February, 2009

Dear Colleague,

Welcome to the first policy Insights Bulletin from The National Leadership Consortium on Developmental Disabilities (NLCDD). This is the expanded version of the bulletin which is also found at www.nlcdd.org. NLCDD was formed in 2006 to focus on key leadership development issues in the field of services and supports for people with intellectual and developmental disabilities. One of our efforts is a series of week-long intensive leadership development institutes focused on emerging leaders in the field. As the generation of professionals who have been in leadership roles for so long are retiring, new leaders are stepping up to move forward the agenda of full community inclusion, self-determination and person centered supports and services.

As a supporter of participants in our week-long Leadership Institutes, Liberty Healthcare is interested in the implications of changes in public policy as they impact people with intellectual and developmental disabilities. Thanks to Liberty Healthcare’s support, Robert M. Gettings has agreed to undertake an analysis of key issues that impact people with I/DD today, as they are unfolding. Liberty Healthcare Corporation exercises no editorial control over the content.

This first bulletin is one of a series developed by Mr. Gettings who, for three decades, led the National Association of State Directors of Developmental Disabilities Services. He is one of this nation’s leading experts on public policy as it impacts people with intellectual and developmental disabilities.

The National Leadership Consortium on Developmental Disabilities, which I co-direct with Nancy R. Weiss, is a project of the University of Delaware's Center for Disabilities Studies.

We are interested in your feedback on this bulletin and on future topics to be explored. Please feel free to contact me at sme@udel.edu.

Best wishes,

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Reassessing the Impact of Managed Care in the Developmental Disabilities Sector

In the mid-1990s, knowledgeable observers were predicting that it was only a matter of time before state governments began to apply the principles of managed health care to the delivery of publicly-funded services for individuals with intellectual and developmental disabilities (I/DD). For a variety of reasons, managed care largely fizzled within the developmental disabilities sector while thriving in the acute health and behavioral health sectors.

In recent years, however, a number of states have been granted authority to apply the principles of managed health care to the delivery of Medicaid-funded long-term services. Most of these plans are targeted to low-income frail elders and other adults with physical disabilities, but a few also encompass specialized services to persons with intellectual and developmental disabilities. Why are states moving in this direction? Are we on the brink of a revival of interest in managed care for the I/DD population? How do key elements of contemporary Medicaid managed long-term care plans compare to traditional managed health and behavioral health care plans? Which states are spearheading the thrust toward managed long-term services for the I/DD population? What steps have they taken to achieve their goals and what are the remaining challenges they face? What are the views of I/DD stakeholders in these states regarding the introduction of managed long-term services? Is it likely that other states will adopt similar approaches? If so, what lessons can be gleaned from the experiences of the early adopting states? And, how will public developmental disabilities services and service systems be impacted by managed care? These are among the key questions that will be examined in this report. The key study findings and conclusions are summarized in the inaugural issue of the Policy Insights bulletin series.

A subsequent bulletin in this series will examine the role of federal Medicaid and Medicare policy in promoting or impeding the development of state managed long-term services initiatives. In particular, this later bulletin will review the options available under current federal policies to states interested in creating a Medicaid managed long-term care program. It also will explore the ways in which the Centers for Medicare and Medicaid Services (CMS), the federal agency responsible for administering the Medicare and Medicaid programs, has permitted states over the years to utilize various statutory and regulatory waiver options to accomplish their system reform goals.

Aims, Organization and Methodology

This report focuses primarily on the experiences of the four states – Arizona, Michigan, Vermont and Wisconsin – which currently operate specialized services for individuals with developmental disabilities under the umbrella of a Medicaid long-term services plan. In Arizona, Michigan and Vermont, the plan is in effect statewide and incorporates essentially all publicly-funded long-term supports for the covered populations, while in Wisconsin the plan is being phased in over a multi-year period, with statewide implementation scheduled to be completed in 2011. Wisconsin’s plan limits participation to adults, 18 years of age or older; whereas in Arizona, Michigan and Vermont there is no lower age limit on the participation of persons with developmental disabilities.

The information contained in this report is based, in part, on publicly available documents, most of which can be found on the websites of the four target states (see relevant web links in the references listed at the end of this bulletin). These written materials were supplemented by information obtained during a series of telephone interviews with selected stakeholders in each state. The common aim of these interviews was to obtain first-hand perspectives on the impact of the state’s managed Long Term Care (LTC) plan on services to persons with developmental disabilities. With this objective in mind, interviews were arranged in each state with one or more
representatives of local provider organizations, statewide consumer advocacy groups, local single-point-of-entry agencies (including agencies that now function as managed care organizations), and at least two state officials (typically high-level officials from the state DD program office and the Medicaid or other state agency responsible for administering the overall managed LTC plan).

**Past Interest in Managed Long-Term Care**

The earlier spurt of interest in managed long-term services for persons with developmental disabilities was precipitated by several converging trends. First, during the 1980s, states began enrolling large numbers of Medicaid beneficiaries in managed health care plans in an effort to control the runaway growth in program outlays and increase the emphasis on wellness and preventive care. Most states focused initially on enrolling healthy, low-income women and children in managed health care plans; but, by the mid-1990s a growing number of states were enrolling individuals with chronic disabilities in such plans, including persons with developmental disabilities. Given the large – and rising – portion of total Medicaid outlays consumed by health and long-term services for elders and other persons with chronic disabilities, state officials recognized that finding cost-effective approaches to serving this segment of Title XIX beneficiaries was key to containing the future growth in Medicaid outlays. Managed care appeared to offer some intriguing possibilities.

Second, by the mid-1990s a number of states had created (or were actively engaged in designing) behavioral health plans for Medicaid beneficiaries with chronic mental illnesses. Like the acute and preventive health plans that preceded them, these behavioral health plans applied managed care principles to the financing and delivery of mental health services. States typically contracted with a private, for-profit behavioral health firm which received monthly capitated, per participant payments, adjusted in accordance with the predicted service needs of enrollees. The managed care entity was contractually obligated to provide the range of covered services needed by each eligible plan enrollee and was at financial risk should it over spend the total payments received from the state.

By the mid-1990s, a number of behavioral health organizations were examining the possibility of expanding the scope of their operations to include long-term services for Medicaid-eligible persons with intellectual and developmental disabilities. Policymakers in these states also were interested in expanding the reach of existing managed care arrangements to the I/DD population – especially in states where services to persons with mental illness and developmental disabilities were co-managed at the state and/or sub-state level. The practicality of this approach became evident in 1998 when Michigan became the first state to receive approval from CMS to operate specialty services for persons with mental illnesses, developmental disabilities, and substance abuse disorders under managed care contracts with local mental health boards.

Finally, despite healthy rates of growth in state and federal spending, waiting lists for I/DD community services continued to grow longer and longer in many states. As state policymakers began searching for ways to assure universal access to needed services while placing future outlays on a sustainable course, managed care appeared to be a promising approach. Proponents of managed care emphasized the savings which could be realized by replacing high cost services with more affordable and flexible support arrangements. Their contention was that the only way to achieve this objective was to wrap all existing sources of financial support into a single, capitated funding stream and hold the managed care entity(ies) accountable for ensuring that all plan enrollees gained access to needed supports at aggregate expenditures no greater than the total capitated payments received from the state.

Opposition to the introduction of managed care, however, was strong among disability advocates as well as many I/DD professionals. At the time, the mass media was full of reports recounting the excesses of managed health care. Like their fellow citizens, many DD stakeholders had been denied, or seen friends and family members denied, medical services by corporate health plans more interested in protecting the bottom line than
in assuring that their enrollees received the care they required. As a result, skepticism about introducing managed care to the I/DD service sector ran high.

This opposition occurred at a time when many states were expanding community I/DD services at a brisk pace, which tended to reduce pressure to introduce managed care techniques as well as other radical system reforms. In the early 1990s, CMS began allowing states to substantially expand enrollments in their Medicaid Home and Community-Based waiver programs. In July, 1994 CMS formalized this policy by issuing revised Home and Community-Based Services (HCBS) waiver regulations that eliminated the agency’s so-called “cold bed” rule, which linked the maximum number of persons who could be served in a given waiver program to the state’s institutional capacity. States still were required to specify in their waiver requests the unduplicated number of individuals they intended to enroll. But, henceforth, this information was to be used solely to calculate the cost-effectiveness of the proposed waiver services. [N.B., Not incidentally, the waiver utilization and expenditure caps protected states from having waiver services treated as an open-ended entitlement, thus allowing states to regulate program outlays within appropriation levels approved by the state legislature.] This policy change was especially advantageous to state/local I/DD service systems. Due to the substantial sums of general revenue dollars already invested in community services, many states were able to expand I/DD waiver services throughout the second half of the 1990s and into the 2000s with only modest increases in state and local expenditures. Between 1992 and 2002, for example, the number of HCBS waiver participants with intellectual and developmental disabilities increased by more than fivefold, growing from 62,429 to 373,946. During this same period, total HCBS waiver expenditures on behalf persons with I/DD grew from $1.65 billion to $13.22 billion, or by over 800 percent.

Moreover, commercial health plans, upon further study, discovered that successful cost avoidance strategies in the health care and behavioral health sectors (e.g., minimizing the use of hospital emergency rooms; pre-authorizing referrals to medical specialists; and limiting the need for hospital admissions through improved access to out-patient care) were not likely to yield the same savings in the I/DD service sector. With funding tied to wrap-around capitated payment rates, behavioral health plans, for example, had strong incentives to minimize the number and length of inpatient admissions to mental hospitals and psychiatric units in general hospitals by investing in expanded outpatient services and using pro-active medication management techniques. But, the long-term support needs of persons with intellectual and developmental disabilities are far less episodic in nature than those of individuals with recurring mental illnesses and, consequently, less susceptible to such cost-avoidance strategies.

In addition, private health insurance policies usually include some coverage of mental health services that can be expanded through state insurance statutes [e.g., minimum coverage requirements and equal access (parity) laws], thus reducing demand for state-funded mental health services. There is no equivalent private insurance coverage within the I/DD sector. Government is virtually the sole payer for I/DD long-term services and, consequently, there are few opportunities to shift cost to the private sector. Many states, furthermore, had substantially reduced the number of persons residing in public I/DD treatment centers, leaving a residual population which would be expensive to serve regardless of their place of residence. Few, if any, states, therefore, could expect to achieve large savings by adopting a managed care strategy that emphasized further deinstitutionalization.

**Key Features of the Managed Care Systems of Four States**

Yet, despite these hurdles, four states decided to include long-term supports for individuals with intellectual and developmental disabilities in their Medicaid managed long-term services initiatives. Why did they elect to include the I/DD population in these initiatives? And, what are the similarities and differences among the approaches adopted by these states? This section of the report reviews the principal features of the Medicaid
managed long-term services programs in Arizona, Michigan, Vermont and Wisconsin. We begin by examining the factors influencing the decision by these states to adopt a managed care framework and then proceed to analyze the main operating components of each state’s program.

Motivating Factors

Each of the four states pursued its own unique pathway toward a managed long-term support system, although, as will become evident to the reader, the one, over-riding factor motivating each of these states was a recognition on the part of policymakers that the state’s existing course was fiscally unsustainable. Still, as we shall see, key elements of the strategy adopted by each state were heavily influenced by the history of disability services within the state.

Each state took advantage of various waiver authorities in the Medicaid program, the Section 1115 Waiver/Demonstration Authority and Section 1915(b) and 1915(c) Waiver Authorities.

Enacted in 1962, Section 1115 of the Social Security Act delegates broad authority to the Secretary of Health and Human Services to waive various provisions of the Act in order to permit “… any experimental, pilot or demonstration project which, in the judgment of the Secretary, is likely to assist in promoting the objectives” of programs authorized under the statute. While over the years this authority has been used to launch experiments related to various programs established under the Act (including Supplemental Security Income (SSI) and Temporary Assistance for Needy Families [TANF; former Aid to Families with Dependent Children (AFDC)], in recent years it has been used primarily to establish broad-scaled Medicaid reform initiatives in selected states, with the principal focus on managed health care and long-term services arrangements.

Section 1915(b) empowers the Secretary of Health and Human Services to grant waivers to the “freedom of choice” provision and certain other requirements of federal Medicaid law (i.e., Section 1902(a)(10) of the Act, which prohibits a state from restricting a beneficiary’s choice among qualified providers of a Medicaid reimbursable service). These so-called “freedom of choice” waivers permit states to mandatorily enroll beneficiaries in managed health care plans. Section 1915(c) of the Act empowers the Secretary to approve waivers of certain statutory requirements (the statewide availability of services; comparability in the provision of services to all eligible beneficiaries; etc.) in order to furnish home and community-based services to Medicaid beneficiaries who otherwise would require care in a Title XIX hospital, nursing facility or ICF/MR. The Medicaid managed long-term services programs in Michigan and Wisconsin are based on a combination of waivers granted under Section 1915(b) and Section 1915(c) of the Act, with the (b) waivers allowing the state to adopt a managed care operating format and the (c) waivers permitting the state to claim reimbursement for elements of home and community-based services which otherwise would not be reimbursable under federal Medicaid law. Both Section 1915(b) and Section 1915(c) were initially added to Act as part of the Consolidated Omnibus Budget Reconciliation Act (COBRA) of 1985.

Arizona. While the balance of factors was different in each state, Arizona’s experience clearly stands apart. Prior to 1982, the State of Arizona did not participate in the Medicaid program. The health and long-term services available to low-income, uninsured citizens at the time were provided by county governments, with some financial assistance from the State. Faced with increasing demand for health care coverage combined with a recession-induced fiscal crisis, however, by the early 1980s several county assistance agencies were on the brink of bankruptcy. The State, not surprisingly, got drawn into the crisis and decided to negotiate a deal with the federal government under which the State would receive federal Medicaid payments for health care services provided to low-income individuals and families in exchange for operating those services in compliance with federal standards. This agreement was formalized in a Sec. 1115 demonstration/waiver program called the Arizona Health Care Cost Containment System (AHCCCS).
The principal advantage of the AHCCCS waiver/demonstration program was it allowed the State to share with the federal government a wide range of program costs which heretofore had been borne entirely by state and local governments. The other significant, but less apparent, advantage was that the State was able to mandatorily enroll AHCCCS beneficiaries in a managed health care program, a step not permitted at the time under standard Medicaid policy. When a long-term care component [called the Arizona Long Term Care System (ALTCS)] was added to the AHCCCS waiver/demonstration program in the late 1980s, the basic requirements governing the new program were a mirror image of the original AHCCCS managed care requirements. There were (and are) two components of the ALTCS program – one focused on elders and adults with physical disabilities and the other on individuals with developmental disabilities.

**Michigan.** Beginning in the mid-1980s, the State Department of Mental Health [which later was folded into the umbrella Department of Community Health (MDCH)] launched an initiative aimed at giving county mental health boards [later redesignated as Community Mental Health Services Programs (CMHSPs)] greater flexibility in administering state and federal funds in return for developing stronger managerial capabilities. The Department established a set of criteria for allowing enhanced county managerial control. Any board that was able to demonstrate that it had the requisite capabilities to plan, develop and manage a catchment area-wide network of MH/DD services was certified a “full service” board. Various federal and state funding streams were amalgamated and full service boards operated under a “global budget,” which afforded them greater latitude in tailoring services and supports to the needs of each service recipient.

By the early 1990s, all 49 CMHSPs had been certified as full service programs and were operating under global budgets. Numerous steps had been taken to decentralize decision-making, strengthen the boards’ planning, fiscal, and network management capabilities. In addition, the Department established methods of holding the boards accountable for their performance. All of these actions were important precursors to the managed long-term services system that would follow. By the late 1990s, it became clear to MDCH officials, CMHSP managers and external advocates that, if quality services were to be made available to all eligible individuals and system-wide finances stabilized over the long haul, further actions would be necessary to expand access to federal funding and streamline the management of available public dollars at the local level. The State Medicaid plan already included funding for a wide array of specialty services for persons with mental illnesses, developmental disabilities, and substance abuse problems. The State plan covered targeted case management services, personal care, rehabilitative, clinic and ICF/MR services. In addition, the State was operating two home and community-based waiver programs targeted to persons with developmental disabilities. The opportunities to capture additional federal financial participation through standard Medicaid policy, therefore, were very limited.

The solution MDCH officials came up with, following extensive discussions with system stakeholders as well as federal CMS officials, was to transform the state’s 49 (now 46), county-based CMHSPs into a network of pre-paid, capitated managed care organizations with responsibility for overseeing all publicly-funded mental health, developmental disabilities, and substance abuse services. The transformation was accomplished through a combination of statutory waivers granted under Section 1915(b) and (c) of the Social Security Act. Participants in the plan were to receive their primary and acute health services through Medicaid managed health care plans or on a fee-for-service basis. Individuals eligible for Section 1915(c) home and community-based waiver services would continue to receive services through the waiver program. But, as a result of the Section 1915(b) waivers, wrapped around these services would be Medicaid-funded benefits for persons who did not qualify to receive HCB waiver services (primarily persons with mental illnesses and substance abuse disorders, but also some individuals with developmental disabilities). In effect, the combination of the two sets of statutory waivers, allowed Michigan to claim federal financial participation (FFP) for all persons meeting federal-state Medicaid eligibility criteria and in need of specialty mental health, developmental disabilities, and substance abuse services, without reference to whether they otherwise would need institutional services. Moreover, as a result of the Section 1915(b) waivers, the State was allowed to consolidate all local, state and
federal Medicaid funding sources and administer them on a capitated payment basis through a statewide network of Pre-Paid Inpatient Health Plans (PIHPs) operated by the CMHSPs.

**Vermont.** The Global Commitment (GC) to Health was developed in response to a major crisis in Medicaid financing. The state was facing a $600 million gap in funding for its Medicaid program in 2004-05 and was looking for a way to sustain the expansions in health and long term services that had been instituted over the years. The key goal of the Section 1115 waiver/demonstration program which state officials negotiated with CMS was to gain the flexibility necessary to both sustain existing health and LTC initiatives and make new, “upstream investments” in improving access to health and health-related services. In order to secure CMS’s backing, the state agreed to assume a degree of financial risk by operating its program under a global federal spending cap. The cap was set at $4.7 billion spread over a five-year period.

