Medicaid Resource and Technical Assistance Paper

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Introduction to ITCA Resource and Technical Assistance Paper

This Paper was commissioned by the IDEA Infant Toddler Coordinators Association (ITCA) in response to its interest and need for information on Medicaid. The landscape of Medicaid is changing, nearly daily. As this Paper was developed, a number of national and state concerns were surfacing related to the Medicaid program. Federal budget cuts related to Medicaid have been approved by Congress for implementation in the next budget year. These reductions will affect every state, some more than others.

Congress anticipated the use of Medicaid and several other resources for the provision of Part B and Part C services under the Individuals with Disabilities Education Act (IDEA). These clarifications were reflected in P.L. 99-457 passed in 1986, which authorized Part C of the IDEA and which further confirmed the Congressional intent set forth in P.L. 94-142 for Part B. Recent reauthorization of the Individuals with Disabilities Education Improvement Act of 2004 (IDEA), P.L. 108-446, was completed in December 2004 with regulations currently proceeding through the public hearing process.

Historical statutory requirements of Part B were equally applied to Part C in new language in P.L. 99-457 to support the use of Medicaid and other resources to finance services in an Individualized Education Program (IEP) and Individualized Family Service Plan (IFSP). These points were simple and straightforward. States were prohibited from using Part C or Part B funds to satisfy a financial commitment for services that would have been paid for by other federal, state or local agencies but for the enactment of the legislation and the inclusion of the service in the IFSP or IEP. Secondly, these arrangements were reflected in the federal requirement for interagency agreements between appropriate state agencies to define the responsibilities of each agency for providing or paying for early intervention services (EIS) or a free appropriate public education (FAPE). The third point in the statute and regulations emphasized that P.L. 99-457, as with P.L. 94-142, would not be construed as permitting a state to reduce medical or other available assistance, or

to alter the Title V Maternal/Child Health Block Grant or Medicaid eligibility with respect to the provision of FAPE or EIS.

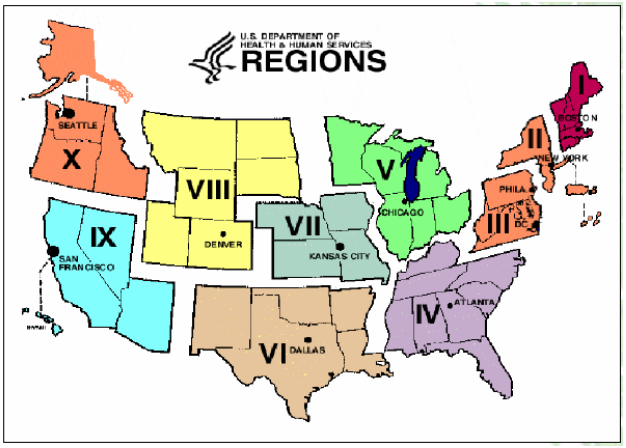
Medicare and Medicaid were products of the Great Society promoted under the administration of Lyndon B. Johnson. Appendix A provides a brief overview of this wide-sweeping national legislation and its impact upon the American landscape.

The Administration of Federal Healthcare Initiatives

The Centers for Medicare and Medicaid Services, or CMS, is responsible for the administration of three federal health care programs that are the focus of this section. With their central offices based in Baltimore, CMS has Regional Offices in ten major cities throughout the U.S. CMS Regional Offices are often the first point-of-contact for beneficiaries, health care providers, state and local governments, and the general public. Regional CMS employees are responsible for the essential day-to-day functions for Medicare, Medicaid, and the State Children's Health Insurance Program (SCHIP), including:

- Customer Service (primarily for Medicare)
- Program Operations, Management and Evaluation
- Communication, Education and Outreach
- Partnership with State and Local Health and Social Service Programs

Figure 1 defines the CMS regions; catchment areas are defined as follows:



Region I. Boston: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont. The Boston Regional Office is responsible for oversight of the Quality Improvement Organizations (QIOs) and for End Stage Renal Disease Networks in 14 states (CT, ME, MA, NH, RI, VT, NY, NJ, PA, DE, MD, DC, VA, WV),Puerto Rico and the Virgin Islands.

Region II. New York : New York and New Jersey, as well as the U.S. Virgin Islands and Puerto Rico.

Region III. Philadelphia: Delaware, Maryland, Pennsylvania, Virginia and West Virginia and the District of Columbia.

Region IV. Atlanta: Alabama, North Carolina, South Carolina, Florida, Georgia, Kentucky, Mississippi and Tennessee.

Region V. Chicago: Illinois, Indiana, Michigan, Minnesota, Ohio and Wisconsin. The Midwest Consortium Division of Survey and Certification (CDSC) works with states to ensure that providers within Region V and Region VII (Iowa, Kansas, Missouri, Nebraska) participating in the Medicare and/or Medicaid programs uphold federal quality standards.

Region VI. Dallas: Arkansas, Louisiana, New Mexico, Oklahoma, and Texas.

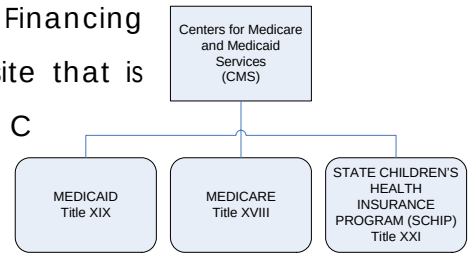
Region VII. Kansas City: Iowa, Kansas, Missouri, and Nebraska. Kansas City is responsible for oversight of the Quality Improvement Organizations (QIOs) and for End Stage Renal Disease Networks in 13 states (IA, KS, MO, NE, ND, SD, KY, MN, MI, WI, IL, IN, OH). The Regional Office is also responsible for national enforcement of Health Insurance Portability and Accountability Act provisions in states which are not in substantial compliance.

Region VIII. Denver: Colorado, Montana, North Dakota, South Dakota, Utah and Wyoming.

Region IX. San Francisco: Arizona, California, Hawaii and Nevada, as well as the Territories of American Samoa, Guam and the Commonwealth of the Northern Mariana Islands.

Region X. Seattle: Alaska, Idaho, Oregon and Washington. Region X also serves as the focal point for the Quality Improvement Organizations (formerly known as Peer Review Organizations) in each of 13 western states: Alaska, Arizona, California, Colorado, Idaho, Hawaii, Montana, New Mexico, Nevada, Oregon, Utah, Washington, and Wyoming, as well as the Pacific Territories of American Samoa, Commonwealth of the Northern Mariana Islands, and Guam.

CMS, formerly known as HCFA or the Health Care Financing Administration, operates a comprehensive web site that is available to a wide audience of users. Part C planners should become familiar with this web site[1], particularly for the services it offers related to



[1] CMS web site: http://www.cms.hhs.gov/

providing individual state information, CMS updates, including formal policy letters to the State Medicaid Directors. Regulations for these three important programs can also be found on this site.

This Section introduces the basic components of the Medicaid program, Medicare and the State Children's Health Insurance Program. These three federal programs are important for state Part C planners to understand as they work with their state Medicaid agencies. Websites, frequently used terminology and acronyms, and other resources selected to provide enhanced information on key topics are provided for the reader throughout this Paper. Section A discusses the Medicaid program in depth, including its unique requirements and components.

Overview of the Federal Poverty Level (FPL)

Each year in April, the federal government recalculates the Federal Poverty Level or FPL which is used as a primary basis for eligibility for a variety of federally supported programs. These programs include Medicaid, SCHIP, Head Start, Food Stamps, the Home Energy Assistance Program (HEAP). DHHS supports a web site that provides this information. [2]

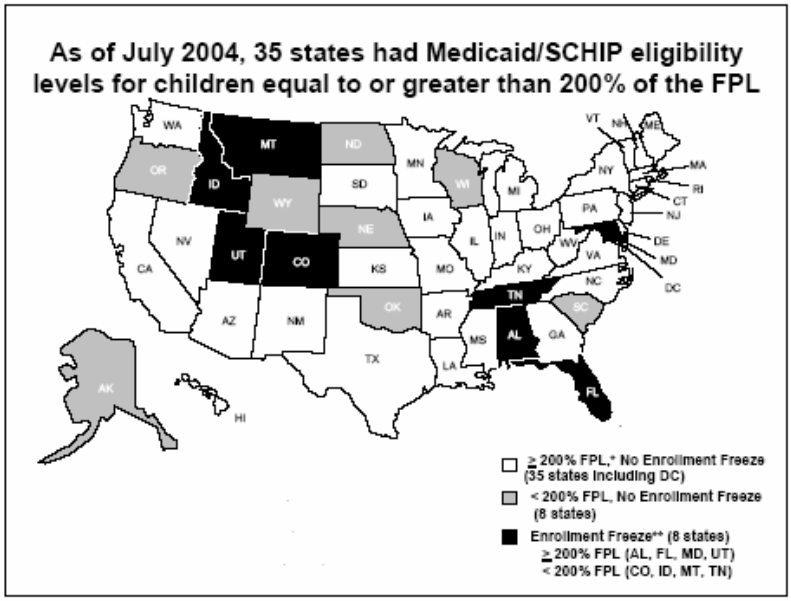


Figure 2: Medicaid/SCHIP eligibility for children equal to or greater than 200% FPL; Source: Based upon a national survey conducted by the Center on Budget and Policy Priorities for KCMU, 2004. published by The Kaiser Commission on Medicaid and the Uninsured, January 2005. The Federal Poverty Level (FPL) for a family of three in 2004 was $15,670. This figure includes states that froze children's enrollment for at least a portion of the time period April 2003-July 2004.

[2] FPL web site: http://aspe.hhs.gov/poverty/05poverty.shtml

The FPL is a set of income guidelines which are loosely based on consumer prices and account for family size. The 2005 FPL chart and explanatory information are found in Appendices B and C to this Paper. While the programs discussed in this Paper each have alternative methods for creating eligibility that is not income based, Part C planners should understand the process of FPL since it is the most widely used eligibility tool from the perspective of federally sponsored/supported programs. Figure 2 displays the Medicaid/SCHIP eligibility levels using a common standard of 200%.

Another way to view eligibility for Medicaid is through a "pathways" model developed by the Kaiser Commission on Medicaid and the Uninsured. From the Part C perspective, this approach may assist state planners to better strategize funding opportunities for children in the "special considerations" groups as recently affirmed through the 2004 reauthorization of IDEA, statutory changes to Part C. Figure 3 on the next page displays the differences in population between the mandatory vs. optional coverage groups as defined by federal Medicaid regulations.

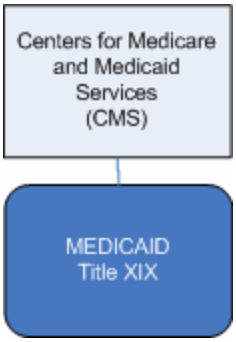
This information is useful to Part C planners because, rather than solely depicting eligibility from a FPL perspective, it discusses the eligibility of children related to "special considerations" or other eligibilities that open Medicaid participation for them. Often, Part C planners have more information about the special considerations or characteristics of the potential Part C population, and can use these data to construct some basic assumptions. This includes enrollment in or eligibility for a variety of other programs including TANF (Temporary Assistance for Needy Families), child protective services (Title IV-E), as well as children demonstrating exceptional medical needs. The impact of these considerations or characteristics will vary from state to state, and within states as well.

Figure 3: Major Medicaid Eligibility Pathways for Selected Groups

Mandatory Coverage	Optional Coverage
Low-income Children	
Primary Pathways	
Infants under age 1 with income ≤ 133% FPL	Infants under age 1 with income ≤ 185% FPL
Children age 1 to 6 with income ≤ 133% FPL	Children age 1 to 6 with income ≤ 185% FPL
Children age 6 to 15 with income ≤ 100% FPL	Children age 6 to 15 with income ≤ 133% or 185% FPL
Section 1931 children	Targeted low-income children (CHIP children)
Children in welfare-to-work families	Transitional coverage for children in welfare-to-work families
Title IV-E foster care children	Non-Title IV-E foster care children
Title IV-E adoption assistance children	Non-Title IV-E adoption assistance children
Other Pathways	
	Medically needy
	Ribicoff children
Children with Disabilities	
Primary Pathways	
Supplemental Security Income (SSI) recipients	Katie Beckett children
	Home or community-based waiver children
Other Pathways	
SSI recipients as of 8/22/96	Medically needy
Pregnant Women	
Primary Pathways	
Pregnant women with income ≤ 133% FPL	Pregnant women with income ≤ 185% FPL
Other Pathways	
	Medically needy
Low-Income Adults	
Primary Pathways	
Certain adults in low-income families with children	Adults in two-parent households with dependent children
Other Pathways	
	Medically needy
	COBRA continuation beneficiaries

Source: Kaiser Commission on Medicaid and the Uninsured, 2005

The Basic Medicaid Program: A Thumbnail Sketch



The Medicaid program is the first of three federal health care programs administered by CMS. Medicaid has been an important piece of the nation's health care system and has evolved over the past 40 years to meet the health and long-term care needs for one in ten Americans including individuals with low-incomes, the working poor, children, the elderly and the disabled. In the absence of Medicaid, local systems of care – state, county and municipalities – would be required to provide a considerable degree of care for individuals who tend to be poor and often very sick, without the benefit of the federal and perhaps state support.

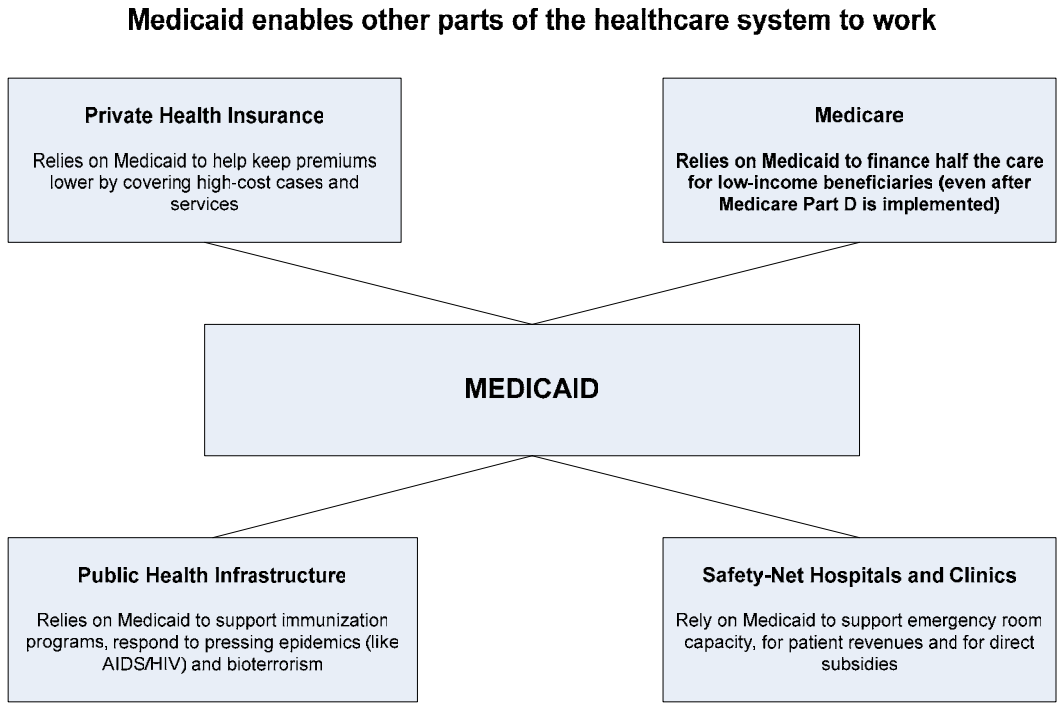


Figure 4: The United States Health Care System; Source: The Kaiser Commission on Medicaid and the Uninsured, January 2005

In 2003, Medicaid provided coverage to:

- 25 million children
- 14 million adults (primarily low-income working parents)
- 5 million seniors
- 8 million persons with disabilities

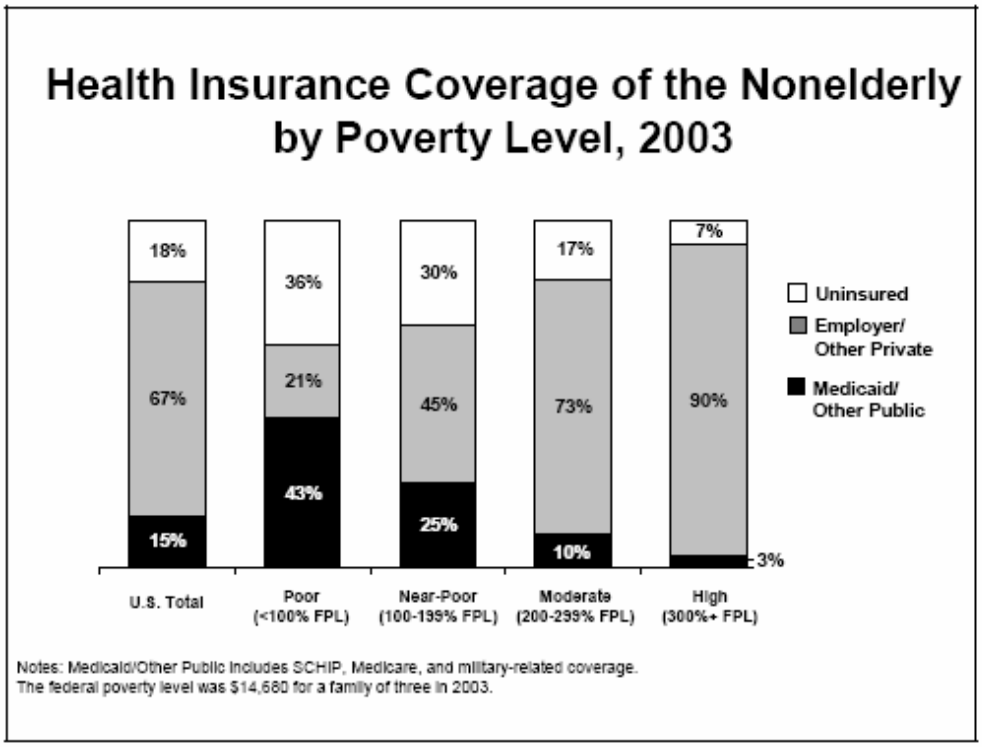


Figure 5: Health Insurance Coverage of the Nonelderly by Poverty Level, 2003. Source: Kaiser Commission on Medicaid and the Uninsured and the Urban Institute analysis of the March 2004 Current Population.

While low-income children and parents make up 75% of the Medicaid population, they account for only 31% of Medicaid spending. The majority, or 69%, of Medicaid spending is directed towards the elderly and people with disabilities, who make up only 25% of the enrolled population nationally.

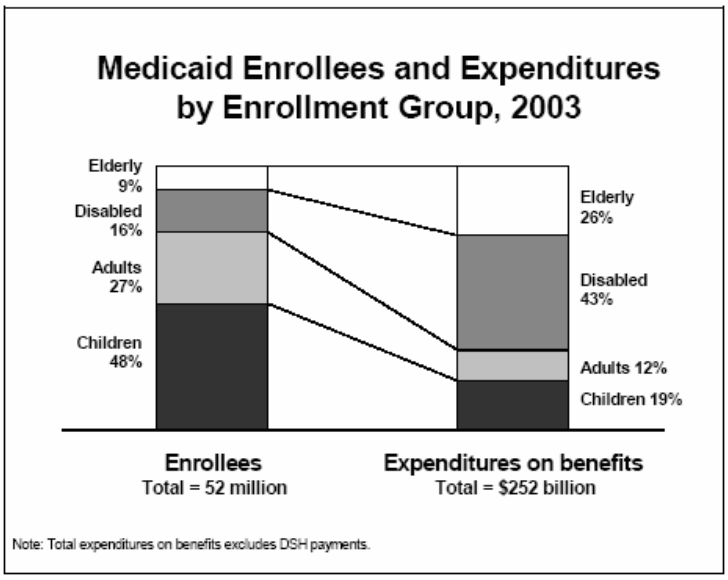
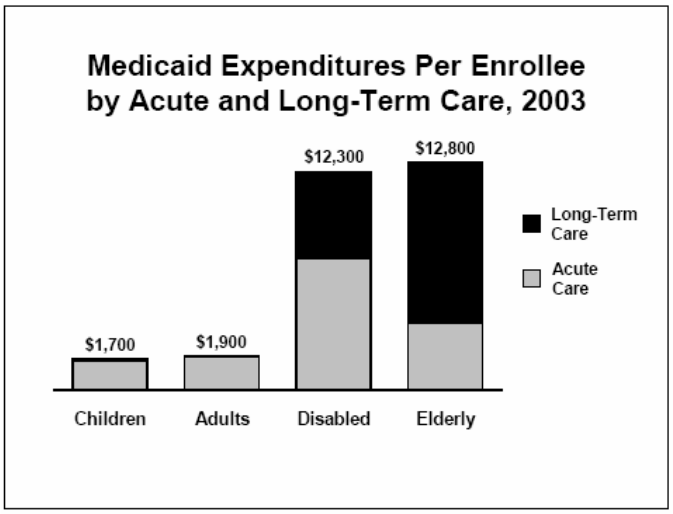


Figure 6: Medicaid Enrollees and Expenditures by Enrollment Group, 2003; Source: The Kaiser Commission on Medicaid and the Uninsured, January 2005 estimates based on CMS, Congressional Budget Office (CBO)and Office of Management and Budgets (OMB) data, 2004.

Figures from the Congressional Budget Office (CBO) for 2003 estimate that Medicaid spending per child was $1,700 compared to $12,300 for an individual with a disability(s), and $12,800 for an elderly enrollee. These differences reflect the need for intensive and costly acute and long-term care services by the disabled and elderly populations, versus the general need for preventive and emergency care needs of children and their enrolled parents.

Figure 7: Medicaid Expenditures Per Enrollee by Acute and Long-Term Care, 2003; Source: The Kaiser Commission on Medicaid and the Uninsured, January 2005; estimates based on CBO and Urban Institute data, 2004



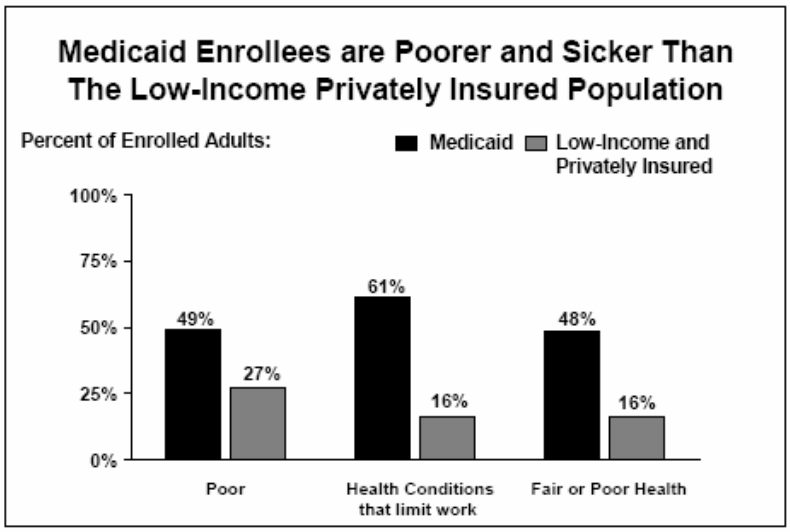


Figure 8: Health Status of Medicaid Enrollees; Source: Coughlin et al, 2004, based on a 1999 and 2002 NSAF analysis for KCMU; published by The Kaiser Commission on Medicaid and the Uninsured, January 2005.

Figure 8 demonstrates the health status of adults enrolled in Medicaid. In significant part, this explains the dispro-portionate costs of total Medicaid expenditures towards this population which accounts for 31% of the total national enrollment in Medicaid.

Medicaid is currently the nation's primary source of insurance coverage for many groups including the poor and near poor, children, and the elderly and people with disabilities. As Figure 9 illustrates, of all child enrollment in Medicaid, African American and Hispanic children represent the majority of recipients.

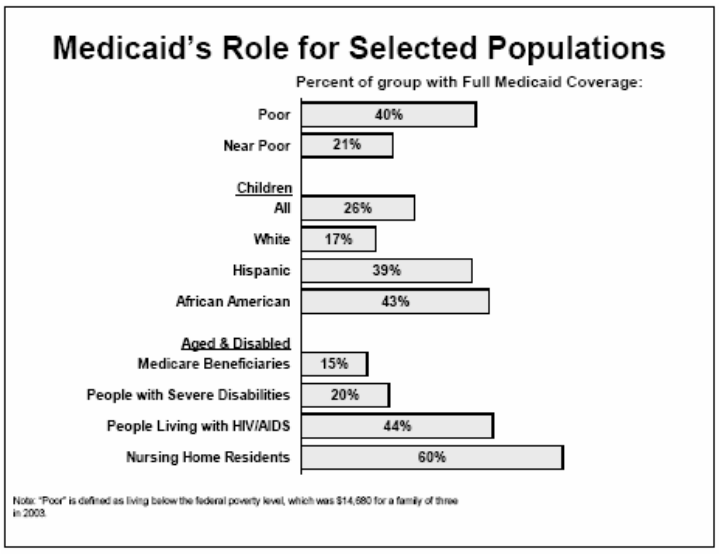


Figure 9: Medicaid: Issues in Restructuring Federal Financing, Kaiser Commission on Medicaid and the Uninsured, January 2005.

