current systems and activities, establishing a QA/QI taskforce, gaining participant feedback and satisfaction information regarding the waiver services, establishing a uniform data collection and reporting system, and conducting a feasibility study for a single incident reporting system for the HCBS waivers. The taskforce was established but the QA/QI grant activities were just getting underway at the time of our site visit because of an unanticipated delay in hiring a project director. Ultimately Arkansas aspires to Develop and implement web-based common applications for waiver programs develop and implement web-based common assessments for waiver programs, web-based, individual-centered plans of care for waiver programs; a move from paper-based, program-specific processes to automated, common processes using IT, and the addition of technology experts to the relevant Divisions.

In conjunction with these efforts, the DMS created a Waiver Quality Management Unit, whose administrator is responsible for gathering information on all waivers and demonstrations, reviewing current quality assurance methodologies in place, developing new interagency agreements with operating Divisions, assisting with waiver renewals and reviews, and obtaining technical assistance from Medstat, the CMS national Quality Management contractor with reference to Quality Management.

In its further planning for System Transformation, the Department of Human Services proposed to develop and implement an automated comprehensive quality management strategy based on CMS' HCBS Quality Framework and Interim Procedural Guidance with a focus on participant experience and outcomes.

DAAS is responsible for the Nursing Home Ombudsman program and the Adult Protective Services program, both of which are housed in each Area Agency on Aging. DAAS also developed an Ombudsman capacity specifically for the Medicaid waivers that the Division operates. A toll free number has been established and educational materials that clearly state the rights of individuals served under the waivers; the phrase "Your Voice, Your Choice" exemplifies the tone of the brochure.

As indicated above, DDS operates its own licensing and quality assurance efforts for its programs. The efforts include vigorous approaches to improving the quality of care and life at each of the six state-run institutions for MR/DD. At the end of our case study period, DDS joined those states participating in the National Core Indicators; the intent was to begin applying them to the MR/DD HCBS waiver, and then expand to all DDS services. Adopting the Core Indicators advances the State's intent of systematically gathering information about consumer experience and outcomes. When fully implemented the State will be able to compare its DD programs within Arkansas and compare its performance to that of other participating states.

### **Consumer Direction**

Consumer direction is well-developed in Arkansas, and in particular models that permit cash allowances in lieu of in-kind case-managed service. During the years of social marketing for the cash and counseling demonstration, a high degree of acceptance for consumer direction evolved among potential consumers, political figures, many (though not all) service providers, and the general citizenry. Once the demonstration was completed and no further randomized control

group was needed, Arkansas made the Independent Choices program a permanent part of its State Medicaid Plan. Consumer direction is also built into the Alternatives Waiver for Persons with Physical Disability; indeed consumer-directed attendant care is the core services. Attention is now being given to injecting more opportunity for consumer direction in the MR/DD waiver and the Elder Choices waiver; the former has been enhanced by a project to develop a personal attendant capacity for persons with MR/DD under the States C-PASS grant. Cash allowances in lieu of in-kind respite services are being used in the Older American's Act Family Caregiver Program, and in its Next Choice initiative, Arkansas is developing plans to offer cash allowances in lieu of service for Medicaid recipients who leave nursing homes.

### **Institutional Downsizing**

No specific initiatives to downsize or close nursing homes, ICF/MRs, or state developmental disability programs were noted. As choices are more available for people of all ages and disabilities, the institutional sector is expected to shrink.

### **Data Capacity**

Arkansas has two parallel data systems (one for aging clients and one for DD clients), reflective of the two separate divisions within their Department of Human Services dedicated to these program areas. The State has a relational database in place, which is not the case with most of the states in our study; however, linking client characteristics and service utilization data is presently not a straightforward or simple process. The lack of consistent and accurate data on the cost of home and community-based programs compared to institutional programs has made it difficult to justify major shifts in funding within the Arkansas budget structure.

Arkansas is eager to develop state of the art Information Technology, with an automated system to collect, warehouse, analyze, and report information to guide program development and monitor quality. The goal is to develop a routine, automated way to gather feedback from consumers and

providers; goals related to information technology are inextricably linked to Arkansas' plans for quality management and to improving access to services and streamlining eligibility. Thus, DHS is exploring ways to use its Medicaid Management Information System (MMIS) in an automated comprehensive quality management system. Given that CMS provides funding of 90% federal share for MMIS enhanced development under some circumstances. DHS plans to request this enhanced funding from CMS to add the necessary capabilities to the MMIS.<sup>17</sup>

The web-based case record that will result from these developmental efforts would be made available (privacy requirements permitting) to participants, service providers, case managers, program administrators, quality monitors, and perhaps others. The vision is to give those with the most need to know ready access to information about plans of care, service delivery, and cumulative case information. DHS foresees this electronic record as crossing all current boundaries of agencies and services to finally provide one comprehensive record for each individual that can be accessed and used by all involved in their service and support.<sup>18</sup>

### **Mental Health Linkages**

The Division of Behavioral Health Services (DBHS) within DHS is responsible for an integrated system of mental health and addiction prevention and treatment services, including acute psychiatric care for adults, forensic services, and adolescent inpatient and outpatient services, including adolescent sex offender services. DBHS is also responsible for research and training

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<sup>17</sup> As part of the Systems Transformation Grant that CMS awarded Arkansas in September 2005, Arkansas will explore whether the enhancements it develops will be directly to the MMIS or through outside systems and platforms that will interface with the MMIS, or a combination of both.

<sup>18</sup> A precedent is the Arkansas' Networked System for Welfare Eligibility and Reporting (ANSWER) that is used in Arkansas' 75 counties to determine eligibility for Medicaid, Food Stamps and Transitional Employment Assistance (TEA). Information is entered into the system by the caseworker gathered during an interactive interview with the customer. Once the information is entered the caseworker determines eligibility for the above-referenced programs, using a system that applies program-specific rules. Under consideration is enhancing this system to include long-term care.

related to behavioral health, and for mental health programs in skilled nursing facilities. The DBHS programs are contracted through 15 private non-profit mental health centers, each of which offers a full array of diagnostic and treatment services within its defined geographic area. DBHS operates and oversees quality for Arkansas State Hospital, a facility with 90 general inpatient beds, 80 forensic beds, 16 adolescent acute beds, and 16 adolescent sex offender beds; entry to Arkansas State Hospital is through the mental health centers, which have sites in all but 5 of the 75 counties. DBHS also operates a specialized nursing home, now called the Arkansas Health Center (formerly the Nenton Services Center Nursing Facility), which is a 350-bed long-term psychiatric nursing facility serving Arkansas elderly whose specialized needs cannot be met through the regular nursing homes.