One of the major areas of flexibility gained by the state was the ability to include in the GC initiative state expenditures for health and health related activities which heretofore had not qualified for federal Medicaid financial participation. In other words, the funding base for drawing down federal Medicaid payments became considerably broader under the GC waiver/demonstration program. The second major area of flexibility was the authority under GC for the state to make new and expanded investments with the “excess dollars” generated by expending less than projected amounts for Medicaid reimbursable services.

Developmental disabilities services were rolled into the Global Commitment along with all other components of the state’s Medicaid program except for long-term services to low-income elders and other adults with physical disabilities. The latter services are provided under a separate Section 1115 waiver/demonstration program (called “Choices for Care”) which was approved around the same time as the Global Commitment. Managed care-like techniques had been used in administering DD services for more than a decade before the Global Commitment waiver/demonstration program was initiated. State officials stressed at the time (and still indicate) that they had no intention of altering the financing and management of DD services by folding them into the Global Commitment. And, indeed, as will be discussed in further detail below, few, and mostly unrelated, changes have occurred in the management of DD services over the past three years.

**Wisconsin.** Discussions concerning long-term care reform began in 1994 within the State Department of Health and Family Services [DHFS; recently renamed the Department of Health Services (DHS) when children and family services were transferred to a separate, cabinet-level agency called the Department of Children and Families]. An intra-departmental work group hammered out a set of principles to guide the long-term reform effort; but in 1995 the director of DFHS announced that the Department would be bidding out the administration of all health care and long-term supports for persons with chronic disabilities to one or more nationally recognized health management organizations. This plan, when announced, created great consternation within the aging and disabilities communities. Following legislative intervention, a compromise plan was worked out between the Department and the advocacy community. The main features of this compromise, announced in December, 1997 and subsequently enshrined in law in 1999, specified that: (a) the new managed care concepts would be piloted in a limited number of counties and evaluated before legislative authority was sought to implement the program statewide; (b) the program, to be called Family Care, would encompass long-term services only; (c) the Wisconsin Partnership program, which involved the co-management of health and long-term care benefits under a single umbrella plan, would be operated separately from the Family Care (FC) program, with FC participants given the option of enrolling in either Family Care (LTC services only) or a Partnership plan offering an integrated array of health and long-term supports; and (d) all FC enrollees would have the option of self-directing their services and supports.

Gov. Tommy Thompson, as part of his January 1998 State of the State Address, called for the creation of the Family Care program. The pilot counties were selected using an RFP process later that year. Five of the pilot counties chose to offer Family Care services to all eligible target populations (i.e., frail elders; adults with physical disabilities; and adults with developmental disabilities), while one county (Milwaukee Co.)
elected to limit services during the pilot period to eligible seniors. A subsequent independent assessment of the pilot programs concluded that Family Care had:

- Substantially increased participant choice and access to needed services, while improving quality by focusing on social outcomes;
- Eliminated waiting lists for services in the participating counties;
- Improved access to information concerning long-term service options among the target populations;
- Achieved a high-level of consumer satisfaction; and
- Saved an average of $452 monthly per participant in four out of the five participating counties during 2003 and 2004 (with smaller savings in the fifth county) when compared to previous fee-for-service funding arrangements.

Based on these findings, Gov. Jim Doyle, in his 2006 State of the State Address, announced plans to implement the Family Care program statewide by 2011. As an initial step in this direction, planning grants were awarded to ten groups located in various catchment areas across the state. At the end of the planning process, the expectation was that some or all of the participating organizations would ban together to form a Managed Care Organization (MCO) that would contract with DHS to provide Family Care services. In most cases, these MCOs would serve multi-county catchment areas, with the pilot counties serving as the base for an expanded, multi-county alliance in selected areas of the state.

**Key Components**

Next let us examine the basic features of each state’s Medicaid managed long-term system before reviewing the manner in which various tasks (eligibility determination; quality management; the provision of health services) are handled within each state. This section looks at the foundations of each state’s approach to operating a managed long-term services system.

**Arizona.** One unique feature of the ALTCS model is that all health, behavioral health and long-term services are managed by a single Managed Care Organization (MCO), functioning under contract with AHCCCS, the single state Medicaid agency. While other states administer Section 1115 waiver/demonstration programs that integrate the delivery of health and long-term supports for individuals with chronic disabilities (e.g., TX, MA, FL, NY and MN), none of these programs currently include people with developmental disabilities among the eligible target populations and most operate in only selected areas of the state.

While the benefit package, eligibility requirements and the capitated payment structure are virtually identical for the two components of the ALTCS program, services to elders and persons with physical disabilities are administered differently than services to persons with developmental disabilities. Long-term services to frail elders and other persons with physical disabilities (EPD services) are managed by the AHCCCS agency through eight Program Contractors which function as MCOs. Initially, county governments were granted the right of first refusal to act as the sole MCO for ALTCS/EPD services within their respective geographic catchment areas (although some counties chose not to exercise this option). But, beginning in the Fall of 2000, AHCCCS expanded the number of ALTCS/EPD contractors and began offering beneficiaries a choice between at least two MCOs in each catchment area of the state.
In contrast, DD services are administered, statewide, under an exclusive contract between the AHCCCS agency and the Department of Economic Security (DES), with the department’s Division of Developmental Disabilities (DDD) functioning as the sole MCO for ALTCS/DD services. DES/DDD operates under the same contractual requirement as other AHCCCS program contractors. The one, significant difference is that ALTCS/DD funds are part of DDD’s annual budget and as such are subject to the annual appropriation process. In contrast, ALTCS/EPD contractors receive their funding (in the form of capitated payments) directly from the AHCCCS agency.

AHCCCS pays ALTCS program contractors prospectively on a capitated, per member, per month basis in a manner similar to its arrangement with acute care MCOs. AHCCCS uses a system of blended capitated rates. The rate includes the cost of nursing facility services (or ICF/MR facility services in the case of DD participants), acute medical care services, behavioral health services, case management (or service coordination) services, and an administrative cost allowance. These rates are based on AHCCCS fee-for-service rates, the program contractors’ financial statements, service utilization (encounter) data, and historical trends in program costs. Beginning October 1, 2005, the weighted average statewide capitation rate paid to ALTCS/EPD contractors was $3,171 per member, per month and $3,004 per member, per month for the ALTCS/DD contractor.

ALTCS services are funded by federal, state and county funds (with county funding applicable to ALTCS/EPD services only). The state’s matching share of ALTCS/DD services is appropriated by the legislature as part of the DES/DDD budget. In the early years of the ALTCS/EPD program, the counties paid most of the state’s matching share of service costs. In November 1997, however, the state legislature froze the county contribution level at the FY 1997-98 level and required the state and the counties each to pay 50 percent of any cost increases during FY 2000-01. In December 2001, the legislature created a revised state/county funding model for ALTCS/EPD services, effective in FY 2001-02 and thereafter. Under the revised formula, the legislature establishes the percentage of cost increases to be borne by the counties on an annual basis.

As of July 1, 2008, a total of 43,727 individuals were enrolled in the ALTCS program. Of this number, 20,198 were children and adults with developmental disabilities, while frail elders and other adults with qualifying physical disabilities made up the remainder of the enrollees. Slightly more children than adults were enrolled in the ALTCS/DD component of the program.

The number of individuals receiving ALTCS/DD services has grown steadily over the years. For example, in the mid-1990s the number of enrollees was approximate 7,000, or roughly one-third of the current enrollment. While new enrollments have leveled off in recent years, the total number of ALTCS/DD participants increases each year by about two to three percent, according to DDD officials.

**Michigan.** Under the initial, 1998 plan approved by the federal Health Care Financing Administration (HFCA*), the CMHSPs were to function as Pre-Paid In-Patient Health Plans (PIHPs). These plans had to meet the federal criteria of an Organized Health Care Delivery System (OHCDS), a designation CMHSPs had previously carried under the state’s primary DD waiver program, called the Habilitation Supports waiver. Capitated payments to the CMHSPs were to be based on historic Medicaid payments and calculated monthly on a per-eligible recipient basis. Adjustments were made monthly to account for changes in the number of eligible individuals in each CMHSP catchment area. Separate capitated rates were established for developmental disabilities, mental health and substance abuse services. In the case of DD services, prior expenditures for Habilitation Supports waiver services and certain Medicaid state plan services (e.g., targeted case management (TCM) and ICF/MR services) were taken into account in calculating the initial capitation rates. Expenditures for services to children with developmental disabilities under the state’s Section 1915(c) children’s waiver program

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were excluded from the carve-out although no lower age limit was imposed on the receipt of Specialty Services under the plan.

The PIHP contracts between MDCH and CMHSPs included an arrangement under which the state and county governments would share the financial risk of furnishing services to all eligible individuals on an entitlement basis. Under this arrangement:

- The CMHSP assumed responsibility for 100 percent of cost over-runs up to 105 percent of the total annual contract amount.
- MDCH and the CMHSP shared evenly in cost overruns between 105 percent and 110 percent of the total annual contract amount;
- MDCH assumed all cost overruns exceeding 110 percent of the total contract amount; and
- CMHSPs could retain unexpended amounts between 95 percent and 100 percent of the total contract amount but were required to re-invest such “savings” in expanding and enhancing the quality of services to beneficiaries. All unexpended amounts below 95 percent of the total contract amount had to be returned to MDCH.

When the initial statutory waivers came up for renewal, HCFA pressured the state to adopt a competitive process of selecting PIHPs. HCFA officials argued that some of the CMHSPs – especially those serving sparsely populated areas of the state – lacked the managerial capabilities and the financial reserves to function successfully as a managed care organization. Michigan officials, with strong backing from disability advocates, county boards and provider organizations, were unwilling to abandon the local service delivery network that had been built over three decades. They were concerned that an open bidding process might seriously undermine the state’s person-centered goals. After lengthy negotiations, a compromise PIHP procurement plan was developed that set a minimum threshold for the number of eligible individuals (20,000) in any given PIHP catchment area. As a result, of the revised procurement plan, the number of PIHPs statewide was reduced from 49 (one per CMHSP) to 18 and many counties which previously had operated its own PIHP were required to join other nearby counties to form a PIHP.

The specifications of the revised procurement plan reflected the values of the state’s community mental health/developmental disabilities services system as it had evolved over the preceding thirty years. The process of planning services for all enrollees, for example, had to be person-centered and individualized. All services and supports had to be furnished in the least restrictive and most integrated setting consistent with the individual’s needs and designed to promote maximum community inclusion, participation, independence and productivity. Bids were solicited through an RFP (request for proposals) process in 2002. Several PIHP models emerged. In some catchment areas, a lead county was designed to act as the PIHP, with the other participating counties playing supportive roles. [N.B., In Michigan this approach often is referred to as the “hub and spokes” model.] In other catchment areas, the participating counties formed a separate corporation to function as the PIHP, with the participating counties overseeing the performance of this entity. Finally, in populous urban and suburban counties, with 20,000 or more eligible beneficiaries, the CMHSP functions, in effect, as the PIHP (although the functions of the CMHSP and the PIHP differ).

In recent years, the CMHSP in many counties has been spun off as a separate “mental health authority.” The county commissioners appoint the members of the authority’s board and channel the county’s share of service costs to the authority. The authority files regular progress reports with the county, but otherwise functions as an autonomous corporation. In some counties the CMHSP continues to function as a unit of county government, including in Detroit and Wayne County, the two most populous jurisdictions in the state.
The PIHP is responsible for receiving (in the form of capitated payments) and managing all Medicaid funding for specialized services to persons with mental illnesses, developmental disabilities and substance abuse disorders. The use of these funds is subject to the terms of a detailed contractual agreement between the PIHP and MDCH. The CMHSP continues to play a vital role in the management of community mental health, developmental disabilities and substance abuse services, even in counties where it no longer functions as the PIHP. By state statute, the CMHSP serves as the single-point-of-entry to public MH, DD an SA services. The CMHSP also manages all non-Medicaid dollars received from MDCH. In addition, some PIHPs contract with CMHSPs for the provision of services which they traditionally have furnished to eligible persons. In other cases, the CMHSP serves as the prime contractor for a wide array of services and supports furnished to participants in the Specialty Services program; the CMHSP in turn sub-contracts for some or all of those services with non-profit and proprietary service providers. Arrangements vary from one catchment area to another, but, as a general rule, the CMHSP works closely with the PIHP serving its area to ensure that eligible individuals gain access to the services and supports they need.

**Vermont.** There are four critical features of the Global Commitment waiver that deserve to be highlighted. First, a global cap is imposed on the total amount of federal Medicaid payments the state may receive. The state is allowed to draw down no more than $4.7 billion in federal reimbursements for services over the five years the demonstration program is in effect. By most assessments, the cap is generous, since state officials initially estimated that expenditures for covered Medicaid services would run a little under $4.2 billion over the five year period. And, thus far state officials report expenditures have remained well within the cap. But, should the state reach its federal spending cap, it would face some difficult choices. It could: (a) cover excess expenditures out of 100 percent general fund dollars; (b) trim program benefits; (c) tighten eligibility; (d) impose co-payments and deductibles on non-categorically eligible populations; (e) reduce expenditures for non-Medicaid health programs where “excess” Medicaid revenues previously have been diverted; or (f) rely on a combination of such actions.

Second, the GC waiver allows Vermont to establish a managed care organization within the structure of state government. The Office of Vermont Health Access (OVHA), an independent executive branch agency, performs this and other state Medicaid managerial functions.

Third, the GC waivers afford the state the flexibility to use federal Medicaid funds to cover non-Medicaid health care costs with the “savings” (i.e., expenditures below projected outlays) realized through program operations. If aggregate expenditures are below projections in any given year, the state is allowed to use the “excess” amount to cover a broad array of non-Medicaid health costs. Within certain limits (e.g., the actuarial soundness of the premium), the state, in effect, controls the amount it pays itself, which means it can regulate the amount of “excess” revenues available after all Medicaid bills have been paid. The state’s GC waiver agreement with CMS lists a variety of ways in which such “excess” revenues might be deployed. Among the possible uses of such funds initially identified by the state were mental health and substance abuse programs, community-based treatment for sex offenders, tobacco cessation programs, newborn screening, domestic violence reduction programs, emergency medical services, school-based nursing services and support for Vermont educational institutions, such as the state’s medical school and other training programs for health care and dental professionals. Thus far, OVHA officials report, the state has been able to redeploy about $55 million annually to cover such investments in the improved health and welfare of Vermont citizens.

Finally, the GC waiver gives Vermont additional flexibility to reduce benefits, increase cost-sharing requirements and wait-list recipients who qualify for benefits under optional eligibility categories or as part of “expansion” populations. Although state officials had no plans to trim benefits or increase cost-sharing for selected services when the GC waiver/demonstration program was designed (and have not done so to date), they asked for this expanded authority (compared to steps that can be taken under conventional Medicaid policy) in case it should become necessary to bring expenditures into line with the global federal
funding cap. This expanded authority does not apply to services for persons categorically eligible for Medicaid services, including elderly or disabled beneficiaries who qualify on the basis of SSI eligibility.

**Wisconsin.** Underlying both the Family Care and the Family Care Partnership models are two principal operating components -- an Aging and Disability Resource Center (ADRC) and a Managed Care Organization (MCO). The concept of an Aging and Disability Resource Center was pioneered in Wisconsin. Subsequently, the federal Centers for Medicare and Medicaid Services (CMS) decided to promote the nationwide adoption of the model, and many states (usually with federal assistance) have established ADRCs over the past few years.

Each Family Care catchment area will have one or more ADRCs to help people with chronic disabilities and their families locate and mobilize the resources necessary to address their needs. These centers also are responsible for Family Care intake, eligibility determination and assessment of needs, as well as for providing prevention, early intervention and outreach services designed to help individuals maintain their independence. As of September 1, 2008, 28 ADRCs, serving 36 counties, were in operation. DHS was reviewing ADRC applications from two additional organizations and had received letters of intent from six other potential applicants.

In addition to one or more ADRCs, each of the ten Family Care catchment areas must have a Management Care Organization (MCO) to assist eligible persons in arranging and managing their services. These MCOs receive a fixed, per capita amount of funding each month from DHS on behalf of enrollees in the Family Care program. The amount of the capitated payment varies according to the acuity-based mix of individuals served by the particular MCO. The results of a standardized, individual assessment of each enrollee’s long-term support needs are taken into account in determining the acuity factor, which in turn is used in arriving at a single, monthly, blended capitated payment rate per enrollee. Actual expenditures on behalf of any given enrollee, however, might be higher or lower than the capitation figure as long as aggregate MCO expenditures do not exceed the agency’s total services budget.

The Management Care Organization serves as the hub of the state’s redesigned long-term care delivery system. It is responsible for: (a) developing a comprehensive network of providers of long-term services (as well as health care providers in the case of Partnership programs); (b) accepting prepaid capitated payments from DHS to provide all services covered by the benefit package; (c) purchasing or providing such services based on the contents of an individualized service plan designed by the enrollee in collaboration with his or her interdisciplinary team (IDT); (d) providing care management services on an ongoing basis to protect the health and well-being of enrollees and to support the achievement of enrollees’ personal-experience outcomes; and (e) assuring and continually improving the quality of care and services furnished to Family Care enrollees.

As of September 1, 2008, eight Managed Care Organizations (MCOs) were serving Family Care enrollees in a total of 22 of the state’s 72 counties and three Family Care Partnership programs were serving enrollees in 13 counties. Total enrollment in the Family Care program had reached 15,688, while enrollment in the Family Care Partnership program was 2,994 (not including the 869 served by the PACE program in Milwaukee). Slightly more than 4,000 adults with developmental disabilities (4,116) were enrolled in managed long-term services, with the vast majority (3,894) participating in Family Care services.