The Kaiser Commission on Medicaid and the Uninsured note in their January 2005 Report that the per capita growth in Medicaid has been consistently half the rate of growth in private insurance programs. Figure 10 illustrates this fact. Kaiser reports that, "Compared to private health programs, Medicaid also has far lower administrative costs" and has been a fairly efficient program. Program growth over

the recent years is attributed to increased enrollment driven largely by the economic turndown, and not increased per capita costs.[3]

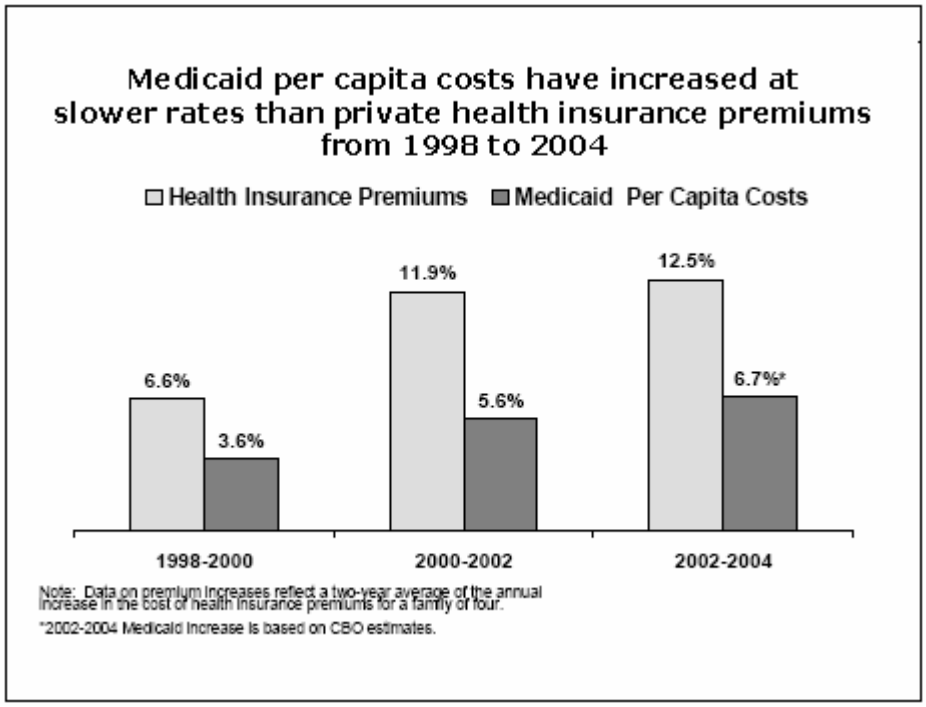


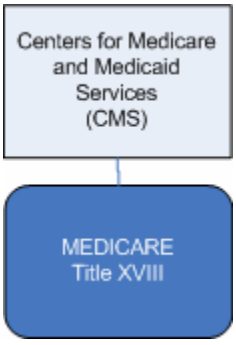
Figure 10: Increase in Medicaid Per Capita Costs vs. Private Health Insurance Premiums, 1998-2004; Source: The Kaiser Commission on Medicaid and the Uninsured, January 2005, KFF/HRET Survey of Employer-Sponsored Health Benefits, 2004 and KCMU and Urban Institute analysis of HCFA/CMS-64 and MSIS data (1988-2004) and CBO Medicaid baseline (2002-2004), 2004

Medicaid spending accounts for 1 of every 6 dollars spent on personal health care and nearly half of all spending on nursing home care,[4] with federal contributions ranging from 50% to 77% depending upon the state's per capita income. FMAP projections for 2006 result in reductions in federal participation in Medicaid for 27 states, very modest increases for 11 states, and no change for 12 states and the District of Columbia. These states are those positioned at the 50% mark, or the lowest federal contribution permitted under federal regulations.

[3] The Kaiser Commission on Medicaid and the Uninsured, Medicaid: Issues in Restructuring Federal Financing, January 2005 (www.kff.org/kcmu)
[4] Smith, et al, 2005. Based on National Health Care Expenditure Data, CMS, Office of the Actuary; Center on Budget and Policy Priorities, Isaac Shapiro and Robert Greenstein, February 5, 2005

As the federal deficit projections continue to mount, entitlement programs like Medicare and Medicaid will likely be targeted by Congress. State economies for the most part are dealing with their own budget deficits; these issues, when combined, promise to force changes at the federal and local levels. As the Kaiser Commission points out, "During the upcoming budget debate, it is critical to weigh the implications of cuts in federal funding and fundamental changes in Medicaid and the role it plays in the healthcare system. While some may argue for Medicaid needs to be constrained, others argue that Medicaid is currently under-funded to meet the responsibilities expected by the program." These observations are echoed by Holahan and Ghosh in a recent Urban Institute publication[5] commissioned by the Kaiser Commission.

Medicare: A Thumbnail Sketch



This section focuses on Medicare as the second of three federal health care programs administered by CMS. Medicare is our country's health insurance program for people age 65 or older. Certain people younger than age 65 can qualify for Medicare, too, including those who have disabilities and those who have permanent kidney failure. The program helps with the cost of health care, but it does not cover all medical expenses or the costs for most long-term care. Part C planners will benefit from some basic Medicare information, as this may pertain to individuals with disabilities in their states.

Medicare is financed by a portion of the payroll taxes paid by workers and their employer. It also is financed in part by monthly premiums deducted from Social Security checks.

Medicare is divided into two different parts which help pay for different kinds of health care costs:

[5] Trends: Understanding The Recent Growth in Medicaid Spending, 2000-2003, Holahan, John, Ghosh, Arunabh, Urban Institute's Health Policy Center, pp. 54-60, Washington, D.C. January 2005

- Hospital insurance (also called Medicare Part A) helps pay for inpatient care in a hospital or skilled nursing facility (following a hospital stay), some home health care and hospice care.
- Medical insurance (also called Medicare Part B) helps pay for doctors' services and many other medical services and supplies that are not covered by hospital insurance.
- Medicare Part C, now called Medicare Advantage Plans, is comprehensive health plans that provide Part A and B services (and will include Part D in 2006).
- Part C is a new prescription drug benefit program that will begin January 1, 2006.

Medicaid and Medicare are actually two different programs. Medicaid is a state-run program that provides hospital and medical coverage for people with low income and little or no resources. Each state has its own rules about who is eligible and what is covered under its state's Medicaid program.

Some people qualify for both Medicare and Medicaid. Often called "dually enrolled," these individuals may be eligible for one or both of the Medicare benefits outlined above, as well as Medicaid. Part C planners will find this information important since, while these determinations are based upon each individual state's eligibility and the diversity of options implemented under its Medicaid program, it most often affects individuals with disabilities of any age, particularly those receiving Supplemental Security Income (SSI) for disability purposes, or those individuals requiring nursing home care. The specific definitions for these categories are found in Appendix D to this Paper.

The prevalence of "dually enrolled" children in Part C varies from state to state. These are typically children with significant or complex medical and health care needs, often identified early on in life. About 42% of all Medicaid spending for benefits is for elderly and disabled individuals who are dually eligible for Medicare and Medicaid. A majority of this funding is directly to individuals over age 65 who

reside in nursing homes (15%) and individuals over age 65 who receive home/ community based care (47%). Thirty-six percent of recipients are individuals under age 65 in home/community based care, and 2% in nursing homes. This long-term care may be augmented by other federal programs such as the Older Americans Act, the Rehabilitation Act, and Social Services Block Grants, as well as individually designed, state funded programs. While this may not be an issue for the Part C population, it is important for Part C planners to understand the application of Medicare as it relates to the general operations of state sponsored health care services. Concerns related to the continuum of care for individuals with disabilities as they transition from Part C and into other systems may also be addressed by this information.

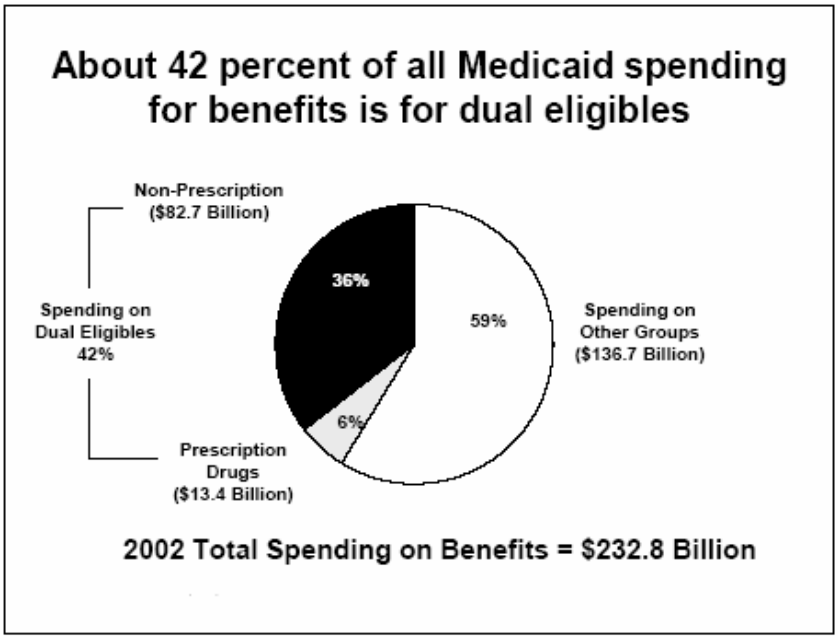


Figure 11: Medicaid Spending for Dually Eligible Individuals; Source: The Kaiser Commission on Medicaid and the Uninsured, January 2005

The Americans with Disabilities Act and Olmstead

The Americans with Disabilities Act (ADA) has implications for Part C planners. The ADA was passed in 1990 during the administration of George H. Bush, enacted by Congress to establish a clear and comprehensive prohibition of discrimination on the basis of disability. The stated purpose of this law was to ensure that the federal government played a central role in enforcing the law's standards on behalf of

individuals with disabilities by using the authority of Congress to enforce the Fourteenth Amendment and to regulate commerce, to address the major areas of discrimination faced daily by individuals with disabilities. These areas are:

- Employment
- Public Service
- Public Accommodations and Services operated by Private Entities
- Telecommunications

An estimated 54 million people in the United States, or nearly one in every five, have a disability that meets the standard under the ADA.[6]

The Olmstead decision[7] rendered in 1999, in part, may affect the Part C population due to the emphasis on community-based services for individuals with disabilities otherwise entitled to institutional services when community placement can be reasonably accommodated and is appropriate. This Supreme Court core decision was that institutional isolation is discriminatory and illegal under the ADA.

Medicaid is affected by Olmstead because it is the major source of public financing for long-term services and supports for people with disabilities. These supports tend not to be medical services, but rather assist the individual with personal care services, therapy and durable medical equipment designed to maximize cognitive and physical performance and support independence. There have been five (5) State Medicaid Directors' letters jointly issued by CMS and the Office for Civil Rights (OCR) posted on the CMS web site. In 2000, Congress established the Real Choice Systems change Grants program which focuses on grants to states and territories to create the infrastructure and service options necessary for long-term community integration.

The New Freedom Initiative is an executive order from President George W. Bush dated June 2001 that requires all Executive Branch agencies to take steps to fully comply with the requirements of Olmstead. This administration has proposed

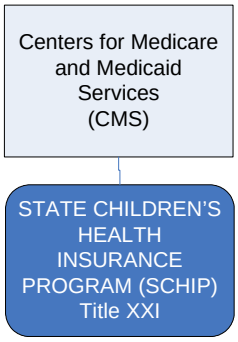
[6] National Council on Disability
[7] Olmstead v L.C., 119 S.Ct.212187 (1999)

legislation that would establish a new federal demonstration program through Medicaid which would provide full federal funding for one year for each person transitioned out of an institution into the community.

While there had been a national movement towards community care prior to Olmstead, this decision was originally anticipated to lead to rapid expansion of Medicaid community-based, long term services. This hasn't happened for a variety of reasons, primarily due to the fiscal crisis that many states are experiencing and due to the remaining federal statute limitations.

In several states, the passage and implementation of Part B of Medicare, the prescription drug benefit, will also likely affect children with disabilities who are dually enrolled in Medicare and Medicaid.

The State Children's Health Insurance Program: A Thumbnail Sketch



The State Children's Health Insurance Program or SCHIP, is the third federal health care program administered by CMS. It was formulated and passed by Congress during the Clinton presidency in 1997, in an effort to address the needs of low-income and middle income uninsured children whose families lacked the ability to secure health insurance for them. Sometimes called the "working poor," these families often are engaged in low-wage employment that either doesn't provide health insurance, or where the payments for participation are beyond their financial ability. SCHIP was meant to be a bridge between Medicaid and private health insurance, and is constructed very differently than Medicaid. Due to the regulations governing SCHIP, it has impacted state Medicaid programs to one degree or another.

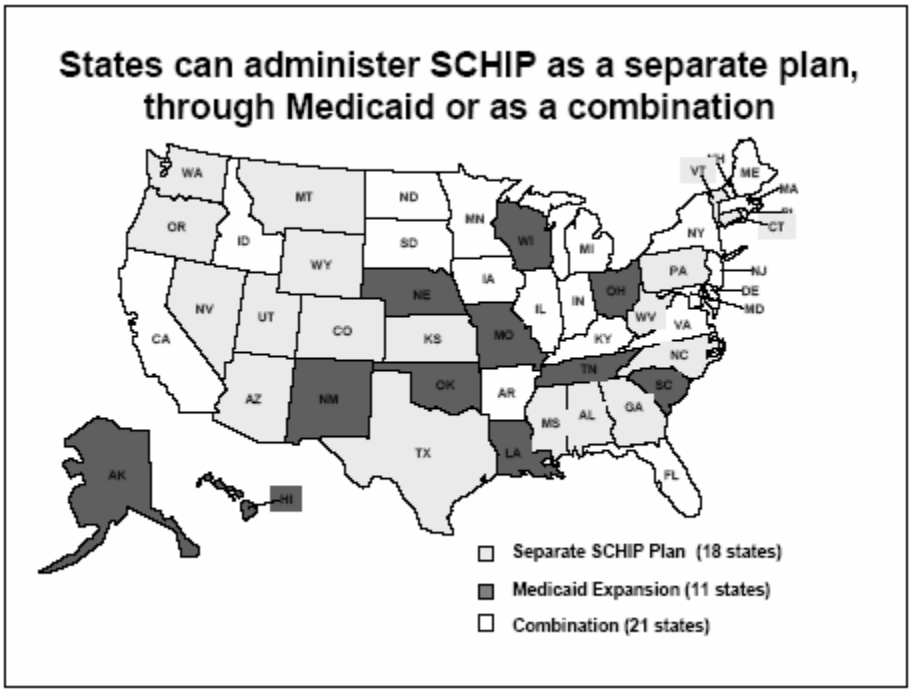


Figure 12: State SCHIP Configuration; Source: The Kaiser Commission on Medicaid and the Uninsured, January 2005

Federal regulations permit states a great deal of latitude in determining how to construct their SCHIP program. They may operate SCHIP as a stand-alone, "separate" program, implement a Medicaid "expansion" program, or operate a combination of both at the same time. As of June 2003, 13 states and the District of Columbia operated only a Medicaid expansion program, 20 states operated only separate programs, and 15 states operated combined Medicaid expansion and separate programs.

Two states (Arkansas and Tennessee) no longer report data for the SCHIP program and include coverage for these children under their Medicaid system.

Seven (7) states[8] include adults in their SCHIP system, which is consistent with the provisions of a waiver granted by federal CMS. These seven states serve slightly fewer than 250,000 adults collectively with significant increases in the adult population noted in Arizona and Illinois, and slight increases in other states except for New Jersey where changes in eligibility and premiums contributed to a drop in enrollment. The General Accounting Office (GAO) has been fairly critical of state's

[8] Arizona, Colorado, Illinois, Minnesota, New Jersey, Rhode Island, Wisconsin

efforts in expanding care to include adults, citing that this is not within the scope of the funds authorized under SCHIP.[9]

State efforts in implementing SCHIP often include some sort of participation fee on the part of the enrollee. This may be in the form of a premium, co-payment or cost sharing for selected services.

SCHIP is often considered as a model for Medicaid reform in that federal funds to states are capped, nationwide and state-by-state. SCHIP funding did not adjust for the changing economic landscape or the continuing decline in employer-based insurance. These two events alone have increased the need for publicly funded coverage for children. SCHIP was adopted as part of the Balanced Budget Act of 1997 (BBA) which at that time, due to the government's focus on deficit reduction, created a requirement that linked SCHIP funding to the broader legislation related to the deficit. This resulted, for example, in 2002, in an extreme dip in federal funding of more than 26%.

Early on, it was difficult for states to identify SCHIP children separate from those eligible but not enrolled in Medicaid. The extensive SCHIP outreach efforts resulted in subsequent increases in Medicaid enrollment. These were children who were already eligible for Medicaid but not enrolled for a variety of reasons. While several states needed additional SCHIP funds to cover the program costs and enrollment growth, still others had excess funds that they were not able to spend within the award period.

For these and other reasons, there has been an effort to continually review and refine SCHIP, which is due for reauthorization in 2007. Four major legislative changes have been implemented since the inception of this program largely dealing with the issues of unspent funds through reallocation, redistribution or retention. Program options similar to those under Medicaid were enacted, permitting states to implement targeted initiatives while assuring the federal government that they were

[9] General Accounting Office: "Medicaid and SCHIP: Recent HHS Approvals of Demonstration Waivers Projects Raise Concern." July 2002, and "SCHIP: HHS Continues to Approve Waivers that are Inconsistent with Program Goals." January 2004.

already covering children up to 200% of the poverty line coupled with a demonstration of substantial and sustained efforts in outreach and enrollment.

Efforts recently in 2004 to redirect unspent SCHIP funds were not successful, resulting in the return of $1.3 billion dollars to the U.S. Treasury.

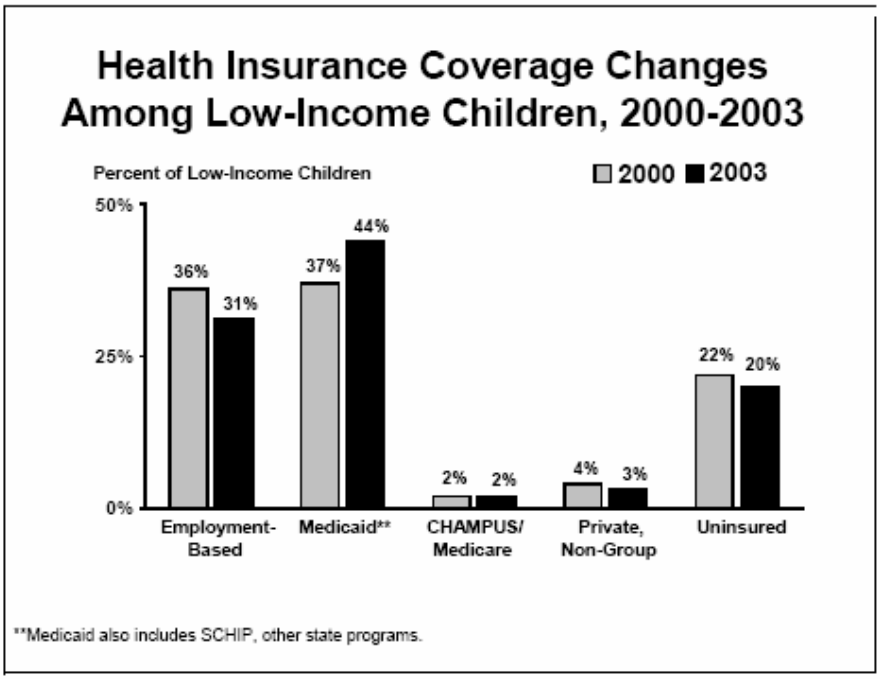


Figure 13: Health Insurance Coverage changes among low-income children, 2000-2003, Source: Urban Institute, Figures from March CPS 2001, 2004

SCHIP has assisted states in increasing the enrollment of young children in publicly supported health care. Figure 13 illustrates the shifting of coverage for low-income children from 2000-2003. While the numbers of uninsured children were reduced by 2% over this time period, the dependence upon Medicaid and SCHIP increased by 7% for low-income children. Enrollment in SCHIP has dropped in recent years due to state-directed efforts to manage growth and costs. The SCHIP federal-state financing approach intentionally "caps" this federal allocation, different from the current open-ended entitlement for federal financing under Medicaid.

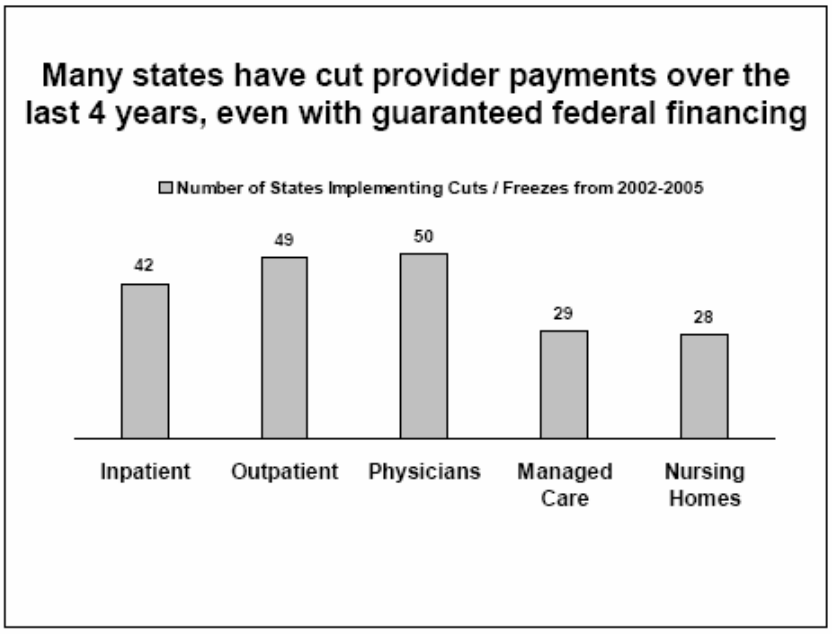
Provider Relations and Impact

Medicaid accounts for one of every six dollars of health care spending and nearly one of every two long-term care dollars, and is the country's major payer for mental health services, HIV/AIDS care, newborn deliveries and services for children with special needs. Medicaid purchases services from a variety of providers including hospitals, physicians, agencies and individual practitioners in the private healthcare

market place. As such, these entities and individuals come to rely heavily upon Medicaid as a primary source of income.

Medicaid payments are generally lower than the cost of providing care to recipients; most providers shift these costs to other payers by charging higher rates than are allowable under Medicaid. Historically providers report excessive delays and paperwork related to the Medicaid claims process. Between low rates and barriers to timely, appropriate payment, many providers still report that they have refused to serve this population (which is entirely within their right). Once a provider enrolls with Medicaid, however, they may not implement restrictions such as limiting the number of Medicaid recipients that they would serve. A majority of states have moved to electronic payment systems, with the payment of a "clean claim" in a matter of days. In addition, many states moved to Medicaid managed care systems in order to remedy provider network shortages.

Table 14: Provider Reimbursement Reductions; Source: The Kaiser Commission on Medicaid and the Uninsured, January 200



In recent years, the sharp declines in state revenues and large budget shortfalls have caused states to implement a number of efforts to control Medicaid costs. All 50 states and the District of Columbia have imposed some restrictions on provider reimbursement over the last four years; physician, inpatient and outpatient payments were the most likely to be frozen or reduced during this period of time.

State Medicaid reimbursement is typically much lower than market rates for private insurance. Concerns have been expressed by Kaiser Commission on Medicaid and the Uninsured and The Urban Institute, among others, that continued efforts to include reduction of provider fees as one mechanism to reduce the costs of Medicaid and SCHIP will make it increasingly difficult for providers to participate in this public program. Fears are that this may result in a decline in provider willingness to serve this population.

Why Is This Information Important for Part C Planners?

The complexity of health care financing cannot be understated – either from the perspective of the consumer or the state planner! Children and their families will come to the Part C system in each state with different situations and opportunities, many of them inter-related or connected, requiring careful planning and coordination. While a primary outcome for Part C planners is to ensure the delivery of needed early intervention services for eligible children and their families, a secondary focus is to facilitate the transition of children at age three, or when they are no longer eligible, to other systems of support and service. The challenges that Part C has experienced related to "transition" typically involve more than a change in the service delivery model or eligibility; families complain that they have lost important and essential supports and services made available through Part C. This kind of planning – often termed long-term, life-span or continuum planning – is very important to families, as reported by many Part C Coordinators.

These same individuals have also reported that, for a variety of reasons, it is increasingly important for Part C systems to be integrated within the state's systems of care for children as well as for individuals with disabilities. Understanding how systems interact with one another, and across populations, helps Part C to piggy-back on important benefits and opportunities; it also provides a stronger defense against serial reductions which often happen to free-standing programs which may be serving small numbers of children, often at a high cost.

Medicaid accounted for 8% of federal expenditures in 2004; Medicare accounted for 12% and Social Security for 21%. While increases in expenditures are anticipated,

the federal contributions to states for Medicaid are not a dominant contributor to the overall budget deficit projections. The federal government financed, overall, 57% of the $266 billion in total Medicaid spending. [10]

The potential impact, for example, of the Olmstead decision upon Part C may lead to greater opportunities that support services emphasizing the child's daily routines and typical activities, provided within the context of the family and community. Some states have implemented responses to Olmstead which have improved the state's ability to offer supports to children under the age of three by reducing the waiting lists for home and community-based "waiver slots." Other changes include compensating family members for home care services that would normally be publicly provided.

Resources for Further Investigation

As the national healthcare debate moves forward, Part C planners will benefit from understanding the implications of the full range of public programs and services (federal and state funded alike) in their efforts to incorporate the needs of families and very young children into the public policy discussion and decision-making at all levels.

The National Governors Association (NGA) has developed a variety of documents and position papers that likely will guide Medicaid reform in 2005-2006. One paper, entitled "Medicaid in 2005: Principles & Proposals for Reform" was authored by Vernon K. Smith and Greg Moody with Health Management Associates and formed the basis for the NGA's formal position paper discussed earlier in this document. Each of these documents can be obtained from the NGA website[11]. The above Paper is provided for the reader as Appendix E to this Paper.

[10] Kaiser Commission on Medicaid and the Uninsured, January 2005
[11] http://www.nga.org/cda/files/0501MEDICAID.pdf

Additionally, the National Conference of State Legislatures[12] has developed a variety of publications for their state legislative members on Medicaid, children's health, services to individuals with disabilities, long-term care, etc.

Very recently, Families USA published their response to the NGA position paper. This response, entitled: The Good, The Bad and The Ugly: Analysis of the National Governors Association's Medicaid Reform Proposal, can be downloaded from their website[13] and is provided for the reader as Appendix F to this Paper. Appendix G provides a recent position paper formulated by the American Academy of Pediatrics released in July 2005 relates to Medicaid reform.

The Center on Budget and Policy Priorities[14] routinely publishes information on a variety of healthcare related subjects, including topics such as the impact of higher Medicaid copayments (Appendix H) on recipients. The National Association of State Medicaid Directors[15] provides excellent information related to Medicaid and SCHIP programs from their unique perspective. The National Conference of State Legislators[16] publishes a variety of position and research papers on health care including Medicaid, and issues related to children and disabilities. They have published, for example, a resource paper for Legislators entitled "Managing Medicaid Costs: A Legislator's Tool Kit (2001). These resources are a small listing of a variety of web sites and publications that will assist Part C planners to keep pace with the rapidly unfolding issues and proposals related to health care in general, and Medicaid specifically. Appendix I to this Paper contains a comprehensive Internet listing of resources that may be of interest to Part C planners.

Process for Information and Data Collection

In early June 2005, an electronic communication was sent by the contractor to each state Part C Coordinator. The communication explained the nature and purpose of the Study, and invited their participation. This communication is

[12] http://www.ncsl.org/
[13] http://www.familiesusa.org/site/PageServer?pagename=Medicaid_Index
[14] http://www.cbpp.org/
[15] http://www.nasmd.org/
[16] http://www.ncsl.org/programs/health/healthmc.htm

provided in Appendix J. Twenty-three (23) states responded with materials and/or participated in discussions with the contractor focused on their state's current and planned Medicaid activities. States were given the option of having their specific information discussed anonymously; seven (7) states elected this option for some or all of the information shared. In at least six (6) states, conversations were held with state Medicaid administrators at the request of their Part C partners.