From 2001 to 2002, a Governor's Mental Health System Taskforce was established to address recognized problems in the mental health system, including over-reliance on centralized institutions, poor discharge planning from the institutions, insufficient community mental health services, over-reliance on hospitalization at the entry point of the 15 Community Mental Health Centers, use of incarceration in lieu of mental health services, and lack of parity in insurance between mental health and physical health services.<sup>19</sup> As a result of that planning, new program thrusts were developed including Crisis Stabilization Centers, Assertive Community Treatment (ACT) Teams (which provide wraparound services), and Crisis Intervention Teams (CITs) (to promote jail diversion). A pilot CIT was established in the Little Rock area, involving collaboration between the Little Rock Police Department, the University of Arkansas medical school, the National Association for Mental Illness, and the Little Rock Comprehensive Mental Health Center. Noting positive results within several months, DHS requested funding for the

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<sup>19</sup> Governor's Mental Health System Task Force (2002). The State of the State's Public Mental Health System. Report submitted to the Governor in June 2002,

expansion and the Governor included the funds in his 2003 budget. Public concern is particularly high about adolescents with serious mental health problems, revealed by teenage suicides and publicized tragedies of school shootings, one of which occurred in Jonesboro, AR.

The GIST Olmstead report released in 2003 reinforced the Mental Health System Taskforce recommendations and gave great weight to shortfalls in mental health services. Indeed, the GIST established as its 2<sup>nd</sup> most important of a long list of priorities, “Restructure Mental Health Services Delivery.” GIST recognized the challenges of providing HCBS for dually diagnosed individuals with both a physical or developmental disability and a mental health disability were recognized to support expensive inpatient settings at centralized locations rather than developing stronger community treatment. Some concern about adolescents with serious mental health problems—suicides—Jonesboro school incident stimulated attention to community mental health needs of children.

### **Acute Care Linkages**

Arkansas utilizes 1115 (a) waivers to develop its strong Children’s Health Program (ARKids B, which expands Medicaid to all uninsured children statewide), its Women’s Health services for family planning and (with 1915(b) waivers a non-emergency transportation program and a primary care case management program (mandatory except for those spending down to eligibility and those dually eligible for Medicare and Medicaid) and medical transportation programs. The Primary Care Case Management waiver (ConnectCare) has gained national recognition for reducing use of emergency rooms and inappropriate use of specialists. Arkansas is also planning PACE initiatives for dually eligible individuals; six sites are conducting feasibility studies and Arkansas hopes its first PACE program will be operational in 2006. One of the projects that appear most valuable is a partnership between a Medical Center in Jonesboro and the East Arkansas Area Agency on Aging.

Arkansas perceives that its state is relatively unhealthy with high incidence of stroke and heart disease, diabetes, and obesity. The Governor's strong personal interest in chronic disease management, already mentioned, has resulted in public health initiatives funded by tobacco settlement funds. But dually eligible individuals (i.e. people potentially on both Medicare and Medicaid), who are among the most needful of chronic disease management to integrate the acute care and long-term care services are not covered in the primary care case management of ConnectCare. The problem of access to any primary care providers at all is exacerbated because many physicians are declining to accept new Medicaid or Medicare patients because of low reimbursement rates. Similarly, reimbursement policies do not encourage attentive primary care management of elderly patients or conducting home visits.

DAAS identified Georgia's SOURCE program as a promising model for coordinating care for Medicaid recipients with chronic illnesses. This is a voluntary primary care case management (PCCM) program which combines primary care, social case management, and home and community-based services; for SOURCE clientele, access to Georgia's HCBS waiver services is managed by the primary care coordinators. Arkansas has studied the SOURCE program, made site visits to Georgia, and brought SOURCE leaders to Arkansas. Since a number of modifications in existing Arkansas policy would be needed to implement the features of Georgia's program, Arkansas plans to pilot this effort in two AAA regions. The Health Department's evidence-based disease and disability work group are also involved in the planning. The efforts to adapt the SOURCE program are discussed further in Section III.

Also worth noting as an opportunity for improving chronic disease management for seniors in Arkansas are two major health sciences program: 1) the Donald W. Reynolds Center has selected Arkansas as a state where it is investing substantial resources to establish aging programs, and underwritten the innovative Donald W. Reynolds Center on Aging at the University of

Arkansas; and 2) the John A. Hartford Foundation has awarded a Center of Excellence in Gerontological Nursing, also housed at the University of Arkansas. The SA-HELLO (South Arkansas Health Education Living and Life Options), profiled in Section III, is a collaboration of these two university-based health programs, the Southwest Arkansas AAA, and DAAS. This has enabled the development of web-based tools that combines state of the art general information about disease management with local information about resources.

### **Housing Linkages**

The Governor's Taskforce on Supportive Housing is specifically charged to assist with compliance with the Olmstead decision. Its major initiatives are twofold: 1) the Arkansas Development Finance Authority (ADFA) set aside funding for a Bridge Rental Assistance Fund for rent subsidies for consumers waiting for federal assistance for transitioning from nursing homes or avoiding placement; 2) also in collaboration with ADFA and funded in part through a 2004 RCSC grant, the University of Arkansas at Fayetteville is charged to develop universal design housing standards and design prototypes and implement them through state agencies.