**Program Benefits**

**Arizona.** DDD contracts with four AHCCCS-participating health maintenance organizations (HMOs), or health plans, to provide primary, acute and preventive health services to ALTCS/DD participants. The four health plans receive sub-capitation payments from DDD, based on the number of ALTCS/DD eligible individuals they
enroll and, like all other AHCCCS-qualified health plans, they bear the financial risks of expenditures in excess of the aggregated capitated payments received from DDD. In most areas of the state, ALTCS/DD participants are permitted to choose between two qualified health plans serving their area of the state. Following the passage of the federal Deficit Reduction Act of 2005, CMS approved the state’s request to have AHCCCS health plans designated as Special Needs Plans. As a result, qualified health plans in Arizona (including those under contract with DDD) may integrate Medicaid and Medicare funding of health services for dually eligible individuals.

Long-term services and supports are purchased by DDD through a network of over 3,000 “qualified vendors” and “individual independent providers”. A “qualified vendor” is a public or private non-profit or for-profit agency – or a professional in independent practice – that has a formal contractual agreement with DDD. An “individual independent provider” (IIP) is a person who becomes “qualified” by meeting certain DDD requirements, completing a certification process, and entering into an Individual Service Agreement with DDD. Individuals and families eligible to receive ALTCS/DD services may: (a) identify their own IIP or an individual willing to become an IIP; (b) select from a list of IIPs maintained by DDD; (c) chose a qualified vendor they know; (d) select from a list of qualified vendors furnished by DDD; or (e) choose to be automatically assigned a qualified vendor by DDD. All service arrangements are completed by support coordinators on the staff of DDD’s seven regional offices. DDD does not procure services through an intermediary or managed care organization and does not make sub-capitated payments to provider agencies furnishing long-term supports. Providers instead receive payments based on a published, unit cost rate schedule.

The home and community-based services benefit under the ALTCS/DD program covers the following types of services: home health nursing and nursing aid services; attendant care and housekeeping services; respite services; transportation; day treatment and training programs; and habilitation services in residential and non-residential settings. DDD also provides support coordination services to all ALTCS participants and institutional care for those who qualify. All admissions to institutions are subject to the prior approval of the Assistant DES commissioner for developmental disabilities services.

**Michigan.** A PIHP is afforded broad latitude in how it deploys funds received via capitated payments. It may purchase services otherwise available through the state’s Medicaid plan or acquire more individualized, cost-effective services and supports that reflect the recipient’s needs and desires. MDCH has delineated the following alternative developmental disabilities services and supports which a PIHP may purchase on behalf of eligible program beneficiary, although, under the terms of the state’s agreement with CMS, Medicaid service claims are not limited to this specific range of services and supports:

- Crisis stabilization and response;
- Assessment and evaluation;
- Support and service coordination;
- Prevention and consultation services;
- Community living supports (in-home and out-of-home support staff; and assistive technology (adaptive equipment and supplies; and environmental modifications);
- Housing assistance;
- Skill-building assistance;
- Family support services, including respite care and family skills development;
- Enhanced health care services; and
- Assistance with challenging behaviors.

For individuals who qualify for benefits under the state’s Section 1915(c) Habilitation Supports waiver program, expenditures are reported separately; but, depending on the individual’s needs and desires, these services can be supplemented with state plan services and services available under the Section 1915(b) waiver program.

**Vermont.** The long-term services and supports available to persons with developmental disabilities did not change as a result of implementing the Global Commitment to Health. The Section 1915(c) waiver program through which most services to persons with developmental disabilities were financed prior to 2005 no longer exists; but, the same services remain available under the GC waiver/demonstration program. These services include: service planning and coordination; home supports (including shared living/home provider; supervised living; group living; staffed living; and ICF/DD services); employment services; community supports; family supports; and clinical and crisis services. The one minor change is that Flexible Family grants, which used to be funded with state general revenue dollars, have been rolled into the GC funding bundle. These grants are designed to assist families caring for an eligible child with disabilities in their homes.

There are two types of services for children with developmental disabilities which continue to be offered on a fee-for-services basis under the state’s Medicaid plan: children’s personal care services; and high technology home care services.

**Wisconsin.** Under the Family Care model, existing long-term care programs and benefits are combined in a single, flexible funding stream and transmitted to CMOs in the form of capitated payments. Enrollees are eligible to receive the same types of long-term supports that they presently receive under the state’s existing Medicaid home and community-based waiver programs, including, in the case of adults with developmental disabilities, services offered through the Community Integration Program (CIP), the Community Options Program waiver (COPW), and the Brain Injury Waiver Program (BIW). These services include: adaptive aids; adult day care; adult family home; Certified Residential Apartment Complex; children’s foster care and treatment foster care (for individuals between age 17 years, nine months and 22); communication aids/interpreter services; Community-Based Residential Facility services; consumer education and training; counseling and therapeutic resources; daily living skills training; day services; financial management services; home delivered meals; home modifications; housing counseling; personal emergency response system services; prevocational services; relocation services; respite care; self-directed services support broker; skilled nursing services; specialized medical equipment and supplies; supported employment; supportive home care; transportation; and vocational futures planning.

In addition to such waiver-related services, the Family Care benefit also includes certain Medicaid state plan (or Medicaid “card”) services closely related to long-term care. These services include: disposable medical supplies; durable medical equipment; home health; mental health and substance abuse services; occupational, physical and speech therapy; personal care; skilled nursing services; nursing facility services; and intermediate care facility services for persons with mental retardation (ICF/MR).

**Eligibility**

**Arizona.** To qualify for ALTC/DD services, a child or adult must meet DDD’s statutory test of eligibility and also the financial and functional eligibility criteria of the ALTCS/DD program. The basic eligibility criteria set forth in Arizona law specifies that a person must: (a) be a U.S. citizen or a qualified immigrant; (b) an Arizona resident with a Social Security number; (c) have a qualifying disability that occurred prior to age eighteen and
which imposes substantial functional limitations in at least three out of seven areas of major life functioning (self-care; receptive or expressive language; learning; mobility; economic self-sufficiency; capacity for independent living; and self-direction); and (d) for children under age 6, have a significant developmental disability and for persons over 6 years of age, have one of the following diagnoses: cerebral palsy; autism; epilepsy; or a cognitive disability.

In addition to the above statutory criteria, an individual must meet financial and medical eligibility criteria that are specific to the ALTCS program. The basic test of financial eligibility is that an individual’s income may not exceed 300 percent of the federal benefit rate, the amount the Social Security Administration uses in determining eligibility for Supplemental Security Income (SSI) benefits ($637 a month for single individuals as of January 1, 2008). In addition, an individual’s resources may not exceed $2,000, after certain non-countable resources are excluded (e.g., the value of a home, an automobile, etc.). Nearly all ALTCS participants qualify on the basis of the SSI test.

All applicants for ALTCS services are subject to Pre-Admission Screening (PAS), conducted by a registered nurse or social worker employed or retained by the AHCCCS agency, to determine if they are at imminent risk of institutionalization in a nursing facility or ICF/MR. If necessary, the registered nurse or social worker may refer a case to a AHCCCS physician for a final determination. AHCCCS has developed five standardized PAS instruments: one is used in screening persons who are elderly or otherwise physically disabled. The remaining instruments are tailored to four age groups of persons with developmental disabilities (0-3; 3-6; 6-12; and 12+). All of the PAS instruments use weighted scores to provide information on the functional, medical, nursing and social needs of the individual. The results of the screening are used in determining the ALTCS eligibility of the applicant. The needs of ALTCS recipients are reassessed on an annual basis as well as at any time there are major changes in the person’s health/functional status.

**Michigan.** As part of 1995 revisions to Michigan’s Mental Health Code, the state legislature adopted a new definition of a “developmental disability” which parallels the functional federal definition of the term. To qualify for services, an individual must have a mental or physical impairment occurring prior to age 22 which is likely to continue indefinitely and causes substantial functional limitations in at least three out of the following seven areas of major life activity: self-care; receptive and expressive language; learning; mobility; self-direction; capacity for independent living; and economic self-sufficiency. An individual meeting the above criteria also must be in need of a combination of specialized or generic care, treatment and services of lifelong or extended duration.

Any individual meeting the above definition who is financially eligible for Medicaid services may receive specialty services and supports under Michigan’s combined Section 1915(b)/(c) waiver program. Only individuals in need of ICF/MR level of care may participate in the state’s Section 1915(c) Habilitation Supports waiver program. But, unlike arrangements in other states, an individual with a qualifying developmental disability may receive Medicaid-funded community supports through the 1915(b) portion of the Specialty Services program, even though he or she otherwise would not require services provided in an ICF/MR.

**Vermont.** To be found eligible for developmental services in Vermont, a school aged child or adult must have a diagnosis of mental retardation or a pervasive developmental disorder and exhibit substantial deficits in adaptive behavior occurring before age 18. The term “mental retardation” is defined in state law as “significantly sub-average cognitive functioning documented by a full scale score of 70 or below on an appropriate standardized test of intelligence and resulting in substantial deficits in adaptive functioning.” The term “pervasive developmental disorder” is defined in statute as an “autistic disorder, Rett’s disorder, childhood disintegration disorder, Asperger’s disorder, and pervasive developmental disorder not otherwise specified.” A modified version of this definition applies to infants, toddlers and pre-school aged children.
Eligibility determinations are made by the Designated Agency (DA) serving the particular catchment area of the state. Persons found eligible are enrolled in services only when they meet the funding priorities spelled out in the state’s “System of Care” plan. The latter determinations are made based on an individualized needs assessment, also conducted by the local DA.

**Wisconsin.** In order to receive managed long-term services benefits available through the Family Care program, an individual must be 18 years of age or over and:

a. be a member of one or more of the following target groups:
   - Frail elderly individuals;
   - Persons with developmental disabilities; and
   - Persons with physical disabilities.

b. Meet the level of care criteria (functional eligibility) and financial eligibility requirements of the program. Generally, an individual must meet the state’s Medicaid financial eligibility criteria and be in need of nursing facility or ICF/MR level of care in order to qualify for Family Care benefits.

c. Reside in an area of the state served by a Family Care MCO.

Functional eligibility is determined through the use of a web-based instrument that gathers information about the applicant’s functional and health status as well as his/her need for assistance. The screening tool is used to determine eligibility for various programs and benefits related to frail elders and persons with physical and developmental disabilities, including certain mental health services, adult long-term care programs and children’s long-term support programs. There are separate versions of the tool for adults and children with long-term care needs (even though children, 17 years of age or younger, are not eligible to participate in the Family Care program). The screen is applied by experienced professionals who have completed an online training course and passed a certification examine. Wisconsin law defines the term “developmental disability” in a manner very similar to the federal functional definition of the term. A “decision tree” has been prepared to assist screeners in determining the eligibility of persons with developmental disabilities.

**Individual Service Planning Process.**

**Arizona.** DDD operates out of seven regional offices, each of which has on its staff a complement of support coordinators. When an individual is found eligible for ALTCS/DD services, a support coordinator is assigned, with responsibility for convening an interdisciplinary team to develop an Individualized Service Plan for the person. Once the team, including the individual and a person of his/her choice, has reached agreement on the contents of the plan, the support coordinator inputs the provisions of the plan into a system-wide case management data base, called FOCUS, which is maintained by the Division. The computer program includes a matrix indicating the average number of support hours allocated for individuals with similar support profiles across the entire ALTCS/DD system. The support coordinator then decides on the types of services and number of units of each required by the particular enrollee. If the requested supports falls within the average numbers specified in the matrix, the support coordinator is authorized to approve the plan and begin the process of selecting an appropriate provider(s). If on the other hand the number of requested units of service exceeds the norm established by the matrix, the support coordinator must receive the approval of the regional office director or, in certain circumstances, the Assistant DES Commissioner for Developmental Disabilities Services. This system of prior authorization, with its tiered levels of decision-making, DDD officials report, is a key to ensuring the cost-effectiveness of services as well as the equitable distribution of resources based on demonstrated needs.
Once the unit allocation decision process is complete, the regional office notifies provider agencies in the particular service area (if the subject individual/family is seeking a qualified provider) and solicits expressions of interest in serving the particular individual. The individual/family and a member(s) of his/her interdisciplinary team are afforded an opportunity to meet with representatives of interested service providers before making a selection. Except in unusual circumstances, the consumer and his/her family are given a choice between two or more qualified providers of any given service.

**Michigan.** Besides changing the state’s DD service eligibility definition, the 1995 revisions to the state’s Mental Health Code also mandated the use of person-centered planning throughout the state-local mental health/developmental disabilities service system. PIHPs are required to use a person-centered planning approach in preparing service plans for all participants in the Specialty Services program. The extent to which a PIHP’s planning process is truly person-centered is one of the elements of plan performance which is monitored by MDCH during its biennial site reviews (see further discussion under “Quality Management” below). Service plans are developed by an interdisciplinary team that includes the person receiving services plus an individual(s) of his/her choosing (e.g., a family member, friend or advocate). Some PIHPs have established an internal utilization review unit to screen individual service plans for consistency and cost-effectiveness before they are approved and implemented; other PIHPs, however, use more informal procedures to ensure the cost-effectiveness of service plans.

**Vermont.** When an individual initially applies for services, a service coordinator is assigned by the Designated Agency (DA) to coordinate the intake process which consists of determining the individual’s service eligibility, completing a developmental needs assessment and investigating the person’s circumstances (e.g., the extent to which informal supports are being provided by family and friends; the appropriateness of the person’s current living situation; etc.) Based on the findings, a preliminary statement of needs is prepared and the case is referred to the DA’s local Funding Committee. This committee may accept, reject or modify the proposed service plan. If the plan is rejected, it must be revised and re-submitted to the Funding Committee. If the plan is accepted, with or without modifications, it is forwarded to one of two state level committees for review – either: (a) a committee that reviews service plans where the individual is deemed to be a public risk; or (b) the Equity Committee which reviews all other plans and plan amendments. The responsible state level committee accepts, rejects or modifies the proposed plan. All new and amended service plans (if they involve additional expenditures) must be reviewed and approved at the DDAS level before they can be implemented by the DA.

The DA is responsible for either purchasing or providing the services and supports spelled out in each individual’s service plan. There have been no changes in the process outlined above since the GC waiver/demonstration program went into effect.

**Wisconsin.** The contents of the individual service plan are determined by an interdisciplinary team (IDT) working closely with the individual and, as appropriate, with his/her family. At a minimum, the IDT must include the individual plus a social worker and a nurse employed or working on behalf of the Management Care Organization (MCO). The job of the IDT is to help the individual: (a) formulate a set of desired outcomes; (b) develop a service plan designed to help her/him achieve those outcomes; and (c) follow up to make sure that the provisions of the plan are being carried out.

MCOs use a standardized process, called the Resource Allocation Decision (RAD) method, to weigh the cost-effectiveness of expenditures in connection with a proposed service plan. The method uses a series of questions or probes, to help the team determine the services required to achieve stated personal outcomes in the most cost-effective manner. The results of the process, DHS officials concede, sometimes require individuals and families to scale back their expectations if achieving certain outcomes fully and immediately proves to be unreasonably difficult or expensive.
Coordinating Health Care and Long-Term Supports

Arizona. As pointed out earlier, one of the distinctive features of the ALTCS program is the co-management of an individual’s health care and long-term supports. Because DDD contracts directly with health plans, it is possible to include provisions reflecting the unique health and allied health needs of persons with developmental disabilities. Thus, for example, health plans are contractually obligated to provide a second wheelchair for non-ambulatory ALTCS/DD recipients when an individual otherwise would be unable to navigate around his or her place of residence without assistance. Health plans also are required to appoint liaison representatives to dialogue with long-term support providers and work out any problems that arise. DDD district offices hold monthly trouble-shooting meetings with representatives of health plans serving their respective catchment areas. The central office staff of DDD also meets quarterly with health plan representatives to review system-wide issues and concerns and identify possible quality improvement initiatives.

DDD also contracts with the Division of Behavioral Health Services (DBHC) within the Arizona Department of Health to ensure that ALTCS/DD recipients gain access to needed mental health services. DBHC, in turn, contracts with managed behavioral health organizations serving a designated county or counties to provider behavioral health services. The DDD contract with DBHC becomes a distinct element in the contracts with county-based BH organizations, with its own set of requirements and accountability mechanisms.

DDD and its sub-contractors are subject to quality improvement activities initiated by AHCCCS. For example, because of the significant number of choking incidents being reported by providers of long-term supports system-wide, several years ago AHCCCS initiated a quality improvement project focused on offering provider agencies training in feeding techniques that avoid the aspiration of food and learning how to respond quickly when choking emergencies occur.

Michigan. Medicaid beneficiaries with developmental disabilities receive medical and other health services either on a fee-for-service basis or through Medicaid managed health care program, referred to in Michigan as Qualified Health Plans. [N.B., Dual eligibles – i.e., persons who are qualified to receive both Medicare and Medicaid benefits – may elect to opt out of mandatory enrollment in a Qualified Health Plan.] Most specialty mental health services for persons with developmental disabilities, serious mental illnesses and substance abuse disorders are carved out of managed health care plans and furnished through the PIHPs. The Specialty Services plans and the Qualified Health Plans are required to have written procedures in place for coordinating the delivery of health care and specialty services. In all instances, PIHP support coordinators (case managers) are responsible for facilitating access to primary and acute care services for PIHP beneficiaries on their caseloads.

Vermont. A number of years ago, DDD issued health and wellness guidelines which all Designated Agencies (DAs) and Specialized Service Agencies (SSAs) are required to follow. Mainly as a result of these guidelines – and having nothing to do with the decision to roll developmental services into the Global Commitment waiver/demonstration program – individuals with developmental disabilities who are receiving developmental services have ready access to health care, according to individuals involved in managing DS services at the state and local level. The requirements of the health and wellness guidelines are applied somewhat differently to individuals receiving day supports only versus persons receiving 24-hour residential services but, in both instances, DAs and SSAs are obligated to follow various procedures aimed at ensuring that their clients receive the health services they need.

Wisconsin. MCO interdisciplinary teams are responsible for helping Family Care enrollees to coordinate their health care services. Each care management team includes a social worker and a nurse. Among the primary roles of the team nurse are to ensure that the enrollee’s health care status is taken into account in developing his or her individual service plan and also to serve as a liaison with medical practitioners responsible for meeting the individual’s health care needs.
Family Care enrollees also have the option of enrolling in a Family Care Partnership program in certain areas of the state. Partnership contractors (which may include Family Care MCOs) are responsible for delivering all Medicaid-reimbursable health care and long-term services under a risk-based contract. Partnership organizations also maintain risk-based contracts with the federal government to furnish Medicare Part A, Part B and Part D benefits to program enrollees. In future years, DHS officials hope to initiate Partnership programs or expand the service areas of existing programs to currently un-served areas of the state.