In addition to information provided directly by the states, the contractor conducted a wide search of publicly-available documents from state web sites (Part C, Medicaid, etc.) and several federal resource sites including CMS. Information for many of the current participants as well as ten (10) additional states was obtained through this mechanism. In summary, relevant information concerning Part C and other approaches to accessing Medicaid was obtained for 35 states; a variety of resources from 29 states are found in the Appendix/Resource section.

Narratives concerning individual state activities were reviewed and verified by state Part C planners and, in some instances, by state Medicaid administrators. Resource information is provided for a variety of related populations, not just Part C systems. This is in specific response to ITCA's request for a variety of state examples that may have relevancy to states that are currently reviewing their Medicaid relationships and want to consider other options that have been successful elsewhere. Some aggregate data was obtained from the ITCA National Survey and state Annual Performance Reviews (APRs).

ITCA convened a panel of reviewers which spent considerable time and effort in reading and commenting on each section of this Paper. Their input was invaluable to the contractor in ensuring that appropriate examples and explanations were provided, and contributed significantly to the thoroughness of this Paper.

SECTION A: OVERVIEW OF MEDICAID: FEDERAL RESPONSIBILITIES, OPPORTUNITIES AND CHALLENGES

This Section of the Technical Assistance Paper responds to ITCA's requirement in the Scope of Work to:

- Research Medicaid as a funding source for state early intervention systems.

INTRODUCTION AND BRIEF OVERVIEW OF THE SOCIAL SECURITY ACT

This Section focuses on Medicaid, discussing the general program requirements of this federally sponsored health care program. This Section provides an overview of Medicaid from the perspective of Part C, designed to help Part C planners understand the federal intent of Title XIX of the Social Security Act, known as Medicaid, and its relationship to Part C, IDEA regulations.

Title XIX of the Social Security Act is a Federal/state entitlement program that pays for medical assistance for certain individuals and families with low incomes and limited resources. This program, known as Medicaid, is a partnership between the federal and state governments (including the District of Columbia and the Territories[17]) which became law in 1965 to assist states in furnishing medical assistance to eligible needy persons. Medicaid is the largest health care program in the country, serving over 53 million Americans. This Section is intended to assist Part C Coordinators to better understand Medicaid as a funding source for state early intervention systems.

The Social Security Act contains many programs that Part C planners come into contact with on a fairly routine basis, due to the interagency nature of early

[17] In addition to the District of Columbia, U.S. Territories include American Samoa, Guam, Northern Marianas, Puerto Rico and the Virgin Islands.

intervention. Initiatives under the Social Security Act were designed to improve the lives of individuals who are low-income, disabled, blind and/or aged. Services include not only health care, but benefits to veterans, employment, social services, and services for those individuals with disabilities. Since the 1960's, there have been many changes to this section of federal law.

This section of federal law contains not only the requirements governing Social Security but also Supplemental Security Income (SSI), unemployment, Temporary Assistance to Needy Families (formerly AFDC, now TANF), child-welfare services, benefit programs for the aged, blind and disabled, the Social Services Block Grant program (SSBG), the Maternal and Child Health Block Grant, Medicaid, Medicare and SCHIP. As earlier highlighted, the majority of these programs are income-based, relying upon the Federal Poverty Level[18] (FPL) to guide eligibility determination decisions.

Also as earlier stated, there is considerable reciprocity between many of these programs. SSI provides a monthly stipend to individuals who have a severe disability and who meet certain income and resource (property, assets, inc.) restrictions. Children under age 18 who are SSI recipients quality for both Medicaid and the SSI program. Some states automatically enroll SSI recipients in Medicaid; in others, children have to go through a separate enrollment process. To be eligible for SSI, a child must have a physical or mental condition that:

- Results in severe functional limitations[19]
- Is expected to last at least 12 months or result in death

Many state Part C systems across the country participate in the SSI disability determination process for enrolled children by sharing evaluation and assessment information. Obtaining SSI also hinges on financial eligibility. The Social Security Administration (SSA) utilizes a process called "deeming" to assign a portion of the family's income to the child. This is a very complicated process with calculations

[18] See Appendix B and C for FPL regulations and conversion table
[19] www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm

dependent on the type of income the household receives, whether or not there are other children (with or without disabilities), and whether it is a single or two-parent household.

The SSA also looks at household resources, such as savings accounts, but other resources, including the family's home, are not counted towards this amount. As long as the amount deemed available to the child is less than $2,000, the child can qualify for SSI.

Children with special health care needs (CSHCN) may be eligible for the state programs serving this population. Individuals may also have private health insurance which results in a triage or hierarchy in the manner in which federal program funds are accessed at the state level, once these non-federal resources are tapped.

OVERVIEW OF FEDERAL INTENT, PURPOSE AND REGULATORY LANGUAGE OF TITLE XIX, THE MEDICAID PROGRAM

Title XIX, passed by Congress in 1965, set forth to establish an entitlement program for families with young children and those who are aged, blind or disabled. This system for national healthcare ensured access and delivery of rehabilitation and other services to help individuals attain or retain their capability for independence or self care. For the purposes of this Paper, we will focus on very young children within the context of the Part C system; this law, however, applies to all children and much of the information contained in this Paper can be applied to other populations.

Title XIX, Grants to State for Medical Assistance Programs, established the purpose for Title XIX under Section 1901, the appropriations section of the law. This section reads as follows:

> *For the purpose of enabling each State, as far as practicable under the conditions in such State, to furnish (1) medical assistance on behalf of families with dependent children* ***and of*** *aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services,* ***and*** *(2) rehabilitation and other services to help such families and individuals* ***attain or retain*** *capability*

> *for independence or self-care, there is hereby authorized to be appropriated for each fiscal year a sum sufficient to carry out the purposes of this title. These sums made available under this section shall be used for making payments to states which have submitted, and had approved by the Secretary, State Plans for medical assistance.* [20]

The purpose, as stated above, for establishing and funding Medicaid is quite inclusive. Medicaid was established for two primary purposes.

- First, to furnish medical assistance to families with dependent children, and to those who were aged, blind or disabled.

- Secondly, to furnish rehabilitation and other services to help these families and individuals be as independent as possible. This portion of the law makes no distinction between habilitation and rehabilitation; both are included in Medicaid through the statement "attain" (habilitation) or "retain" (rehabilitation) their capability for independence or self-care, and – as you review the federal statutory language, are clearly provided <u>in conjunction</u>[21] with health care benefits and not instead of.

The meaning of the language, "as far as practicable under the conditions in such State," is uncertain. It may relate to the individual state's ability to actually provide or fund such services, or perhaps the need for these services, which we know varies greatly from region to region, state to state, community to community.

Within broad national guidelines established by Federal statutes, regulations, and policies, each state:

(1) establishes its own lead agency;
(2) establishes state eligibility criteria;
(3) defines services, including those required, that will be provided
(4) determines the type, amount, duration, and scope of services;
(5) determines who are eligible providers;

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[20] Emphasis by author
[21] Emphasis by author

(6) sets the rate of payment for services; and
(7) administers its own program.

Medicaid is a voluntary federal program that, currently, all states and Territories choose to participate in. In exchange for their participation, states receive federal Medicaid matching funds for at least 50 percent and as much as 80 percent of the costs of this **mandatory** coverage, depending on the state. In exchange, states are also able to draw down federal Medicaid matching funds at the same rate for **optional** populations and services such as the low-income elderly and disabled at risk of nursing home and other expensive long-term care services. Exceptions to this federal participation policy are applied to the Territories where capped Medicaid allocations are provided.

Medicaid policies for eligibility, services, and payment from state to state vary considerably, even among states of similar size, demographics or geographic proximity. An individual who is eligible for Medicaid in one state may not be eligible in another; the services provided by one state may differ considerably in amount, duration, or scope from services provided in a similar or neighboring state. In addition, state policy makers and/or legislatures may change Medicaid eligibility, services, and/or reimbursement approaches or methodology including rates. Additionally, Congress has the authority to change the Federal requirements for this program, which may affect individual states to one degree or another depending upon how they have constructed their Medicaid program.

Each state's Medicaid program has infrastructure or operational requirements that support the ongoing operations of the program. These requirements are designed to ensure early identification, screening, referral and services to eligible children and their families, promote quality services through training and monitoring, address individual and systemic problems through complaint resolution procedures including due process, and promote interagency systems of service that utilize existing resources and supports that reduce duplication and maximize the opportunities for early and sustained, quality health care for its eligible population. These functions

qualify for "administrative match" at 50% or 75% if provided by medical professionals.

OVERVIEW OF FEDERAL INTENT, PURPOSE AND REGULATORY LANGUAGE OF PART C, IDEA: EARLY INTERVENTION PROGRAM FOR INFANTS AND TODDLERS WITH DISABILITIES

The purpose of Part C is four-fold. According to recent statutory changes as a result of the reauthorization of the Individuals with Disabilities Education Act (IDEA), it is the policy of the United States to provide financial assistance to States

> (1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, inter-agency system that provides early intervention services for infants and toddlers with disabilities and their families;
>
> (2) to facilitate the coordination of payment for early intervention services from Federal, State, local, and private sources (including public and private insurance coverage);
>
> (3) to enhance State capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to infants and toddlers with disabilities and their families; and
>
> (4) to encourage States to expand opportunities for children under 3 years of age who would be at risk of having substantial developmental delay if they did not receive early intervention services.

Part C is a voluntary program on the part of states. In return for their participation, states are allocated federal funds based upon the Birth-3 population of each state against the national total. Exceptions to this federal participation policy are applied to the Territories where capped Part C allocations are provided. At this point in time, all states and Territories participate in the Part C legislation.

Part C is the first legislation to mandate interagency collaboration and partnership in all facets of the system. Within the scope of Federal statute and regulations, each state:

(1) establishes its own lead agency;
(2) establishes state eligibility criteria;
(3) defines services, including those required, that will be provided
(4) determines the type, amount, duration, and scope of services;
(5) determines who are eligible providers;
(6) identifies and facilitates the coordination of a variety of federal, state, local and individual resources to ensure the payment for services; and
(7) administers its own program.

Part C also has a series of infrastructure or operational requirements that create and support the ongoing operations of the early intervention system. These requirements are designed to ensure early identification, referral and services to eligible children and their families, promote quality services through training and monitoring, address individual and systemic problems through complaint resolution procedures including due process, and build interagency systems of service that utilize existing resources and supports that reduce duplication.

In order to participate in Part C funding, states must submit a state application that defines how they will respond to the regulatory requirements. The state application addresses the areas of state program administration, eligibility criteria, service delivery including provider identification and compensation, training and technical assistance services, monitoring and data reporting. New language in the IDEA reauthorization requires the development and submission of a six-year Performance Plan with annual progress reports through the annual performance report or APR process.

The Office of Special Education Programs (OSEP) within the U.S. Department of Education is responsible for receipt, review and approval of these plans and any amendments. OSEP has worked diligently with states in a partnership to consolidate the planning and reporting process, and focus on key areas or components to maximize not only compliance, but also the provision of quality services to families and very young children. OSEP also provides ongoing monitoring and facilitates technical assistance through contracted entities including the National Early Childhood Technical Assistance Center (NECTAC) and the Regional Resource

Centers (RRCs). OSEP provides oversight to ensure compliance with federal regulations, while the state lead agency is required to implement a comprehensive quality monitoring system to ensure local compliance for all Part C regulations, with a particular emphasis on targeted components or cluster areas of the regulations.

Both Medicaid and Part C share considerable similarities in their mission and scope of responsibility. Regulatory requirements to reach beyond the lead agency and work with other state partners are common between the two programs. These requirements relate not only to financing services, but extend to include outreach, early referral and enrollment, monitoring for quality services which may include training and technical assistance, documentation and reporting requirements, etc.

Not all children eligible for Part C will also be eligible or enrolled in Medicaid. Medicaid is an important resource for some children in Part C; the impact of this relationship varies from state to state depending upon a variety of variables including state Medicaid income eligibility, poverty, Part C eligibility criteria, etc.

In recent years, partnerships between child-serving programs and services and Medicaid have increased substantially, particularly since the passage of the SCHIP. Joint efforts have focused on activities such as outreach or case finding, informing parents of services, and assistance in access and scheduling appointments. Section 2906 of the State Medicaid Manual outlines the requirements for oustationing locations to facilitate Medicaid enrollment. These individuals facilitate the application process while state agency personnel are the only ones authorized to make determinations of eligibility. A variety of programs including Early Head Start, Head Start and Part C may serve to provide these outreach functions, particularly in light of these frequency contacts with families with very young children. Federal financial participation (FFP) is available as an administrative match for costs incurred by the state to implement and provide outstationing services. This FFP would include the administrative costs such as salary, fringe benefits, travel, training, equipment and space directly attributable to the outstationing of eligibility personnel, who may be state employees, provider employees, volunteers or provider contractors.

While enrollment in Medicaid and SCHIP has grown over the years, there are still millions of uninsured children – despite being income eligible for Medicaid.

While all of the reasons for the lack of enrollment in federally sponsored health care programs are not known, it is suspected that lack of accurate information and knowledge about Medicaid or SCHIP may be a major reason. "Getting the word out" is particularly important since recent legislation separated Medicaid from welfare, meaning that eligibility for Medicaid is no longer based upon whether a family receives public assistance. Additionally, the expansion of Medicaid eligibility in 1989 now make it possible for all children under age 6, whose family incomes are below 133% of the FPL, to enroll in Medicaid; several states have chosen to raise the income standard to 185% or even higher. Part C systems, as well as Head Start, child care and Early Head Start programs, can support their state's Medicaid program by providing outreach services as a natural extension of their engagement with all families. This activity would then permit the organization to be reimbursed for these efforts by the state Medicaid agency which is allowed to claim outreach as an administrative cost, assuming an interagency agreement between the two entities.

There are other areas for collaboration between Part C and a state Medicaid program, including a variety of infrastructure or administrative responsibilities that may be coordinated in order to reduce duplication and consolidate effort. Figure 15 on page 35 depicts the variety of individual program components which are shared obligations by both Medicaid and Part C. For example, both Part C and Medicaid are required to conduct outreach to inform and engage potentially eligible children. Both systems require provider standards and methods to ensure that providers maintain licensure or certification, and are appropriately informed of their obligations under each system. For many Medicaid beneficiaries, a plan of care is required. Services in both systems need to be defined, and include appropriate methods for identification (evaluation and assessment).

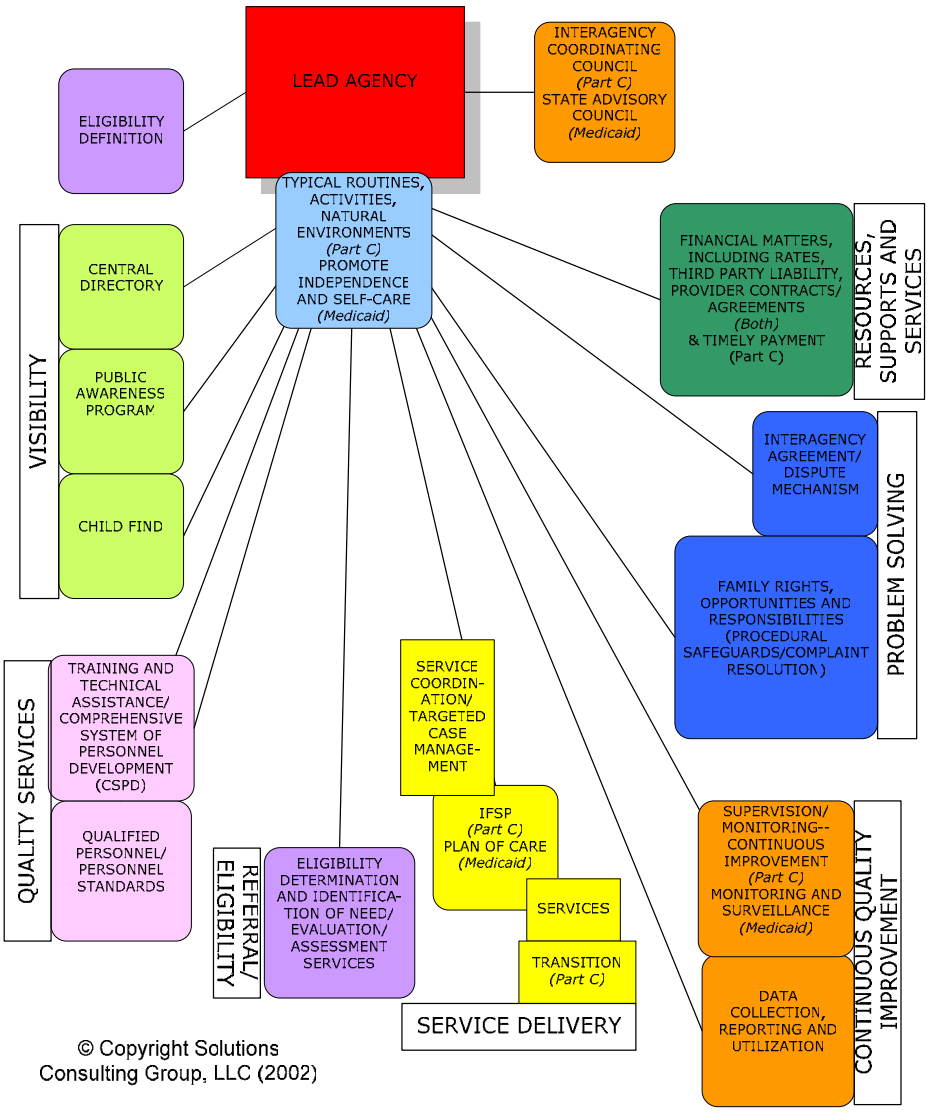
Medicaid and Part C systems share additional infrastructure requirements in that there are contracting requirements for providers, and requirements to ensure

reasonable reimbursement in a timely manner. Both systems have complaint resolution processes for consumers and providers.

And, both systems have comprehensive data collection and reporting requirements, complemented by monitoring and surveillance requirements by the lead agency to ensure regulatory compliance and quality service delivery. Each state's Medicaid and Part C system have a requirement for a council which acts in an advisory capacity.

The recent rulings under Olmstead have brought Medicaid and Part C into even further consistency. Olmstead emphasizes the importance of community integration, the value of individual, person-centered planning, and the opportunities to create and maintain non-traditional services that support the recipient and his/her family within their home and community environments.

Figure 15: Part C and Medicaid Operational Components



State partnerships have been cultivated, for example, that recognize the provider credential and enrollment responsibilities of Part C by the state Medicaid agency. Under these arrangements, Medicaid relies upon the Part C system to identify and enter into contractual relationships or agreements with providers for the provision of Part C services for which Medicaid reimbursement is provided. Still other states collaborate in their monitoring and quality assurance services by conducting joint monitoring of provider agencies or sharing their monitoring results across agencies to save time, expense and provider burden. In some states, Part C as well as other

early childhood serving entities are qualified by the state Medicaid agency to enroll children on a temporary basis in Medicaid if they appear to be eligible based upon their ages and family income. This is particularly true for those agencies providing subsidized child care under the Child Care and Development Block Grant (CCDBG).

As such, Part C is a potentially powerful partner to each state's Medicaid program through their connections, early on, with families of very young children and through the compatibility in their individual federal missions. In later Sections of this Paper, we will discuss financing partnerships between Part C and Medicaid which are largely based upon the mutuality of mission and federal requirements of both programs.

FEDERAL AND STATE ADMINISTRATION OF THE MEDICAID PROGRAM

There are typically three levels of management within the administration of the Medicaid program across the country. The Department of Health and Human Services is the federal lead agency for Medicaid, Medicare, and SCHIP. The next level of management is through CMS based in Baltimore, Maryland with ten regional offices throughout the country serving as the second level or tier of management. States must identify a "lead agency" for the administration of their Medicaid program. This third level of administration and management is typically located in departments of health or social services. Additionally, some states have regional or district offices responsible for local administration of their Medicaid program. The location of the specific lead agency for each state can be found on the CMS website.[22] This website also contains a wealth of information concerning each state's individual Medicaid program.

Medicaid state lead agencies typically have considerable interaction with their regional offices, far more than with the central office in Baltimore. Because of the sensitive nature of these communications, most – if not all – state Medicaid agencies

[22] http://www.cms.hhs.gov/medicaid/statemap.asp

prefer that all regional or central office communications are made through the state Medicaid lead agency. It is unusual for state departments other than the Medicaid lead agency to directly negotiate or confer with the regional or central administration of CMS.

Medicaid lead agencies often have individual department "liaisons" who are responsible for all intergovernmental communications, facilitating negotiations between state agency personnel and appropriate Medicaid staff. This allows the Medicaid agency to develop a strong understanding of its partner agencies, while consolidating communications and establishing greater collaboration in an organized and systemic manner. It is obviously important for Part C planners to understand what the protocol within their agency and state is for communications.

This structure is very similar to the manner in which governors of most states organize their staffing, with representatives assigned to specific departments, agencies and legislative bodies in an effort to consolidate and streamline communications.

A critical player in many states related to Medicaid is the state Legislature. After all, they are responsible for fiduciary matters including the identification of state match for all Medicaid functions. In the majority of states, decisions related to the construct of the Medicaid program are the purview of the state lead agency. There are occasions though where the state Legislature is intimately involved with determining eligibility, setting rate structures, etc. States report that they are seeing more of this direct kind of involvement by their Legislatures as a result of the economic downturn nationally coupled with anticipated reductions in the federal and state Medicaid budgets. The National Council of State Legislatures has developed or commissioned a variety of publications for their members including a "primer" on Medicaid available through its website. [23]

Overview of Federal Medical Assistance Percentages (FMAP)

[23] http://www.ncsl.org/programs/health/medicaidsnapshot.htm

The FMAP (Federal Medical Assistance Percentages) is the method by which the federal government determines how much it will cost share with individual states for the provision of Medicaid covered services. Similar to the FPL, the FMAP are recalculated annually which determines the basic percentage that the federal government shares with each state for Medicaid financing purposes. The federal statute requires the Department of Health and Human Services to publish the FMAP between October 1 and November 30th of each year. Figure 16 illustrates how FMAP affects state spending decisions, highlighting the impact that FMAP has at 70%, 65% and 50% (the minimum). State share is much lower for states at the higher FMAP, resulting in a higher overall benefit to states with high FMAP. Poorer states have more eligible individuals and are more likely to have significant health care needs as a result of poverty.

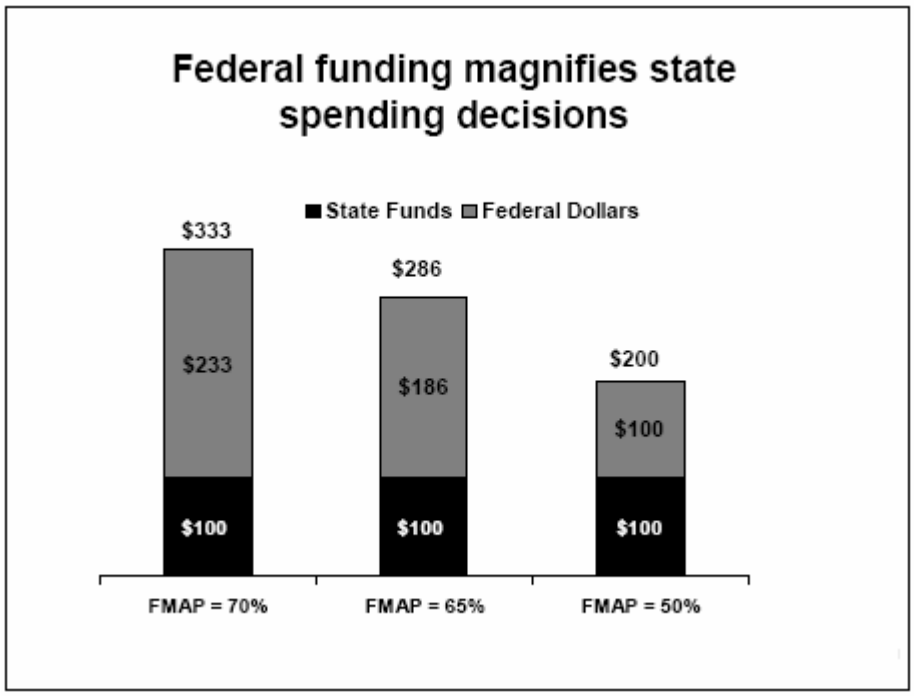


Figure 16: Federal funding magnifies state spending decisions, Kaiser Commission on Medicaid and the Uninsured, 2005

Appendix K presents the FMAP projections for 2006, highlighting the data for 50 states and the District of Columbia. There are 12 states receiving FMAP at the minimum level or 50%. While federal language permits FMAP between 50 to 83%, the highest FMAP for 2006 is projected for Mississippi at 76%. Only nine states (9) are projected to grow in FMAP (GA, HI, IN, IA, NE, OH, OR, PA, RI) while the remaining 30 states will experience a reduction. For the most part, increases in FMAP are minor; reductions were more pronounced. Alaska will experience the greatest reduction and is projected to go

from 57.58% FMAP in 2005 to 50.16%. State Part C planners will want to review the FMAP annually to note any changes which may affect them.

With the exception of the District of Columbia, the FMAP for the U.S. Territories, including Puerto Rico, is capped. Americans residing in all five Territories have a federally imposed capitation on Medicaid service funds received from the federal government. Territorial governments must provide a 50-50 match for services up to the cap and pay 100% above the cap. The Territories have faced great challenges with the Medicaid cap in covering the costs of the basic mandatory set of Medicaid acute/primary care services. The cap also prevents the Territories from utilizing some of the other approaches, such as Home and Community Based Services Waivers (HCBS), which have allowed several states considerable leeway to adopt and develop family support programs for people with disabilities and their families. The Medicaid federal funding for the Territories has been an issue for several years. Legislation submitted to remedy this has not been successful. As Congress approaches major Medicaid reform in 2005-2006, this issue has again been raised by the National Governor's Association (NGA) in their position paper entitled Medicaid Reform: A Preliminary Report, dated June 15, 2005 (Appendix E).

States may receive a different level of federal financial participation or FFP under certain circumstances. For example, administrative claiming is typically at 50% irrespective of the state's FMAP unless the services are provided by a physician or nurse, resulting in an increase to the FFP to 75%.

Medicaid State Plan Process

In order to participate in Medicaid funding, states must submit a State Plan that defines how they will respond to the regulatory requirements. This plan is a comprehensive document that describes the nature of scope of the state's program and provides assurances that it will be administered in conformity with the specific requirements stipulated in the Medicaid Act, as well as in compliance with other applicable official policies that are generated from time to time from CMS. The State Plan addresses all areas of state program administration, Medicaid eligibility criteria, service coverage, and provider reimbursement. Routinely, states file "State Plan amendments" which identify changes to their operations.