In 2001 Arkansas received grant funds from the Robert Wood Johnson Foundation Coming Home program to create Assisted Living as a category in the State's health facility regulations; provide Medicaid waiver reimbursement for Assisted Living services in addition to Medicaid personal care; and to provide new financing for low-to-moderate income Assisted Living facilities. Act 1230 of the 2001 Legislature, the Arkansas Assisted Living Act, enabled residential care facilities to convert to Assisted Living Facilities. Arkansas promulgated regulations for assisted living facilities and CMS approved a 1915(c) waiver to allow for billing for assisted living services. Barriers have been numerous; some existing institutional providers have resisted the concept; few entities are expert in both financing and delivering health care; financing mechanisms for

affordable assisted living are extremely complex; tax credits for assisted living have become harder to sell; and building costs have escalated.

### **Section III: Featured Management Approaches**

#### **Independent Choices and Other Cash Options**

##### Cash and Counseling Demonstration

Arkansas developed and rigorously tested as part of a 3-state national demonstration the use of cash allowances for Medicaid programs. This program, called Independent Choices, was implemented with Robert Wood Johnson funding for technical assistance and a formative and summative evaluation funded by the U.S. Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation. A large number of reports on the Cash and Counseling Demonstration are readily available, some specifically describing the Arkansas program and results, and some making comparisons among the 3 states that implemented Cash and Counseling.<sup>20</sup> Each participating state crafted its own variation on Cash and Counseling and, thus, the data were not pooled for the evaluation. Arkansas was the first program implemented the first to complete enrollment, and the first to generate outcome data.

In Arkansas the eligible groups were adults age 18 and over who were eligible for the State Personal Care Option. During the demonstration phase, consumers were recruited, the program explained, and consumers willing to accept cash allowances were randomly assigned to the experimental group or the control group, which received usual services. State-employed nurses

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<sup>20</sup>See Phillips, B & Schneider, B (2002). Moving to Independent Choices: The Implementation of the Cash and Counseling Demonstration in Arkansas. (Final Report to OASPE May 2002). Princeton, NJ., Mathematica Research Policy; Foster, L, Brown, R, Phillips, B, Schore, J, & Carlson, BL (2003). Does Consumer Direction Affect the Quality of Medicaid Personal Assistance in Arkansas? (Final Report to OASPE March 2003); and Phillips, B, Mahoney, K, Simon-Rusinowitz, L, Schore, J, Barrett, S, Ditto, W, Reimers, T, & Doty, P (2003). Lessons from the Implementation of Cash and Counseling in Arkansas, Florida, and New Jersey (Final report to OASPE, June 2003) Princeton, NJ., Mathematica Research Policy. These and other reports can be found on the OASPE website at <http://aspe.hhs.gov/> /index.cfm

conducted the eligibility assessments as required by Arkansas law for the Personal Care Option. The two relevant waiver programs—ElderChoices and Alternatives for Persons with Physical Disabilities—were not cashed out, and consumers were able to simultaneously use both programs if they had the need and eligibility. The dollar amount of the allowance for Independent Choices was based on the number of hours in the individual’s personal care plan at \$8.00 an hour minus an adjustment to achieve budget neutrality given that on average most consumers do not receive all the hours in their care plan in a given year. The median monthly allowance was \$313, but the range was considerable. Arkansas did not permit consumers to hire spouses, but otherwise family members could be hired. Consumers or the consumer representative (if the consumer could not manage his or her own allowance) prepared a written spending plan with a counselor (called a “consultant) indicating the services and goods they wished to purchase; in Arkansas the consultant could approve plans themselves unless they included goods and services not on a pre-approved list, in which case the state made final approvals. Counselors communicated with the consumer or consumer representative by phone and during home visits, and were responsible for verifying that the check requests conformed to the worker time sheets and the spending plans before funds were disbursed. Consumers kept receipts, except for the incidental cash expenses. Goods needed to be related to managing the disability, but Arkansas took a liberal view of allowable expenses, including pieces of furniture, microwave ovens, and washing machines. Portions of the allowance could be saved for larger one-time purchases. Consumers also could elect to receive 10% to 20% of their allowance as cash for incidental expenses—for example, taxi fares—that could not readily be reimbursed through the invoicing process. If the consumer’s allowance was managed through a representative, such representatives were prohibited from paying themselves as personal care providers. Payroll tasks such as issuing checks and submitting payroll tax returns were preformed by fiscal agents, called “bookkeepers” in Arkansas. Unlike the other two states in the

demonstration, Arkansas combined the counseling and the fiscal agent function and Arkansas was the only state not reporting quality problems with the fiscal agent. Consumers were allowed to opt to handle the fiscal arrangements themselves but this option was almost never selected.

Arkansas did not require consumers to pay for services from either the Counselor or the Bookkeeper; however, the state counted the costs of these services as part of the fiscal neutrality calculation, so consumers paid for them indirectly through reduced allowances. The State contracted with a small number of agencies for the consultant and bookkeeper function, each with responsibility for a section of the state; one agency dropped out during the demonstration and the clients were transferred to the remaining agencies. The State found it important not to vest the consultant function in the existing agencies providing targeted case management and home care because of expected opposition to the program. Indeed, providers initially lobbied against it, and anecdotally some providers advised Medicaid clients, especially seniors, to avoid the program. The outreach was successful, however, particularly when the Governor sent a letter to all potentially eligible individuals informing them of the program.

Summarizing the operational lessons from Arkansas' startup period: 1) combining the counseling and fiscal agency function seemed desirable; 2) home visits at convenient hours for family members were important for initial recruitment; 3) the agency doing counseling needed a sizable caseload to work effectively in the role, which argues for fewer contractors for this function; 5) timeliness in making the first allowance payment available seemed essential to avoid consumers dropping out of the program; 4) fraud was virtually non-existent, though some mistakes were made that resulted in over-payment and required a mechanism for consumers to pay back the amount over a period of time as though the overpayment were an interest-free loan. In Arkansas, about 10% of the seniors receiving personal care and 15% of the younger adults opted for the cash

demonstration; almost half of the seniors also chose to use a representative to handle their spending plans.

Outcomes for consumers, family caregivers, and workers, as evaluated by Mathematica Policy, Inc, were highly favorable to the experimental group in terms of satisfaction of all parties concerned and reduction of unmet needs. No adverse health consequences were identified. An unintended result in Arkansas was that the control group members were likely to receive no services or fewer services than planned at an unexpectedly high rate. This problem was related to difficulties agencies were having in recruiting labor and spoke to the advantages of flexible arrangements through Cash and Counseling. The evaluation also suggested that Cash and Counseling participants used nursing homes and hospitals less frequently than the control group participants.