In addition, DHS is planning to introduce a third service delivery option, called Family Care Plus, but not before 2010 at the earliest. Under this option, risk-based contractors (which may include Family Care MCOs) will be responsible for furnishing all Medicaid state plan services, as well as all Medicaid institutional and home and community-based services, to enrollees. In other words, Family Care Plus contractors will provide an integrated array of Medicaid-funded health care and long-term support services; but, unlike Family Care Partnership contractors, Family Care Plus contractors will not co-manage the Medicare benefits of program enrollees. The introduction the Family Care Plus model is tied to the completion of planned upgrades in the state’s Medicaid Management Information System (MMIS).

Self-Directed Services and Supports

**Arizona.** ALTCS/DD participants may elect to self-direct all or only selected portions of their individualized service plans. At present, approximately 20 percent of ALTCS/DD participants direct at least a portion of their service plan – typically the hiring and supervision of personal attendants or support workers. With a network of over 3,000 certified independent individual providers, families have a broad range of providers from which to choose. Family members and neighbors may serve as paid personal care workers as long as they are willing to go through the certification process. In addition, for a number of years, the Division has maintained a contract with a fiscal intermediary that is available to handle all back office administrative support tasks for individuals/families choosing to self-direct their services. But, at the current time there is no established system of individual budgets and, with the exception of about 250 individuals who participate in a consumer/family-run cooperative, few ALTCS/DD participants manage an individual budget and self-direct all of their own supports.

**Michigan.** As one of the original states selected by the Robert Wood Johnson Foundation to pilot the concept of self-determination (as were Arizona, Vermont and Wisconsin), Michigan has been involved in offering self-directed support options to persons with developmental disabilities for over a decade. When the Medicaid Managed Specialty Services program was designed in the late 1990s, one of the aims of the MDCH planning team was to build into the Section 1915(b)/(c) waiver program self-directed support options for participants. Since 2004, all PIHPs and CMHSPs have been required contractually to offer participants and their families the option of self-directing their services. However, the contract language permitted local entities to postpone the implementation of key feature of this requirement (i.e., direct employment of support workers by consumers and direct contracts between consumers/families and providers) until 90 days after the department issued a revised Technical Advisory on the Choice Voucher System and standards governing fiscal intermediary services.

These guidelines and standards were not issued by DMCH until September 30, 2008. In a memo transmitting this advisory, the director MDCH’s Mental Health and Substance Abuse Administration noted that the department views self-determination as “an essential priority” and urged PIHPs and CMHSPs “to expand the provision of innovative and individualized options for individuals who choose to participate [in self-determination] arrangements...”, in cooperation with affiliated CMHSPs. The new guidelines spell out the procedures PIHPs are expected to follow in assuring that persons/families electing to self-direct their services are able to do so. In addition, the guidelines state that PIHPs must contract with a fiscal management service to assist individuals who choose (often with the help of family members and friends) to self direct their services. As in other states, the fiscal management service is available to pay providers, withhold and report payroll taxes, and carry out other financial support services on behalf of the individual/family. According to MDCH
officials, approximately 3,000 Specialty Services recipients statewide currently have an individual budget and are self-directing some or all of their services.

**Vermont.** Despite the state’s early involvement, self-directed services have grown slowly in Vermont, with most of the growth occurring in family directed versus individually directed services. Approximately 50 (+ or -) individuals/families currently manage their entire service plan. Shared management – where the family elects to oversee certain elements of the service plan (e.g., the purchase of respite and/or personal care services) and have a community agency manage other services (e.g., supported employment, day habilitation, etc.) is far more common across the state’s DS system. The state maintains a financial intermediary to assist individuals and families who choose to self-direct. This agency (Transitions II) handles the “back office” transactions associated with being the employee of record (e.g., paying service providers; withholding payroll taxes; filing necessary financial reports; etc.).

The state has encountered problems in maintaining a pool of qualified Independent Service Coordinators (ISC) to assist individual/families who choose to self-direct their services. Because of the low population concentrations in Vermont communities and the small number of individuals/families who have elected to self-direct, it is difficult for ISCs to make a living.

Several years ago, the Division decided to restrict self-direction to persons who are not living in a 24-hour residential setting. This decision was made because DDD officials were uncomfortable with some of the residential choices consumers were making – both in terms of the legality of expenditures and the risks posed to the consumer’s health, safety and overall well-being.

**Wisconsin.** A self-directed services option is available to all Family Care enrollees who choose to use it. Persons electing this option receive an individual budget, keyed to the amount that otherwise would be spent on their behalf under a provider-administered service option. The budget is available to purchase services geared toward meeting the person’s personal-experience outcomes, even if the service is not a regular part of the benefit package or the provider of the service does not participate in the MCO’s provider network.

Each MCO develops its own plan for offering self-directed supports. However, the MCO’s plan must offer self-directing enrollees a way of: (a) authorizing payments to providers and keeping track of the balance available in the individual’s budget; (b) selecting and hiring support workers (which may include family members, friends or neighbors); and (c) training and supervising support workers.

An individual may choose to self-direct all or only a portion of his or her service plan. For individuals who elect to self-direct some or all of their supports, the interdisciplinary team is responsible for explaining the available choices, helping the individual to assess his or her needs, determining the resources available, and keeping track of expenditures and the remaining balance in the person’s individual budget. Under certain circumstances, the MCO may impose limits on the self-directed service option, but, in doing so, it must inform the individual of the steps necessary to remove such restrictions and the enrollee’s right to file a grievance or request a fair hearing.

The state recently received permission from CMS to operate a new consumer-directed HCBS (Sec. 1915(c)) waiver program in tandem with Family Care. The effective date of this new program was July 1, 2008. All Family Care enrollees have received a letter from DHS informing them that they have a right to enroll in the so-called IRIS (Include, Respect, I Self-Direct) program, rather than being served through the Family Care MCO. The same financial and functional eligibility screens used to establish a person’s eligibility for Family Care services are used in determining IRIS eligibility. IRIS services are available only in counties which have implemented Family Care. Participants are required to self-direct all of their services. A self-direction option will continue to be available under the Family Care and Family Care Partnership programs, but, in the latter instances, as noted above, FC participants have the option of self-directing all or only a portion of their services.
DHS has contracted with the Independent Consultant Agency (ICA) to assist IRIS participants statewide, to develop individual support plans, identify non-paid supports, locate qualified providers, make sure that participants receive adequate training and know how to file requests for budget adjustments and exceptional needs requests. ICA also will: (a) approve all Individualized Support and Services Plans for IRIS participants; (b) create a pool of qualified IRIS consultants to assist program participants; and (c) perform various quality oversight activities. DHS also has contracted with a financial services agency (FSA) – the Milwaukee Center for Independence – to receive and account for the funds of IRIS participants’ Medicaid cost-sharing payments. The FSA also will: (a) train participants in managing their individual budgets; (b) answer financing questions posed by participants and vendors of IRIS services; (c) help IRIS participants to hire support workers; (d) manage IRIS payment claims; (e) complete participant satisfaction surveys; and (f) monitor the quality of financial management services provided to IRIS participants.

Monitoring and Improving the Quality of Services

Arizona. In addition to facility and program licensing requirements and onsite monitoring of group living arrangements by teams of officials from DDD’s central and regional offices, the state Division of Developmental Disabilities requires each ALTCS/DD provider agency to have its own quality management plan, which is subject to DDD approval. This plan must spell out how the agency intends to collect quality data, evaluate trends and identify deficiencies, as well as the steps it will be take to remediate problems and promote quality improvements. DDD also is required under its contract with AHCCCS to maintain its own quality management plan. In recent years, the Division’s staff has been analyzing data from multiple sources in an attempt to identify system-wide problems and initiate related quality improvement programs. The AHCCCS agency also adopts its own quality improvement projects in which DDD, as the ALTCS/DD managed care organization, is required to participate.

Michigan. Each PIHP is required by MDCH to have its own quality management plan. This plan spells out the procedures and methods to be used in reporting, investigating, remediating and tracking major incidents, assessing consumer satisfaction and otherwise monitoring the quality of services furnished by providers under contract with the PIHP. In addition, the department has a well developed program to monitor the performance of PIHPs. These monitoring activities can be divided into two main categories: prospective and retrospective functions. The prospective functions are typical of the activities undertaken by most managed care entities -- e.g., pre-contract reviews of the plan’s capabilities and a requirement that all providers adhere to state licensing and other appropriate standards.

The state also uses a variety of post-service delivery approaches to review the performance of PIHPs, including annual site visits, performance outcome measures and participant surveys. For example, the MDCH Division of Quality Management and Planning conducts annual, two-phase site visits to each PIHP, with each phase separated by 4-6 months. The review team includes MDCH staff, a clinician, a master’s degree nurse, and at least one service participant. Team members who are service recipients are drawn from a pool of recipients/advocates who are employed by various disability organizations.

Members of the team review the clinical records of a ten (10) percent sample of individuals served by the PIHP and then interview a sub-sample of such individuals. The interviewer asks the participant and members of his/her family about the service planning and delivery process, as well questions concerning health and safety issues. The result of each visit is summarized in writing and posted on the department’s web site. If a plan of correction is necessary, a follow up visit is scheduled and the team interviews some of the same participants who were interviewed during the initial visit.

In addition to MDCH’s on-site reviews, the department retains an outside contractor – called an External Quality Review Organization – to assess the PIHPs’ compliance with certain, specified federal and state standards. [N.B., The retention of an EQRO is a standard requirement in all CMS waiver agreements with states.
using a managed care approach. Arizona, Vermont and Wisconsin also employ an EQRO as part of their overall quality management plan. Among the compliance areas reviewed by the EQRO are access and availability of services, coordination of care, and the disposition of participant appeals.

The department also has developed a Mission-Based Performance Outcome Indicator System. PIHPs are required to report aggregate performance data on a quarterly basis. Forty indicators are used to measure PIHP performance in three quality domains: access, efficiency, and outcomes. Examples of outcomes include the percentage of participants enrolled in supported employment services and the percentage of participants living in their own homes. Access indicators examine such areas as the timeliness of inpatient screening, the timeliness of outpatient assessments, and the percentage of individuals denied services as a result of a negative assessment. The department’s staff compares data reported by each PIHP, posts these comparisons on its website and attempts to identify outliers. Under-performing PIHPs become the focus of improvement plans or, after repeated failure, termination actions, while high performing PIHPs are cited as sources of replicable best practices.

**Vermont.** Over the years, Vermont has built a comprehensive, multi-faceted system for assessing the quality of developmental services. The centerpiece of this system is the biennial reviews which the Division of Disability and Aging Services (DDAS) conducts of each Designated Agency as well as other services providers. These onsite reviews are conducted by a team of full-time DDAS staff members and always include a registered nurse and a consumer interviewer. During the course of its review, the quality management team examines a sample of ten percent of the recipients of agency services, tracking personal outcomes against the person’s service plan and interviewing family members and support staff during the process. The team also reviews:

- Critical incident reports;
- Grievance and appeal records;
- Safety and accessibility (in newly unlicensed residential settings only);
- Consumer and family survey results;
- The results of reviews of behavioral support plans and intrusive procedures by the local Human Rights Committee; and
- Decisions by the local Ethics Committee with respect to abating life-sustaining treatment.

The results of these on-site reviews play an important role in the re-designation of DAs, a process that occurs once every four years.

There are numerous processes in place which supplement the findings of the biennial, on-site review. For example, the licensing division of DAIL reviews and licenses all residences in which three or more individuals with disabilities live. In addition, the Office of Public Guardian, an independent unit within the Agency of Human Services, monitors the welfare of the nearly 700 adults with developmental disabilities and/or disabilities related to the aging process who have been placed under public guardianship. Public guardians are expected to have face-to-face contract with persons on their caseloads at least once a month; they also are available to deal with emergencies 24 hours a day.

Following the reorganization that created the Department of Disability, Aging and Independent Living (DAIL) in 2003, a committee was established to explore the feasibility of merging quality reviews for providers of aging and disability services system-wide. Following a year and half of study, a joint review protocol was instituted. But, earlier this year, the joint reviews were suspended after the director of DDAS received a flurry of complaints – mainly from home health and adult day health agencies serving frail elders. Many providers of aging services, which previously had not been subjected to on-site reviews, found DDAS reviews, based on the

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*The former Department of Aging was combined with the Developmental Disabilities Division of the former Department of Development and Mental Health Services to form DAIL.*
long-established DS model, to be intrusive. An internal committee has been formed to assess the Division’s experience with joint quality reviews and come up with possible alternatives.

According to state officials who participated in designing the joint review protocol, the main flaws in the system were: (a) the lack of a sufficient number of trained reviewers, given the four-fold increase in the number of agencies to be reviewed with essentially the same personnel complement; and (b) the difficulty in bridging differences in the cultures of the DS and aging service systems. These problems, they stressed, are not related to the implementation of the GC waiver/demonstration program.

**Wisconsin.** DHS strives to ensure the quality of Family Care services at the front end of the process by building personal outcomes into each individual’s service plan and tracking progress toward achieving these goals over time. The individual and his/her IDT monitor these outcomes on a regular basis. The MCO in turn monitors the quality of services furnished to enrollees as well as the performance of IDT members. As a result of a recent change in the Family Care program, ADRCs have been assigned a broader role in monitoring service quality. Board members of the centers will review complaints, determine whether MCOs in their respective areas have an adequate number and types of providers, and ascertain whether the ADRC and the MCO are properly coordinating their activities.

MCOs are obligated under the terms of their contracts with DHS to investigate critical incidents and report their findings to the state. The department monitors the degree to which MCOs and ADRCs comply with the terms of their contracts and requires them to take corrective actions when deficiencies are identified.

Finally, the terms and conditions of DHS’s Medicaid waiver agreement with CMS requires the department to retain an External Quality Review Organization (EQRO) to ensure that stated outcomes are being achieved. More specifically, the EQRO is responsible for: (a) monitoring the performance of MCOs against a series of benchmarks; (b) reviewing MCO policies and procedures governing provider networks, service plans, and appeals and grievances procedures; and (c) interviewing Family Care enrollees, providers and MCO staff. The results of the EQRO’s 2003 and 2005 reviews of the Family Care program are posted on DHS’s website.

**Grievance and Appeals Procedures**

**Arizona.** Grievance and appeals procedures in all four states are governed by federal managed care regulations implementing provisions of the Balanced Budget Act of 1997. In Arizona, an enrollee may file a grievance with his or her support agency. If the agency and the consumer are unable to reach an amicable agreement, the individual/family may present their grievance informally to the DDD regional office, which then is responsible for mediating the dispute. Dissatisfied consumers also may file a formal grievance with the MCO (DDD in the case of ALTCS/DD services). If the MCO turns down the enrollee’s request, it must notify the enrollee in writing of its decision within 14 days. If the enrollee is dissatisfied with the MCO’s determination, he/she may file a formal Medicaid appeal with AHCCCS, as the single state Medicaid agency. This appeal is heard by an independent hearing officer from the state Office of Administrative Hearings (a separate state agency from AHCCCS). The state Medicaid authority can accept, reject or modify the hearing officer’s ruling, but must inform the enrollee of the agency’s final action on the appeal.

**Michigan.** Most of the PIHPs have customer services representatives (often parents and advocates) who handle enrollee complaints. Many disputes are resolved at this level through informal mediation. When an individual or a family is unable to satisfy its concerns though an informal dispute resolution process, the other available options are to file a Medicaid appeal or register a complaint with MDCH’s Recipient Rights office, an internal advocacy unit within the department. The overall number of appeals is very low, according the MDCH officials.
**Vermont.** Prior to the Global Commitment, there were eight to ten separate grievance and appeals procedures managed by participating state agencies; and each agency followed its own policies, protocol and timelines. It took two years, but OVHA has instituted a uniform set of G&A policies across all GC participating agencies.

Key components of the former DDD grievance and appeals guidelines, however, remain in force, although a number of modifications have been made in these guidelines to bring them into alignment with the general G&A requirements (e.g., common timelines, forms and reporting procedures). One unique feature of the DS guidelines which has been retained is the provision governing mediation and arbitration of disputes. The legislative committee that handles DS appropriations insisted on the retention of these and other unique features of the DS guidelines after advocacy groups raised concerns.

**Wisconsin.**

If an individual or his/her family disagrees with the contents of the person’s individual service plan, the MCO is required to state in writing that the plan: (a) reasonably and effectively addresses the needs and personal outcomes identified during the assessment/service planning process; (b) does not significant impair the individual’s chances of achieving his/her desired outcomes, as least over the long term; (c) considers the individual’s needs as well as the cost and services available to the MCO in addressing those needs; and (d) was prepared after working with the individual and trying to come up with an approach acceptance to both parties, including MCO-proposed alternative approaches to achieving individual outcomes.

If an individual is dissatisfied with the service plan approved by the MCO, he/she may: (a) file a grievance or appeal with the CMO; (b) file a grievance or appeal with the Wisconsin Department of Health Services; or (c) request a state fair hearing. These avenues of relief may be pursued separately or in combination with one another.

**Services to Children with Developmental Disabilities**

**Arizona.** All individuals with developmental disabilities, regardless of age, are eligible to participate in the ALTCS/DD program. But because the standard of eligibility for ALTCS services is tied to institutional need, only a small portion of young children – especially infants and toddlers -- qualify for ALTCS services. Overall, only about 20 percent of children who qualify for DDD services are ALTCS eligible, compared to about 69 percent of adults. As noted above, the screening tool used to determine ALTCS eligibility is divided into four age groups: 0-3; 3-6; 6-12 and over 12 years of age. These tools were developed in 1994 and, at this point, are somewhat outmoded according to DDD officials. Very few infants and toddlers qualify for ALTCS services because the incidence of admissions to institutions among this population is very low in Arizona as well as nationwide. As a result, among the 0-3 population, only infants with severe, chronic medical conditions that require constant care are found eligible for ALTCS services. The number of children ages 3-6 and 6-12 found to be eligible is progressively higher, but still below the adult eligibility rate. The rate among children over age 12 approaches the adult rate as the age of the child increases.