Each state Medicaid plan may be composed of more than 1,000 pages, developed over time since the inception of the program. The typical plan is housed in several filing cabinets at the state level. The CMS website[24] provides state specific information related to its State Plan and Amendments.

Updates and amendments (State Plan Amendments or SPA) to a state's Plan may be submitted at any point along the way, and are typically subject to the public hearing process through individual state regulations. The CMS Regional Offices are responsible for receipt, review and approval of these plans and any amendments. A State Plan amendment may constitute many different sections of the state Medicaid plan, making it difficult sometimes to locate all relevant documents. The SPA process requires that changes are made to all relevant sections of the State Plan.

Many states find it tremendously beneficial to work in close collaboration with their Regional representatives when crafting new initiatives, or considering changes to current services. This type of "informal review" helps to ensure that the CMS Regional Office understands the state's intent, and provides the opportunity for

[24] http://www.cms.hhs.gov/medicaid/statemap.asp

dialogue that helps to ensure the final plan amendment is written in such a manner as to promote smooth approval in a timely manner.

CMS has a 90 day "window" with which to review and respond to each State Plan or State Plan amendments. If the Regional CMS office fails to make any comment within this time period or files requests for additional information, approval or disapproval, the plan is deemed approved. If additional information is required, CMS communicates this in writing to the state. This communication effectively "stops the clock" until such a time as the state responds. Regional office administrators are responsible to engage administrators from the Central Office where a final determination of disapproval is to be rendered, or where significant state-regional office differences exist that can not be mediated.

The Administration's goal of realigning HCFA into CMS was to streamline communications and improve standardization across the country; however there still exists a significant difference between regions as reflected in the diversity of historic state initiatives.

The CMS Regional Offices also provide ongoing monitoring, technical assistance and oversight to ensure compliance with federal regulations, while the state lead agency is required to implement a comprehensive quality assurance and surveillance system to ensure local compliance and quality.

Medicaid Program Components

This section of the Paper provides information on the Medicaid program focusing on its essential, **mandated** requirements. Section B of this Paper discusses approaches and options to accessing Medicaid which sometimes affects these core requirements. States have discretion in determining which groups their Medicaid programs will cover and the financial criteria for Medicaid eligibility. States may also choose to offer a range of services beyond the mandated list, and may include specific populations which are not federally required.

This section of the Paper provides general guidance in understanding the federal Medicaid regulations. States can always exceed these federal requirements, just as in Part C; once they do this, they are then held to the higher standard through monitoring and surveillance activities.

Equity and Accessibility Principles

Medicaid regulations have established three key principles that states must address throughout their State Plan process. These are the requirements of §1902(a)(23), the free choice of provider, as well as §1902(a)(1) (statewideness), and §1902(a)(10) (comparability) of the Social Security Act.

The purpose of the free choice provision (§2100 of the Medicaid regulations) is to allow Medicaid recipients the same opportunities to choose among available providers of covered health care and services as are normally offered to the general population. This means that Medicaid recipients are subject to the same reasonable limitations in exercising such choice as are nonrecipients. Under §1902(a)(23) of the Social Security Act, a State Plan for medical assistance under title XIX must provide that any individual eligible for medical assistance (including drugs) under the plan may obtain the services available under the plan from any institution, agency, community pharmacy, or practitioner qualified to perform the services required, who undertakes to provide him these services, including an organization which provides such services or arranges for their availability on a prepayment basis.[25] The state Medicaid agency is not prohibited from:

- imposing reasonable and objective qualification standards for provider eligibility,
- establishing the fees which will be paid to providers for furnishing medical and remedial care under the plan, or
- restricting the free choice of providers in accordance with one or more of the exceptions provided for under §1915(a) or under a waiver as provided for under §1915(b).

[25] This requirement does not apply in the case of Puerto Rico, the Virgin Islands, and Guam.

Similar to the Part C requirement for a "central directory," the state Medicaid agency is responsible to provide recipients with information including a listing of enrolled Medicaid providers and to make this information available for individuals who do not read or speak English.

Under §4120, states are required to demonstrate that State Plan services are available statewide and that there are systematic methods to ensure that the local offices operating the Medicaid program are informed of all state policies, standards, procedures, etc. The statewideness principle of Medicaid was established to ensure that the residency of an individual was not a factor in accessing covered services and that all Medicaid recipients had equal opportunity to receive necessary services throughout the state.

Under §4130 of the Medicaid regulations 42 CFR 440.240, comparability of services means that the services available to any categorically needy recipient under a State Plan must not be less in amount, duration, and scope that those services available to a medically needy recipient. Services available to any individual in the categorically needy group or a covered medically needy group must be equal in amount, duration, and scope for all recipients within the same group. This provision was established to ensure that services to Medicaid's primary population – the categorically needy – would not be diluted by state efforts to cover other populations. There is one exception to the comparability requirements in that states may provide additional services to pregnant women.

Federal Medicaid regulations, under §1915(b) of the SSA, permit states to waive any or all three of these requirements under certain circumstances. Waivers for these and other requirements are discussed in Section B of this Paper.

Medicaid Eligibility

Medicaid is a means-tested, federal-state, individual entitlement program with historical ties to the Aid to Families with Dependent Children (AFDC) and Supplemental Security Income (SSI) cash assistance programs. Medicaid's association with AFDC and SSI has guided Medicaid's historical eligibility categories.

Because Medicaid is an individual entitlement, both the states and the federal government have relied on eligibility policy as a tool for limiting their financial exposure for the cost of covered benefits.

Medicaid's role is to cover basic health and long-term care services for low-income residents of the United States. However, being poor does not assure Medicaid coverage. As shown in Figure 17 on the following page, Medicaid in 1995 covered only about 55 percent of the nonelderly poor earning less than $12,590 for a family of three. Medicaid's reach to individuals with incomes just above the poverty line is even more limited, covering only 17 percent of the near-poor. Despite Medicaid, low-income people are considerably more likely to be uninsured than those with higher incomes. While a portion of the low-income uninsured are eligible for Medicaid – but not enrolled, a substantial share are excluded from Medicaid coverage by program eligibility rules that reflect policy choices at both the federal and state level.

Medicaid has two types of eligibility – mandated and optional – for states to consider as they craft their program. Medicaid provides coverage for three basic groups: children and their parents, the elderly, and people with disabilities. Eligible individuals must have low incomes, few assets and meet immigration and residency requirements.

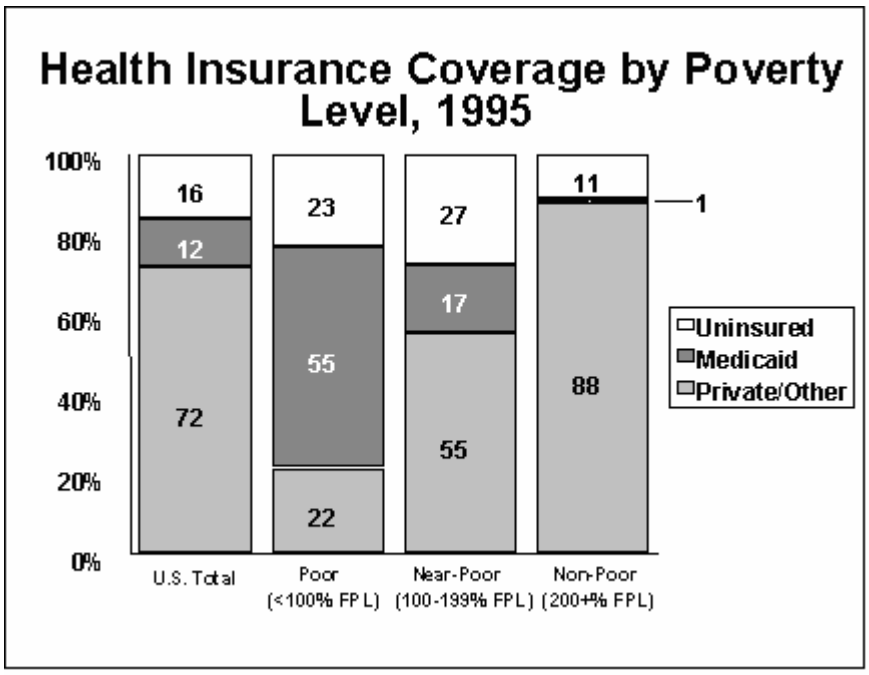


Figure 17. Health Insurance Coverage by Poverty Level, 1995. Kaiser Commission on Medicaid and the Uninsured.

Given the trend in the reduction of employer-sponsored health care programs since 1995, it is extremely likely that these data have changed substantially as they relate to the non-poor and access to private or other health insurance coverage. Figure 17 above displays the disparity in access to health insurance across the economic spectrum, however.

Medicaid Eligibility: Mandatory Populations

The mandatory populations for Medicaid eligibility include pregnant women and children under age 6 with family incomes less than 133% FPL, and older children ages 6 to 18 with family incomes less than 100% of poverty. States also include some low-income parents as well as people with disabilities and the elderly who are eligible for Supplemental Security Income (SSI) or similar state-set requirements. With the passage of SCHIP, many states were able to increase the level of FPL that would qualify for Medicaid. Figure 18 on the next page provides a summary of income eligibility levels for children ages Birth-1 and 1-5. The reader can see the dramatic variations among and between states.

States Birth-5 (N=28)	FPL	States Birth-1 (N=23)	States 1-5 (n=23)
AL, CO, MT, ND, NV, OR, UT, VA, WY	133%		AZ, CA, DE, FL, GA, IL, IA, KS, MS, NJ, NY, NC, PA, TN, TX, WV
SD	140%	AZ	
ID, IN	150%	KS, WV	KY, ME, MA, MI, SC
AK	175%		
CT, NE, OK, WI,	185%	KY, ME, MI, MS, NC, PA, SC, TN, TX	NH
AR, DC, HI, LA, MD, OH, WA	200%	CA, DE, FL, GA, IL, IA, MA, NJ, NY	
NM	235%		
RI	250%		
	275%		MN
	280%	MN	
VT, MO	300%	NH	

Figure 18. State FPL by Child, Age Birth-1, 1-5 (Information Source: Beneath the Surface: Barriers Threaten to Slow Progress on Health Coverage of Children and Families, Table 1; data based on a review conducted by the Center on Budget and Policy Priorities for the Kaiser Commission on Medicaid and the Uninsured, October 2004.)Chart created by Solutions Consulting Group, LLC for this publication.

There are a number of anomalies within these data. Some states (ME, NJ, IL, GA) include infants born to mothers enrolled in Medicaid at a higher FPL than those born to non-Medicaid eligible women. MA and PA provide state-financed coverage to children whose families have incomes above the SCHIP levels; Hawaii offers a similar opportunity to families whose income exceeds 200% FPL through a state program by paying a premium. Vermont and Minnesota have developed a demonstration waiver to serve very young children.

Regional variations according to the four census areas (Northeast, Midwest, South and West) indicate generally higher levels of FPL for infants in the Northeast states, with one-third of the nine states maintaining common FPL eligibility for children Birth-5 (CT, RI, VT). One-third of the states in the Northeast have FPL eligibility above 235% of poverty, two of which maintain this eligibility for children Birth-5 (RI and NH). The lowest FPL for children Birth-1 in these states starts at 185% (ME, PA) and at 200% for MA, NJ and NY.

In the Midwest, one half of the total of 12 states in this geographic grouping, or six states (ND, SD, NE, WI, OH, MO), maintain the same FPL for children Birth-5, ranging from 133% (ND) to 300% (MO). It is of note that MO earlier announced proposals for dramatic reductions to its Medicaid program, anticipating that within the next three years, it will no longer participate in the federal Medicaid program. North Dakota's Medicaid program has established FPL for 1-5 at 133% with South Dakota slightly above at 140% for both populations. Minnesota establishes eligibility for Birth-1 at 280% and for 1-5 at 275%.

The Southern region, including the District of Columbia, has a total of 17 states with 7 or 41% offering the same FPL for children Birth-5 ranging from 133% (AL, VA), 185% (OK), and 200% (AR, DC, LA, MD). Infants in DE, FL and GA share the 2005 FPL eligibility in those states, while demonstrating a higher eligibility at 133% for children ages 1-5.

Eleven of the 12 states (92%) in the Western region have common FPL for children Birth-5. Six of these states have established Birth-5 Medicaid eligibility at 133% (CO, MT, NV, OR, UT, WY), followed by Idaho (150%), Alaska (175%), Hawaii and Washington (200%) and New Mexico at 235%. Only Arizona and California have different FPL eligibilities, with Arizona being the more restrictive of the two for both populations.

In reviewing the IDEA Part C Child Count as of 2003, excluding at risk, there were a total of 11 states categorized by OSEP in the "broad" Part C eligibility criteria with Medicaid FPL at 133%. Six states reported counts above 2.3% and five states had counts less than 2.3%. What was notable about these data is that five of the six states above 2.3% were states with Birth-5 FPL at 133%. For states in the "moderate" eligibility category, three states with Birth-5 FPL at 133% reported above 2.4% and a total of six states (4 with Birth-5 FPL eligibility) reported below. There were three states in the "narrow" eligibility category, all reporting less than 2.13% enrollment, only one of which was a Birth-5 FPL eligibility.

For those states with the highest FPL, Vermont and New Hampshire (in the "broad" category with 300% FPL for Birth-5) reported a child count above 2.3%, at 3.42% and 2.60% respectively. Minnesota, with 280% for Birth-5, is included in the "broad" category and reported a total of 1.78% 0-3 year olds served for 2003.

While the FPL is only one eligibility mechanism, it is the most frequently employed nationally to enable low-income families to enroll in their state's Medicaid program. For Part C planners, this information is very important. There does not appear to be any correlation between the state's FPL for Medicaid and Part C enrollment. However, the existence of different FPL eligibilities for children Birth-1 and 1-5 may create coverage challenges for children enrolled in Part C if other avenues of Medicaid enrollment are not available, and create a greater reliance on other funding sources for children over age one who are eligible for Part C.

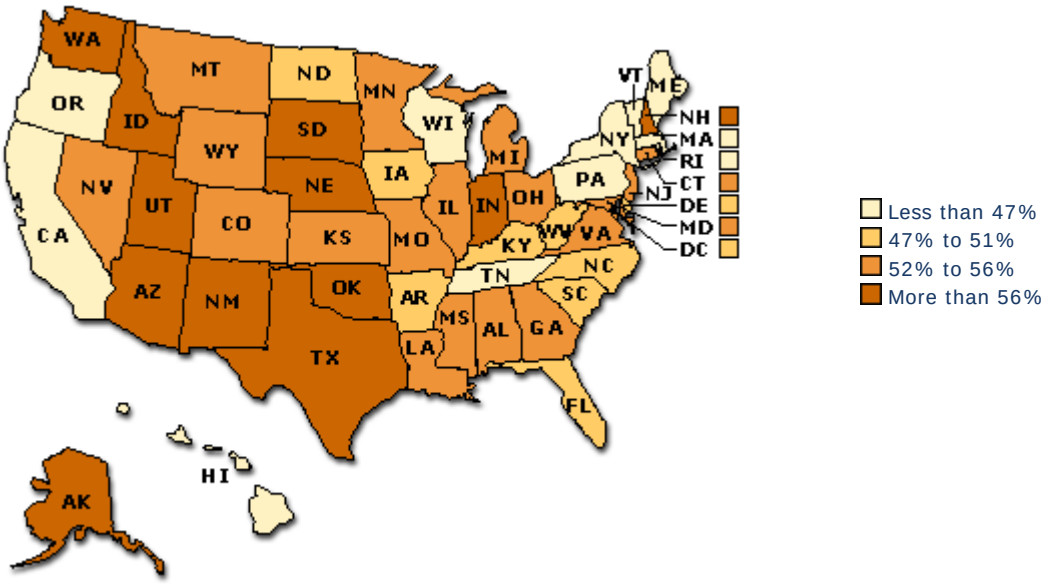
Historically, receipt of Medicaid assistance has been tied to AFDC, the federal entitlement program for cash assistance to families. Under the 1996 welfare law (the Personal Responsibility and Work Opportunity Reconciliation Act, P.L.104-193), AFDC was replaced by TANF, a block grant that allows states to determine their own eligibility criteria and benefit levels. The link between receipt of cash welfare benefits and automatic eligibility for Medicaid was severed. States are still required, however, to determine Medicaid eligibility for all families with children, whether receiving TANF benefits or not, as if their AFDC State Plans of July 16, 1996 were still in effect.

Other "categorically needy" eligibility criteria established by the federal government for state Medicaid programs includes:

a) Children under age 6 whose family income is at or below 133% FPL.
b) Pregnant women whose family income is below 133% FPL.
c) Supplemental Security Income (SSI) recipients in most states.
d) Recipients of adoption or foster care assistance under Title IV of the Social Security Act.
e) Special protected groups (typically individuals who lose their cash assistance due to earnings from work or from increased Social Security benefits, but who may keep Medicaid for a period of time).

f) Certain Medicare beneficiaries.

Figure 19: Distribution of State Medicaid Enrollees by Enrollment Group, FFY2000; Map by group: Children, Kaiser Commission on Medicaid and the Uninsured



This map illustrates the total child enrollment in state Medicaid programs, ages Birth-18. It is typical that Birth-5 enrollment is greater than the Medicaid enrollment for older children where there tends to be lower FPL. This may be due to the increased enrollment opportunities for infants and very young children under age five, greater visibility for the needs of very young children and linkages with the health care system, and the general tendency for adolescents not to seek heath care in general. Certainly the link to immunizations could be significant in terms of assisting the linkages to Medicaid and the general health care system for very young children.

Twenty-one[26] states have consistent FPL eligibility for children Birth-18; six[27] have consistent FPL eligibility for children 5-18. There are no national data which provide

[26] AK, AR, CT, DC, HI, ID, IN, LA, MD, NE, NJ, NM, OH, OK, RI, SC, SD, VT, VA, WA, WI

[27] IA, ME, MA, IL, NH

an enrollment breakdown for ages other than Birth-18. Part C planners will benefit from understanding their individual state's eligibility criteria and working with their state Medicaid agency to identify enrollment for the 0-3 population, particularly if these data can be provided by county/district or parish. Medicaid enrollment for children eligible for Part C tends to average 15-23% above their cohort enrollment.

Optional Medicaid Eligibility: Categorically Needy

States also have the **option** to provide Medicaid coverage for other "categorically needy" groups. These optional groups share characteristics of the mandatory groups, but the eligibility criteria are somewhat more liberally defined. Examples of the optional groups that states may cover as categorically needy (and for which they will receive federal matching funds) under the Medicaid program are listed below; those pertaining to the target population of this Paper are underlined.

- infants up to age one and pregnant women not covered under the mandatory rules whose family income is below 185 percent of the Federal Poverty Level (the percentage to be set by each state);
- optional targeted low income children;
- certain aged, blind, or disabled adults who have incomes above those requiring mandatory coverage, but below the Federal poverty level;
- children under age 21 who meet income and resource requirements for TANF, but who otherwise are not eligible for TANF;
- institutionalized individuals with income and resources below specified limits;
- persons who would be eligible if institutionalized but are receiving care under home and community-based services waivers;
- recipients of state supplementary payments; and
- TB-infected persons who would be financially eligible for Medicaid at the SSI level (only for TB-related ambulatory services and TB drugs)
- low-income, uninsured women screened and diagnosed through a Center's for Disease Control and Prevention's Breast and Cervical Cancer Early Detection Program and determined to be in need of treatment for breast or cervical cancer.

Optional Medicaid Eligibility: Medically Needy

The option to have a "medically needy" program includes those individuals who may have too much income to qualify under the mandatory or optional categorically needy groups. This option allows them to "spend down" to Medicaid eligibility by incurring medical and/or remedial care expenses to offset their excess income, thereby reducing it to a level below the maximum allowed by that State's Medicaid plan. States may also allow families to establish eligibility as medically needy by paying monthly premiums to the state in an amount equal to the difference between family income (reduced by unpaid expenses, if any, incurred for medical care in previous months) and the income eligibility standard.

Eligibility for the medically needy program does not have to be as extensive as the categorically needy program. However, states which elect to include the medically needy under their plans are required to include certain children under age 18 and pregnant women who, except for income and resources, would be eligible as categorically needy. They may choose to provide coverage to other medically needy persons: aged, blind, and/or disabled persons; certain relatives of children deprived of parental support and care; and certain other financially eligible children up to age 21.

As of 2000, there were 31 states with medically needy eligibility affecting children; 35 states with medically needy eligibility for individuals with disabilities. It is impossible to discern how many of these recipients are very young children. Approximately one-half of the federal expenditures for these services were directed towards the elderly, and slightly less than that for individuals with disabilities. Very few resources were directed towards children of any age in this optional category.

The next Figures illustrate the overall state enrollment variations between two medically needy eligibility categories: children (Figure 20) and persons with disabilities (Figure 21).

Figure 20: Medicaid Medically Needy Enrollees by Eligibility Category, 2000
Map by group: Children, Kaiser Commission on Medicaid and the Uninsured

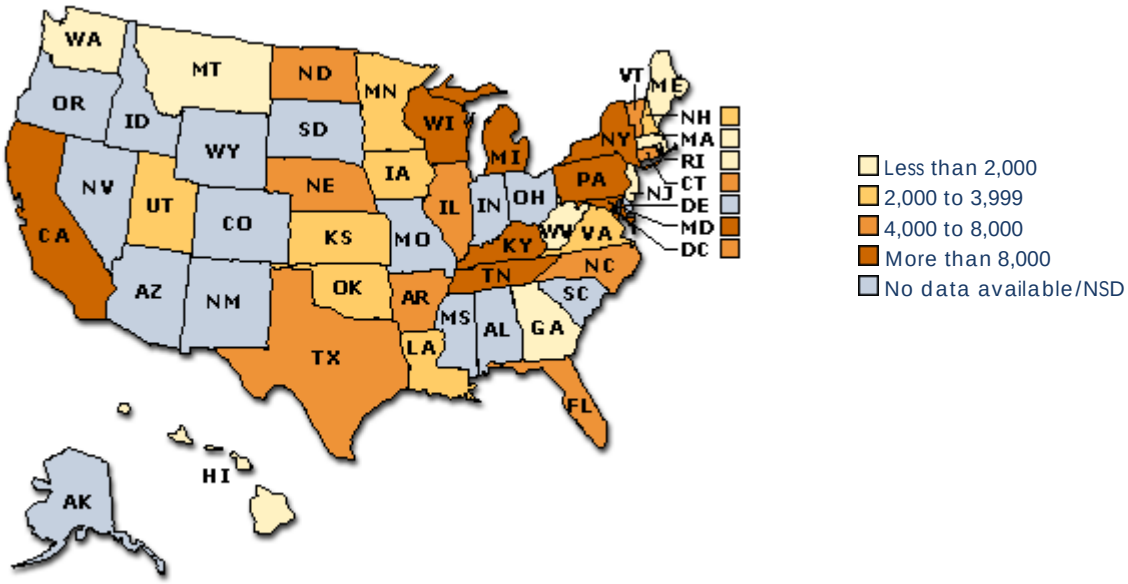
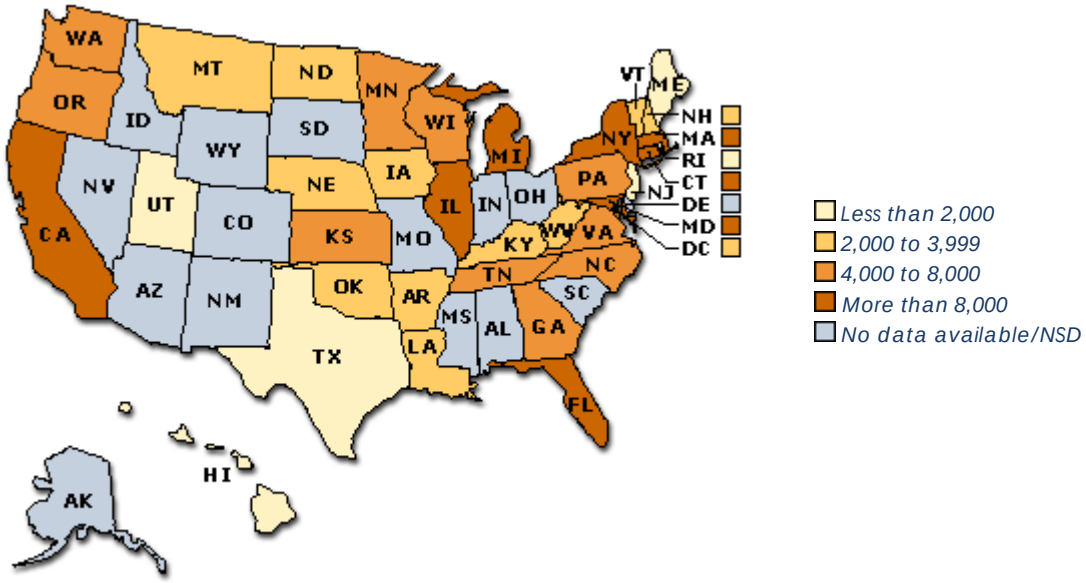


Figure 21: Medicaid Medically Needy Enrollees by Eligibility Category, 2000
Map by group: Disabled, Kaiser Commission on Medicaid and the Uninsured



Medicaid Eligibility: Immigrants and Qualified Aliens

The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 (PRWORA) (Pub. L. 104-193), as amended, made significant changes to the eligibility of immigrants for Medicaid and the State Children's Health Insurance Program (SCHIP). These changes essentially made it more difficult for non-United States citizens to access many public aid programs including Medicaid. Many of the current eligibility rules revolve around the date that TANF became effective (1996). Assuming all other eligibility guidelines are met, legal immigrants are eligible for SCHIP or Medicaid if they arrived in the United States before August 22, 1996. The language in PRWORA states:

- Only citizens and so-called "qualified aliens" are eligible for the full range of benefits provided under either Medicaid or SCHIP. Non-qualified aliens who otherwise meet the eligibility criteria of a state's Medicaid program are eligible under Medicaid for treatment of an emergency condition only.
- Certain immigrants who entered the United States on or after August 22, 1996 were barred from receiving Medicaid or SCHIP benefits for five years.
- In determining the eligibility of some immigrants for Medicaid or SCHIP, the income and resources of the immigrant's sponsor must be counted in determining the immigrant's eligibility. This is commonly referred to as "alien sponsor deeming."