#### Cash Allowances Post-Demonstration

After the demonstration period ended in 2003, Arkansas incorporated Independent Choices into its operations. In June 2005, the program has almost 1500 enrollees and had expended about \$4.8 million up to that point in the year. The program still operates through fiscal agents/counseling contractors; at present 5 such providers hold contracts with DHS,

Utilizing a planning grant from OASPE, DAAS and DMS are now working on developing a new option to exchange Medicaid nursing home benefits for a daily cash allowance for consumers who opt to leave nursing homes and choose HCBS. Called Next Choice, the complexities of planning include establishing the eligibility requirements (e.g., length of time in a nursing home) and conducting data analyses to establish the maximum allowance. Once again counseling and fiscal intermediary services will be part of the program.

## **Web-based Information Systems: SA-HELLO and AR-GetCare**

As indicated above, Arkansas modeled a unique collaborative effort in South Arkansas that resulted in a statewide web based directory of services and information system for seniors and people with disabilities in the region, Called SA-HELLO (South Arkansas Health Education Living and Life Options), the program is the result of collaboration between aging centers at the University of Arkansas Medical School and Nursing School, the AAA and DHS agencies. The web application has an arm for consumers or potential consumers of services and one for providers, who may enter information about their programs.

Consumers may turn at any time to an 8-question self-assessment form, which very briefly establishes the type of functional needs that exist, the health diagnoses, and the consumer's preference for receiving care at home or in a group setting. Based on responses to these questions, a list of potential services is generated. Consumers may then learn more about the services generically (clicking to download educational material) or may go directly to a local list of providers. Thus, SA-HELLO has an educational as well as a linking function. Consumers may enter the database in multiple ways, skipping the self-assessment and simply seeking information about categories of services. Once the SA-HELLO program was deemed effective, it was developed for state-wide use in the AR-GETCare system.

## **Together We Can**

Established under the C-PASS Real Choice System Change Grant, Together We Can is an effort to develop community planning, consumer direction, and advocacy capability for MR/DD. The C-PASS grant was a catalyst to establish a services network in 17 counties to improve funding for family and individual supports in Arkansas. The Advisory Committee is comprised of more than 50% consumer members (self advocates or parents). A multi-agency approach to service planning was developed based on long-term individually-centered goals. A team of volunteer

members from AmeriCorps/VISTA implemented the family support pilot. During the final phase of the grant, “family circles” were established in three counties and received \$5,000 each to begin supporting several families. DDS is using information gleaned from the Together We Can project to design a statewide effort to enhance consumer direction and community integration in the MR/DD world. The initial implementation did not include the Little Rock area.

### **Consumer Empowerment/Aging and Disability Leadership Academy**

Throughout the report, we have alluded to the activities of the GIST (Governor’s Integrated Services Task Force), an important force for System Change in Arkansas. On May 16, 2000, a proclamation by the Governor authorized the Director of DHS to “develop a working group to conduct a comprehensive review of all services and support systems available to people with disabilities in Arkansas.” The Olmstead Working Group comprised of consumers, advocates, providers and stakeholders issued a report<sup>21</sup> with the recommendation that “DHS study the possibility and feasibility of developing a single point of entry.” The group also recommended the appointment of an ongoing advisory task force, the Governor’s Integrated Services Task Force (GIST) comprised of persons with disabilities, guardians, advocates and providers to assist the State in developing and implementing a comprehensive working plan for the State of Arkansas. The GIST completed plans in March 2003 and presented a detailed, prioritized list of recommendations (recording the tallies for and against each proposal). The GIST also monitors accomplishments against the priorities in the plan. Stakeholder involvement is a serious endeavor in Arkansas, and sufficient DAAS personnel are assigned to staff the activities.

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<sup>21</sup> *The Report of the Olmstead Working Group* prepared for Governor Mike Huckabee. Arkansas Department of Human Services. February 15, 2001.

The GIST itself has an educational function in the development of activated consumers. However, DAAS has gone beyond Taskforce functions to create (using grant funds) the Aging and Disability Leadership Academy. Those interested in attending the weekend sessions in Little Rock may apply, including information about their own interests, experience, and goals. Those selected attend sessions at the expense of DAAS. At the time of this report, 3 classes had graduated from the Academy. This strategy is designed to establish networks of informed and activated consumers throughout the state. The interesting application process also provides DAAS with information about the concerns of stakeholders.

### **Consumer Directed Care Act/Nurse Delegation**

The number-one priority established in the GIST Olmstead plan was: “Clarify the Nurse Practice Act to encourage flexibility in caregiving while ensuring quality.” The choice of a technical priority such as this suggests the amount of education and self-study undertaken by the GIST. Essentially, the GIST came to believe that registered nurses needed protection from perceived liability so they can delegate medication management to trained unlicensed assistive personnel, or that some comparable step needed to be taken for efficient management of health care tasks in the community.

To act on this recommendation, DAAS undertook study of nurse practice acts nationwide, and convened a summit to bring leaders from the Board of Nursing and relevant state agencies together with consumer stakeholders and national nursing and long-term care authorities to discuss possible options. As a result of several years of activity, the 2005 Legislature enacted Act 1440, the Consumer Directed Care Act, which exempts home health maintenance activities from the Nurse Practice Act. This enables competent adults to have designated a care aide perform health maintenance activities, i.e., activities that enable a minor child or adult to live in his or her home such as assisting the individual to take prescribed medications.

## **Primary Care Case Management**

Section II described Arkansas' intent to develop a primary care case management program, adapting Georgia's SOURCE program to Arkansas' needs. DAAS proposes to develop and implement a system of primary care case management targeting dually eligible persons and others with chronic illnesses. The goals are: maintain participants' health and function; promote self-care; reduce service delivery fragmentation; and reduce inappropriate emergency room use, hospitalizations, and nursing facility placement caused by preventable conditions. Arkansas will adapt the Georgia SOURCE model, beginning with a pilot in two regions of the state. PCCM services will be provided by case management agencies, which will contract with primary care physicians and a medical director, probably a geriatrician. Enrollees will choose a participating PCP as their physician. PCPs will conduct thorough patient evaluations, manage medical services, and meet quarterly with patients' case manager. PCPs will receive case management fee from the agency (\$15-20 per patient per month in Georgia), in addition to Medicare and Medicaid reimbursement for services.