Because so many young children with substantial disabilities are ineligible for ALTCS services, access to services for children under 6 years of age is far more restrictive than for older children, adolescents and adults. DDD’s annual budget totals approximately $700 million, of which only $60 million represents state general revenues that are not part of the state’s ALTCS program. As a result, DDD has limited wiggle room in funding services for ALTCS ineligible children. On the other hand, according to some DDD officials, the state has one of the nation’s better birth-to-three early intervention programs.
Michigan. There is no lower age limit on enrollment in the state’s Medicaid Managed Specialty Services carveout. However, for children living with their families, parental income is taken into account in calculating the eligibility of the child. As a result, children with disabilities living in middle-to-upper income households generally are not financial eligible to participate in the program and, consequently, the number of children receiving services under the Section 1915(b)/(c) waiver program is small. The state does operate a home and community-based waiver program for children with severe disabilities (where the deeming of parental income/resources is waived). In addition, Michigan was the first state in the nation to develop a permanency planning program to afford children with disabilities the opportunity to grow up in a family environment. This program, in combination with large family support and family subsidy programs – as well as access to special education services through age 26 -- allow most families to raise their children -- even children with very severe disabilities – at home.

Vermont. The state’s Medicaid plan provides personal care coverage for children plus home care benefits for technologically dependent children and adults. The number of recipients of children’s personal care services has grown steadily in recent years, from 200 recipients in 2000 to 1,696 in 2007. One-to-one staff support is provided for an individually prescribed number of hours per week to assist the family with activities of daily living. About a third of the families that receive in-home personal care services for their children also receive Flexible Family Support grants from the state; an additional 18 percent of such families receive wrap-around supports from the state’s HCBS waiver program.

The High Technology Home Care state plan benefit offers an array of intensive home care services for children and adults who are dependent on medical technology. About three-quarters of the 93 individuals receiving such services in 2007 were children under age 21. The program furnishes skilled nursing care and high-technology aides; it also coordinates treatments, medical supplies and sophisticated medical equipment for technology-dependent Medicaid beneficiaries, with the goal of preventing institutionalization and transitioning such persons from hospitals and other institutional settings to home-based care.

These services are managed by the DAIL Division of Disability and Aging Services. OVHA is not involved in the delivery of these services, but does have authority to pursue innovations in the delivery of health and long-term supports under the Global Commitment to Health. One example of such an innovation is a pilot program to assess the impact of allowing personal care benefits for children under the state’s Medicaid plan to be managed in a more flexible manner. Using the flexibility permitted under the GC waiver, OVHA has allowed a specified number of families (maximum: 150; current enrollment: 115) to use personal care dollars to purchase assessments, prepare a plan of care and, in some instances, hire a care coordinator, plus acquire therapy services. DAIL and OVHA officials will evaluate this flexible funding strategy before deciding whether it should be expanded (with or without modifications) or discontinued. OVHA officials stress that the state may initiate such innovations in service delivery without the prior approval of CMS.

Wisconsin. Discussions regarding the redesign of the state’s system of services for children with severe, chronic disabilities began in 1997. A comprehensive set of proposals for restructuring services to such children emerged from these discussions. The overarching aim of the Children’s Long Term Support Redesign initiative was to make it easier for children and families to access needed services by: (a) creating a single source of information about available services and supports, establishing functional eligibility criteria that are uniformly applied, and responding in a timely manner to the needs of children and families; (b) broadening the array of family centered services in order to afford families enhanced choices and control; (c) improve the coordination of available services; (d) establish procedures and outcome measures to ensure the quality of services; and (e) streamline the financing of children’s services so that available funds are used more effectively and in a family-centered manner.
The Council on Children’s Long-Term Support recommended that services to children be excluded from DHS’s Family Care program because:

- Children are more likely to thrive in a family-centered system of support that acknowledges the central roles played by parents both as planners and managers of their children’s services;
- The needs of children change rapidly as they go through succeeding developmental stages;
- State, county and provider staff members must have specialized expertise in serving children and families;
- Services to children with disabilities are supported through a wider range of funding streams, thus requiring a stronger emphasis on interagency coordination and collaboration;
- Based on prior experiences with managed health care, Wisconsin families were concerned that the needs of their children would not be effectively addressed through a managed long-term care system; and
- Parents of children with severe disabilities were worried about potential cost shifting among various funders of services, including the public schools and private health insurers.

As the cornerstone of the redesign process, Wisconsin requested and received permission from CMS to operate three new home and community-based waiver programs targeted to children with cognitive and developmental disabilities, mental illnesses, and physical disabilities. These three programs, which focus on children under 22 years of age, were approved in November 2003. As of June 2007, approximately 2,500 children with severe disabilities were receiving services through the children’s waiver programs. Most of the new funding made available thus far for children’s waiver services has been directed toward children with autism spectrum disorders living with their families and receiving intensive in-home treatment services.

As part of the Children’s Redesign initiative, the Department of Health Services also has instituted a “one stop” process for screening children with severe disabilities. The new screening process is used to establish eligibility for family support services, Katie Beckett services and other state benefits. In addition, a network of five Regional Centers for Children with Special Health Care Needs has been established across the state to assist families in locating appropriate services and supports for their children. Finally, the state’s Medicaid prior authorization process for therapies has been modified to allow longer approval periods (up to 6 months) for the continuation of services that meet the department’s standards of medical necessity.

Despite lingering parental opposition to a managed care model, DHS’s FY 2007-09 budget request included a proposal to pilot managed long-term supports for children with disabilities during the second year of the biennium. This provision was dropped from the final departmental appropriations measure; but DHS is expected to renew its request when it presents its FY 2010-11 budget request. The departmental Council on Children’s Long-Term Supports has voiced its support for conducting a managed care pilot program, but also has expressed concern that no new appropriations were included in the department’s FY 2007-09 budget to fund this initiative. The Council also has: (a) criticized the general paucity of new funding to implement the Children’s Redesign initiative, especially in comparison to the funding and organizational attention given to implementing the Family Care program statewide; and (b) called for greater equity in the distribution of funds among the three children’s waiver programs. As noted earlier, thus far the lion’s share of new money has been directed to services for children with Autism Spectrum Disorders.
Similarities and Differences.

Having reviewed in some detail the principal operating features of the Medicaid managed long-term care programs in these four states, let us now examine the similarities and differences among these plans. By this point, it should be evident to the reader that the managed LTC plans of these four states are not cookie-cutter models. They share certain similarities; but, they also differ from one another along several key dimensions. More importantly, however, when viewed from a broader perspective, the operating arrangements in these states deviate markedly from typical Medicaid managed health care plans.

Contrasts with Traditional Managed Health Care Plans. In particular, none of these states thus far has selected a commercial health maintenance organization (HMO) to act as the entity responsible for purchasing and managing long-term services (although AZ/DDD contracts with commercial health plans to deliver primary, acute and preventive health services to ALTCS/DD enrollees; and, the option to select an HMO or a similar organization as a Family Care MCO exists under Wisconsin’s current procurement policies). Indeed, in Arizona and Vermont, an agency of state government functions as the MCO (with respect to DD long-term supports at least in Arizona). Michigan and Wisconsin, in contrast, procure Medicaid-funded long-term services through risk-based contracts with a network of area-wide MCOs (or PIHPs as they are referred to in Michigan). But, thus far at least, the MCOs in these states are all “home grown” organizations. In Michigan (as well as a number catchment areas of Wisconsin), MCOs have been formed largely from the elements of the existing local service delivery system. [N.B., the alternative model which has emerged in Wisconsin is a locally-based HMO, which has operating a Partnership program for years and recently has decided to expand its operations into long-term services only (Family Care) plans.] In both states, former county disability officials have been selected to fill key positions in the newly formed MCOs, thus lending a sense of continuity to the transition to managed care.

The notion of risk sharing, a central feature of any managed health care plan, assumes a somewhat different form in the managed LTC programs of these four states. In Vermont and Arizona, state government assumes 100 percent of the financial risk of extending long-term supports to all eligible persons with developmental disabilities. In fact, in both cases, expenditures are subject to limits imposed through the biennial legislative appropriations process, which raises the question: do the programs in these states qualify as true managed care plans. Under the managed LTC programs in Michigan and Wisconsin, state government shares the financial risks of cost overruns with county or multi-county managed care entities; and, in both cases, the state specifies the minimum financial reserves an MCO must retain and offers them incentives to build their cash reserves. Michigan limits the risk PIHP exposure to 7.5 percent over the total amount of the plan’s annual contract with the state. Wisconsin has not established the same types of “risk corridors” in its contracts with MCO.

The long range financial viability of the home-grown MCOs in Michigan and Wisconsin may not be fully established, although Michigan has been operating under a shared risk arrangement with its PIHPs for over a decade without any major financial disasters. Wisconsin has a more limited track record with its MCOs, with only the six, original pilot counties having accumulated significant financial track records to date.

What would happen in Wisconsin or Michigan if one of the MCOs/PIHPs were to become financially insolvent? Neither state appears to have a clearly articulated Plan B (although, it is a contingency that has been discussed). The state may be able to step in on a temporary basis, possibly through some type of receivership authority, to stabilize the situation. But, because there are no other “deep pockets” to turn to, over the long haul state government is widely (and probably rightly) seen as the ultimate guarantor of these plans.

Having compared some of the key financing features of these plans, let us turn next to an examination of other similarities and difference among the long-term services programs of these four states -- beginning with the locus of state and local management responsibility. These similarities and differences are summarized in Table A on the following page.
**Locus of State Management Responsibilities.** In two of the states (Arizona and Vermont), responsibility for administering and managing long-term services for persons with developmental disabilities is shared between the state DD program agency and the single state Medicaid agency, with the state Medicaid agency responsible for overall management of the state’s Section 1115 waiver/demonstration program and the DD program agency responsible for overseeing the service procurement and delivery process. In Michigan and Wisconsin, all functions are carried out by the single Medicaid agency, which also serves as the DD program agency (as well as the program agency for other eligible target populations). The Mental Health and Substance Abuse Administration within the Michigan Department of Community Health administers all Medicaid (and state) funded services to persons with mental illnesses, developmental disabilities and substance abuse disorders. Similarly, in Wisconsin the state Department of Health Services acts as the single state Medicaid agency and also the program agency for elder and disability (including developmental disabilities) services.

**Locus of Local Management Responsibilities.** In Arizona, the seven district offices of the state Division of Developmental Disabilities manage all aspects of the delivery of ALTC/DD services as well as state-funded DD services, including the direct provision of support coordination services. In Michigan, DCH’s Mental Health and Substance Abuse Administration contracts with a network of 18 Pre-paid In-patient Health Plans (PIHPs) to procure all Medicaid-funded specialty services for eligible individuals with mental illness, developmental disabilities and substance abuse problems. The functions of the PIHP are supplemented by 46 county and multi-county Community Mental Health Services Programs (CMHSPs), which act as the single-point-of-entry to public MH, DD and SA services and also administer all non-Medicaid funded services. The functional relationships between the PIHP and the CMHSP vary from one catchment area of the state to another, with the functions of both entities consolidated in the more populous counties of the state, usually in a local, quasi-public mental health authority. A network of ten area-wide non-profit Designated Agencies act as the single-point-of-entry to DD services in Vermont. These agencies, acting under contract with the state Department of Disabilities, Aging and Independent Living (DAIL), also are responsible for eligibility determination and either providing or purchasing all community services for the DD population, with the exception of certain services furnished by Specialized Service Agencies, under direct contracts with DAIL. In counties participating in Wisconsin’s Family Care program, a Managed Care Organization (MCO) is responsible for planning and procuring all long-term services required by program enrollees. A separate network of Aging and Disability Resource Centers in Wisconsin is responsible for assisting individuals and families to locate appropriate services and for determining Family Care eligibility.
# TABLE A

## Four State Comparison of Medicaid Managed Long-Term Service Plans

<table>
<thead>
<tr>
<th>KEY FEATURES</th>
<th>AZ</th>
<th>MI</th>
<th>VT</th>
<th>WI</th>
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<tbody>
<tr>
<td><strong>State Management Responsibility</strong></td>
<td>AHCCCS &amp; DDD for DD services</td>
<td>MDCH</td>
<td>OVHA &amp; DAIL</td>
<td>DHS</td>
</tr>
<tr>
<td><strong>Local/Area-wide Management Responsibility</strong></td>
<td>7 DDD Regional Offices</td>
<td>46 CMHSPs &amp; 18 PIHPs</td>
<td>10 DAs</td>
<td>10 MCOs</td>
</tr>
<tr>
<td><strong>Local Service Providers</strong></td>
<td>Qualified vendors &amp; independent providers under contract with DDD</td>
<td>CMHSPs &amp; other service providers under contracts with PIHPs</td>
<td>DAs, SSAs &amp; other providers under contracts with DAs</td>
<td>Service agencies and independent providers under contract with MCOs</td>
</tr>
<tr>
<td><strong>Other Components</strong></td>
<td>–</td>
<td>–</td>
<td>SSAs</td>
<td>ADRCs</td>
</tr>
<tr>
<td><strong>DD Eligibility</strong></td>
<td>Persons w/ MR &amp; related conditions</td>
<td>Persons with DD</td>
<td>Persons with MR &amp; related conditions</td>
<td>Persons w/ DD</td>
</tr>
<tr>
<td><strong>Combined Funding Streams</strong></td>
<td>HCBS and ICF/MR dollars; health plan coverage; behavioral health coverage</td>
<td>HCBS waiver and ICF/MR dollars; certain state plan coverages; + state and county match</td>
<td>HCBS waiver and ICF/MR dollars + flexible family grants</td>
<td>HCBS waiver and ICF/MR dollars; certain state plan coverages; + state and county match</td>
</tr>
<tr>
<td><strong>DD Services</strong></td>
<td>HCB waiver + ICF/MR services; health plan services; behavioral health services &amp; limited state only services</td>
<td>HCB waiver + ICF/MR services &amp; parallel Sec. 1915(b) services + state plan coverages</td>
<td>HCB waiver + ICF/MR services &amp; state plan services &amp; flexible family grants</td>
<td>HCB waiver + ICF/MR services + state plan services + state/county aid</td>
</tr>
<tr>
<td><strong>Federal Waivers</strong></td>
<td>Section 1115</td>
<td>Sec. 1915(b) + (c) combo waivers</td>
<td>Section 1115</td>
<td>Sec. 1915(b) + (c) combo waivers</td>
</tr>
<tr>
<td><strong>Capitation</strong></td>
<td>State level only (AHCCCS contracts with DDD)</td>
<td>MDCH contracts with 18 PIHPs; state only aid to 46 CMHSPs</td>
<td>State level only (OVHA contracts with AHS); funds transferred to AHS departments</td>
<td>DHS contracts with MCOs</td>
</tr>
</tbody>
</table>
Eligibility Determination. Eligibility is a two-tiered process in all four states. First, to qualify for state assistance, an individual must meet the state’s statutory definition of a “developmental disability” or of “mental retardation” and certain specified related conditions. Then, there is a secondary test of whether the individual’s disabilities are of sufficient severity to qualify him/her for enrollment in the state’s Medicaid managed long-term services program. Michigan and Wisconsin have adopted the federal definition of a developmental disability, which uses functional descriptors only. In contrast, Arizona and Vermont link eligibility to a definition of “mental retardation” plus other, defined etiological conditions, plus the functional descriptors used in the federal definition.

In Arizona, the regional offices of the Division of Developmental Disabilities are responsible for determining whether applicants for DDD services meet the state’s statutory definition, while the AHCCCS agency staff conducts the functional and financial eligibility screens which determine whether an applicant is eligible for ALTCS/DD services. In Michigan, the CMHSPs are responsible for determining whether an individual meets the state’s definition of a “developmental disability” as well as whether the applicant qualifies for Medicaid-funded services, including services available through the Specialty Services carve out. The Designated Agencies in Vermont are responsible for determining both whether an applicant for developmental services meets the state’s statutory definition and if she/he is in need of Medicaid-funded services through the state’s Global Commitment waiver/demonstration program. Finally, in Family Care counties in Wisconsin, the ADRC is responsible for determining basis statutory eligible and conducting the functional and financial screens which determine whether an applicant is entitled to participate in the Family Care program. [N.B., Until the Family Care program is implemented state-wide, county agencies will continue to determine whether applicants meets the statutory definition and whether they are eligible to receive Medicaid-funded services, including HCB waiver services.]

Consolidated Funding. All four states have consolidated a variety of funding streams to form a single, flexible financing source for long-term services and supports. In Arizona, the capitated payments DDD receives from the AHCCCS agency includes Medicaid funding for both home and community-based and ICF/MR services. Also included in the capitated payments are the dollars necessary to enroll ALTC/DD recipients in participating health plans and purchase necessary behavioral health services. Since Arizona did not participate in the federal-state Medicaid program prior in the initiation of the AHCCCS waiver/demonstration program, the federal portion of ALTCS/DD costs was introduced to the system at that point (1989) and has continued to cover more that half of all program costs ever since. Capitated payments for MH/DD/SA Specialty Services in Michigan are drawn from the following pre-existing sources: HCBS waiver services (primarily the state’s Habilitation Services waiver program), ICF/MR services, certain other state Medicaid plan services (e.g., personal care; clinic services; and rehabilitative services); plus state and county matching contributions. HCBS waiver services for children with developmental disabilities and Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services, however, are not included in the Specialty Services bundle and continue to be offered on a fee-for-services basis. In Vermont, funding under the state’s former DD home and community-based waiver program, ICF/MR funding plus Flexible Family support grants have been rolled into the Global Commitment funding package. A variety of other state plan coverages, including personal care services, EPSDT benefits and home-based care for technology dependent children are billed separately on a fee-for-services basis. Like Michigan, Wisconsin draws upon a mix of HCBS waiver services (in particular the state’s Community Options and Community Integration waiver programs), ICF/MR services, certain elements of state plan services (such as personal/attendant care services for adults) to finance Family Care services. Waiver services for children, EPSDT services, and the special Katie Beckett coverage option for SSI-eligible children with severe disabilities continue to be offered on a fee-for-service basis.