Children born in this country are eligible if they meet the financial or other criteria of the individual state's eligibility requirements even if their parents are not citizens. Families may have concerns about what kinds of information might be collected during the eligibility determination period for Medicaid or SCHIP; these parents should be informed of the following:

- Medicaid does not share any information provided by applicants with the Immigration and Naturalization Service (INS). This is not necessarily the case for other public aid programs though.
- Parents are not required to give documentation of their own citizen status when applying for Medicaid for their children.

- Parents do not have to provide their own social security number if applying for their child, but do need to have a social security number for their child in order to complete the Medicaid application.

States typically require that applicants to Medicaid are state residents and request proof of residency (often a cancelled envelope to their mailing address) and, for young children, legal custody in the case of non-custodial parents.

Medicaid Eligibility: When Does Coverage Start and Stop?

Medicaid coverage may start retroactively to any or all of the 3 months prior to application for the period that the individual would have been eligible during the retroactive period. Coverage generally stops at the end of the month in which a person's circumstances change. Most states have additional "state-only" programs to provide medical assistance for specified poor persons who do not qualify for the Medicaid program. No federal funds are provided for state-only programs.

A child or adult who establishes Medicaid eligibility is not, on the basis of that initial determination, entitled to maintain eligibility indefinitely. Federal Medicaid regulations require states to redetermine eligibility of a Medicaid beneficiary at least once every 12 months. This redetermination, like the original determination, is designed to ensure that a beneficiary continues to meet each of the financial and/or non-financial requirements for eligibility. Due to a change in income, resources, or family composition, these beneficiaries may no longer meet the eligibility requirements of their state through any pathway and will lose their Medicaid entitlement. There are a few but limited exceptions which do not affect very young children.

Fluctuations in monthly income are common among low-income families, seasonal workers such as construction, agriculture, fisherman, etc. These changes can lead to the loss of Medicaid coverage by a child or family whose income may spike during one part of the year but spends most of the year earning under the federal poverty level. This occurs commonly in states that use 1-month, 3-month, and 6-month redetermination periods. To respond to the reality of eligibility "churning," the

Balance Budget Act of 1997 gave states the option of extending Medicaid coverage with federal matching funds to children under 19 for a period of up to 12 months after the initial determination of eligibility regardless of any change in financial or non-financial circumstances that would otherwise make them ineligible. This option does not extend to low-income adults with dependent children.

Medicaid Eligibility and Family Finances

Medicaid does not require that an individual who meets its categorical, income, resource, immigration status, and residency requirements also be uninsured. Medicaid treats insurance coverage as a payment source, not as part of its eligibility criteria. More specifically, private insurance coverage under Medicaid is considered part of "third party liability" that the Medicaid program uses to reduce its costs of coverage. In most cases, when a Medicaid beneficiary also has private coverage, the private insurer must pay first. Then Medicaid will pay for Medicaid-covered service(s) for which the private insurer is not obligated to pay.[28]

Medicaid eligibility is not directly tied to employment for many of the Medicaid coverage categories. For example, a pregnant woman whose income is equal to or less than 133 percent of the federal poverty level is eligible for Medicaid coverage in every state whether or not she worked before or during her pregnancy. On the other hand, as a result of the 1996 welfare law, a state has the option to deny Medicaid eligibility to non-pregnant women with dependent children for whom the state has terminated cash assistance under TANF based upon her refusal to work; Medicaid coverage for the children may not be terminated for this reason.

Earnings to an individual or a family from work will affect income eligibility for Medicaid. At income levels near Medicaid eligibility thresholds, a small increase in earnings can result in a loss in Medicaid eligibility even though the increase in

[28] This policy stands in sharp contrast to the approach taken under SCHIP under which states are expressly prohibited from using federal SCHIP matching funds to pay for services to children with private health insurance.

earnings may not be sufficient to enable the worker to afford private health insurance coverage. To mitigate this disincentive to work or to increase the hours worked, states are required to extend "transitional" Medicaid coverage for up to one year to women (and their dependent children) who lose cash assistance due to earnings; this applies only to individuals in TANF who access their Medicaid coverage through this public welfare benefit.

For many states, families actively involved in Part C planning and implementation activities often need to be extremely alert to any new earnings that they may experience as a result of their involvement in early intervention. Even mileage or child care reimbursement, since it is reportable as income on a 1099 to the IRS, may cause a family to lose valuable entitlements.

In completing this discussion on Medicaid eligibility, it is important to note that Medicaid enrollment does not necessarily mean “free” or at no cost services to the family or child. States have long been able to implement limited cost sharing mechanisms, although few have until recently. Federal regulations prohibit cost sharing to Medicaid covered services for individuals under age 18, services to pregnant women, specialized institutional or hospital services, emergency services or hospice services. This may be subject to change however, with the variety of recommendations that have been made to the federal Medicaid regulations – particularly those recommendations as recently supported by the National Governor’s Association.

Medicaid federal regulations do permit an enrollment fee, premium or similar charge for other individuals and are careful to caution against costs which would result in harm or inability of the enrollee to obtain appropriate and needed services. Cost sharing is usually limited in scope and amount, and often represents a nominal co-payment on the part of the recipient. As federal and state budgets continue to be challenged, we may anticipate that additional cost sharing provisions will be instituted at both the federal and states level. These may include cost sharing on more services, or increased cost sharing amounts overall.

Eligibility: In Summary

Medicaid does not provide medical assistance for all low income persons. Even under the broadest provisions of the federal statute (except for emergency services for certain persons), the Medicaid program does not provide health care services, even for very poor persons, unless they are in one of the groups as discussed. Low income is only one test for Medicaid eligibility; assets and resources are also tested against established thresholds. Categorically needy persons who are eligible for Medicaid may or may not also receive cash assistance from the TANF program or from the SSI program. Medically needy persons who would be categorically eligible except for income or assets may become eligible for Medicaid solely because of excessive medical expenses.

States may use more liberal income and resources methodologies to determine Medicaid eligibility for certain AFDC-related and aged, blind, and disabled individuals under §1902(r)(2) and §1931 of the Social Security Act.

Medicaid Scope of Coverage

When states choose to offer the **optional** categorically needy and/or medically needy programs, there are scope of coverage requirements that have to be met. These services generally include the following:

(1) Inpatient hospital services
(2) Outpatient hospital services
(3) Prenatal care
(4) Vaccines for children
(5) Physician services
(6) Nursing facility services for persons aged 21 or older
(7) Family planning services and supplies
(8) Rural health clinic services
(9) Home health care for persons eligible for skilled-nursing services
(10) Laboratory and x-ray services
(11) Pediatric and family nurse practitioner services

(12) Nurse-midwife services

(13) Federally qualified health-center (FQHC) services, and ambulatory services of an FQHC that would be available in other settings

(14) Early and periodic screening, diagnostic, and treatment (EPSDT) services for children under age 21

In order to finance these services, states may also receive federal matching funds to provide certain optional services. These optional services are listed in Figure 22 on page 59.

If a state chooses to include the **medically needy** population, the State Plan must provide, as a minimum, the following services:

- prenatal care and delivery services for pregnant women;
- ambulatory services to individuals under age 18 and individuals entitled to institutional services;
- home health services to individuals entitled to nursing facility services; and
- if the State Plan includes services either in institutions for mental diseases or in intermediate care facilities for the mentally retarded (ICF/MRs), it must offer comparable benefits to medically needy groups which include many, if not all, of the optional services, depending upon the State Plan.

States may also receive federal funding if they elect to provide **other** optional services. The most commonly covered optional services under the Medicaid program include:

- o clinic services;
- o nursing facility services for the under age 21;
- o intermediate care facility/mentally retarded services;
- o optometrist services and eyeglasses;
- o prescribed drugs;
- o TB-related services for TB infected persons;
- o prosthetic devices; and
- o dental services.

Figure 22: Optional Medicaid Services

Basic medical and health care services	• Prescribed drugs
	• Clinic services
	• Emergency hospital services
	• Diagnostic services
	• Screening services
	• Preventive services
	• Nurse anesthetists' services
	• Tuberculosis-related services
	• Chiropractors' services
	• Private duty nursing
	• Medical social workers' services
Services that support people with disabilities to live in their communities	• Personal care services
	• Rehabilitative and/or clinic services
	• Case management services
	• Small group homes that operate as intermediate care facilities for persons with mental retardation and developmental disabilities (ICFs/MRs) for 15 or fewer residents
Aids, Therapies and Related Professional Services	• Podiatrists' services
	• Prosthetic devices
	• Optometrists' services
	• Eyeglasses
	• Dental services
	• Dentures
	• Psychologists' services
	• Physical therapy
	• Occupational therapy
	• Respiratory care services
	• Speech, hearing, and language therapy
Services involving short- or long-term institutional stays	• Inpatient psychiatric hospital services for children and young people under age 21
	• Nursing facility services for children and young people under age 21
	• At large intermediate care facilities for persons with mental retardation and developmental disabilities (ICFs/MRs) with more than 15 residents
	• Inpatient hospital services for persons 65 years or older with mental illness in institutions for mental diseases (IMDs)
	• Nursing facility services for persons age 65 or older with mental illness in institutions for mental diseases (IMDs)
End of life care	• Hospice care services
Special treatment for children	Through the Early, Periodic, Screening, Diagnosis and Treatment (EPSDT) program requirement, states must provide children access to all Medicaid covered services (including optional services) when they are medically necessary, whether or not they cover such services for adults

Source: Navigating Medicare and Medicaid, 2005: A Resource Guide for People with Disabilities, Their Families, and Their Advocates. Advancing Independence, Bob William and Henry Claypool, with the Health Policy Institute, Georgetown University, Jeffrey S. Crowley, The Henry Kaiser Family Foundation, February 2005

Amount, Duration and Scope of Services

Within broad federal guidelines and certain limitations, states determine the amount and duration of services offered under their Medicaid programs. They may limit, for example, the number of days of hospital care or the number of physician visits covered. If they implement this kind of a policy, two restrictions apply: (1) limits must result in a sufficient level of services to reasonably achieve the purpose of the benefits; and (2) limits on benefits may not discriminate among beneficiaries based on medical diagnosis or condition.

In general, states are required to provide comparable amounts, duration, and scope of services to all categorically needy and categorically related eligible individuals. There are two important exceptions. First, medically necessary health care services that are identified under the EPSDT program for eligible children, and that are within the scope of mandatory or optional services under federal law, must be covered even if those services are not included as part of the covered services in that state's Plan. Secondly, states may request "waivers" to pay for otherwise uncovered home and community-based services (HCBS) for Medicaid-eligible persons who might otherwise be institutionalized. These opportunities are discussed in Section B of this Paper. As long as the services are cost effective, states have few limitations on the services that may be covered under these waivers. One exception is that, other than as a part of respite care, states may not provide room and board for the beneficiary.

Medically Necessary

CMS permits states to place appropriate limits on a service based on criteria which may include medical necessity. With one significant exception, there is no language in the federal Medicaid regulations that defines “medically necessary” although this term is used quite frequently through general Medicaid descriptions and text, leaving this up to states to determine. The exception involves children

under age 21 who are entitled to participate in the EPSDT Program[29] which requires Medicaid to pay for specific screening services as well as diagnostic and treatment services that are necessary to "correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services."

For many states, medical necessity is referred back to the physician's professional judgment. Some states have used the EPSDT language in crafting a definition which causes the physician to relate its decision for a service to the outcome of the service to prevent significant illness or disability, or to alleviate pain. Nebraska's provider contract language lists eight requirements including the requirement that a service or equipment be "consistent in type, frequency and duration of treatment with scientifically based guidelines of national medical, research or health coverage organizations of governmental agencies."[30]

The Tennessee Legislature authorized new legislation in 2004 that created a definition of medical necessity that requires each service or item purchased be the "least costly" alternative course of diagnosis or treatment for which there is adequate "clinical scientific evidence" of its safety and effectiveness.[31]

Information from state Part C planners indicates that any requirement for "medically necessary" documentation is often addressed by obtaining a prescription for a specific service from, preferably, the child's primary care physician. Requirements for "script" for services vary from state to state, with some requiring prescriptions for evaluations or assessments while others don't, and some requiring "script" for treatment by a specific therapist while not from another specialty area. Some states, such as Indiana, require the physician's signature on the IFSP

[29] Early Periodic Screening, Diagnostic, and Treatment services
[30] Negotiating the New Health System: A Nationwide Study of Medicaid Managed Care Contracts, Third Edition (1999), Rosenbaum, S., et al.
[31] Tennessee's New "Medically Necessary" Standard: Uncovering the Insured?, Kaiser commission on Medicaid and the Uninsured, July 2004

to respond to that state's requirement for medically necessary. [32]

Provider Qualifications

Any person or entity meeting state standards for the provision of Medicaid covered services who wishes to become a Medicaid provider of those services must be given the opportunity to do so. States have tremendous latitude, typically within the confines of their state licensure and certification standards for providers and practitioners, to define provider standards in their State Plan who are appropriate to meet the diverse needs of their general and targeted populations. State typically defer to the existing licensure and/or certification requirements established by state boards, establishing these as their minimum standard for provider enrollment, including supervision responsibilities where required for lesser qualified personnel. Some states have broad provider definitions; others are quite narrow and may not include individuals beyond licensed practitioners of the healing arts which are typically defined as physicians, physicians assistants, nurse practitioners and nurses.

Site or Location of Service Delivery

A review of the federal regulations revealed that federal Medicaid is silent in terms of stating preferences or requirements related to the site of service delivery. Certain waiver programs under Medicaid do however provide states with the opportunity to restrict or direct the location of service delivery to specific locations.

State Regulations, Policies and Procedures

Each state augments its Medicaid State Plan with a series of state generated regulations, policies and procedures that provide more detail and substance to the operations of the state's Medicaid program. While State Plan amendments are not subjected to the public hearing process, changes in state regulations typically must proceed through this process accompanied by public announcements declaring

[32] Individualized Family Service Plan

the anticipated or planned changes, the reason for change (federal or state), the potential impact upon residents, etc. The hearing process permits affected individuals to write or express their concerns or support within a specified period of time. This doesn't necessarily mean that changes will be made, but that the public comments will be considered by the state agency as decisions are made to implement the proposed changes.

Reimbursement for Medicaid Covered Services

In addition to determining the range of services within its Medicaid program, defining services and identifying and enrolling appropriately qualified providers, each state Medicaid agency is responsible for determining specifically how services will be reimbursed. Through the State Plan process, states advise CMS of the various methodologies or approaches to rate determination that are to be employed. Federal Medicaid or CMS does not approve or disapprove of a specific rate, but it does review the methodologies carefully to be sure that they meet with federal regulations prior to approving any State Plan document or amendment.

For this reason, it is important to understand how a state calculated the reimbursement rate for specific services – what were the covered costs contained within the rate, and do they match reality? Often rates were developed and never revisited, resulting in disproportionately lower reimbursement for more historical services than for newer ones. Historically, Medicaid required that transportation and scheduling assistance for an eligible recipient to and from necessary services be offered and funded. States must describe the methods that they will use to meet this requirement. With many of the changes in Medicaid (particularly over the past 15-20 years), services are being more appropriately delivered to the recipient in home and community based settings – even when funded under basic or standard Medicaid. Yet, few states have revisited their rates to consider including the cost of transportation to the provider when traveling to home and other community settings. In these days of high gas prices and the federal Part C requirements for services in the home and community settings that are typical for very young children, this can pose a tremendous barrier to the utilization of Medicaid by unduly

restricting or reducing the numbers of providers who are willing to enroll and be part of the early intervention service delivery system for Medicaid recipients in Part C.

In the past, Medicaid established no standard for how the rates will be structured, permitting each state to define the length of a "unit" as well as their reimbursement for each unit. Depending upon the specific service and how it is crafted under the state Medicaid program, "units" may range from episodic (e.g., once a year), to a monthly rate, or a fixed-time rate that may be as small as six (6) minutes. States are currently moving to national procedure codes which have defined units under HIPAA[33] administrative simplification. Once fully implemented, the entire health care industry will be using the same code sets. This change is anticipated to eliminate the great variation that occurred under local codes. Information about the Health Care Common Procedure Coding System (HCPCS or "hic-pics") can be obtained from the CMS web site.[34] See also Appendix Y for more discussion of the potential impact of code changes for Part C. New Mexico reports that they have been able to use modifiers to the HCPCS code that identify the service as an early intervention service, thus helping track and report expenditures by Medicaid for IDEA Part C services. This topic is also discussed in more depth starting on page 180 of this Paper.

In addition to the amount of reimbursement, the unit of reimbursement may also be a barrier to provider participation because it is directly related to the type and volume of documentation that a provider must maintain for each service provided. A specific plan may be required that describes the anticipated activities to be conducted, the actual delivery of these activities, and the impact or progress that the service caused to occur. Providers document their outcomes against these plans and it is this documentation that is used by each state Medicaid agency to conduct audits for utilization and surveillance. If Part C has different documentation requirements than Medicaid, providers are often required to complete multiple sets

[33] Health Insurance Portability and Accountability Act
[34] http://www.cms.hhs.gov/hipaa/hipaa2/regulations/transactions/default.asp

of documentation (including for their own agency's or practice billing and client records purposes) which can be extremely time consuming and burdensome.

Certification of Medicaid "Match" or Federal Financial Participation

Earlier in this section, the FMAP or Federal Medicaid Assistance Percentages that form the basis of Medicaid financing from the federal level were discussed. The higher the FMAP, the lower the state share or "match." While federal funds may not be used to meet the state share for Medicaid match, other funds including state general funds, state tax or locally raised funds may be used as match. Generally the state Medicaid agency is responsible for the provision of state match through the state budgeting process. Services to Part C eligible children who are also Medicaid eligible or enrolled would be the responsibility of the Medicaid agency but for the existence of Part C, and for the match for these services as well. This would be certainly true for mandated services, as well as for optional services that the state has included in its Medicaid State Plan for this and other populations. For example, if the State Plan includes the provision of physical, occupational or speech/language therapy, then it would be most appropriate for the state Medicaid agency to continue to supply the match for the Part C population.

State Part C planners should be prepared for match discussions for those functions which are not constructed in the State Plan, or that are specifically designed for Part C. Examples would include the following:

- In the determination of the rate for reimbursement for a Medicaid covered service for the Part C population, the state Medicaid and Part C planners agree to a higher rate of reimbursement to reflect what they determine are "additional" costs specific to Part C (provider transportation to home and community settings, training and supervision required for Part C providers, etc.). In this instance, the Part C agency would reasonably be expected to provide the match for those costs over and above the standard Medicaid rate.

- In the event of administrative claiming, the state Part C system generally assumes the match requirement.

- For services that are mutually agreed to and included in a State Plan amendment specifically for the Part C system, such as targeted case management or special instruction, the state Part C system generally assumes the match requirement.

For state match generated outside of the state Medicaid agency, there are a couple of ways for these funds to be secured by Part C. These arrangements are typically articulated in either the State Plan amendment (SPA) or an interagency agreement. One approach would be a specific state general fund appropriation for Part C to the state Medicaid agency or from the Part C lead agency; another option is an intergovernmental transfer from Part C to the state Medicaid agency of state funds for match purposes. In the case of the later example, these funds could be billed to Part C on a monthly or quarterly basis based upon the total amount of invoices paid.

State Part C lead agencies may establish methods for Medicaid match "certification," which means that they assure to the state Medicaid agency that the needed amount of state or other non-federal funds are guaranteed at either the state or local level for specific functions that meet the match requirements. In the situation of administrative claiming, for example, sufficient state or non-federal funds must be identified in the Part C budget at either the state or local level against salaries and other expenses that will billed to Medicaid based upon the proportion of Medicaid enrolled children in the Part C system. The state Part C agency or local entity assures or "certifies" the match; no money for this purpose changes hands and the state Part C agency receives only the federal share of the reimbursement once they bill the state Medicaid agency for services provided.

Certification of match is very common for states with school-based health services for special education, which is one option under EPSDT. In this example, state general education funds or locally raised tax revenue is used to certify the state

match requirement. The local school district invoices for the services provided and receives the federal share.

If the Part C system at any level certifies match for direct services, providers will receive the federal share of the payment when they bill for delivered services. Part C planners will need to figure out how the state share is apportioned. One approach used by at least one state is through the use of local match using locally raised tax revenues through the certification process. Other states pay the difference separately to providers; still others are billed and pay Medicaid on a routine basis for the match needed to ensure that providers receive the full reimbursement.

Another potentially viable option for some states which may streamline the reimbursement and "match" tracking process is for Part C planners to consider contracting with the Medicaid fiscal agent to process and pay claims.

Third Party Liability

Medicaid requires that individuals with private health insurance coverage use this form of coverage first to pay for Medicaid covered services, and then steps in to pay what isn't covered by the third party resource. The Medicaid recipient's consent for these charges in contained in the Medicaid application itself.

Some state Medicaid agencies employ a "pay and chase" system which reimburses the provider according to state Medicaid rates and then "chases" the third party resource for reimbursement. Others require the providers to bill third party liability first and, if denied or partial payment for a covered service is received that is less than the Medicaid rate, they may submit these costs to the state Medicaid agency for reimbursement.

There are few situations in which third party liability may be bypassed by a state. Federal regulations permit states to waive the required use of cost avoidance (e.g., using third party resources) if the costs to the state to seek and collect the third party funds would exceed the amount to be recovered. Some states, with partnerships

between the state Medicaid agency and education department for the provision of school-based Medicaid covered services for students have been able to forgo third party collections for Medicaid covered services due to the federal education requirement for "FAPE"[35] where services are provided at no cost to the family.

For early intervention services, it is common for the Part C lead agency to offer to pay the deductible and co-payments for families if they meet the state's "inability to pay" criteria, in order to access private insurance for IFSP services. States with a number of dually covered Part C enrolled children need to carefully monitor how the private insurance for these families is being accessed, since these costs may result in violating the "inability" to pay standard, or loss of coverage for the child and/or family.

A potential key partner to state Part C systems is their Maternal and Child Health CSHCN Program – children with special health care needs, serving children from birth to age 19 or 21 who meet the individual state criteria. While CSHCN isn't a focus of this Paper, it is important to note the reciprocity between CSHCN and Medicaid as it affects Part C children and their families. CSHCN provides care coordination (service coordination) and often funds specialty medical services that are not funded by Medicaid, and that may quality as IFSP services for the purposes of Part C enrolled children and families. CSHCN is required to utilize Medicaid as a payor of first resort after private insurance before expending any MCH block grant or state matching funds. Depending upon a state's criteria for CSHCN, children may be multiply enrolled – covered by private insurance, Medicaid, CHSCN and Part C – each with their own area of expertise and service that come together to create coordinated and comprehensive care.

State CSHCN programs are refocusing their efforts away from the provision of direct services to more infrastructure development and support, very similar to the goals and responsibilities of the state Part C systems. MCH has funded a series of competitive grants under the Early Childhood Comprehensive Systems (ECCS)

[35] Free Appropriate Public Education

initiative which focuses on key systemic or infrastructure areas also of importance to Part C, such as early referral, medical home, infant mental health, etc. CHSCN is often an intermediary source of public support for families who may not qualify for Medicaid but whose child has special health care considerations.

Quality Assurance/Surveillance, Utilization and Review

In addition to extensive data reporting by each state's Medicaid agency to CMS at the federal level, CMS also conducts routine on-site state audits to determine if the program is being operated in a cost-efficient manner and if the funds were properly expended for the purposes for which they were appropriated.

Further, individual states are required to implement rigorous monitoring systems for all Medicaid covered services irrespective of what kind of Medicaid program they are. This monitoring is accomplished through a combination of efforts – data review, complaint investigation, on-site records reviews, financial audits, and compliance reviews. State Medicaid agencies must ensure that providers are appropriately licensed and maintain their liability insurance and conduct background checks periodically. They check records to ensure that delivered services matched those anticipated in the plan of care; they verify through provider documentation review that services were delivered as billed to Medicaid. They read through documentation to ensure that the delivered service meets the Medicaid definition, and verify the time billed against this documentation. Providers with missing or inadequate documentation are subject to a recovery which means that the state Medicaid agency "recoups" the funds paid to the provider for those services.

Depending upon the type of provider, Medicaid also may conduct a facilities audit to ensure that the provider meets various state and program licensure requirements.

Provider reviews are typically performed at least annually, although complaints or review of data that suggests over-utilization may prompt an interperiodic audit. Each state Medicaid agency submits an extensive plan with CMS that outlines their review and sampling plan and procedures. Data on these reviews and audits are routinely reported to CMS with the implication for "settlement" between the state

agency and CMS for the federal share of those funds that were received back as a result of recoupment.

A provider's failure to meet review criteria can result in dis-enrollment from the Medicaid program, and further litigation based upon individual circumstances; some Medicaid agencies have reciprocity with their state licensure boards and are required to report these providers for possible action by their respective licensure board.

Some state Part C systems have created unique partnerships with their state Medicaid agencies by sharing the responsibilities that each program has in terms of monitoring and surveillance.

Complaint Resolution Procedures

State Medicaid agencies, just like Part C lead agencies, are required to have comprehensive systems in place to respond to consumer complaints in a timely manner. Complaints may be filed if a child is determined to be ineligible, a service payment is denied, or there are problems with the provider.

SECTION A: REFLECTIONS

Section A of this Paper provides the reader with an overarching understanding of the basic or standard Medicaid program and its many requirements. There is a considerable amount of commonality between Medicaid and Part C when one considers the required components highlighted on page 35 of this Section (and further elaborated on pages 108-110 of Section B) and how both Medicaid and Part C must incorporate these components into their administrative and operational systems. This "Reflections" portion of Section A is intended to serve as a guided "self-study" assisting the reader to identify certain key operational facts about his/her own state's Medicaid Program.

Key resources to investigation of each state's Medicaid program may be found through the CMS website[36] which displays not only federal Medicaid information (programs, regulations, etc.) but also provides the option for the reader to search and read about an individual state's Medicaid program as well. Due to the length of time that Medicaid has been in operation, not all documents have been converted to electronic files. CMS has made an effort, however, to post all State Plan Amendments and key State Plan sections that reflect recent state submissions.

There is a wealth of data available through the Kaiser Commission on Medicaid and the Uninsured.[37] Click on an individual state and obtain information that leads to the state-specific web site, provides contact information and much more for the 50 states and Guam, Puerto Rico and the Virgin Islands. There is also a section on this website offering 50-state comparison data that the reader may find interesting and useful.

Accessing the individual state's Medicaid lead agency website will provide an overview of many programs, including Medicaid, with contact information. Many

[36] http://www.cms.hhs.gov/medicaid/resources.asp
[37] http://www.statehealthfacts.kff.org/cgi-bin/healthfacts.cgi?action=profile

states agencies post an organizational chart on their website so that the reader can get an idea of the infrastructure of the agency.

Other relevant and potentially valuable important websites are found in Appendix G to this Paper. After taking some time to review the information contained in this Section as well as any website investigation, collect the resources together and attempt to answer the following important questions!