In current thinking, each agency's medical director will participate in weekly team meetings to review cases with case managers. Medical directors will play an important role in correcting problems such as overmedication and inappropriate medication, advising case managers about dealing with PCPs and medical conditions, and calling physicians directly when necessary to discuss recommendations. Arkansas Medicaid will pay case management agencies a fee, and the agencies will pay PCPs for managing PCCM participants (Georgia Medicaid pays agencies \$150 per member per month, and the agencies pay PCPs \$15-20 per member per month). Payments to PCPs reflect the extra time required for communicating with case managers, plus the medical complexity of dually eligible persons. Other medical and HCBS services will remain fee-for-service, and PCPs will continue to bill Medicaid for other services provided to participants.

PCCM case managers will play a major role. They will conduct thorough in-home assessments, arrange and monitor community services, encourage compliance with medical appointments and medications, promote self-care of chronic conditions, etc. Case managers may accompany clients to doctors' appointments, if needed, to discuss compliance and other issues. Participants will be instructed to contact their case manager prior to any hospital or nursing home admissions, so case managers can help avoid unnecessary admissions and help plan discharges and transitions back to the community. PCCM agencies will be responsible for meeting emergency needs around the clock.

Georgia's Care Paths will be adapted as protocols for planning supports and services, and monitoring outcomes. There is a Care Path for each SOURCE level of care. The Care Path is customized for the participant, using his or her preferences, health status and service needs. Goals cover community residence, keeping medical appointments, satisfaction with support services, nutrition and weight, skin condition, clinical indicators and lab values, medication compliance, ADLs and IADLs, behavior, and caregiver support. The Care Path shows who is responsible for each goal, including the participant, case manager, physician, and personal care aide. Performance on each goal is rated quarterly.

All ElderChoices (65+) and Alternatives (physically disabled, aged 21-64) waiver participants, and other adult Medicaid participants with chronic conditions will be invited to enroll. MMIS claims data will be used to identify individuals with chronic conditions and high costs. The proposed Next Choice waiver will likely be included as well. While the program will be voluntary for participants, a high level of participation is projected because participants will receive more intensive primary care and case management services, and will be actively involved in planning care and outcomes.

A number of hurdles must be met to implement this idea. CMS authorization is required for PCCM. Voluntary PCCM can be authorized by a State Plan Amendment, but a 1915(b) waiver may be required for selective contracting. Selective contracting will be used to limit the number of case management agencies and HCBS Medicaid providers. Objections are anticipated from existing waiver program agencies, which want their participants to receive better primary care, but do not want to relinquish managing their waiver services. Arkansas's *any willing provider* law is likely to hamper agencies' ability to select physicians, though they can still set standards and guidelines for participation. Medicaid HCBS providers are likely to resist selective contracting and accountability measures. HCBS providers frequently appeal to legislators for relief from DHS actions that affect their revenues.

As is the pattern in Arkansas, the program will initially be piloted in two multi-county regions, including rural counties with access problems and low rates of health screening. DAAS anticipates contracting with two case management agencies during the pilot. After the pilot, the program (adjusted, as needed) will be expanded statewide, adding other case management agencies, so participants can be offered a choice of at least two PCCM agencies, or in rural areas at least one agency offering a choice of physicians.

#### **Section IV. Quantitative Markers of Rebalancing**

##### **Markers of Change in Nursing Home Residents**

In order to assess the potential effect of HCBS on nursing home use, we examined the MDS data on all Arkansas nursing homes for the years 2002, 2003 and 2004. We reasoned that if HCBS was having an effect, the case mix in nursing homes should become higher i.e., the level of disability (both functional and cognitive) should increase. Because nursing homes serve at least two streams of clients, one requiring post-acute care (PAC) after discharge from hospitals and

another the more traditional long-term resident, we examined the case mix at two points in time: admission and three months after admission. The former would include the PAC population, but the latter should be a more direct reflection of long-term care HCBS was intended to defray.

## Methods

To create the new admission sample we used all MDS admission assessment records in 2002, 2003 and 2004 to calculate the NH Case Mix at admission. The numbers of new admissions in 2002, 2003 and 2004 were 14,570, 15,290, and 14,059, respectively. This included multiple admissions of the same individual in the same or different NH.

For the 3 months after admission sample we used MDS quarterly records in 2002, 2003, and 2004 to calculate NH Case Mix at 3 months after admission. First, we selected all MDS quarterly records into a separate data file. Then we merged this data file with the admission records data files using both a unique resident ID and a unique facilitate ID. Then, we calculated the day-difference between the admission date and the assessment date of the quarterly data file. The first quarter assessments were identified if the day-difference was between 75 days and 105 days. Finally, we used these first quarter assessment records in our case mix analysis

We calculated the ADL score following the method developed by Morris and colleagues for the MDS ADL Long-Form.<sup>22</sup> Specifically, we used variables G1AA (bed mobility), G1BA (transfer); G1EA (locomotion on unit), G1GA (dressing), G1HA (eating); G1IA (toilet use), and G1JA (personal hygiene). The original coding for these variables were between 0 and 4 (0 for independent, 1 for supervision, 2 for limited assistance, 3 for extensive assistance, and 4 for total dependence) and a number 8 was used when the activity did not occur during the entire 7 days of assessment. We recoded the number 8 (activity did not occur during the entire 7 days) as 4 (total

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<sup>22</sup> Morris, J. N., B. E. Fries, et al. (1999). "Scaling ADLs within the MDS." Journals of Gerontology. Series A, Biological Sciences & Medical Sciences. **54A**(11): M546-M553.

dependence). We finally created a summation score of total ADL dependence by adding the value of these 7 variables. Therefore, the possible score of our ADL variable is between 0 and 28. A higher score means higher ADL dependence.