Service Package. The long-term services benefits offered through the managed care organizations in Arizona, Michigan and Wisconsin to eligible persons with developmental disabilities include: a wide range of home and community-based services; service coordination (or case management); and ICF/MR services when deemed to be the only viable alternative. Vermont offers a similar range of services to persons with developmental
disabilities, but rather than providing them through a managed care entity, the state Department of Disabilities,
Aging and Independent Living uses its network of Designated Agencies and Specialized Services Agencies to
provide or procure such services. These services are supplemented by coverages available under the state
Medicaid plan, including physical, occupational and speech therapy, EPSDT benefits, personal care services,
and home-based services for technology dependent children and adults. Besides long-term services and
supports, Arizona DDD contracts separately with qualified health plans for the provision of primary, preventive,
and acute health services as well as for behavioral health services furnished through a contract with the state
Division of Behavioral Health Services.

Each of the four states has a low institutional utilization rate, especially with respect to beneficiaries with
developmental disabilities (see Table B below). Only Wisconsin serves a significant number of individuals in
public and privately-operated ICFs/MR; and here steps have been taken in recent years by the state to reduce the
number of persons residing in large public and private ICF/MR-certified facilities – as evidenced by the fact
that the overall census of such facilities declined by 42 percent between July 2005 and July 2007 (from 1,822 to
1,059). Vermont closed its only state-run I/DD facility in 1993 and, for a number of years, has had only one, 6-
bed community residences operating as an ICF/MR. Michigan has no privately operated ICFs/MR and only one
remaining state-operated developmental center, which is scheduled to close next year. Only about 130 residents
live in Arizona’s one remaining, state-operated I/DD facility (the Training Program at Coolidge); and, virtually
all of the remaining ICF/MR-certified beds in the state are located in small, four to six-bed community
residences.

When it comes to operating a Medicaid managed long-term services program, there are distinct advantages to a
low rate of institutionalization. First, when the institutionalization rate is low, huge amounts of money don’t get
drained away from the overall funding pool to support a comparative small number of individuals, many of
whom could receive equal or better services at a lower average per capita cost in home and community-based
settings. Second, it is almost always easier to avoid an institutional placement than it is to arrange for an
institutionalized individual to return to the community, especially if services and supports are provided early to
avoid the kinds of crises that so often precede institutional admissions. Finally, the state and its local service
delivery agents (MCOs, etc.) are able to concentrate their energies and resources on building a more flexible,
resilient network of community resources, without having to deal with the political and logistical challenges of
simultaneously managing a major deinstitutionalization initiative.

### Table B

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<tr>
<th>ICF/MR and NF Utilization in Four States, July 2007</th>
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<tbody>
<tr>
<td>Total Public/Private ICF/MR Residents</td>
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<td>---------------------------------------</td>
</tr>
<tr>
<td>Arizona</td>
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<tr>
<td>Michigan</td>
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<td>Vermont</td>
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<td>Wisconsin</td>
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Federal Waivers. Arizona and Vermont rely on federal Medicaid statutory waivers granted in accordance with the provisions of Section 1115(a) of the Social Security Act. In contrast, the authority to operate the Medicaid managed long-term services programs in Michigan and Wisconsin is based on statutory waivers granted under Section 1915(b) and (c) of the Act.

Stakeholder Assessments of Four State Managed LTC Systems

In preparing this bulletin, as mentioned earlier, the author sought feedback from key I/DD system stakeholders in each state. In particular, all interviewees were asked about their current views regarding the state’s decision to institute a Medicaid managed long-term support system. What do they see as the principal strengths and weaknesses of the system today? Has managed long-term care lived up to the promise of making services more accessible to eligible individuals with developmental disabilities? Has the quality and appropriateness of services furnished to the I/DD population improved or deteriorated? The answers to these and other key questions raised during the interviews are summarized in this section of the report.

Prior to conducting the interviews, a series of interview guides were prepared, with each guide tailored to the features of the particular state’s managed LTC plan. To give participants an opportunity to consider their responses in advance, a copy of the appropriate guide was transmitted to the interviewee several days in advance of the schedule call time. Each of the guides requested input on similar topics, including the respondent’s overall assessment of the strengths and weaknesses of the plan, his or her views concerning key components of the plan – in particular resource allocation methods, access to services, the coordination of health and long-term supports, quality management, self-directed supports, grievance and appeal procedures, and any unique issues related to serving children with chronic disabilities. In addition, based on the interviewee’s experiences with the managed LTC plan in his/her state, each respondent was asked to summarize the advice he/she would offer stakeholders in another state that was considering instituting a managed LTC program which was to include services to the I/DD population.

Overall Assessment

One of the major reasons for interviewing selected stakeholders in each state was to obtain first hand assessments of the impact Medicaid managed long-term services has had (and is having) on the availability and quality of public services to persons with developmental disabilities. What better way, the reasoning went, to gain insights into the operational effects of these plans than to talk to a varied group of stakeholders who are passionately committed to improving the lives of individuals with disabilities. Each respondent, therefore, was asked for his or her overall assessment of the impact of state’s Medicaid managed LTC plan on persons with developmental disabilities.

The views expressed by the interviewees reflected a wide spectrum of opinions, ranging from enthusiastic support to disappointment and even disillusionment. While acknowledging important unrealized goals and the need for further improvements, proponents of their state’s managed LTC plan found significantly more pluses than minuses. A high level state official in Michigan, who was involved in designing the original plan, called the state’s Specialty Services carve-out “the best thing we ever did.” The director of the state Mental Health Administration at the time the carve-out was approved echoed this sentiment, saying “if I had it to do over again, I definitely would do the same thing we did in 1998.” Four current and former top officials of the Arizona Division of Developmental Disabilities – all of whom had formerly held key DD posts in other states -- said they were highly skeptical about the state’s managed long-term support program upon their arrival in the state; but, over the years, all of them have become strong supporters of the ALTCS approach to serving persons with developmental disabilities.
Non-government advocates and provider agency executives tended to be less sanguine about the state’s managed LTC program, with some respondents expressing considerable frustration with the continuing gap between promises and reality. A legal services advocate in Michigan reported that all of the problems associated with the state/local MH/DD services system that existed at the time the Specialty Services carve out was initiated still exist today. He went on to say that the basic aim of the carve out was to capture additional federal dollars, and, although that goal was realized, access to services and supports valued by people with disabilities and their families hasn’t improved appreciably during the intervening years. A provider agency executive in the same state agreed, saying that, for the most part, the shift to a managed care format has not resulted in the promised improvements in services and supports for individuals with developmental disabilities. The layers of new bureaucratic controls, he indicated, have diverted attention from the central goal of assisting people with disabilities to live high quality lives of their own choosing. He added that community provider agencies are treated like “second class citizens” within the service system.

But, support for these plans in each state reached beyond public officials. The long-time director of a major statewide advocacy organization in Michigan, for example, told the author of this bulletin, “there is not a soul I know who would go back to the old system if they had the choice.” A former county manager of DD services in Wisconsin, who now heads a multi-county Family Care alliance, reported that the waiting list for DD services in his county has been eliminated and the vast majority of persons with disabilities are receiving better services today than they were before implementation of the FC program.

Even the sharpest critics of their state’s managed LTC program concede that a managed care approach has important advantages when compared to past system management practices. Indeed, none of the interviewees – even a few who initially opposed including I/DD services in the plan -- suggested that people with developmental disabilities would be better off were I/DD services to be carved out of the managed care program. For example, a director of protection and advocacy services in one state said that the promise of equitable statewide access to services – especially opportunities for participants to live, work, recreate and participate in communities of their own choice – remains a largely unrealized goal; but, he also pointed out that assuring everyone access to services when they need them – without long delays -- is “a very big deal”—a deal, he implied, that makes the ongoing battle to improve the quality and appropriateness of services under the plan worthwhile.

**Strengths and Weaknesses.**

**Strengths.** When asked to pinpoint, based on their personal experiences, the principal advantages of a managed care approach, the respondents offered various explanations. These explanations can be summarized as follows:

- The obligation to make services and supports available to all eligible individuals when, where and how they need them. This central feature of any managed care program was the advantage most frequently cited by the interviewees. Often it was expressed in terms of eliminating the need for waiting lists – a troublesome reality for proponents of I/DD services in most states. As one regional director of DD services in Arizona pointed out, the commitment to “serve all comers” has become “the great engine that drives growth in the Division of Developmental Disabilities’ budget.” Over the past twenty plus years, the Division has experienced a steady increase in ALTCS funding – during both favorable and unfavorable fiscal periods – in order to meet projected increases in demand for services plus other factors influencing service costs (including inflationary pressures and emerging service delivery challenges). It is hard to conceive of how a similar record of growth could have been achieved, especially in a fiscally conservative state like Arizona, he added, in a conventional fee-for-services environment.
The flexibility to design supports around the needs and aspirations of each individual once all relevant Medicaid and non-Medicaid funding streams have been combined. In Wisconsin, for example, there are over forty separate funding sources for long-term services to elders and persons with physical or developmental disabilities. When the Family Care program is implemented in a county, all of these funding streams are combined in a single, flexible benefit package, thus affording the local managed care organization the latitude to develop more individually tailored support plans.

The emphasis on cost-effectiveness and the related tools to craft support plans that make more sense and also often cost less. One former county DD waiver manager in Wisconsin, who now functions as the CEO of a multi-county Managed Care Organization, noted that one of the key responsibilities of her former position was to obtain all of the resources possible for each person enrolled in a state HCBS waiver program. Because the number of waiver slots was finite, she felt obligated, as an advocate for the individual, to help the person/family maximize the resources available through both the waiver program as well as through other, related state Medicaid plan benefits. As a result, the person’s service plan was largely a product of the benefits which the county program manager (with the help of the service coordinators who worked for her) was able to negotiate on the person’s/family’s behalf, rather than a plan tailored strictly to the person’s needs and desires. Under the Family Care model, she explained, the incentives are fundamentally altered. Now, you can focus on the types of services and supports most appropriate to the person, she said, knowing that all relevant funding streams have been rolled together in a single federal-state benefit that can be deployed in a very flexible manner. Aware that the MCO is obligated to enroll all eligible persons who apply for services, she added, the prudent use of available resources and achieving equity of access across all enrollees become the predominant management priorities.

A former state and county program administrator in Michigan agreed with this point. Under the old fee-for-services approach, he pointed out, CMHSPs and other provider agencies faced incentives to overserve eligible clients. So, for example, if state guidelines governing the Habilitation Supports waiver program permitted participants to receive up to thirty hours a month of habilitation training services, you could be pretty sure that every eligible person would receive the thirty hours of services, whether they needed it or not – because that is how a CMHSP (or other provider agencies) could maximize their income. Once CMHSPs began to receive capitated payments tied to the number of eligible persons in their respective catchment areas, he added, these incentives went away. Instead, the focus shifted to figuring out how the appropriate array of services and support could be provided to each individual in the most economical manner given his or her needs and preferences. Before the advent of the Specialty Services program, service waiting lists were common within the DD sector, he said. Because of the way the fee-for-service system worked, he pointed out, the consumer “either got a Cadillac [program] or nothing at all.” As a result, within the service system, there were “the haves” and the “have nots.”

The emphasis on cost-effectiveness is illustrated most dramatically in the area of access to institutional care. Since all individuals who meet the eligibility criteria and have long-term care needs are enrolled in the state’s managed care program, the managed care organization has a strong incentive to develop community support arrangements for institutionalized recipients and other persons with complex service needs, especially when there is evidence that the alternative costs will be less than the cost of institutional care. This is a more meaningful factor in Wisconsin, which still serves approximately 1,000 adults with developmental disabilities in large (16 bed+) congregate care facilities, than it is in the other three states, as Table B illustrates.

The benefits of coordinating the delivery of long-term supports with the provision of health care services. The prevalence of chronic health conditions is very high among persons who require long-term supports. Indeed, among senior citizens (and to a lesser, but nonetheless significant, extent among other persons with physical, mental and developmental disabilities) the need for long-term services is a direct
consequence of the person’s compromised health status. Therefore, it is not surprising to find that the Medicaid managed LTC plans in each of the four states contain provisions for coordinating the delivery of health care and long-term supports to program enrollees. A number of interviewees emphasized the payoffs associated with these provisions of the plan, indicating that the coordination of health and long-term services benefits has emerged as a major advantage of operating services within a managed care framework. Officials from Arizona, where the state Division of Developmental Disabilities is responsible for overseeing the delivery of acute/preventive health, behavioral health and long-term supports for all ALTCS/DD-eligible persons, were especially vocal proponents of coordinating the provision of health and long-term services (see further discussion under the “Coordination of Health Care and Long-Term Supports” above).

Individuals with complex medical support needs have the option in some areas of Wisconsin of enrolling in the Family Care Partnership program. The advantage of the Partnership option for such individuals is that the managed care entity is responsible for furnishing health care as well as long-term services to enrollees, whether those services are reimbursed through the Medicare program or Medicaid program. This option has been used primarily by frail elders thus far, but there are younger individuals with disabilities – including some persons with developmental disabilities – who can benefit from receiving a coordinated array of health care and long-term supports. Indeed, a couple of Partnership programs have begun to enroll more than an token number of persons with developmental disabilities.

- Another major advantage of a managed care approach cited by some interviewees is that it establishes a fixed point of accountability for meeting the entire continuum of an enrollee’s support needs. This point was stressed in particular by interviewees from Arizona, where, as noted above, the state Division of Developmental Disabilities is responsible for assuring that ALTCS/DD-eligible individuals receive the acute and preventive health, behavioral health and long-term supports they need. While the responsibilities of the local/area-wide management entities in Michigan, Vermont and Wisconsin are not quite as broad, they control essentially all federal, state and local long-term service dollars, which, as several interviewees from these states pointed out, makes it easier to fix accountability when performance lags behind expectations.

- When dollars are managed globally and there is an obligation to serve all eligible persons, the managed care entity has incentives to intervene BEFORE a major life crisis occurs, especially when there is evidence that the particular intervention is likely to be cost-effective over the long term. A top level DD official in Arizona contrasted this approach to the crisis-driven service policies of other states, saying she believes the ALTCS/DD system’s early intervention capabilities it is one of the reasons why Arizona has been able to maintain such a low rate of institutionalization over the years. The executive director of a major consumer advocacy organization in Michigan pointed out that persons eligible to receive services under the state Specialty Services carve out do not need to meet an “institutional needs” test in order to receive federally-assisted supports since the PIHP has the option of enrolling such individuals in Section 1915(b) waiver services. This option gives the PIHP, he said, the capability of intervening early without foregoing federal financial participation in the cost of such services.

The available support options often are broader under a managed care approach, especially in sparsely populated areas of the state. Under the managed long-term support program in Michigan, Wisconsin and Arizona, program enrollees are assured of having access to at least two providers of any covered service. As several interviewees from these states pointed out, the right to choose between two or more qualified providers of services did not exist under the former fee-for-service system. When there was only a single service provider in town, consumers/families faced a “take-it-or-leave-it” choice. A managed care approach introduces competition, the argument goes, thus forcing all providers to maintain a high level of performance or face a decline in their customer base.
With a larger customer base and access to single-stream funding, area-wide MCOs are able to build and maintain much stronger management capabilities. A CEO of a multi-county Family Care Alliance in Wisconsin, for example, emphasized that MCOs are forced to adopt standardized approaches to managing the service delivery process in order to achieve consistency in access to services and uniformity in the way eligible individuals are treated. Moreover, under the Family Care model, she stressed, the MCO has the resources necessary to hire staff specialists to perform various managerial functions. For example, her agency has set up a quality management department, a contract management department, a network management and resource development department, etc. She contrasted this situation with her years as a DD service manager for a county human services agency. In that position, she had to act as the chief budget officer, the quality assurance monitor, the system planner, the network development specialist, the contract manager, etc. With staff specialization, she concluded, the MCO gains the ability to manage the service delivery process far more pro-actively.

A colleague from another area of the state made a similar point when he reported that the Family Care MCO he now directs has been able to develop state-of-the-art IT capabilities that permit business processes to be fully integrated with the agency’s clinical records. And, a former director of the Arizona Division of Developmental Disabilities, who now heads up a large community provider agency in the state, was getting at the same point when he lauded the “data-driven” decision-making capabilities of the state’s ALTCS/DD program.

The additional federal payments a state receives as a result of its managed care agreement with CMS has helped to stabilize the overall financial status of the state’s Medicaid program. As noted earlier, the decision to pursue a managed care strategy was strongly influenced in all four states by the recognition on the part of state policymakers that the future costs of maintaining the existing fee-for-service system were simply unsustainable. The infusion of a significant amount of new federal dollars was an essential pre-condition to launching and maintaining the managed long-term services plans in each of these states. But, as time passes and the new dollars become integrated in the state’s budget, the significance of the federal funding role becomes less prominent in the minds of system stakeholders. This probably is the reason why only the interviewees from Vermont focused on this advantage of the plan.

The commitment to achieving geographic equity in the provision of long-term services and supports benefits all current and potential service recipients. One important goals of the Medicaid managed LTC plans in each of these states is to achieve geographic equity in access to services and supports, regardless of an eligible individual’s place of residence. In other words, the intent is to ensure that all eligible individuals are able to receive the same, types, quantity and quality of services regardless of where they live in the state. Opinions vary regarding the progress achieved to date in the area of geographic equity as well as the vigor with which state and local officials are pursing this goal, especially in states (Wisconsin and Michigan) where counties traditionally have played a leading role in financing and delivering services to persons with developmental disabilities. Nonetheless, virtually everyone agrees on the importance of affording eligible individuals equitable access to services regardless of their county of residence.