1. What is the name of your Part C system/program?

Name: _____

2. What is the name of your state's Medicaid program?

Name: _____

3. What is the name, if different, of your state's SCHIP program?

Name: _____

4. What is the name of your state's CSHCN program?

Name: _____

5. What is your state's lead agency for the State Medicaid Program:

Name: _____

6. Agency location and key contact people (name, title, telephone and e-mail):

Title	Name	Contact Information
Part C lead agency Medicaid liaison		
Medicaid Director		
EPSDT Coordinator		
Governor's Ombudsman for HealthCare		
Director, children and/or family services bureau		
Other key people		

Other key people		
Other key people		

7. Medicaid Agency organization chart, particularly if located in same agency as Part C.

8. What is your state's eligibility for Medicaid for children, Birth-1?

9. What is your state's eligibility for Medicaid for children, 1-5?

10. Are there special enrollment criteria for newborns?

11. Does your state practice presumptive enrollment?

12. Are there outstationed Medicaid enrollment personnel in your state? If so, who are these individuals and how are they linked to Part C?

SECTION B. MEDICAID OPPORTUNITIES AVAILABLE TO PART C SYSTEMS

This Section of the Technical Assistance Paper responds to ITCA's requirement in the Scope of Work to:

- Evaluate the allowances and features of each Medicaid reimbursement mechanism available to states,
- Provide considerations for Part C planners, and
- Highlight or feature successful state experiences in maximizing the use of Medicaid to reimburse costs for early intervention.

SECTION OVERVIEW

The variety of options available to states under the Title XIX, Medicaid federal regulations related to financing for Part C are delineated within relevant Part C system components, including but not limited to direct services to families and eligible children. Specific detail is provided from the federal regulations and examples of Part C utilization are presented. This Section also includes a discussion of the considerations related to each method of reimbursement related to Part C, early intervention services and state-specific successes and challenges in implementation.

The reader is cautioned that the history, political will, demographics dynamics and economy of each state influences the organization and design that each state's Medicaid Program has taken. In Section A, the reader was provided with an opportunity to investigate and document what is happening "now" for each state related to the standard Medicaid program. Understanding the history of how things came to be can be a powerful guide to understanding the potential for change. Because the Medicaid program is crafted by each state to address its own needs, individual state Medicaid "programs" vary substantially.

To the extent possible, this Section discusses specific Part C examples to include challenges that states are currently facing in accessing Medicaid for Part C system support and services for early intervention services. Resources include state web sites, document files available through the ITCA, etc., which serve to augment this Section for the reader.

Part C services are relatively "new" to the states, having been in place since P.L. 99-457 was passed in 1986 with full implementation required by 1991. Most states developed individual Medicaid options and programs for a variety of other populations based upon specific state needs. Within the past 15 years, many have developed initiatives addressing the needs of very young children with disabilities or developmental delays. State Part C planners will benefit considerably from understanding what is currently happening in their state with respect to other populations of individuals with disabilities, as it is highly likely that this will guide the Part C dialogue and decision–making. It is always helpful to locate a historian(s) who can help the Part C planners to understand why decisions were made the way that they were – who and what was of key influence at the time? In one state, the development of a comprehensive family support waiver was precipitated by a class action suit; in another, it was the result of a highly motivated state official. Understanding the history "behind the scenes" helps state Part C planners to organize their proposals to the state Medicaid agency with an increased likelihood of a positive reception.

These "history" lessons can help Part C planners to better understand what may be perceived as barriers by the state Medicaid agency. In one state, the state Medicaid director was adamant against enrolling individual practicing specialists. Over lunch, the Part C planner was able to learn that – "years back" – the state had enrolled a large number of a variety of private practitioners only to have a significant Medicaid audit finding which resulted in a fairly substantial "recovery" or payback to the federal government. Consequently, the state Medicaid agency was totally opposed to entertaining any similar proposals. The two individuals were able to discuss what went wrong and the overall impact from the audit findings. They figured out – together – how to implement policies and procedures that would

allow provider expansion for Part C while still meeting the state Medicaid agency's concerns related to documentation and training that the agency believed were critical to reducing the opportunity for future audit problems.

States often become involved in discussions of this kind when exploring Medicaid funding for service coordination for Part C enrolled children and families. Supported and, in some cases, required by CMS in order to access Medicaid funds, many states have moved to external, independent "case management" systems that are separate from the provision of direct service for other populations. One historical perspective that led to this separation was the CMS's opinion that combining the delivery of case management/service coordination with direct services (either by the same or two different people) failed to protect the recipient if problems in direct service arose. Issues of conflict of interest including fiduciary conflict were cited as a key barrier to the practice of "blended" roles including service coordination/care coordination/case management. Their information was derived from several state audits which had raised issues related to the integrity of service coordination or case management functions especially related to the provision of appropriate levels of services.

By way of these examples, the unique characteristics of each state are demonstrated in terms of its history and approach to accessing federal funds. Part C planners have a responsibility to ensure that the Part C system is not only compliant with federal regulations, but also that it is responsive and reflective of the state's philosophy and values in serving families with very young children. There are federal and state funds, including Medicaid, where the individual access and utilization may compromise the Part C system to the point that it no longer is either federally compliant or, that it "lives" its principles and values. A state's decision about its Part C service coordination model is an excellent example of this point. As the individual Medicaid options are discussed in this Section, there is a discussion which explores a variety of considerations pertinent to state Part C planners that reflect the integration of Part C and Medicaid requirements. These considerations are an important part of the overall planning and negotiation process.

As state Part C planners investigate either accessing Medicaid or realigning the manner in which they currently access these funds to support Part C systems, it is vital to have clarity and agreement about the mission, vision and priorities related to practice. There are a number of funding resources including Medicaid that may not be compatible with a state's philosophy or practice of early intervention. In these kinds of situations, Part C planners must decide if the changes required to accessing a fund source are consistent with the state's values and tenets for early intervention. Service coordination is one excellent example of a potential conflict. There are a variety of Part C service coordination models successfully practiced throughout the states and territories. State Part C planners should determine first which model **or** models best fit the state's philosophy and practice outcomes, and then investigate funding sources that will support this model(s).

Section A discussed the standard Medicaid program in which all states and Territories currently participate. This Section of the Paper reviews the variety of options available under the standard Medicaid program. States may develop state plan amendments which meet the specific needs of their state population. These options are organized as follows:

- Early Periodic Screening, Diagnostic and Treatment (EPSDT)
  - Including School-based Health Services
- Administrative Claiming
- Federal Medicaid Waivers
  - Freedom of Choice Waivers (1915a)
  - Home and Community Based Waivers (1915b)
  - Demonstration Waivers (1115b)
  - Managed Care Programs
  - Targeted Case Management
  - Rehabilitation Services
  - TEFRA (Tax Equity and Fiscal Responsibility Act of 1982) a.k.a. the Katie Beckett Option
- Partnerships through Interagency Agreements
  - SSI
  - SCHIP
  - State Vocational Rehabilitative Agency
  - Title V/Maternal and Child Health
- Enrollment of Beneficiaries in Group Health Plans

Several states currently access Medicaid for covered "therapy" services as defined by Part C through standard Medicaid. Providers for Part C meet the state licensure requirements and typically will bill Medicaid directly for their services. Under these circumstances, the state lead agency for Part C often has no information as to how much Medicaid revenue is generated for these services, even if Medicaid is billed for eligible and enrolled children. This type of situation is more common in Part C systems that are more locally managed versus more centrally administered systems.

DEVELOPMENTAL VS. MEDICAL OR HEALTH SERVICE

Many state Part C planners continue to express concerns and barriers to accessing Medicaid to support early intervention services due to the appearance of "conflict" between the developmental approach of Part C and the medical approach of the Medicaid program. Return to the original legislated purpose of this expansive federal initiative as discussed in Section A of this Paper before considering individual initiatives under Title XIX, Medicaid:

> *For the purpose of enabling each State, as far as practicable under the conditions in such State, to furnish (1) medical assistance on behalf of families with dependent children* ***and of*** *aged, blind, or disabled individuals, whose income and resources are insufficient to meet the costs of necessary medical services,* ***and*** *(2) rehabilitation and other services to help such families and individuals* ***attain or retain*** *capability for independence or self-care, there is hereby authorized to be appropriated for each fiscal year a sum sufficient to carry out the purposes of this title. These sums made available under this section shall be used for making payments to states which have submitted, and had approved by the Secretary, State plans for medical assistance.*[38]

Medicaid is an entitlement program to ensure preventive and necessary health care for families with young children and those who are aged, blind or disabled. While the primary focus of this program has been upon low-income individuals, several other options exist for coverage based upon certain characteristics and not income. Medicaid includes not only medical assistance, but habilitation **and**

[38] Emphasis by author

rehabilitative services designed to attain **or** retain the individual's capacity for independence and self-care. Services under Medicaid are not limited to the restoration of ability, but also include the cultivation or development of ability. While the standard Medicaid program in any state may be limiting in terms of population, scope and coverage, the variety of options available under federal Medicaid regulations provides opportunities for a state to individually craft initiatives that conform to the unique needs of its residents. As the examples provided throughout this Paper will attest, states have approached Medicaid financing in a variety of creative ways that have helped to not only support early intervention services financially, but that have strengthened the Part C system in terms of infrastructure and quality care to very young children and their families.

Part C legislation sets forth clear requirements for the inclusion of federal funds in the "system of payments" that each state is required to develop and implement. This is reflected in the most recent reauthorization under P.L. 108.466 (Sec. 631. Findings and Policy) as follows:

> *"(b) Policy.--It is therefore the policy of the United States to provide financial assistance to States--*
> *(1) to develop and implement a statewide, comprehensive, coordinated, multidisciplinary, interagency system that provides early intervention services for infants and toddlers with disabilities and their families;*
> *(2) to facilitate the coordination of payment for early intervention services from Federal, State, local, and private sources (including public and private insurance coverage);*
> *(3) to enhance their capacity to provide quality early intervention services and expand and improve existing early intervention services being provided to infants and toddlers with disabilities and their families; and*
> *(4) to encourage States to expand opportunities for children under 3 years of age who would be at risk of having substantial developmental delay if they did not receive early intervention services.*

State Part C systems are required to coordinate a variety of federal, state and local resources, including family resources, depending upon the specific state policies, in the provision of a variety of needed services to the eligible child and family. Part C was the first federal legislation to establish the "payor of last resort" requirement as set forth in the current Part C regulations, as follows: (emphasis by author)

Sec. 303.126 Payor of last resort.

The statement must include an assurance satisfactory to the Secretary that the State will comply with the provisions in Sec. 303.527, including the requirements on--

(a) Nonsubstitution of funds; and

(b) Non-reduction of other benefits.

(Approved by the Office of Management and Budget under control number 1820-0550)(Authority: 20 U.S.C. 1437(b)(2))

Sec. 303.527 Payor of last resort.

(a) Nonsubstitution of funds. Except as provided in paragraph (b)(1) of this section, funds under this part may not be used to satisfy a financial commitment for services that would otherwise have been paid for from another public or private source, including any medical program administered by the Secretary of Defense, but for the enactment of part C of the Act. ***Therefore, funds under this part may be used only for early intervention services that an eligible child needs but is not currently entitled to under any other Federal, State, local, or private source.***

(b) Interim payments--reimbursement. (1) If necessary to prevent a delay in the timely provision of services to an eligible child or the child's family, funds under this part may be used to pay the provider of services, pending reimbursement from the agency or entity that has ultimate responsibility for the payment.

(2) Payments under paragraph (b)(1) of this section may be made

for--

(i) Early intervention services, as described in Sec. 303.12;

(ii) Eligible health services (see Sec. 303.13); and

(iii) Other functions and services authorized under this part, including child find and evaluation and assessment.

(3) The provisions of paragraph (b)(1) of this section do not apply to medical services or ``well-baby'' health care (see Sec. 303.13(c)(1)).

(c) Non-reduction of benefits. Nothing in this part may be construed to permit a State to reduce medical or other assistance available or to alter eligibility under title V of the Social Security Act (SSA) (relating to maternal and child health) or title XIX of the SSA (relating to Medicaid for children eligible under this part) within the State.

(Approved by the Office of Management and Budget under control number 1820-0550)(Authority: 20 U.S.C. 1440)

Notes to this regulatory section confirm the intention of the Congress that the existence of Part C was not a “license” to any state agency to withdraw or reduce funding for services that currently are or would be made available to eligible

children but for the existence of the Part C system. Congress intended that other funding sources would continue, and that there would be greater coordination among agencies regarding the payment of cost through the efforts of the Part C system in building coordinated, community based, comprehensive, statewide systems of care.

Congress further clarified its intent[39] concerning financing for Part C through Medicaid by including in §411(k)(13) of the Medicare Catastrophic Coverage Act of 1988, (P.L. 100-360) an amendment to Title XIX of the Social Security Act. This amendment states, in effect, that nothing in this title shall be construed as prohibiting or restricting, or authorizing the Secretary of Health and Human Services to prohibit or restrict, payment under subsection (a) of §1903 of the Social Security Act for medical assistance for covered services furnished to an infant or toddler with a disability because those services are included in the child's IFSP adopted pursuant to Part C of the Act. There exists now regulatory reciprocity between the variety of federally sponsored programs including Medicaid, Maternal and Child Health, TriCare (formerly Champus), etc., to ensure the availability and utilization of these resources for eligible children participating in the states' Part C systems.

This amendment also clarified several other items that had been identified as barriers to states in accessing Medicaid benefits for children with disabilities. P.L. 100-360 made it clear that services in an IFSP or IEP[40] could be funded under Medicaid for a covered child despite the fact that at least IEP services must be provided "free" or "at no cost" to the child. Medicaid does not reimburse for "free" services such as would ordinarily be provided by a school health center to the general population (e.g., vision screening), but has made an exception for children with disabilities enrolled in state programs through the IDEA.

Within broad federal guidelines, states determine the amount and duration of services offered under their Medicaid programs. The amount, duration, and scope

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[39] 58 FR 40959, July 30, 1993, as amended at 63 FR 18296, Apr. 14, 1998

[40] Individualized Family Service Plan or Individualized Education Program under the Individuals with Disabilities Education Act, IDEA

of each service must be sufficient to reasonably achieve its purpose. States may place appropriate limits on a Medicaid service based on such criteria as medical necessity or utilization control. For example, states may place a reasonable limit on the number of covered physician visits or may require prior authorization to be obtained prior to service delivery. In addition, states may create "prior authorization" requirements which may be centralized, regionalized, or assigned to the child's primary care physician for determination. In several states, the Medicaid agency has recognized the IFSP or IEP team as the appropriate vehicle for making service frequency and intensity decisions, and relies on the IFSP or IEP document as the method for documenting "prior authorization" and medical necessity. In some instances, state Medicaid regulations require a physician's signature on these documents.

Many of the specifics of these requirements, and others, were later expounded in legislation commonly referred to as "OBRA'89" governing Medicaid coverage for children ages 0-21[41]. Due to its impact upon the potential relationship between Part C and Medicaid, the next section of the Paper starts with a discussion of the EPSDT program[42] which, under OBRA'89, helps to articulate and clarify many of the issues that Part C Coordinators have raised as barriers to collaboration and access to Medicaid funds.

EARLY PERIODIC SCREENING, DIAGNOSIS AND TREATMENT – EPSDT

What Is EPSDT?

The Omnibus Budget Reconciliation Act of 1989 (OBRA'89) significantly strengthened and clarified Medicaid's existing mandatory EPSDT benefit for children. EPSDT is a separate program under the standard Medicaid program which targets children who are enrolled in Medicaid, ages 0-18 and, in some states, up to age 21. Regardless of "how" a child becomes eligible for Medicaid, all eligible children are

[41] Individual states have elected to include children up to age 18, 19, 20 or 21.
[42] Early Periodic Screening, Diagnostic and Treatment

entitled to participate in the state's EPSDT program. There can be no difference, once enrolled in EPSDT, in the kinds of service that an individual child receives based upon other Medicaid program eligibility. Under EPSDT, all pre-existing conditions must be fully treated.

State EPSDT programs are known by very different names throughout the country, as is the case for Part C. Sometimes the name is "coupled" to include the state Medicaid program and/or SCHIP. Services covered under EPSDT are displayed in Figure 24 (page 94); those services not covered are summarized in Figure 25 (page 95).

Federal law and regulations require states and territories to provide Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services to Medicaid eligible children under the age of 21 as part of their Medicaid program. The purpose of EPSDT is to identify "physical and mental defects" and to provide treatment to "correct or ameliorate any defects or chronic conditions found." States/territories are required by federal Medicaid to inform children and their families of the availability of EPSDT services, their benefits, and where and how to obtain them. They are also to provide transportation and scheduling assistance if requested, to assure that the children receive necessary services. It is important for state Part C planners to understand that families elect whether or not they will have their child participate in EPSDT; each state is required to fully explain the benefits to families of this exceptional program in order to encourage full state participation.

To this end, most states have established partnerships with early childhood programs and services in an effort to increase outreach and visibility of the EPSDT program. As discussed in Section A of this Paper, several states have implemented initiatives focused on "outstationing" enrollment efforts including partnerships with Early Head Start, Head Start, child care and early intervention programs which are in constant contact with families of very young children. The passage and requirements of the SCHIP program helped to spur states on to creating more universal methods for individuals to access Medicaid. While individuals in these programs are not able to determine the child's actual eligibility, they are able to explain the Medicaid

program, assist with applications and are the responsible for processing those applications with the state Medicaid agency who determines eligibility.

"Screening" means a periodic comprehensive child health assessment which includes regularly scheduled examinations and evaluations of the general physical and mental health, growth, development, and nutritional status of infants, children and youth. These screenings are to include a physical examination, vision and hearing testing, age appropriate immunizations, any necessary diagnostic laboratory tests, and a dental examination beginning at least at age 3.

"Diagnosis and Treatment" means further assessment of any conditions noted during a screening and the provision of any medically necessary treatment services, irrespective of their inclusion in the state plan as a routinely covered service.

States and territories provide EPSDT services in various ways. Some rely on local health departments to perform screenings and to make referrals to appropriate health care professionals for diagnosis and treatment. Others rely on physicians, dentists and other health care practitioners to perform the screenings during well child exams and to diagnose and treat any problems identified. Federal law and regulations are not specific as to the provider(s) that should render EPSDT services, only that the services must be rendered.

States and territories are prevented, by federal law, from requiring a copayment for any EPSDT service for a child under age 18. They do have the option to impose copayment for medically needy beneficiaries between age 18 and 21. When a provider “signs up” as a Medicaid EPSDT provider, they commit to accepting the Medicaid reimbursement as “payment in full” and cannot charge families any additional amount for the service(s) that they provide.

The following section reviews the four (4) key changes in the national EPSDT program as a result of OBRA’89.

Increase in EPSDT Enrollment

The EPSDT requirements in OBRA'89 were passed primarily to promote increased informing and participation by families with young children in the EPSDT program of Medicaid. Too many children were not receiving the benefits of early screening, problem identification and treatment. OBRA'89 established a goal for participation in EPSDT to be 80% in each state, to be accomplished by the federal fiscal year 1995. As of 1998, participation rates for EPSDT were less than 50% in 25 states; seven of these states demonstrated participation at less than 25%.[43] States continue to cite problems in provider reporting and in data collection across multiple Medicaid programs resulting in low numbers; many believe that their served population is higher but that providers aren't reporting this information or it is being captured in a manner that isn't reflected in the overall reporting.

Expansion and Clarification of EPSDT Screenings

Secondly, OBRA'89 established the requirement for routine and interperiodic screenings under EPSDT, and required that any federally allowable diagnostic or treatment service identified through a screening would be provided for the child regardless of whether the state includes the service in its Medicaid state plan. (Refer to the listing in Figure 22, page 59 in Section A, for this comprehensive listing.) Most states use the periodicity schedule as established by the American Academy of Pediatrics (Appendix L) to guide their EPSDT services. The screening content was clarified to include the following:

- Comprehensive Health and Developmental History to include physical and mental health
- Developmental Assessment
    - Gross motor
    - Fine motor
    - Communication skills or language development
    - Self-help and self-care skills
    - Cognitive skills
- Assessment of Nutritional Status

[43] HCFA letter to Associate Regional Administrators, January 19, 2001 re: Assuring Access to Care for Medicaid Children, Timothy M. Westmoreland.

- Complete physical examination
- Medical laboratory tests for lead screening, iron deficiency, cholesterol

EPSDT requires that providers question parents or guardians about dietary practices to identify unusual eating habits or poor diets. EPSDT requires dietary counseling and nutrition education, and suggests referrals to Women, Infants and Children program to address these needs.

The EPSDT requirement for the Comprehensive Unclothed Physical Examination also includes:

- Immunizations
- Appropriate Laboratory Tests
- Health education
- Vision and Hearing Screens
- Dental Screening Services

EPSDT requires that health education, guidance and counseling be given to parents or guardians and children at every visit. This is important because parents and guardians can better understand what to expect in terms of their child's development when provided with appropriate, timely and meaningful information. Further, EPSDT facilitates referrals to other social service agencies, such as family planning clinics, vocational rehabilitation, and Head Start. These two requirements alone are areas of common agreement and legislative responsibility between a state's Part C system and Medicaid program.

Under EPSDT, services or items that are not "medical" in nature are excluded; services that are considered unsafe or experimental are excluded. Treatment services may require pre-authorization. Services may be provided in the most economic way possible so that if services are less costly in an institution, then a state may restrict services to that setting. In other words, while OBRA'89 expanded the EPSDT program to include considerably more services, states still retain the ability to establish reasonable administrative and cost control policies that Part C planners need to understand for their own state's purposes.

"Unbundling" the Screening Opportunities

Thirdly, OBRA'89 "unbundled" the screenings that a child would receive so that a variety of individuals can perform any part of the screening required and be reimbursed for it, according to individual state requirements for reporting and documentation. These individuals would include, but not be limited to: physicians, local health departments, school health programs, early intervention programs, Head Start, Maternal and Child Health programs, community centers, etc., as well as any other licensed practitioner such as an Occupational or Physical Therapist, or a Speech Language Pathologist. A few states have established specific screening protocols and some may have specific required instrumentation, but this is not the "norm."

"Unbundling" the screenings for Medicaid covered children has the effect of reducing the duplication inherent in the lives of many young children and their families as they participate in the variety of early childhood and health care initiatives typically offered to low-income families. It means that the developmental screening conducted by the Head Start program or an other early childhood program such as Part C would "count" for the purposes of the periodic screening requirement, and that early childhood program or provider (if a recognized provider of EPSDT services by the state) would be compensated for this service. Information flows to the child's physician so that the outcome of this service would be known, reducing the need for the physician to perform the screening a second time.

A Positive Finding on a Screening "Triggers" Needed Service

Once a child is seen by a provider and a screening identifies a problem, a diagnosis is made and an appropriate service can be provided. Any problem identified by a screen under EPSDT must be treated and covered by EPSDT, even if it isn't a covered service by the individual state. States, by law, must cover "necessary health care, diagnostic services, treatment and other measures ...to correct or ameliorate defects and physical and mental illnesses and conditions."[44] When

[44] 42 UCS §1396(r)(5)

combined, the changes to the definition of screening and the obligation of states to provide needed services, many more "nontraditional" services became covered throughout the country under EPSDT and, therefore, are considered as medical services for the purposes of Medicaid funding.

The Medical Home

As clarified in EPSDT through OBRA'89, states must implement procedures that ensure that services are not necessarily duplicated and that children receive the complete screening components in accordance with the prescribed periodicity schedule (Appendix L). While not directly connected to EPSDT, the emergence of the "medical home" projects nationally offers substantial assistance to ensuring that important services for children are coordinated through the child's primary health care provider. A medical home is not a building, house, or hospital, but rather an approach to providing comprehensive primary care. A medical home is defined by the American Academy of Pediatrics (AAP) as "primary care that is accessible, continuous, comprehensive, family centered, coordinated, compassionate, and culturally effective."[45]

In the medical home model, a pediatric practitioner works in partnership with the family to assure that all of the medical and non-medical needs of the child's are met. Through this partnership, the pediatric practitioner can help the family access and coordinate specialty care, educational services, out-of-home care, family support, and other public and private community services that are important to the overall health of the child and family.

The AAP has developed a Policy Statement[46] on the medical home which is important reading for Part C planners. The medical home, whose focus is primarily for children with special needs, works together with the family to ensure that the medical, health, social service and early intervention efforts are coordinated. The

[45] American Academy of Pediatrics: http://www.medicalhomeinfo.org/
[46] *http://aappolicy.aappublications.org/cgi/content/full/pediatrics;110/1/184*

AAP has published a paper[47] on developing medical homes in local communities that would be of interest to Part C planners.

Iowa's Part C system has provided funding through their CSPD[48] system to support the state-wide training initiative focused on physicians and pediatricians for three years.

Bright Futures[49] is a national health promotion initiative dedicated to the principle that every child deserves to be healthy and that optimal health involves a trusting relationship between the health professional, the child, the family, and the community as partners in health practice. Sponsored by the federal Maternal and Child Health Bureau (MCHB), Bright Futures at Georgetown University has been awarded a three-year grant to develop a comprehensive curriculum for training Title V, Medicaid/EPSDT, and other health professionals who provide primary preventive care to infants, children, and adolescents.

[47] http://pediatrics.aappublications.org/cgi/reprint/113/5/S1/1499
[48] CSPD: Comprehensive System of Personnel Development
[49] http://www.brightfutures.org/

Application of EPSDT Opportunities to Part C

As discussed earlier, EPSDT requires states to provide services identified as a result of an EPSDT screening to enrolled children whether or not the service is covered under that state's Medicaid plan. If there is no formal, organized approach by which to access these services, a myriad of issues for states are raised by this screening which "triggers" services that are directly related to some of the basic Medicaid principles and foundations. Questions are raised: just what is the service (e.g., definition of the service), who can provide the service (e.g., qualified provider), how much should the provider be paid (reasonable reimbursement), etc.

Definition of Developmental Screening and Assessment Under EPSDT

"Screening for developmental assessment is a part of every routine initial and periodic examination. Developmental assessment is also carried out by professionals to whom children are referred for structured tests and instruments after potential problems have been identified by the screening process ... In younger children, assess at least the following elements:

- Gross motor development, focusing on strength, balance, locomotion;
- Fine motor development, focusing on eye-hand coordination;
- Communication skills or language development, focusing on expression, comprehension and speech articulation;
- Self-help and self-care skills;
- Social-emotional development, focusing on the ability to engage in social interaction with other children, adolescents, parents, and other adults; and
- Cognitive skills, focusing on problem, solving or reasoning."

CMS State Medicaid Manual, Part 5, EPSDT Section 5123.2

EPSDT offers substantial opportunities to Part C planners. While it minimally allows for the provision of services identified as a result of a screening and confirmation through diagnostic procedures, some states have used the EPSDT option to develop and implement specific Part C initiatives.