We used the Cognitive Performance Scale (CPS) developed by Morris and colleagues to measure the cognitive functioning of elders in NH. (<sup>23</sup>Morris, Fries et al. 1994) The CPS was calculated using variables from section B (B1: Comatose; B2A: Short term memory), section C (C4: making self understood), and section G (GHA: eating) of the MDS. The possible score of CPS is between 0 and 6. A higher CPS score means lower cognitive functioning.

## Results

Table 7 shows the changes in the NH case mix on admission. Between 2002 and 2004, the functioning level of elders admitted to NHs in MN deteriorated slightly from the average ADL score of 14.03 in 2002 to an average ADL score of 14.99 in 2004. Moreover, the proportion of residents admitted with no ADL dependencies, or very few, decreased. During the same period of time, the cognitive functioning of elders admitted into NHs improved slightly. The average CPS score went down from 2.05 in 2002 to 1.95 in 2004. However, the rate of persons with no cognitive impairment or mild impairment increased slightly.

Table 8 shows the NH case mix 3 months after admission for 2002, 2003, and 2004. The ADL functioning at 3 months after admission improved slightly over the 3 year period. The average ADL scores in 2002, 2003, and 2004 were 12.34, 12.27, and 12.30, respectively, suggesting less disability over time. However, the proportion of persons with no and few ADL dependencies decreased. For cognitive functioning, the CPS scores improved slightly between 2002 and 2004.

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<sup>23</sup> Morris, J. N., B. E. Fries, et al. (1999). "Scaling ADLs within the MDS." Journals of Gerontology. Series A, Biological Sciences & Medical Sciences. **54A** (11): M546-M553.

The CPS score in 2002 was 2.05, dropped to 2.51 in 2003 and further dropped to 1.95 in 2004.

Moreover the proportion with no cognitive impairment increased.

Table 7. Change in NH Case Mix at Admission in Arkansas, 2002-2004

	2002	2003	2004
ADL score	%	%	%
0	4.6	4.2	4.4
1	1.7	1.5	1.4
2	2.8	2.9	2.6
3	2.2	2.3	1.9
4	3.6	3.2	3.1
5	2.6	2.6	2.5
6	3.7	3.5	3.3
7	2.9	3.0	3.0
8	3.9	3.7	4.0
9	3.3	3.0	3.0
10	4.4	4.8	5.3
11	3.7	3.8	3.7
12	6.8	7.4	7.9
13	4.0	4.3	4.5
14	4.1	4.3	4.3
15	3.2	3.7	3.8
16	3.5	3.5	3.7
17	3.7	3.5	3.6
18	3.7	3.9	4.6
19	3.8	3.6	3.9
20	3.6	3.5	3.6
21	3.4	2.9	3.0
22	2.6	2.7	2.8
23	2.4	2.1	1.8
24	2.7	2.6	2.5
25	1.9	1.9	1.7
26	2.1	1.9	2.0
27	2.1	1.9	1.8
28	7.2	8.0	6.6
Mean ADL	14.03	14.13	14.99
N*	14,570	15,288	14,059
CPS score			
0	29.0	29.3	30.3
1	14.3	14.2	14.2
2	15.4	15.1	16.0
3	24.2	24.6	24.4
4	4.9	5.3	4.9
5	6.2	5.1	5.0
6	6.1	6.4	5.2
Mean CPS	2.05	2.04	1.95
N*	14,567	15,285	14,056

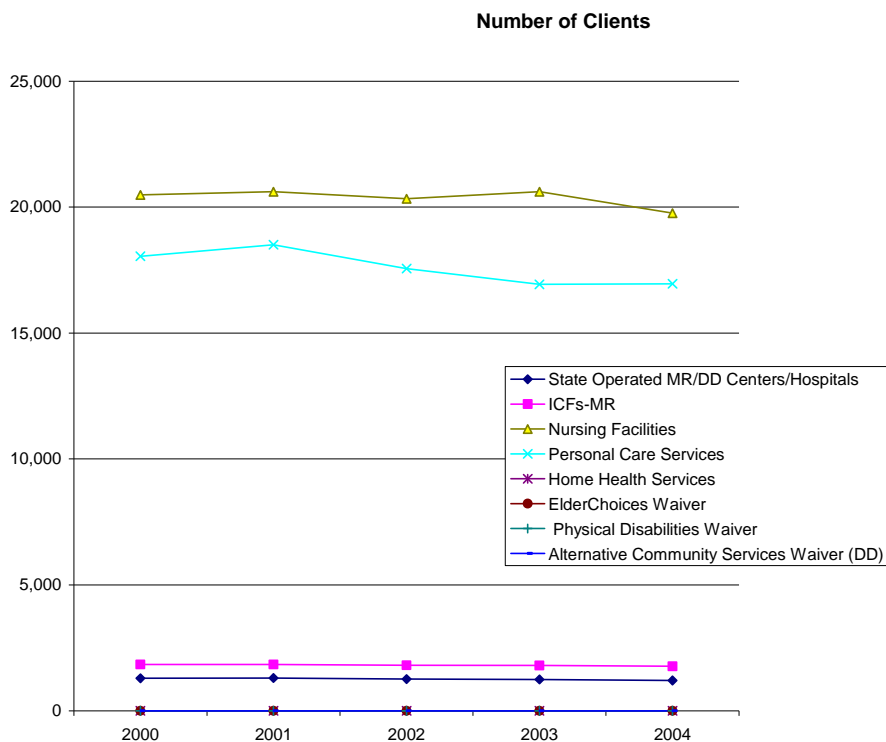
**Table 8. Change in NH Case Mix in Arkansas Three Months after Admission, 2002-2004**