The streamlined process of gaining access to services makes the system more consumer and family-friendly. Another basic commitment of the Medicaid managed LTC plans in each of these states is that consumers and families will find it easy to obtain information, have their eligibility and service needs determined, and receive help in developing a service plan, choosing a service provider(s) and gaining access to needed services and support. The mechanisms used to accomplish this objective vary from state to state but they all involve the same fundamentals (e.g., a central repository of information and guidance on accessing available services; single stream funding; a fix point of accountability for managing all service dollars; and a person-centered planning process).
Weaknesses. All interviewees also were asked, based on their varied and extensive experiences, to pinpoint the major drawbacks associated with their state’s Medicaid managed LTC program. Here again, the responses proved to be quite varied. The principal disadvantages pointed out by the respondents can be summarized as follows:

- Managed care has failed to eliminate – or, some would say, even substantially reduce -- geographic inequities in access to services designed to promote community integration, independence and productivity. Generally, the interviewees agreed that individuals are being promptly enrolled in services once their eligibility has been determined and a service plan has been developed. But, serious concerns were expressed – especially by interviewees from the two states (Michigan and Wisconsin) in which county governments historically have played a lead role in serving individuals with disabilities – about persistent geographic variations in the types of services being furnished. One long-time consumer advocate in Wisconsin explained the situation as follows: The tendency has been to enroll existing HCBS waiver recipients in the same service programs they were participating in prior to the switch to Family Care. For most adults with developmental disabilities, the result is more of the same – i.e., living in a provider-operated group home, attending a sheltered workshop or adult activity center during the day, and having few opportunities to be employed in an integrated work setting or otherwise interact with non-disabled peers. In other words, despite the program’s highly progressive statutory and regulatory goals, the reality is that opportunities to receive supports in new and creative ways, for the most part, are not occurring. Moreover, the way in which the Family Care capitation rates are presently structured, it is not clear that many counties are going to be able to transition to using individualized, person-centered approaches to organizing and delivering supports.

Similar concerns were voiced by other Wisconsin respondents as well as many of the Michigan interviewees. They pointed to the highly uneven access to individualized, person-centered supports from county to county. Concern about such programmatic variations lead the new director of Michigan’s Mental Health and Substance Abuse Administration to circulate a concept paper this summer which lays out some of the challenges facing the Specialty Services program. While acknowledging the service system’s many accomplishments, the paper identifies a series of areas in which the culture of the state’s mental health/developmental disabilities service system must be improved, including the pursuit of such goals as supporting maximum consumer choice and control, expanding opportunities for integrated employment and upgrading the quality of supports and services made available to eligible beneficiaries. More recently, MDCH has circulated a draft “Application for Renewal and Recommitment” (ARR) that outlines a series of revised and enhanced performance expectations designed to address the shortcomings outlined in the earlier concept paper. PIHPs are instructed to review the revised performance expectations and inform the department by January 1, 2009 whether they current meet the department’s revised standards or have a plan for doing so within five years.

Concerns about uneven access to individualized supports were more muted among the interviewees from Vermont and Arizona, where county governments play a far less prominent role. But, even in these states, which pride themselves on the provision of highly individualized services, concerns were voiced about the lack of access to services that promote full community integration. Several respondents from Arizona, for example, mentioned the state’s lackluster track record in enrolling ALTCS/DD recipients in competitive and supported employment services and in developing self-directed service options. They also acknowledged that access to services often is constrained on Indian reservations and in other sparsely populated areas of the state. A couple of the Vermont respondents alluded to the increasing tendency to place two, rather than one person, in a residential setting and the growing difficulty in extending services to individuals – especially children – who do not meet the state’s annual spending priorities. The origin of the latter problems, it should be noted, has little to do with the decision to fund developmental services through the Global Commitment to Health waiver/demonstration program. Instead, they are outgrowths of the state’s increasingly stringent budget restrictions.
Concerns about the potential for “medicalizing” long-term services linger in Arizona and Wisconsin despite substantial efforts to frame the program around person-centered, social support principles. DDD officials in Arizona reported that the agency maintains close, collaborative relationships with the AHCCCS agency, which is responsible for the overall management of the state’s Section 1115 waiver/demonstration program. Nonetheless, the ALTCS/DD component of the program is such a small part of the overall AHCCCS operation that there is a tendency to impose requirements that are quite rational in an acute care setting but make little or no sense in a long-term supports system. The latest example of this phenomenon, one DDD official reported, is the expanded set of pregnancy reporting requirements that AHCCCS has imposed. DDD case managers complain constantly about how onerous and unnecessary these requirements are in a system that reports only about 4 or 5 pregnancies a year. Yet, keeping track of pregnancies, AHCCCS-wide makes a good deal of sense, especially in the case of the TANF population.

Federal managed care requirements usually are framed around the delivery of acute health services and, consequently, sometimes are of questionable utility when applied to a long-term support system. The statutory provisions governing the handling of grievance and appeals procedures, which Congress approved in 1997, offers an example of this phenomenon. The aim of these provisions of the Balanced Budget Act (BBA) of 1997 was to rein in the excesses of managed health care plans at a time when many individuals were being unceremoniously denied services or dropped from coverage without explanation. Congress amended Medicaid law to prevent such practices and also mandated that all recipients who are denied services be notified in advance and informed of their appeal rights, in accordance with a strict set of timelines. The Arizona Division of Developmental Disabilities has encountered serious problems in meeting these timelines due to the multi-staged process it uses to negotiate with a family and gain approval of individual service plans. While some division officials believe that the new requirements represent a healthy reminder of the importance of being responsive to customer needs, many DDD service coordinators view these provisions as a source of unnecessary paperwork that erode the amount of time they are able to spend supporting individuals and families on their caseloads. At the time of the interview, the division was operating under a “notice to cure” (one step below a formal contract deficiency) issued by AHCCCS because of DDD’s failure to meet the administrative timelines spelled out in federal rules.

In a different but related vein, Vermont has encountered problems in squaring the requirements of federal managed care rules and administrative policies with the concept of a state agency functioning as a managed care organization. State officials point out that federal rules are largely modeled around a private, proprietary or non-profit health management organization functioning as an MCO. While none of the problems which have arisen thus far have proved to be “show-stoppers”, they have occurred frequently enough that a special trouble-shooting unit has been established within the Office of Vermont Health Access.

To varying degrees, the targeted states have encountered problems in acquiring and maintaining an adequate number of qualified personnel to administer a managed care system. A managed care system is complex, with many moving parts; and, to function effectively, these systems require the active engagement of skilled management staff at the state level. With the exception of Vermont, the state officials who were interviewed for this report all expressed differing levels of concern about their agency’s capability to recruit and retain the number and types of staff members required. The origin of the problem lies, in part, in public opposition to large state bureaucracies and the related tendency of elected officials to trim state payrolls, especially during tough economic times. AHCCCS’s contracts with its managed care organizations (including DDD) cap expenditures for administrative and overhead costs at eight percent of the total contract amount; but, the state legislature only allows the Division to expend approximately 6 percent of its overall budget for administrative services. As a result, the Division has been unable to put in place all of the management/oversight processes deemed necessary.
Another part of the problem lies in the difficulty in recruiting and retaining government employees with the specialized administrative and technical skills needed to run a huge, multi-faceted managed care system.

Staff recruitment and retention problems extend to local/area-wide managed care organizations in the two states (Michigan and Wisconsin) which have elected to decentralize the MCO function. Both states rely on “home grown” MCOs, constructed largely from the components (including key personnel) of the old county-based service delivery system. Transitioning from a social services mindset to a managed care mindset has proven to be difficult in a significant number of localities. These problems are compounded by the need in some parts of the state to forge multi-county operating agreements and build the financial reserves necessary to navigate the risks of functioning as a successful MCO.

- For individuals involved in a state’s service delivery system, the learning curve in adapting to a newly introduced managed care system often is very steep. One state official in Arizona, with extensive prior experience in managing public DD services in other states, offered the following observation: There is a steep initial learning curve involved when you move into a managed care system. A lot of people have over-simplistic notions of the skills required to manage a conventional fee-for-service system versus a managed care system. Believe me, she said, managed care involves a whole new way of administering services. The CEO of a newly established MCO in Wisconsin made a similar point but in terms of administering services at the local level. She emphasized that a lot of re-tooling is required when you adopt a managed care approach and not everyone adjusts well to operating in the new environment. For example, the job of a care coordinator is no longer simply to link beneficiaries to a prefabricated menu of services they are eligible to receive, but instead involves listening carefully to the consumer and helping him/her to develop a set of outcomes that will lead to a quality life as he or she defines it. Often the job entails saying “no” to unjustified requests, she added, and helping the person to re-focus on what is important in her/his life. It takes about a year of re-training, she said, before most individuals catch on to the responsibilities of a FC care coordinator. And, even with training, the turnover rate among care coordinators in her county was about 25 percent after the Family Care program was introduced.

The concept of “natural supports” and “family stabilization” frequently are used as code words for denying adults access to the out-of-living arrangements they need and desire. Some respondents report that such politically correct terms are being used by local managed care organizations in their states to avoid spending the additional dollars required to purchase out-of-home living arrangements for adults who clearly would benefit from living away from their families. The director of protection and advocacy services in one state called this terminology a ruse aimed at saving money. The sons and daughters of families that continue to provide active supports, he added, are penalized with scaled-back service plans which assume the family will fill in the blanks. It is fundamentally unfair, he added. The executive of a large community provider agency in another state reported that often compromises are necessary in fashioning support plans due to the limitations imposed by the amount of funding the MCO is willing to make available. For some, she said, this decision will translate into living in a larger group setting (up to 4, or occasionally, 6 beds), rather than a more personalized one or two-bed setting.

But, even if you assume a fair distribution of resources, one respondent argued there is inherent tendency within a managed care framework to focus exclusively on the acuity of the individual’s needs while largely ignoring the intersecting needs of the family. In the case of a family raising a child or an adult with a developmental disability in their home, he noted, the needs of the family often are as important a determinant of the types and amount of support necessary as the person’s own disabilities. Yet, these factors tend to be overlooked when the content of an individual’s service plan are based largely on the results of standardized screening tools. He added that top level policymakers and elected officials frequently have a difficult time understanding that the reason for providing in-home supports is to delay the need for an out-of-home placement. It is not well understood that most individuals with
severe disabilities will require a residential placement at some point in their lives. The question is when, not whether, he added.

- A state which elects to construct a managed care delivery system upon the framework of its pre-existing community services system runs the risk of creating confusing, overlapping sets of responsibilities within the restructured system. According to some of the Michigan interviewees, the functions of the Community Mental Health Services Program (CMHSP) and the Pre-Paid In-Patient Health Plan (PIHP) overlap, thus making it more difficult for individuals and families to obtain information and gain access to needed services. On paper, CMHSPs and PIHPs are assigned distinctive roles; and certainly in the state’s most populous counties, the issue usually does not arise because the functions of the CMHSP and the PIHP are carried out by a single organization (typically the county MH authority). But, in other catchment areas of the state, where two or more CMHSPs have banded together to create a PIHP, it is not always easy to figure out the distribution of responsibilities. Efforts have been made in some catchment areas to consolidate and rationalize the responsibilities of the two entities; but, according to some interviewees, a lot of overlapping and duplicative functions remain in some PIHP catchment areas. In testimony before a recent mental health study commission, the state P&A agency recommended that the functions of CMHSP be folded into the responsibilities of the PIHP so there is a single, accountable organization within each catchment area of the state.

- Relieving county governments of their traditional roles, however, could result in a reduction in public accountability. Several Wisconsin stakeholders expressed concern about shifting virtually all responsibilities for administering services to elderly and non-elderly adults with disabilities from county government to a not-for-profit managed care organization. With the shift of power and control from the counties to a non-profit MCO serving (in most instances) multiple counties, local political control is sacrificed. As the executive director of a statewide advocacy organization explained, in the past, if a county human services agency was failing to provide quality services to persons with developmental disabilities, advocates knew they could lobby the county supervisors. But, where is the lever for assuring accountability and promoting change in the restructured system, he asked, when the power lies with an independent MCO? A CEO of one of the new MCOs agreed with the point, saying the shift in responsibility removes “the security blanket” that the counties once provided. MCOs are at financial risk and subject to state sanctions if they fail to maintain the minimum reserves specified in their contracts with DHS. County supervisors are not likely to bail out poorly managed MCOs as they once might have when the county was directly responsible for providing or purchasing services for frail elders and other persons with chronic disabilities. DHS officials are aware of the problem and concerned about the consequences of the power shift. One departmental official who is deeply involved in orchestrating the Family Care expansion noted that it is difficult to find managed care organizations that are experienced in serving individuals with long-term support needs and willing and able to embrace the consumer-centered values which undergird the FC program. Without effective MCOs, she added, the program won’t work.

- In states where county governments historically have underwritten (and are expected to continue to underwrite) a portion of the cost of serving frail elders and persons with physical, behavioral and/or developmental disabilities, it is difficult to establish capitated rates that treat all counties equitably. In fee-for-service systems the level of financial participation and the extent and types of services provided often varies considerably from county to county. When a state adopts a managed care approach, it is not likely to be a position to either pick up the counties’ total share of program costs or set capitation rates at a level sufficient to cover the costs in counties with the most generous programs. As a result, there are likely to be winners and losers among county governments when capitation rates are established. The DD program manager in a large urban county in Wisconsin, for example, estimates that about 12 of Wisconsin’s 72 counties will be financially disadvantaged by the shift to Family Care – especially with respect to services to people with developmental disabilities. In part, this disadvantage grows out of the
state’s decision to base its capitation rates on actuarial data from the original 6 pilot counties, he said, which for the most part reflect the greater reliance on congregate service models in these counties. And, in part, it reflects the fact that some counties historically have contributed far more local money to supplement state LTC dollars than others. Dane County (Madison area) retained its own actuary to assess the impact of shifting to Family Care. The actuary concluded that the state’s initial capitation rates would result in an average $1,400 a month shortfall in funding per enrollee across all target populations in the county. The funding deficit would be far more severe in DD services, where the state’s capitation rates would result in a $2,800 a month shortfall compared to existing funding arrangements. Based on these findings and related analyses, county officials decided not to participate as one of the original pilot counties and instead, to be one of the last counties to enter the program.

Some stakeholders voiced concern about the fiscal capacity of the state to meet the growing demand for services over the long haul. These stakeholders pointed to the spiraling cost of health and long-term services and the projected steep growth in demand as the Baby Boom generation retires and begins to need long-term supports. Where is the money going to come from, they ask, to sustain the program five, ten or twenty years downstream? These issues were raised mainly by stakeholders in Wisconsin, probably because the state is still in the process of phasing in the Family Care program. But, the same question would appear to apply to all of the focus states. Certainly, by most estimates, very challenging days lie ahead for all public human services programs, especially programs with the types of ambitious goals discussed in this bulletin.

Advice to Disability Stakeholders in Other States

Near the end of each interview, the respondent was asked to briefly summarize the advice he or she would offer to stakeholders in another state that was contemplating the adoption of a Medicaid managed long-term services plan. What considerations, they were asked, should be foremost in the minds of persons involved in designing and implementing such a plan.

The responses to this question, again, were varied; but, they can be grouped into two broad categories: advice on the process of designing the state’s plan; and advice on implementing the plan.

Among the process recommendations offered by the respondents were:

- **Assess your state’s situation carefully before deciding to employ the principles of managed care in restructuring publicly-financed long-term services.** The Medicaid director in Vermont emphasized that each state’s situation is different and, therefore, it is essential to craft solutions that address the unique contours of the state’s needs going forward. The long-time director of a statewide advocacy organization in Michigan made the same point but from a slightly different angle. The Specialty Services carve out in Michigan, he noted, was in many ways a logical progression in a series of policy initiatives which state officials had been pursing for over two decades. A similar approach, he added, is not likely to work in many other states, especially states with lengthy waiting lists and under-developed community service systems.

- **Make sure your plan clearly reflects the core values you aim to instill in the program.** Noting that the legislation authorizing the original Wisconsin Family Care pilot projects laid out in clear, unambiguous language the consumer-centered principles that should guide the program, the top executive of a newly formed MCO stressed the importance of having the program’s goals “carved in stone.” As issues have arisen over the year, she noted, it has been extremely useful to be able to refer to those statutory principles and remind everyone: this is what we are suppose to be striving to achieve. A disability advocate in Michigan pointed out the importance of translating these values into the state’s definition of “medical necessary.” The state’s Medicaid Provider Manual specifies, in part, that to meet the state’s
medical necessity criteria for mental health, developmental disabilities and substance abuse services must be “… designed to assist the beneficiary to attain or maintain a sufficient level of functioning in order to achieve his goals of community inclusion and participation, independence, recovery and productivity.”

- Involve representatives of key stakeholder groups – including self-advocates and family members -- in all aspects of developing the basic design features of the state’s plan as well as strategies for implementing it. A Medicaid official in Arizona stressed this point, noting that “a lot of people have the wrong idea about managed care” and need to be involved in the process of building a plan that will work for everyone. The CEO of an area-wide, single-point-of-entry agency in Vermont warned that “these plans are extremely complicated and unless consumer advocates are at the table demanding fair treatment for people with lifelong disabilities, their needs will be overlooked.”

- Take the time to resolve potential issues during the design and initial implementation phases of the program. By doing so, you’ll avoid a lot serious problems downstream. The director of the state DD agency in Arizona made this point when she recommended that participants in the planning process “think holistically” about the changes associated with the transition to a managed care system. “Too many people,” she remarked, “think of managed care simply as the adoption of a capitated funding model or the institution of a new rate-setting model; but it involves much more than that. It’s an entirely different approach to organizing, financing and delivering long-term supports.” A high level human services official in Vermont conceded that the state probably could have avoided some of the problems initially encountered in implementing the state’s Global Commitment to Health waiver/demonstration program had there been more and better advanced planning. But, he added, that, due to the looming fiscal crisis posed by the projected shortfall in Medicaid funding, the governor and the legislature had to move swiftly to rectify the problem.