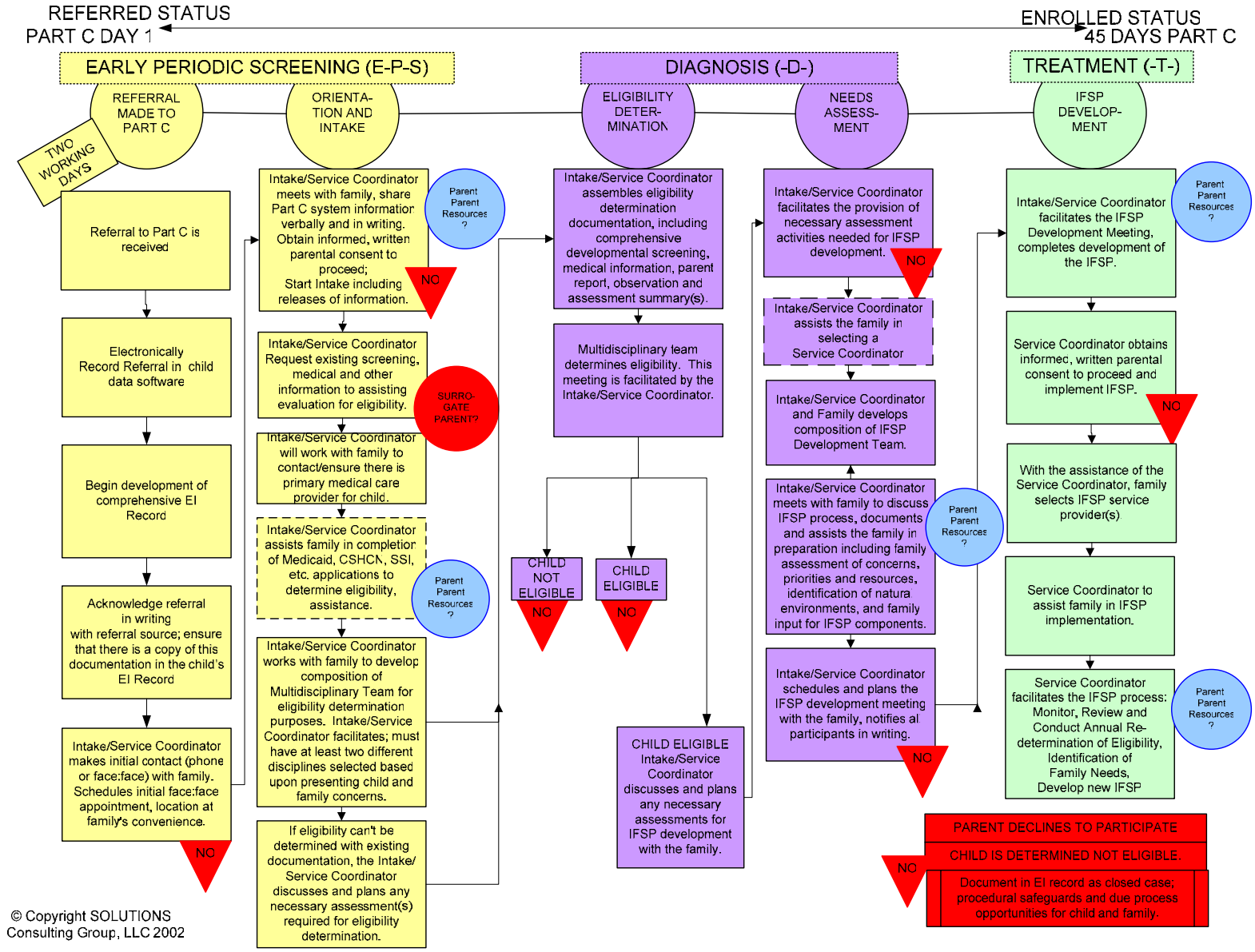
The opportunities that are afforded to states under OBRA'89 mean that the full range of Part C activities and services may be covered through EPSDT for eligible children. The same is true for Part B, or special education services to children 3-21 under the IDEA.

To illustrate these connections, Figure 23 on page 92 of this Paper provides a visual picture of the "steps" within the early intervention process with designation of the specific EPSDT component. In this Figure, states may also include Service Coordination under EPSDT as a required administrative function. States may also

develop these Service Coordination functions covered under a Targeted Case Management service option (discussed on page 123 of this Paper) while the specific services of the early intervention providers in screening, the evaluation for eligibility, assessment for IFSP planning and the IFSP team activities starting with IFSP development through to transition would be covered through any number of Medicaid options including EPSDT. This may be accomplished by creating a new service category called "early intervention services."

Another option for some states has been to utilize the covered services as defined under EPSDT, particularly therapy services, to access services and payment for Part C enrolled children. Providers must meet the Medicaid provider qualifications, which typically are the state licensure standards, and they are reimbursed at the Medicaid rate. Providers complain that the reimbursement is lower, if not significantly lower, than the Part C reimbursement. Paperwork may be duplicative or far more extensive and time consuming, for which there is no compensation by Medicaid. These barriers plus the concern over audit findings often prevent providers from appropriately utilizing this resource. As with the standard Medicaid program, when Part C systems access services in this manner, they often report that they have little if any data to advise them how many children are accessing Medicaid, what the average revenue is, or if all providers are using this fund source for dually enrolled children. The state's failure to "link" the two systems could result in double billing or inappropriate levels of services for recipients if receiving services through both systems simultaneously.

Figure 23: EPSDT and the Part C Process



Further, the lack of oversight by Part C for the IFSP process and consequent services, including ensuring appropriately trained and qualified providers, may be problematic if a state is lacking formal "linkages" with Medicaid that incorporate recognition of the federal Part C requirements. Medicaid practices or requirements inappropriate to Part C (e.g., site of service, service limitations, requirements for prior authorization, limited provider qualifications, etc.) can mean that the Part C lead agency has little ability to exercise its regulatory responsibilities over the early intervention system.

Most states utilize more than one method of accessing Medicaid for Part C services. Often these systems lack checks and balances to be sure that services are properly billed; multiple programs can be difficult to track. For the provider, having more than one set of "rules" to follow is sometimes problematic and can lead to inconsistent practices and consequent compliance findings. Several state Part C Coordinators cited problems with ensuring Part C requirements (e.g., timelines, services in home and community settings, etc.) when formal relationships between the state Medicaid and Part C system have not been established.

In addition to supporting the outreach and engagement activities for EPSDT, the state Medicaid agency has a significant interest in ensuring that dually enrolled children (Part C and Medicaid/EPSDT) receive the services that they need. Figure 24 displays the EPSDT covered services. Figure 25 delineates uncovered services.

Several state Part C planners have been able to create formal partnerships with their state Medicaid agencies and utilize EPSDT to access these federal funds for Part C. CMS has been encouraging states to use EPSDT for the purposes of covering early intervention services, according to some state Medicaid officials interviewed for the purpose of preparing this Paper.

Figure 24. EPSDT Covered Services[50]

Hospital Services • Ambulance • Inpatient hospital care • Outpatient hospital care (day visits) • Emergency room visits
Physical Health Care • Physician/nurse practitioner services: routine check-ups, illness-related visits • Dental visits: routine check-ups/cleanings (including accommodations for children with special needs), fillings, preventive care • Vision care: eve exams, glasses, eye drops, scratch-proof lenses • Hearing care: hearing tests, hearing aides, cochlear implants • Immunizations: according to the established schedule • Lab tests/x-ray services: including blood lead tests • Podiatry care: including orthotic inserts
Mental Health • Psychiatrist visits • Mental health therapy/counseling • Substance abuse treatment • Inpatient psychiatric hospitalization
Medications and Pharmacy Supplies • Prescription drugs • Diapers (for individuals beyond typical toilet training years) • Special foods: diet supplements, thickeners, other foods found in a store's pharmacy section
Home/Community Services and Therapies • Private duty nurses: nursing care in the home or community for children who require medical attention/services • Personal care/personal assistant services: assistance with non-medical services in the home, community or school, including feeding, bathing/personal hygiene, transferring, following behavior plan • Physical Therapy • Occupational Therapy • Speech, hearing, and language therapy (includes audiology services) • Chiropractic services • Nutritional services/counseling • Some behavioral therapy: behavioral therapies for children with autism are generally covered by EPSDT, although there is some controversy about this

[50] Human Services Research Institute, EPSDT: Supporting Children with Disabilities, from the National Center for Family Support, September 2004 (www.familysupport-hsri.org)

Figure 24. EPSDT Covered Services - continued
Supplies/Equipment • Durable medical equipment: wheelchairs, ankle/foot/leg braces, monitors, catheters, oxygen equipment, nebulizers • Augmentative communication devices: communication aides, optical headpointers, headsets • Diabetic supplies: insulin pumps, glucometers, syringes • Protheses
Other services • Transportation to and from doctors' appointments, therapy visits • Case management

Figure 25: Services NOT Covered by EPSDT[51]

Respite care Sometimes it is difficult to distinguish between respite care and personal care (with IS covered). Respite care, though, is for the primary purpose of relieving the child's caregiver and is therefore not covered under EPSDT/Medicaid. Personal care is covered because it is focused on the child's needs and is not intended to replace a primary caregiver.
Habilitation services Habilitation services are those services which help individuals acquire and/or improve social skills and basic living/adaptive skills (such as dressing, feeding, cooking). They are not intended to help people reach their highest level of functioning and are not covered by EPSDT. Sometimes the line between habilitation and rehabilitation (covered by EPSDT) is not clear and there may be disagreement over which category a services fall into. Habilitation services may be provided through a home and community-based waiver program.
Targeted case management Targeted case management differs from case management in that it can deal with resources and services outside of Medicaid. Under targeted case management, states can conduct assessment, care planning, referrals, and monitoring of services for Medicaid beneficiaries. Unlike other Medicaid benefits, states do not have to provide this service to children under EPSDT (although some children might receive it based on their geographic location or disability).
Treatment for another family member EPSDT is a child-centered program. While family members may be included in treatment insofar as they are needed (e.g., mental health family therapy that addresses how familial alcoholism is affecting the child, or parental training to administer the IV), the treatment must not be for the parent's sole benefit (e.g., respite care).

[51] Human Services Research Institute, EPSDT: Supporting Children with Disabilities, from the National Center for Family Support, September 2004 (www.familysupport-hsri.org)

EPSDT Reimbursement Approaches

The specific reimbursement methodology for EPSDT services is at the state's discretion as long as the payment rates are reasonable. States employ a variety of approaches to pay providers including fees for service, negotiated rates, capitated rates, and cost-based reimbursement. Because of the expansive nature of the EPSDT program, Part C systems typically participate in the established reimbursement which applies to all children, 0-21 (or under 21 depending upon the individual state). There are costs to the provision of early intervention services including screening, anticipatory guidance, etc., that may be higher than traditional clinic based services. In order to achieve appropriate reimbursement for these Part C considerations, EPSDT permits states to develop new classes of service (such as early intervention services) and establish provider classifications more in "sync" with Part C as long as the services and providers meet the definition of medical assistance under the federal statute.

Medicaid can reimburse a Part C system for "administrative activities" that providers perform in the delivery of EPSDT services. Administrative reimbursement, sometimes referred to as "admin claiming," is limited to the coordination of services within the rubric of the EPSDT program, and would not include, for example, assisting the family with an application for fuel assistance. The administrative claiming approach to reimbursement in discussed in the next Section of this Paper. This is only one approach to reimbursement for these administrative functions under EPSDT. Another approach is to incorporate an allowance or consideration for administrative functions into the individual service rate which would be reimbursed at the state's Federal Medical Assistance Percentage (FMAP).

A state may use a targeted case management plan that permits Medicaid reimbursement for the Intake or ongoing Service Coordination responsibilities from referral through to the development of the IFSP (as illustrated in Figure 23, page 93) and create another reimbursement approach for the specific services (screening, diagnosis and treatment). This reimbursement would be at the state's FMAP.

In 1991, Maine's 0-5 early intervention system, Child Development Services (CDS), created an Early Intervention Services section within that state's EPSDT program which includes services not already included as EPSDT covered services: developmental therapy (special instruction), social work services and collateral contacts. CDS utilizes the existing EPSDT chapters to access reimbursement for other services including physical, occupational and speech/language therapy, etc. Collateral contacts are defined as face:face contacts between providers once the IFSP or IEP has been developed, designed to facilitate coordination and communication across all team members in the delivery of services. Providers for these services, including collateral contact, must be a Medicaid provider and approved by the state Part C and Section 619 lead agency's licensure or certification requirements. The IFSP or IEP is recognized as the EPSDT plan of care, and is signed by the family and the child's primary care physician. The state CDS administration is responsible for ensuring quality assurance through routine client records reviews, implementation of the competency based personnel credentialing system, and development, maintenance and monitoring of program standards. Resource documents for Maine are found in Appendix ME.

The Illinois Early Intervention System has a comprehensive Interagency Agreement with their Medicaid agency that includes both fee for service and administrative claiming components for all Part C services. This structure was developed through EPSDT and the Medicaid Rehab Option. Illinois resources are located in Appendix IL. The administrative claiming includes their early intervention electronic information management system, central billing office operations, 25 local system points of entry, and early intervention staff at the state level. Reimbursement for early intervention services in this state includes developmental therapy services.

School-Based Health Services (SBHS)

The foundation for the relationship between Medicaid and education was established by the Medicare Catastrophic Coverage Act (Public Law 100-360), as amended in 1988. Medicaid pays for costs of direct, medically necessary services provided to eligible children who have disabilities in accordance with the Individuals with Disabilities Education Act (IDEA). In a report issued by Project Forum[52] (NASDSE, August 2001,) all states have in place a system to access Medicaid in some manner to pay for all or some of their Part B, special education costs. There can be no doubt that Medicaid financing of special education has grown significantly over the years. Medicaid financing is a major contributor to the financing of special education facilitating the states' ability to meet the needs of this population, often under restrictive state budget conditions.

There is no doubt that federal Medicaid recognizes their responsibility – as well as the significant opportunities – to partner with state educational agencies in the provision of needed services to Medicaid enrolled students. It is the specific methods that are used by some states and school districts to claim Medicaid reimbursement for school-based services which CMS believes lack sufficient controls to ensure that these are legitimate claims that have received the attention from the federal government. Much of the responsibility for this lack of clarity and oversight was directed towards CMS (HCFA) in a 2000 GAO Report[53], citing a series of recommendations which were intended to improve the development and consistent use of clear policies and appropriate oversight.

Individual state arrangements vary dramatically from EPSDT access, to Home and Community Based Waivers, to administrative claiming. State Part C planners will want to learn about the specifics of their own state education relationship with Medicaid since this may offer one example for Part C access. As a result of OBRA'89, both Parts B and C are exempt from the "free care" requirements of

[52] http://www.cesa7.k12.wi.us/sped/Parents/ASMT%20Advocacy/nasdse/qta_medi.pdf
[53] Government Accounting Office (GAO), Poor Oversight and Improper Payments Compromise Potential Benefit, April 5, 2000 (http://www.gao.gov/new.items/h600087t.pdf)

Medicaid for children eligible under the IDEA. For Medicaid enrolled children, Medicaid is responsible for paying for those services that are Medicaid-covered services listed in the IEP or IFSP. The requirements for utilizing existing third party resources with Medicaid as the payor of last resort apply to both Parts B and C. This means that, for those children enrolled in special education with both private insurance and Medicaid coverage, the schools would be expected to access the private insurance for covered services before billing Medicaid.

Special education experiences related to accessing Medicaid are important lessons for Part C planners. In some instances, the school-based reimbursement was crafted after existing state mental health/mental retardation structures. States operating a program known as CAFS (Community Alternative Funding System) were informed by CMS approximately two years ago that this program was not in compliance with federal Medicaid requirements. Most recently, Ohio was informed by CMS that its funding for Part B under the CAFS would be eliminated as of June 30, 2005. That state is being encouraged to pursue similar funding through a Home and Community Based Waiver (HCBS) for this population, as well as for those recipients participating in the state's MHMR[54] program. The CAFS was an expansion of an already established Medicaid funding for MHMR services, extending this option to public school children enrolled in Part B, IDEA.

Reasons cited for the termination by CMS include:

- Lack of statewideness (§1902(a)(1))
- Failure of the state to ensure the appropriate amount, duration, scope or quality of care and services due to a lack of adequate funding (§1902(a)(2))
- Failure of the state to assign a single state agency to administer the Medicaid program (§1902(a)(5))
- Services were not comparable in terms of amount, duration and scope (§1902(a)(10)(B))
- Lack of free choice of all qualified providers (§1902(a)(23))

[54] Mental Health and Mental Retardation Program

- Assurance that all providers have a provider agreement with the Medicaid agency(§1902(a)(27))
- Failure to require the Medicaid agency to make payment directly to the provider of services (§1902(a)(32))

In May 1999, CMS (then HCFA) issued a "State Medicaid Director" letter outlining concerns related to the "bundled rates" for school-based providers that were in place, or proposed, for a number of states. "Bundled rates" exist when a state pays a single rate for one or more of a group of different services furnished to an eligible recipient during a fixed period of time. The payment is the same regardless of the number of services furnished or the specific costs, or otherwise available rates, for those services. The bundle may include two or more components usually provided by different providers, each with its own unique provider qualifications, even if the components fall within the same §1905(a) service category. "Bundled rates" are not related to a specific type of procedure and are generally not available to all qualified providers in the community who might wish to be similarly reimbursed. Furthermore, CMS found that schools do not maintain the types of medical documentation that establish the reasonableness or accuracy of a rate. Because of these factors, CMS concluded that the bundled rate methodologies do not produce sufficient documentation of accurate and reasonable payments, and may result in higher payments than would be reasonable on a fee-for-service basis for each individual service and thus do not meet the statutory intent of the law. States with bundled rates were required to revise and submit new reimbursement methodologies for CMS approval.

As most Part C planners can attest, simply having a school-based agreement with Medicaid for IDEA, Part B services does not necessarily mean that a similar opportunity is in place for Part C. Currently, there are 13 states with lead agencies located in the state Departments of Education (CO, IA, MD, ME, MI, MN, MO, NE (co-lead with Health and Human Services), OK, OR, SD, TN, VT (co-lead with Health)). In most of these states, Medicaid arrangements between Part C and B differ. The majority of Part C systems are accessing Medicaid funds through multiple Medicaid avenues. There are a few exceptions.

Oregon includes the Part C population in their School Based Health Services (SBHS) program. This state's materials appear in Appendix OR. Minnesota utilizes a rehabilitation option approach for 0-21 children and has a Third Party Reimbursement Policy Specialist located in the Department of Education to support, in conjunction with the state Medicaid agency, the local educational agency efforts. Minnesota resources are found in Appendix MN.

Another example is the Medicaid state plan amendment (SPA) in place for the State of Iowa, effective since 2001. In this state, all Part C services are contained in the EPSDT program, called Infant and Toddler Services, providing an easy vehicle for both Medicaid and Part C to monitor and track expenditures, utilization, and individual program requirements. In partnership with the state Medicaid agency, the state Department of Education uses the same approach to access Medicaid funds for school-based health and special education services. The Iowa SPA includes Medicaid reimbursement for screenings, assessments and services (group and individual). The program covers a wide range of Part C required services including developmental services (special instruction) and service coordination. Qualified providers are identified as those who meet the state professional licensure standards, with education agency staff required to meet the Department of Education rules.

In Iowa, regional Area Education Agencies (AEAs) implement Part C services at the local level and are responsible for certifying the Medicaid "match." One improvement that the state would like to make is to implement the ability to reimburse only the federal share of the Medicaid payment; right now, they pay the whole fee to the AEA who then returns the state "match" portion together with a certification of match. The local match is generated by state and local funds from a variety of sources. Participants feel that the ability of the AEA to plan their budget and personnel on an annual basis is greatly facilitated by this arrangement.

Reimbursement rates were developed through the administration of a cost study; the state is preparing to conduct an update of the cost study in an effort to rebase the rates. Iowa resource materials are located in Appendix IA.

Idaho's early intervention services for Medicaid recipients are funded by Medicaid through their "Rehabilitative and Health Related Services" option. (Appendix ID) This comprehensive program encompasses a variety of providers including therapists, local school districts, Infant Toddler Programs (ITP), developmental disabilities agencies and psychosocial rehabilitation agencies of services for children Birth-21. Among other services, this "Rehab Option" includes developmental therapy, collateral contact and reimbursement for annual IFSP/IEP team meetings for school based services providers of which Infant Toddler Program is one. The Department of Health and Welfare provides the match for Part C early intervention services. Regional Department of Health and Welfare programs operate the local Infant Toddler services.

Considerations for Part C Planners

Many state Part C systems struggle with the realities of "local control" which are very similar to state education agency challenges. From the public school perspective, this often works as a barrier to the ability of the state agency to collect reliable data as to the participation of children in special education with Medicaid financing as well as the specific dollar amounts of revenue received for these services.

Part C systems are often a complex mixture of interagency systems, including public and private providers, some of whom may serve other populations beyond the Birth-3 age target group of Part C. These systems of services and providers may not be under the direct supervision of the Part C lead agency, operating rather with interagency agreements reflecting the Part C requirements and the "good will" of the sister state agency for Part C compliance.

Similarly, while a state may have in place the provisions for reimbursement of those health care and special education services provided to students eligible under the IDEA, many local districts do not participate. They report that the administrative obligations and expense of doing so exceed the benefits. The collective of these

"costs" may involve additional record keeping and reporting requirements that local districts consider burdensome for school staff. Many local districts elect not to participate in Medicaid reimbursement due to the fact that they have few Medicaid enrolled students, or they feel that the requirements are not reasonable.

Some Part C systems providers, depending upon their structure, may be able to access alternative funding in lieu of billing Medicaid. Not only does this often violate the Part C requirement as outlined in 34 CFR §303.522: Identification and Coordination of Resources, quite often these resources are Part C federal or state funds, which then violates 34 CFR §303.527: Payor of last resort.

Several states have experienced fairly substantial audit findings and recoveries of Federal Financial Participation (FFP) for their school-based services. Depending upon the state structure that the school-based system operates under, this recovery may fall to the state agency's responsibility. Typically these finding are due to poor documentation, excessive or inappropriate administrative charges, and problems with the configuration of services as billed. To this end, CMS (then HCFA) produced a claiming guide[55] for school-based administrative services that is intended to guide local districts and state educational agencies in the proper administration of these claims. There is also an August 1997 document entitled Medicaid and School Health: A Technical Assistance Guide[56] which was updated in 2003.

The release of the Medicaid School-Based Administrative Claiming Guide, which is to go into effect October 1, 2005, has created considerable concern by state officials, school administrators and school boards. Changes include removing many Medicaid administrative expenses for which school districts could be reimbursed. This means loss of a substantial amount of reimbursement for states for Part B, IDEA services. Litigation against federal CMS has been threatened in a unified effort between the National School Board Association (NSBA), the Association of School Administrators (ASA), and the Council of Chief State School Officers (CCSSO).

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[55] http://www.cms.hhs.gov/medicaid/schools/macguide.pdf
[56] http://www.cms.hhs.gov/medicaid/schools/scbintro.asp

Part C planners will benefit from becoming informed about this most recent CMS action and what effect, if any, it will have upon their state. The changes largely affect school reimbursement for administrative activities such as ChildFind, and coordination activities related to IEP development. Changes were also made related to the methodology that states use for time accountability, and may require schools to enroll as a fee-for-service Medicaid provider. It is unknown what, if any, impact these policies will have on Administrative Claiming as practiced by many Part C state systems. (See Administrative Claiming for more discussion, page 107.)

Some states collect the Medicaid revenue centrally while, for others, funds are disbursed to the local district level. Increasingly states are trying to encourage more districts to utilize Medicaid to the point where a few have developed estimates for local earning and will deduct these potential earnings from the district's state subsidy. Recent CMS communications expressed concerns that it was not the intention of FFP to offset state budget short-falls, expressing the opinion that these funds should go directly to the local districts since the intention is that they will benefit.

State Part C planners will want to learn from their state colleagues at Medicaid and the Department of Education what has worked, and what historical or current concerns or issues exist as they chart the options for Part C partnerships with Medicaid. These "lessons" prove invaluable when responding to the concerns that will be expressed by state Medicaid officials, and provide the opportunity for Part C planners to work with the State Interagency Coordinating Councils, providers and families in establishing sound systems for Medicaid reimbursement. Understanding the whole "canvas" of Medicaid financing for persons with disabilities in a state can help Part C planners better coordinate financing to assure a continuum of care for children and their families as they transition from one system to another throughout their lifespan.

EPSDT In Summary

EPSDT is considered by many as the most expansive insurance program for children under age 21. The amendments contained in OBRA'89 helped to ensure that this

federal-state partnership program, originally enacted in 1967, located each eligible child, identified actual or potential health problems through screening and diagnosis, and provided treatment before these problems became permanent. The preventive focus of this program holds tremendous benefit for millions of Medicaid eligible children.

EPSDT requires states to provide a broad array of services to enrolled children based upon identified need, and is a natural "fit" with the state's Part C system in terms of its focus. All of the Part C services conform to the EPSDT requirements and states may identify a wide cadre of providers who can provide any of the screening, diagnostic or treatment services. There are several methods of reimbursement that can help to ensure appropriate levels of payment for qualified providers. If a state elects to include Part C services under the Medicaid/EPSDT program, no family cost participation in the form of additional payments may be required. Families may be required to utilize their private insurance as payor of first resort, under Medicaid federal requirements.

Due to the relationship of disability and poverty, it is reasonable to expect that most states will have a high enrollment or potential eligibility for children in their state's Medicaid/EPSDT program. The overwhelming majority of states are struggling to meet the federally-mandated enrollment percentages; greater partnerships between child serving programs such as Part C assist the Medicaid agency in achieving this requirement.

Earlier this Paper discussed the 80% participation goal for EPSDT as established by Congress; data indicates that nationally this goal is not being met and millions of children are going without important health care services. Most recently (March 2005), a federal judge in Oklahoma ruled that state out of compliance with EPSDT requirements and directed the state's physician association to work with state officials to work out a solution to the problem.

The impending reality of federal and/or state budget cuts on Medicaid must be recognized. Due to the expansive nature of EPSDT, some have suggested that it is

too inclusive and represents an open-ended entitlement which has no fiduciary controls. The National Governor's Association (NGA) recently issued a position paper[57] that appears to seriously erode many of the principles of Medicaid/EPSDT including requiring increased personal responsibility in the form of cost-sharing by consumers for health care benefits provided through the Medicaid program. NGA has also produced a substantial document addressing Medicaid reform.[58]

[57] http://www.nga.org/nga/legislativeUpdate/policyPositionDetailPrint/1,1390,8460,00.html
[58] http://www.nga.org/cda/files/0502MEDICAID.pdf

ADMINISTRATIVE CLAIMING

Each state Part C system and Medicaid program have a great deal in common. Both programs are governed by federal regulatory requirements which include a wide diversity of administrative functions as well as to ensure the provision of needed direct services to eligible individuals. Earlier in this Paper, Figure 15 provided a visual schematic of the Part C system requirements coupled with the Medicaid requirements. (Repeated here for convenience.)