	2002	2003	2004
ADL score	%		
0	7.2	7.4	6.8
1	2.9	2.8	2.9
2	4.9	4.3	4.5
3	3.3	3.9	3.7
4	5.3	4.6	4.4
5	3.4	3.5	4.1
6	5.3	4.6	4.3
7	3.6	4.4	4.3
8	4.3	4.3	4.2
9	3.6	3.2	3.5
10	4.2	4.4	4.5
11	2.9	3.2	3.6
12	4.6	4.4	4.4
13	3.4	3.7	3.4
14	2.9	3.8	3.6
15	3.0	3.2	3.0
16	2.9	3.2	2.9
17	2.6	2.8	2.7
18	2.2	2.8	3.2
19	2.7	2.9	3.3
20	3.0	2.2	3.0
21	3.0	2.5	2.4
22	1.5	2.2	2.0
23	1.9	1.6	1.8
24	2.3	2.2	2.4
25	1.7	2.0	1.7
26	2.0	1.9	1.5
27	1.9	1.4	1.6
28	7.3	6.8	6.5
Mean ADL	12.34	12.27	12.30
N	2,991	4,118	4,071
CPS score			
0	14.1	14.1	15.0
1	14.9	14.7	15.1
2	16.0	17.2	18.1
3	33.0	34.4	32.4
4	6.5	5.9	7.3
5	8.8	7.6	6.8
6	6.7	6.2	5.5
Mean CPS	2.56	2.51	2.44
N	2,991	4,118	4,071

## Relationships between HCBS and Institutional Care

Table 9 shows utilization and expenditure of selected Medicaid programs over a 5 year period from 2000 to 2004. Using this data, we examined relationships between utilization and expenditures across programs over time (See Figures 6-8).

Figure 6 shows the numbers of persons served by a variety of Medicaid state plan and waiver services and three forms of institutional care: state funded MR/DD Human Development Centers, nursing homes, and ICF/MRs. Not all persons counted received services for a full year. The numbers of persons in nursing homes substantially exceeds the numbers served by waivers. However, the number of persons served under the State Plan receiving personal care (including Independent Choices) is considerable. The personal care coverage declined as those on waivers coverage grew. The numbers persons served by home health declined substantially in 2004.



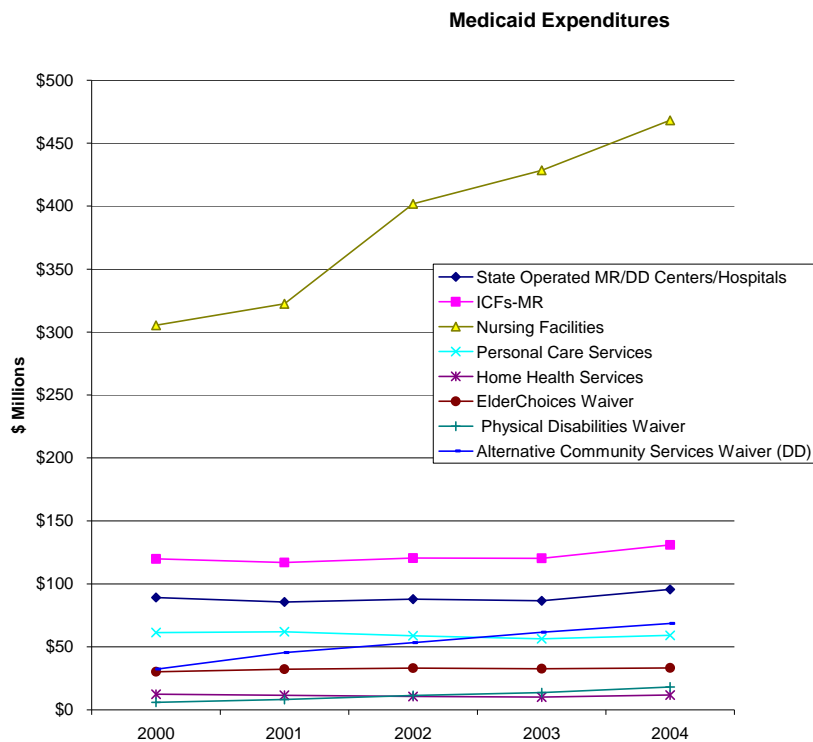
**Figure 6. Clients Served in Selected Programs in Arkansas, 2000-2004**

**Table 9: Utilization and Expenditures for Select Medicaid and Other Long-Term Care Services/Programs, Arkansas, 2000-2004**