Understand the state’s primary motivations for adopting a managed care plan and focus on the actions necessary to secure the interests of people with developmental disabilities. There may be – indeed usually there are – overriding factors that lead a state to adopt a Medicaid managed long-term support plan. Lay and professional advocates for persons with developmental disabilities need to study these underlying motivations carefully and assess the likely impact on existing I/DD services. There will be instances in which the only sensible strategy is to oppose the inclusion of the I/DD population in the plan, especially when the plan is clearly under-financed and/or based on a suspect set of policy aims. In other cases, however, the better course of action is to participate in the process of developing the plan, with the stated aim of building in safeguards that protect the interests of people with disabilities. A long-time state DD official in Vermont reported that disability advocates in that state worked with legislators while the Global Commitment waiver/demonstration proposal was being developed to ensure continued legislative control over program spending decisions. The fact that the legislature still approves biennial appropriations on a program by program basis, she said, means that advocates can take their case to elected lawmakers as decisions regarding program funding levels are being made.

- Design the plan in a manner that promotes the efficient use of available resources. A primary aim of any managed care approach is to achieve efficiencies in the use of scarce resources. Several interviewees stressed the importance of utilizing strategies aimed at ensuring that resources are deployed in an efficient manner. The Arizona Division of Developmental Disabilities, for example, has developed a computerized supports coordination system that allows officials to compare the number of support hours and costs requested as part of an individual’s support plan with the average number of support hours and costs allocated for all individuals statewide who have similar need profiles. Other interviewees, however, expressed a good deal of discomfort with such mechanized approaches to cost containment, arguing that it is inconsistent with the state’s promise to engage in a truly person-centered planning process.
• Learn from the experiences of other states. While acknowledging the uniqueness of each state’s situation, one former state program director said that, in designing a managed long-term services plan, it is helpful to draw upon the experiences of other states – both their success and their mistakes.

With respect to implementation issues, the advice of stakeholders centered around the vulnerabilities which arise in instituting a Medicaid managed long-term services program. In this area, many of respondents appeared to be reflecting on the shortcomings of their own state’s program as they formulated their responses.

• Make sure that the state agency responsible for implementing the program has the necessary resources to actively oversee and, when it becomes necessary, enforce performance expectations. Emphasizing the complex administrative tasks involved, one state agency director put it this way: “Don’t even contemplate the adoption of a managed long-term services plan unless you have the administrative capacity within state government to manage and oversee the quality and appropriateness of services.” A state Medicaid official in another state put the proposition in even simpler terms: “states need to manage managed care,” he said, if they expect to reap the benefits of greater cost efficiency and improved health and social outcomes. A former state agency director was getting at the same point when he stressed the importance of maintaining public accountability for the performance of the state’s long-term services system. A poorly conceived managed care plan – especially one that cedes unbridled control to private health care management firms (as has occurred in several state managed behavioral health programs) – can be a lot worst than a fee-for-service system, he pointed out. The lack of pro-active state enforcement of plan goals and principles emerged as a major concern among the Michigan stakeholders who were interviewed during the course of the present study. Indeed, this issue has become a primary focal area as state officials, in collaboration with county and non-governmental stakeholders, examine the steps that can be taken to strength the state’s Specialty Services program.

Special initiatives need to be launched to ensure that the goals of community inclusion, participation, independence and productivity are reflected in the lives of program participants. With the advantages of single stream funding and the ability to deploy resources flexibly, a managed care approach should result in enhanced opportunities for individuals with disabilities to live fuller, more participatory and inclusive lives in their local communities. But, based on the comments of the interviewees, many jurisdictions across each of the focus states apparently have made limited progress in capitalizing on these opportunities to date. This appears to be particularly true in the two states (Michigan and Wisconsin) that have relied on county governments to play a lead role in organizing and delivering services to persons with disabilities. But, some of the same concerns were voiced by respondents from Arizona and Vermont as well. The comments focused on the uneven access to services highly valued by self-advocates and family members, including self-directed supports, supported employment and “true” person-centered planning. The solution to this problem does not lie in addition rhetoric, these respondents emphasized, but in a demonstrable commitment from all parties – spearheaded by state government – to improving the situation.

• Make sure that community provider agencies have the tools and the qualifications necessary to provide high quality supports. The executive director of one large, statewide provider agency in Wisconsin stressed the need for start-up funds to help provider agencies – especially small “mom and pop” agencies – to transition to a managed care operating environment. The CEO of a newly formed multi-county managed care alliance sounded a similar note when she asked that time and resources be allotted to help local management entities convert from a fee-for-service to a managed care model. Finally, the CEO of a large residential provider agency in another state asked that workforce stabilization not be treated as an academic exercise in efforts to improve the quality of services. These are the people who work directing the individuals with disabilities everyday, he stressed, and if we are unable to offer them fair compensation, reasonable benefits, a positive work environment and recognition for their services, the ability of provider agencies to deliver quality services will be seriously compromised.
The underlying message which the interviewees attempted to convey through their comments might be summarized as follows: a well designed plan and implementation strategy is a necessary pre-condition; but, eternal vigilance is the price of success.

**Implications for Other States**

Are other states likely to head down the same pathways Arizona, Michigan, Vermont and Wisconsin have taken by folding public developmental disabilities services into a Medicaid managed long-term services plan? Any predictions in this area should be taken with a grain of salt – as we should have learned from the wise heads who foretold a mad rush toward the adoption of managed care models during the mid-to-late 90s. But, unquestionably the nation is heading toward a major train wreck when it comes to financing social entitlement programs. Assuming health care cost continue to grow at the current rate, we are told that Medicare and Medicaid outlays as a share of the Gross National Product will increase by five fold between now and 2050 and consume by the late 2040s the equivalent of the entire 2009 federal budget. That, as budget experts keeping reminding us, is an unsustainable scenario. Given the states’ nearly total reliance on Medicaid dollars to finance public developmental disabilities services, it is inconceivable that state/local I/DD service systems will escape unscathed from any major realignment of federal social entitlement programs.

The problem of entitlement financing is exacerbated by the fallout from the current financial crisis on Wall Street. As this bulletin was being completed, governors were scurrying to trim state budgets in the face of plummeting revenue projections and an economy that was slipping into a recession of unknown depth and length. In situations like this one, you can be sure that, in addition to looking for immediate budget cuts, state policymakers will be examining alternative ways of controlling the growth in public outlays over the long haul. If, in their eyes, managed care appears to be a promising tool to reign in health and long-term service costs, they will find ways of using it. Already the State of Rhode Island has submitted a sweeping proposal (referred to as the “Global Compact Waiver”) calling for unprecedented state flexibility in managing all Medicaid expenditures (including funds for services to persons with developmental disabilities) in exchange for agreeing to a cap on federal financial participation.

During the 1990s, discussions of potential applications of managed care technology in the I/DD service sector revolved largely around the concept of a DD managed care carve out. But, as this analysis underscores, the interests of people with developmental disabilities was not the primarily motivation for adopting a managed care approach in any of the four states we examined. And, it probably won’t be a major factor in future state Medicaid managed care proposals. Indeed, as the recent Rhode Island proposal illustrates, states are likely to seek broad authority to operate all or most of their Medicaid programs under policies that deviate from the existing federal statutory and regulatory framework, rather than focusing on specific Medicaid target groups such as individuals with developmental disabilities.

This eventuality will pose serious dilemmas for disability advocates in states that decide to pursue such sweeping program reforms. Do you advocate for having I/DD services carved out of the plan? Or, do you join forces with other interest groups in opposing the adoption of the overall plan by communicating your views to state policymakers, members of the state’s Congressional delegation and responsible federal officials? Or, do you secure a seat at the table and seek to ensure that safeguards are built into the plan which will protect the interests of people with lifelong disabilities? None of these strategies are foolproof. Should the plan be approved despite opposition from the disability community and other affected interests, you will have lost the chance to help shape it in ways favorable to people with disabilities. If you succeed in getting I/DD services carved out of the plan, there is no guarantee that the governor’s budget office and the legislature will treat the program favorably during future funding cycles. Indeed, you may discover, as advocates for children’s disability services in Wisconsin learned, that your interests take a back seat to the state’s broader interests in making sure its managed care initiative succeeds. And, of course, just because you have a seat at the table...
doesn’t necessarily mean you’ll be able to secure important safeguards for people with disabilities as the particulars of the state’s plan are hammered out.

There are no easy answers in this arena. Before adopting a strategy, advocates for DD services need to take stock of the unique circumstances facing their respective states as well as the nature of the reform proposals on the table. In mapping out such a strategy, the advice offered by the stakeholders interviewed during the course of this study represents a solid starting point (see “Advice to Disability Stakeholders in Other States” above).

Don’t be too quick to reject a managed care approach. As the experiences of the four states that were the focus of this study reveal, a managed care plan can be a vehicle that affords all eligible individuals reasonably prompt access to the long-term supports they need. And, while these states have not completely solved all service access problems, most affected consumers and families are better off than they would be if they were living in many other states. If, in addition, the plan allows the state to qualify for additional federal aid and, thereby, stabilize overall financing of the state’s Medicaid program, that’s a plus for all program beneficiaries. At the same time, there is no question that hastily conceived plans that are aimed primarily at slashing state outlays can have disastrous consequences. It is important to note that none of the study states adopted a managed care approach primarily to reduce state spending on long-term services; instead, the goal was to achieve enhanced statewide equity in access to services while at the same time improving the cost-effectiveness and quality of such services.

So what lessons can other states learn from the experiences of Arizona, Michigan, Vermont and Wisconsin in operating services under a managed care umbrella? First, it is vital that each state craft a set of solutions tailored to its overarching policy objectives. The operational approaches used in these states differ from one another and, in many ways, are a reflection of the state’s cumulative efforts over the years to build an effective system for delivering disability services. Second, the federal statutory waivers these programs are based upon were initially approved years ago and it’s not clear that CMS would be willing to negotiate similar agreements with other states today. For example, according to one estimate developed shortly after the approval by CMS of Vermont’s Global Commitment waiver/demonstration program, if the Medicaid program expenditures of the other 49 states were permitted to grow at the same level as GC expenditures, the federal government would spend an additional $105 billion over five years and one-third of a trillion dollars over ten years, compared to the federal government’s growth projections at the time.xi

Even if the provisions of these states’ plans can’t (and probably shouldn’t) be replicated in their entirety by another state, there are important lessons to be derived from the experiences of Arizona, Michigan, Vermont and Wisconsin. For example, the decision of Vermont and Arizona (for DD services at least) to have a state agency play a direct role in managing the overall system – rather than farming out this critical function to a non-governmental managed care organization(s) – makes a lot of sense, if one of the primary goals (as it should be) is to protect the interests of the taxpaying public and assure ongoing public accountability. Arizona’s decision to place administrative responsibility for overseeing the delivery of health, behavioral health and long-term services in the same state agency (the state Division of Developmental Disabilities) has taught us some useful lessons about the advantages of co-managing health and long-term services benefits to persons with developmental disabilities. Michigan’s decision to embed the core values of its approach to serving persons with mental illnesses, developmental disabilities and substance abuse disorders in its definition of “medical necessity” is an effective way of conveying the underlying social goals of the program and, thus, avoiding having the program become overly medicalized. Finally, many of the techniques that are being employed in Wisconsin’s Family Care program to ensure that managed care organizations adhere to the values state policymakers aim to instill in the program are worth studying.
Conclusion

The main aim of this bulletin has been to examine the experiences of four states that have applied managed care principles to the delivery of Medicaid-funded long-term services to persons with developmental disabilities. In deciding to adopt a managed care framework, each state was attempting to address a somewhat different set of issues and achieve a distinctive set of policy goals; but, the common motivating thread was the recognition on the part of policymakers that the state’s existing methods of financing long-term services were unsustainable over the long haul. Each state set out to make services readily accessible to all eligible beneficiaries and, to the enormous credit of all involved parties, thus far this goal has been largely achieved in all four states. On the other hand, far less progress has been made in affording individuals with disabilities similar opportunities to live, work and recreate with their non-disabled peers in all geographic areas of the state. By most reports, access to person-centered support was unevenly distributed across these states prior to the advent of the managed care program and remains so today. Nor is the track record of the four states in promoting self-directed services demonstrably better than that of many other states.

It is impossible to predict how existing service delivery practices in these four states might be impacted were Medicaid funding to be seriously curtailed, either as a result of federal statutory spending constraints or the lack of adequate state matching dollars. Certainly, in each state we could expect a major reassessment of program goals and the system’s capability of achieving those goals. But, given the progressive social agendas which all four states have pursued over the years, it seems reasonable to assume that individuals with disabilities would be as well, or better, off than their counterparts in most other states that operate within a fee-for-services framework. Indeed, given the tools available to emphasize cost-effective support strategies, the four states that were the focus of this review might be better positioned to survive a major realignment in Medicaid funding than would a lot of other states.

In a widely read, well received 1995 analysis of potential applications of managed care within the developmental disabilities services sector, Smith and Ashbaugh wrote:

> [W]hatever mistrust there might be about managed care has to be balanced against its trinity of promises: lower costs, better access, and higher quality. Curbing Medicaid payments to the states means developmental disabilities systems will face a far different fiscal landscape in the foreseeable future than has been true over the past decade. ... This altered [low growth] fiscal landscape has enormous implications for the health and vitality of these systems and even more profound implications for the people and families who depend on these systems for supports. In this vein, dismissing managed care makes no sense. DD service systems will need to take advantage of every tool available in order to survive and be responsive to the people they support.\textsuperscript{xii}

These words were written at a time when Congress was on the brink of imposing an across-the-board cap on federal Medicaid spending. Today, the nation appears to be approaching another crisis in financing not only Medicaid services but other major social entitlement programs as well (e.g., Medicare; Social Security, SSI, Food Stamps, etc.). Given the circumstances, Smith and Ashbaugh’s admonition to consider all of the “arrows in our quiver” seems as relevant today as it was thirteen years ago. And, as unsettling as it may seem, managed care is one of those arrows.
References

**Arizona.** The website of the Arizona Division of Developmental Disabilities (https://www.azdes.gov/ddd/) contains a wide range of information regarding both the Division’s general service policies and policies specific to the Arizona Long Term Care System (ALTCS). For a layman’s description of services provided by DDD, click on “Navigating the System,” a consumer/family guide to DDD services (accessible from the Division’s home page or by clicking on “Consumer & Family Information”). For specific information concerning ALTCS services, click on “ALTCS Member Information.” Further information concerning the ALTCS program can be found on the website (http://www.azahcccs.gov/site/) of the Arizona Health Care Cost Containment System (AHCCCS). In particular, here you can find current ALTCS enrollment data (click on “Statistics and Studies” and then on “Statistics”) or on the terms and conditions associated with Arizona’s Section 1115 AHCCCS waiver agreement with the federal Centers for Medicare and Medicaid Services (CMS).

**Michigan.** Information concerning the Specialty Services waiver program for persons with mental illnesses, developmental disabilities and substance abuse disorders can be found on the “Mental Health and Substance Abuse” web pages of the Michigan Department of Community Health (MDCH; http://www.michigan.gov/mdch/0,1607,7-132-2946_5107---,00.html). Click on the “Mental Health and Developmental Disability” link to access a variety of materials related to the Specialty Services program, including a recent DMCH concept paper on needed system-wide improvements and a draft “Application for Renewal and Recommitment” paper spelling out the steps the department plans to take to rectify existing shortcomings in the program. Here you also can find various reports on the state’s MH/DD/SA waiver program, including recent External Quality Review reports, summary reports on the findings from recent on-site reviews conducted by departmental quality review teams, and an explanation of (and findings from) DMCH’s Mission-based Performance Indicator System. Finally, for information concerning the department’s reporting requirements, from the “Mental Health and Substance Abuse” web page click on to “Reporting Requirements.”

**Vermont.** The website of the Vermont Department of Disabilities, Aging and Independent Living (DAIL) contains a wide range of materials explaining state- and federally-funded developmental disabilities services (http://dail.vermont.gov/). From the DAIL home page, click on the link for the Division of Disability and Aging Services; then click on the “developmental disabilities” link, followed by the “Policies and Guidelines” link. Here you will find various documents, including DDAS’ current “system of care” plan for DD services, plus the 2008 update to the plan; a copy of the department’s most recent annual report on developmental disabilities services; a copy of the division’s “Health and Wellness Guidelines;” and various other documents related to the operation of DD services in Vermont. For information concerning the Global Commitment to Health waiver/demonstration program, go to the website of the Office of Vermont Health Access (http://ovha.vermont.gov/). From OVHA’s home page, click on to “Administration,” Then hit the link to “Global Commitment to Health.” There you will find a copy of the state’s original, 2005 GCH waiver request and various other, related documents. Copies of annual reports on the Global Commitment, as well as quarterly progress reports, also can be found at this location.

**Wisconsin.** The website of the state Department of Health Services (http://dhs.wisconsin.gov/) contains a wide range of information concerning the Family Care initiative. Click on the “Family Care” icon, located in the upper, left-hand portion of the home page. Then, click on the following sections of the Family Care web page: “Background” to obtain general information about the key operating features of the program; “Research and Reports” to obtain copies of various evaluation, quality assessment, progress and other reports on the program; “Program Operations” to obtain details on the operating components of the program as well as the current status of efforts to expand the program statewide; “State and Federal Requirements” to access a copy of the state’s Section 1915(b)/(c) waiver request plus copies of state statutes and administrative rules governing the program; and “History of Long-Term Care Redesign” to access documents related to the development of the Family Care program.


Saucier, Paul and Wendy Fox-Grage, “Medicaid and Managed Long-Term Care,” Issue Brief No. 79, AARP Public Policy Institute, 2005.


iii Under the state Mental Health Code of 1973 county mental health boards were designated the single-point-of-entry to all state and federally-funded mental health, developmental disabilities and substance abuse services as well as the entity responsible for overseeing the organization and delivery of such services at the local level. The law included a provision permitting two or more counties to create a joint board. A number of counties, especially in sparsely populated areas of the state, exercised this option and, as a result, county mental health boards became known as Community Mental Health Services Programs (CMHSPs).


v Memorandum from Michael J. Head, director MDCH Mental Health and Substance Abuse Administration, to various addressees interested in Michigan’s Public Mental Health System, September 30, 2008, subject: “Implementing Self-Determination: The Choice Voucher System Technical Advisory.”


viii Section 2.5., Mental Health/Substance Abuse chapter, Medicaid Provider Manual, Michigan Department of Community Health.


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