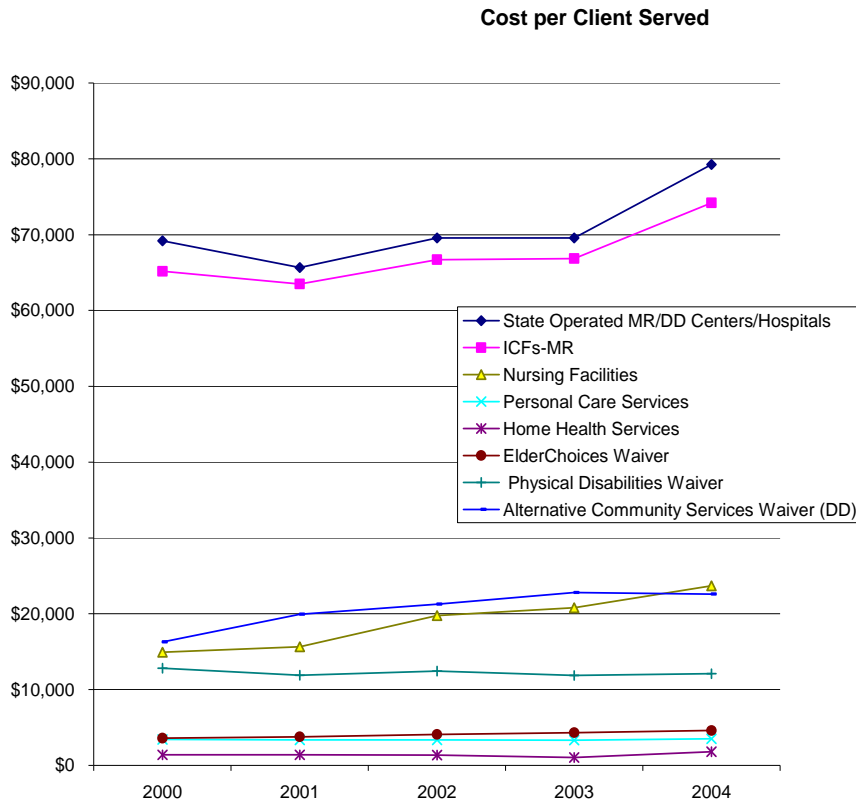
	2000		2001		2002		2003		2004	
	Persons Served	Annual Expenditures	Persons Served	Annual Expenditures	Persons Served	Annual Expenditures	Persons Served	Annual Expenditures	Persons Served	Annual Expenditures
Human Development (MR/DD) Centers	1,290	\$89,237,730	1,304	\$85,602,267	1,263	\$87,854,169	1,245	\$86,607,244	1,207	\$95,651,395
<b>Medicaid State Plan</b>										
Nursing Facilities	20,482	\$305,485,618	20,614	\$322,497,510	20,334	\$401,796,557	20,610	\$428,521,851	19,759	\$468,183,821
ICFs-MR	1,839	\$119,836,477	1,843	\$116,992,245	1,807	\$120,491,521	1,800	\$120,312,860	1,766	\$130,984,655
Personal Care Services	18,049	\$61,345,440	18,511	\$61,955,766	17,558	\$58,812,153	16,934	\$56,392,056	16,957	\$59,112,184
--agency	17,975	\$59,134,231	17,556	\$58,319,052	16,558	\$55,234,872	15,529	\$51,991,133	15,544	\$54,330,431
Independent Choices *	674	\$2,211,209	955	\$3,636,714	1,000	\$3,577,277	1,405	\$4,400,923	1,413	\$4,781,538
Home Health Services	8,946	\$12,361,123	8,266	\$11,493,450	7,918	\$10,648,438	9,797	\$10,082,414	6,515	\$11,660,995
Targeted Case Management	32,800	\$23,127,081	29,450	\$14,370,889	36,615	\$22,083,928	33,465	\$13,318,512	12,213	\$4,027,979
Private Duty Nursing	245	\$13,426,768	245	\$13,010,828	235	\$13,638,477	183	\$9,631,729	149	\$8,573,911
<b>HCBS Waivers</b>										
ElderChoices	8,439	\$30,230,416	8,602	\$32,304,956	8,102	\$33,019,467	7,600	\$32,655,774	7,223	\$33,227,062
Alternatives for Adults w. Physical Disabilities	461	\$5,905,813	691	\$8,205,509	918	\$11,424,060	1,152	\$13,672,619	1,501	\$18,153,903
Alternative Community Services (DD)	1,986	\$32,335,490	2,283	\$45,519,360	2,510	\$53,351,117	2,699	\$61,478,898	3,034	\$68,528,531
Assisted Living	Not applicable because waiver began in 2003						14	\$48,631	75	\$619,683

Figure 7 traces the amount of money spent on each of these programs. The Medicaid expenditures for nursing home care dwarf the rest and have been rising the fastest. Waiver expenditures and MR-DD institutional services have been rising slowly, if at all.

Figure 8 examines the costs per client served. Care for persons with MR/DD is very expensive. The differences in per person between those cared for in state run facilities and those in MR-ICFs are modest. Both rate considerably more than the cost of MR-DD waivers, and all are higher than nursing home costs per client. Nursing home care is substantially more costly than community based care.



**Figure 7. Expenditures for Selected Arkansas Programs, 2000 to 2004**



**Figure 8. Costs per Consumer Served in Selected Arkansas Programs, 2000-2004**

## Conclusions

### General Conclusions

With regard to developing HCBS services and rebalancing towards community care, Arkansas is an innovative state. It has drawn from programs and ideas from all over the United States, typically developing a pilot in one or two regions in the State and quickly bringing the program to scale. Locations for various pilots offer chances for innovation to multiple areas.

The State enjoys strong stable leadership in the Department of Human Services, and the enthusiastic encouragement of its Governor. Arkansas has made extraordinarily good use of grant funds to develop and apply new programs, and is now entering into a period of strategic

planning with even more grant funds available from the recently awarded Systems Transformation Grant.

Arkansas has achieved a strong degree of consumer direction, and, after a good experience with cash grants in its Cash and Counseling demonstration, is exploring further application of cash options. Arkansas has invested heavily in web-based information efforts and the development of materials that can be used directly by an informed group of consumers. It has also invested strategically in enhancing the strength of consumer constituencies.

The Rebalancing bottom line is impressive with reference to utilization of services for seniors and persons with disabilities, but less so for persons with developmental disabilities, where institutional care still dominates. Expenditures for nursing homes also continue to consume disproportionate resources in Arkansas.

The strengths in the Arkansas program are numerous. The barriers are some provider attitudes; fiscal issues, including the uncertainties associated with changing federal Medicaid policy; and the general fragmentation of various waiver and other programs. In an unrelated area, a pending court action around the financing of Arkansas public schooling could result in reallocation of state resources away from the rebalancing programs.

#### Issues for Future Observation

As this Rebalancing Research continues, we will be interested in exploring whether consumer directed options can become more widespread in the MR/DD area, and whether the institutional sector for MR/DD will finally dwindle. Also of interest is how Arkansas strategic planning will proceed. Arkansas is already a state that utilizes strategic planning goals, and will now find that process catalyzed by its System Transformation grant. The DAAS is even considering merging its three waivers (Elder Choices, Alternatives, and Assisted Living) into a

seamless waiver, and the pros and cons of that action will be interesting to explore. Also at issue is whether the MR/DD programs can become more unified with other long-term support program at both state and local levels.

Among the initiatives to track:

- The information technology development and its application to improving access and quality, including efforts to create a way of triaging consumers and investing resources where they will most help in nursing home transitions or diversions.
- The ongoing housing initiatives and the struggle to evolve an assisted living program that combines heavy care and livability. (Current regulations make the heavy care difficult although the livability is emphasized).
- Progress towards a single entry system utilizing a web-based assessment.
- The way the Next Choice program is specified and implemented, its take-up rates, and costs.
- The results of the test of SOURCE in terms of improving integration of acute and long-term care and its effect on existing long-term support programs, and also the results of the PACE implementation
- The experience with the reorganization of state government to incorporate the Department of Health into the new Department of Health and Human Services.