Figure 15: Part C and Medicaid Operational Components

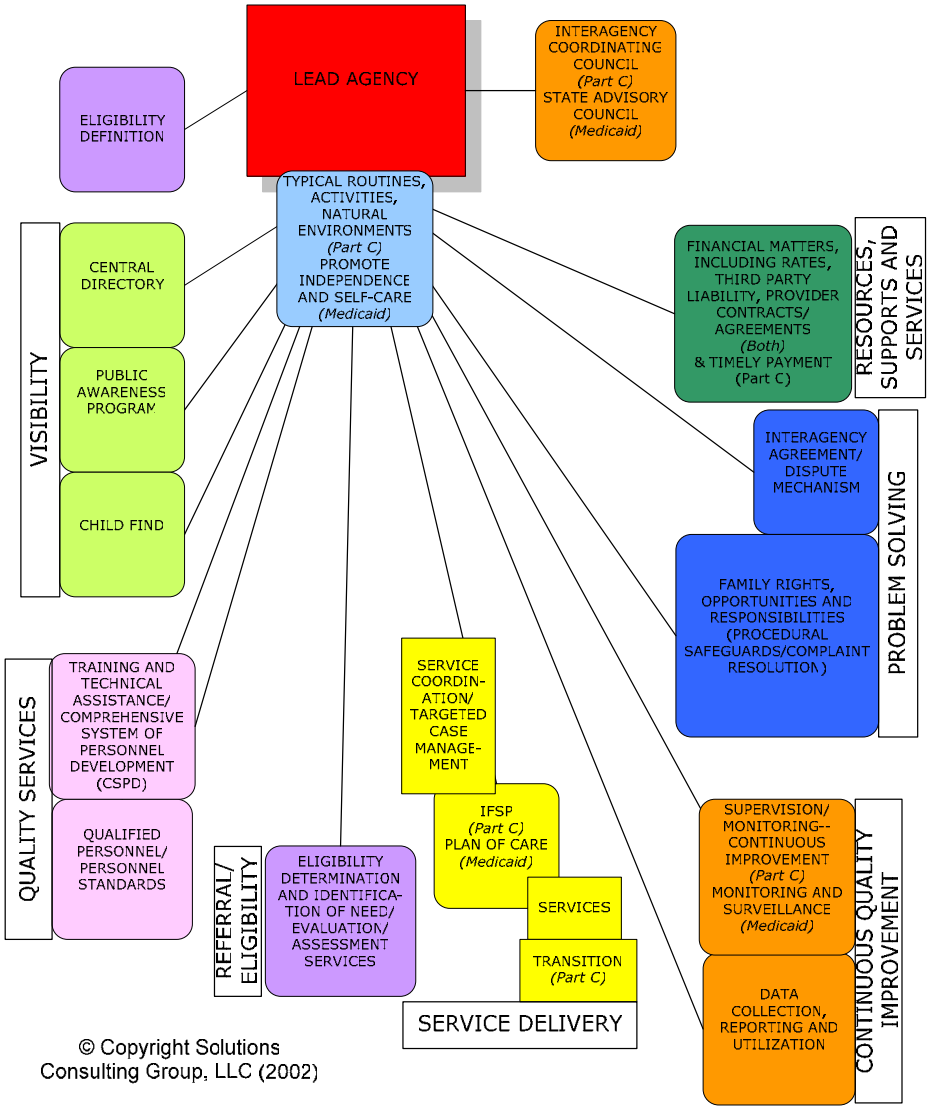

Figure 26, below, examines the similarities between these important federal initiatives from an administrative claiming perspective for state Part C systems.

Figure 26: Comparison of Part C and Title XIX, Medicaid Federal Requirements

Federal Requirement	Part C	Medicaid/Title XIX
Lead agency	Requires assignment of lead agency responsible for the oversight and management of the system.	
Eligibility	Each state defines, within the parameters of federal regulations, its eligibility criteria.	
Visibility	Each state is required to establish an outreach and informing system to increase referrals and make sure that families and potential referral sources know about these resources. Materials must be culturally appropriate and provided in several languages depending upon the individual state demographics.	
Quality Assurance: Qualified Providers	Establishes provider qualifications typically consistent with existing state licensure and credential/certification requirements, as well as establishing provider qualifications for individuals not currently recognized by existing state licensure bodies.	
Quality Assurance: Training and Technical Assistance	Training and technical assistance is required to ensure that participating providers and consumers understand their responsibilities within the system.	
Resources, Supports and Services: Third Party Liability	Both systems require that existing third party resources are accessed before Part C or Medicaid funds are tapped.	
Resources, Supports and Services: Provider Contracts	Each system must include a policy pertaining to contracting or making other arrangements with public or private service providers to provide Medicaid/early intervention services according to the state requirements.	
Resources, Supports and Services: Reasonable and Timely Reimbursement	Each system must include a procedure for securing the reimbursement of payment; including principles related to appropriate and timely reimbursement.	
Problem Solving: Family Rights, Opportunities and Responsibilities	Both Part C and Medicaid/Title XIX have extensive provisions for consumer complaint resolution.	
Problem Solving/Complaint Resolution: Consumer Rights, Opportunities/Responsibilities	Both Part C and Medicaid/Title XIX have provisions for consumer complaint resolution which includes recipients as well as providers.	

Figure 26: continued:

Federal Requirement	Part C	Medicaid/Title XIX
"CQI": Data Collection and Reporting	Both Part C and Medicaid/Title XIX have significant federal data reporting requirements.	
"CQI": Supervision, Monitoring and Continuous Improvement/Monitoring and Surveillance	Both Part C and Medicaid/Title XIX require policies and procedures that will ensure compliance with federal and state regulations, identify and correct problems including fraud, and establish training and technical assistance as a vehicle to ensure providers have access to information that will resolve problems and improve practice.	
"Natural Environments"/Promote Independence and Self Care	Part C requires that services are provided within the family and child's typical routines and activities, emphasizing environments where the child would typically spend his/her time.	Medicaid/Title XIX places a very high value in regulations on assisting and ensuring that individuals achieve independence and the ability for self-care.
Participatory Leaderships	Both systems require a state advisory council or committee with a broad variety of representatives.	
Case Management/Service Coordination	Both systems require some degree of coordination of services for a recipient. Terminology varies as do the vehicles for implementing this. Part C often utilizes the terms intake vs. ongoing service coordination, and Medicaid speaks to administrative case management vs. case management.	
Screening	Part C may implement screening as a component of the eligibility determination process.	Medicaid/Title XIX, particularly through the EPSDT program, requires a screening to determine service need.
Evaluation for Eligibility/Assessment for Service Planning	Both systems require formal processes to determine need, as well as the level (frequency, intensity) of service need, as well as location.	
Plan of Care/IFSP	Both systems require a written plan defining the services, frequency and intensity.	

Figure 26: continued

Federal Requirement	Part C	Medicaid/Title XIX
Services	Within the federal regulations, each state is able to define and create services required to meet the needs of eligible children and families. Federal Medicaid has differing levels of care, some of which are mandated and others which are optional.	
Transition	Both programs encourage transition planning to ensure uninterrupted services for the consumer.	
State Plan	Both programs are required to develop and submit a state plan application and to ensure that any changes are submitted in a timely manner. While federal Part C reestablished a public hearing process and timeline, federal Medicaid does not and relies upon state regulations for consumer input.	

This "snapshot" discussion of the comparability between Part C and Title XIX provides some starting points for discussions in the development or refinement of administrative claiming agreements for early intervention infrastructure activities that benefit services to the Medicaid enrolled population, including those activities that improve accountability and utilization.

Administrative claiming agreements are typically negotiated through an Interagency Agreement and relate to only those common activities which are not child-specific, but which are essential to the total operation of both programs. Several state Part C systems have administrative agreements, which provide reimbursement at 50% FFP[59] for functions such as assisting to locate and identify children eligible for Medicaid and facilitating those applications, ensuring that providers are qualified and properly credentialed (including training and technical assistance), provider recruitment, monitoring and supervision, administrative coordination activities such as facilitating the provision of screening, referral to other services, assessment and the development of the IFSP (Plan of Care).

[59] Federal Financial Participation

The Missouri First Steps system is in the process of transferring all Part C service coordination to its administrative claiming agreement. Service coordinators will be employees of their local systems points of entry (SPOEs) and will be responsible for a variety of administrative tasks including Child Find and provider recruitment. They have made this change in two metropolitan locations and are proceeding to complete statewide implementation. (See Appendix MO for state resource documents.)

Many states "certify" the match for these administrative services. "Certification" of match means that state or local funds within the program or agency's budget are designated specifically for the purpose of meeting the state share. States then invoice the state Medicaid agency on a monthly or quarterly basis, and receive FFP typically at 50%. Exceptions to this FFP are when services are provided by employed licensed practitioners of the healing arts (physicians or nurses) which make these services eligible for a 75% FFP. Administrative claiming assists Part C systems to support state and local level administrative activities, contributing to the total costs of the Part C "system" that then allows the delivery of services to eligible children and their families.

Reimbursement is based upon the total number of enrolled Medicaid children within the Part C system, which the Part C lead agency must document. The amount to be paid is typically based upon a time study which indicates the percentage of overall time spent in these activities, against the total administrative budget of the system. States must conduct an ongoing process of data capture to ensure and document that what is billed actually occurred, typically using random time sampling for this documentation.

Obviously for states with high Medicaid enrollment in Part C, administrative claiming is an excellent method to formalize and recognize the linkages between Part C and Medicaid and to obtain federal funds to support these Medicaid required activities.

FEDERAL MEDICAID WAIVERS

Section 1915 (b) and (c) Waivers

Waivers, under federal Medicaid, provide states with the opportunity to create specific Medicaid initiatives which respond to the needs of specific populations, or provide the opportunity for the state to waive certain provisions of the federal Medicaid regulations. Waivers are often established to support the long-term care needs of individuals who would otherwise be institutionalized. Section 1915(a) of the Social Security Act established several opportunities for states to "waive" any or all of the three federal requirements of standard Medicaid:

1. Statewideness (§1902(a)(1))
2. Comparability of services (§1902(a)(10)(B))
3. Community income and resource rules for the medically needed (§1902(a)(10)(C)(u)(III))

Waivers are commonly grouped in two categories. One, where a state establishes a managed care entity to provide Medicaid services and two, waivers used by states to implement programs and services for specific groups or categories of individuals which permit them to be served within their own homes and communities. Under this waiver opportunity, states are authorized to request approval to provide homemaker/home health aide services, personal care services, adult day health, habilitation, case management, respite care and "other" services. The intent of waiver services is to reduce the frequency of institutionalism, promote self-determination and to permit states to provide targeted programs for individuals based on need which often reflects services not otherwise available under Medicaid to the general population.

The original legislation establishing this section of the Social Security Act was signed into law by President Reagan in 1981. Prior to that point in time, Medicaid funded services for many of these populations were restricted to institutional settings; this legislation provides the opportunity for states to be creative in terms of whom, how

and where services can be provided in order to promote independence and self care. Since 1981, Congress amended this legislation to:

1. Expand the waiver authority to individuals who, absent the waiver, would require hospital level of care;
2. Extend the renewal authority from three years to five years;
3. Limit waivers of Medicaid statutes to §1902(a)(10)(B) rather than the broad §1902(a) waiver offered in the original legislation;
4. Add (with some exceptions) prevocational, educational and supported employment to habilitation services; and
5. Include day treatment or other partial hospitalization services, psychosocial rehabilitation services and clinic services (not necessarily provided in a facility) for individuals with chronic mental illness.

The caveat to this legislation is that it must be cost neutral to the federal Medicaid program. That is, the cost of services under a waiver may not exceed the costs that were or would be typically paid under Medicaid for this same population.

Section 1915(b) offers the opportunity for states to establish managed care programs that mandate specific provider(s), thus relieving a state from the "freedom of choice" requirement. States which have implemented managed care Medicaid programs have largely excluded or "carved out" children enrolled in the Part C system.[60]

Section 1915(c) introduced the Home and Community Based Services (HCBS) waiver opportunity to states, which creates the ability for states to establish a specific service delivery system for specialty care (e.g., case management and respite care), for specific groups of individuals (e.g., pregnant and parenting teens, individuals with HIV/AIDS, etc.), and/or target one specific area of the state for service (e.g., Los Angeles as opposed to the entire state of California). Community based services have largely proven to be far more cost effective than institutional care, and are more favored by recipients and their families. By combining the

[60] Managed Care's Impact on Medicaid Financing for Early Intervention Services, Fox, Harriet B., McManus, Margaret A., Almeida, Ruth A., Health Care Financing Review, Fall 1998, Volume 20, Number 1, pages 59-72.

opportunities under §1915(c), states have been able to craft targeted initiatives that effectively respond to a variety of unique state needs. A combination waiver, for example, may not only target a specific group of recipients for selected services, but also establish a selected group of providers as the only qualified ones to participate under the waiver program.

The institutional standard that most states require recipients to meet is documentation that the individual meets the criteria for an SNF, ICF or ICF/MR[61]. It doesn't mean that these individuals must be in an ICF/MR or hospital; just that they would be eligible for this level of care according to Medicaid.

In October 1998, CMS produced a guidance document entitled "Key Approaches to the Use of Managed Care Systems for Persons with Special Health Care Needs"[62] which relates to states utilization of §1915(b) waivers as well as §1115 waivers. This publication provides a framework covering six broad areas related to the planning and development of care delivery networks, and provides excellent guidance to state planners contemplating a waiver under their state's Medicaid program for any population of individuals with disabilities.

South Carolina used the HCBS waiver[63], under an Independence Plus initiative, to create a streamlined provider agreement for non-traditional Medicaid providers, and will make this program statewide in 2005. Funds are accessed through this model to purchase nontraditional supports for recipients, which allows them to purchase their own direct care workers, as well as supplies and equipment, with an individual budget. Costs are primarily targeted for individuals who are moving from an institution to the community.

Louisiana has a waiver program known as Children's Choice[64] which provides a cash stipend to families of children from birth to age 18, as well as providing for

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[61] Special Nursing Facility, Intermediate Care Facility, or Intermediate Care Facility for the Mentally Retarded
[62] http://63.240.208.148/states/letters/smd-snpf.asp
[63] http://www.cms.hhs.gov/promisingpractices/scspa.pdfhttp:/
[64] http://www.dhh.louisiana.gov/offices/publications/pubs-105/9799.pdf

short-term "crisis" assistance. This program has a limited number of "slots" which restrict enrollment to "first come, first served." There are 6 waiver services not available to other Medicaid recipients which are provided in lieu of institutional care using the $15,000 per individual allocation. In addition to these services, children receive the full benefits of the state's Medicaid program.

1. Case Management - services that assist the families in life planning for the child including gaining access to needed waiver and State Plan services, as well as needed medical, social, educational, and other services, regardless of the funding source for the service to which access is gained. Home visits are required.

2. Family Support - services provided directly to the child that enable a family to keep the child at home and that enhance family functioning.

3. Center-Based Respite - services provided on a short-term basis to children unable to care for themselves due to the absence or need for relief of the parents or to others who normally provide care and supervision.

4. Environmental Accessibility Adaptations - physical adaptations to the home or vehicle necessary to ensure health, welfare, and safety of the child, or which enable the child to function with greater independence in the home, and without which additional supports institutionalization would be required. Excluded are adaptations of general use or those that add to the total square footage of the home. Excluded are fire alarms, smoke detectors, and fire extinguishers.

5. Family Training - training and education services for the families of recipients that are provided by professional organizations or practitioners appropriate to the needs of the child and approved by BCSS[65].

6. Diapers - for children age 3 and older.

While many states report HCBS for individuals with developmental disabilities, only Pennsylvania is reported as having a waiver specifically for Part C children. Pennsylvania's waiver serves almost 16% of all infants and toddlers who receive early intervention services. In FY 2004-2005, Pennsylvania is reported to serve 25,221

[65] Louisiana Bureau of Community Supports and Services, Department of Health and Hospitals

children (unduplicated count) through Early Intervention Services, with 3,985 receiving those services through the Waiver. Pennsylvania defines the institutional level of care for its waiver with a broad definition that allows infants and toddlers to be eligible. The definition is stricter than eligibility for early intervention services, but is not overly restrictive. Pennsylvania received its initial waiver from the federal government in July 1998. A renewal of its waiver was approved in July 2001.

There is considerable variation in what states have developed in response to the waiver opportunity. Part C planners can view the array of approaches at the CMS websites.[66] CMS has commissioned a series of reports highlighting promising practices in home and community-based services. While not endorsing any specific approach, a variety of diverse state examples are "showcased" as Promising Practices in fair detail with contact information for the reader leading to more detailed information for these and other innovative concepts which focus on person-centered care.[67] This document is also provided in Appendix M to this Paper.

Some states have combined the provisions of §1915 (a) and (b) in an effort to manage the costs for the HCBS by placing limits on care, participation or approach to the provision of service. Georgia has successfully piloted a voucher program in the northern part of the state, called "Legacy Express,"[68] which is a county-based program providing vouchers to caregivers of older adults. Vouchers may be spent on service options ranging from respite care and medications to haircuts and lawn care. Georgia's objective in promoting this program is to give caregivers the authority and flexibility to select those service options that work best for them, given their individual circumstances. This program started out as targeted at individuals with Alzheimer's, but has gradually expanded to serve all eligible older adults and their caregivers.

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[66] http://www.cms.hhs.gov/medicaid/1915c/children.pdf
http://www.cms.hhs.gov/medicaid/waivers/waivermap.asp
[67] http://www.cms.hhs.gov/promisingpractices
[68] http://www.cms.hhs.gov/promisingpractices/gaisf.pdf

States must submit a separate application for each waiver program that they are proposing and satisfy all of the applicable requirements. States must demonstrate the cost neutrality in the §1915(b) waiver and cost effectiveness in the §1915(c) waiver. There are often different reporting requirements depending upon the type of waiver granted. Waivers are approved at different periods of time, initially for 2 years and after that for five years. Renewal requests must be submitted for each waiver according to the initial approval schedule. Meeting these requirements may serve as a deterrent for states considering going ahead with applications for a combination waiver. Three states are reported as participating in a combined waiver approach (Texas, Michigan and Wisconsin). States deciding to go through the rigorous application process and reporting requirements will undoubtedly experience a new range of possibilities and innovations for managed care and home and community based services.

While the majority of states don't have a specific waiver for Part C, many children enrolled in Part C may also be eligible for an individual state's waiver program. This largely depends on both the age as defined in the state plan, and if there are restricted numbers of "slots" for the waiver which typically results in a waiting list. The Louisiana EarlySteps system has implemented a combined enrollment application that, with family consent, automatically enrolls eligible children in the Children's Choice waiver program. While many of these children may not be eligible when their name emerges from the waiting list, this practice offers access to the waiting list starting with the child's first enrollment with EarlySteps and has the promise to reduce the waiting list time for children who sign up through the Part C system.

HCBS are one option for state Part C planners to explore, particularly as related to children with extensive needs such as would qualify them for an ICF/MR level of care. Waivers often include a variety of services compatible with Part C, as well as unique family supports including respite care. While not all Part C children may be eligible for a state's waiver, some clearly will be and this would be a resource for IFSP services for these dually enrolled children. Because many state waiver programs serve older children (either by default or design), it is important to state Part C planners to inform service coordinators and providers of these opportunities so that

families can access them as soon as possible. This knowledge assists to ensure that the continuum of care for some children exiting Part C is in place.

The Department of Health and Human Services has published a document entitled: "Understanding Medicaid home and Community Based Services: A Primer" (October 2000) which is provided as Appendix N to this Paper. This Primer provides an expansive discussion of long term care issues and opportunities for individuals with disabilities.

Section 1115(b) Demonstration Waivers

Section 1115 of the Social Security Act provides states with the option of developing experimental, pilot or demonstration projects which are judged by CMS to assist in promoting the objectives of Medicaid. Similar to the §1915 (b) and (c) waiver opportunities, these demonstration waivers must be cost neutral over the life of the project (usually five years) meaning that it cannot cost the federal government more than it would cost without a waiver. What makes §1115 waivers different, in large part, is that a comprehensive evaluation process is required. There are currently 27 states and the District of Columbia operating with an approved §1115 waiver, some of which haven't been implemented. Tennessee's TennCare program was implemented in 1994 under a §1115 waiver. The Kaiser Commission on Medicaid and the Uninsured has produced an assessment[69] of recent waivers related to providing new coverage which cites specific state examples.

Section 1115 waivers have been employed by states to use their federal Medicaid and SCHIP funds in alternative ways. A §1115 waiver can permit states to:

- Cap enrollment in Medicaid;
- Reduce benefits or increase premiums or cost sharing beyond federal standards;
- Cover adults without dependent children who are not elderly, disabled or pregnant using Medicaid funds; and
- Cover groups other than uninsured children using SCHIP funds

[69] http://www.kff.org/medicaid/4158.cfm

Most recently, §1115 waivers have actually resulted in limited gains, reflecting both the absence of additional federal financing as well as the states' difficult fiscal situations. Increasingly states are using §1115 waivers to contain or reduce spending by changing many of Medicaid's key elements affecting benefits, affordability of coverage and care, and enrollment. While §1115 waivers haven't been used to address the Part C needs of infants and toddlers, each state Part C planner should understand the impact of the implementation, if any, of a §1115 waiver in its state as related to the Part C population. In at least two (s) states (IL and ME), the §1115 waiver was used to expand Medicaid enrollment to cover parents of enrolled children. This may be useful information for Part C planners as they assist families to identify and access community resources.

State governments have substantially increased the use of home and community-based service (HCBS) Medicaid waiver programs during the last decade, which has changed the face of the Medicaid program, according to a new report very recently released by the Health Strategies Consultancy with support from the Kaiser Commission on Medicaid and the Uninsured. Spending on HCBS waiver programs has increased from 37% of community-based spending in 1992 to 66% in 2001. Community-based spending for long-term care now accounts for 30% of total Medicaid long-term care spending, up from 15% in 1992. With this marked trend towards greater reliance on the HCBS waiver programs to cover the long-term care of elderly and disabled people in a community-based setting, closer examination of how they operate and what measures states take to control costs will become extremely important.

Section 1932 Managed Care Waivers

Section 1932(a) of the Social Security Act provides the opportunity for states to implement a managed care system for some or all of its Medicaid program. Currently 12[70] states have some sort of 1932 waiver in place. Under section 1932(a), children under age 19 with special health care needs in limited circumstances were

[70] AL, IA, KY, ME, MS, NE, NV, NJ (2), NC, ND, UT, WI

precluded from a state's waiver. Appendix O provides the National Academy for State Health Policy (NASHP) 2000 report on state experiences with managed care and children with special health care needs (CSHCN). Appendix P is the 2000 HHS Report to Congress on managed care as it relates to individuals with special health care needs. Both of these papers provide interesting perspectives and data for Part C planners who are dealing, or who soon will be dealing, with managed care systems in their states.

The discussion related to CSHCN and managed care typically revolves around whether to "carve in" or "carve out" these children from the managed care initiative. This is an important discussion in which all stakeholders need to participate. "Carving in" means including this population in the overall managed care initiative and, sometimes, instituting special provisions for overrides to service levels, etc. "Carving out" means keeping these children in the traditional Medicaid fee for service system and out of the managed care system. Some states have extended choice to families, and ask them to make this decision.

Managed care is designed to organize and "manage" services with a focus on cost management and prevention through the use of a targeted network of providers, limits on specialty care and requirements for referral or prior authorization for certain services which would require the beneficiary to go "out of network." The managed care entity receives a capped amount per recipient that is intended to compensate for all needed services, recognizing that some individuals will require more than is typical while others will be incidental or low users of services.

There are significant philosophical issues and values considerations to this question, particularly from the family perspective. Some families of children with special health care needs including disabilities believe that "carving out" of the Medicaid managed care system is the only way to ensure that their child receives the appropriate level of services that he/she need. Others believe that it is important to work within the managed care system to ensure appropriate services for everyone – their child included. The foundation for many of these discussions has been inclusion

versus the need for carving out. Some are of the opinion that "carving in" creates more institutional support for their child throughout the child's life span.

As states move to initiate the managed care discussion in light of current budget constraints, Part C planners should be prepared to be part of the conversation.

Katie Beckett/TEFRA Waiver

Federal Medicaid law gives states two policy options that allow children with a mental or physical disability to be enrolled in Medicaid even when their family income would normally exclude eligibility. In addition to including this population under a §1915(c) waiver, this eligibility option was authorized by the Tax Equity and Financial Responsibility Act of 1988, TEFRA (also known as the Katie Beckett option) §1902(a)(ii)(VI) of Medicaid law in 1982. Sometimes termed the "deeming waiver," many states offer families this option which permits states to enroll children with disabilities who live at home and need extensive care but who would not otherwise qualify for Medicaid due to their family income and resources. In order to be eligible:

- The child must be a child with a disability as defined in federal disability rules (Supplemental Security Income, SSI, program);
- The child must need the level of care normally provided in a medical institution; and
- Home care for the child must be appropriate and the cost of home care must not exceed the cost of the alternative institutional care.

Compared to the total enrollment in the Medicaid program, the TEFRA option covers a small number of children and enrollment varies widely among states. The average number of children qualifying under TEFRA per state is 1, 230 (the range is from 10 to 4,300 children).

Part C planners should learn about their state's current opportunities afforded under this option, and explore the linkages to Part C services for dually enrolled children. Recent CMS data indicates that TEFRA has been implemented in at least 20 states (AK, AR, CT, DE, GA, ID, ME, MA, MI, MN, MS, NE, NV, NH, RI, SC, SD, VT, WV, WI).

The Babies Can't Wait system in Georgia is an active partner with its state's TEFRA program, providing evaluation and assessment information to assist in the TEFRA eligibility determination application process for children Birth-3. The IFSP serves as the plan of care for dually enrolled children. State leaders report that this is a positive partnership, with reimbursement for TEFRA covered services available to Part C providers. It also establishes a continuum of support for the child and family which continues after their enrollment in the Babies Can't Wait system. Georgia's resources are provided in Appendix GA.

TARGETED CASE MANAGEMENT SERVICES (TCM)

Federal regulations allow states to provide three kinds of case management services under Medicaid. Case management under HCBS and administrative case management have already been reviewed. This section focuses on targeted case management, or TCM as it is more commonly called. Federal statute defines targeted case management services as "services which assist an individual eligible under the plan in gaining access to needed medical, social, educational and other services." TCM permits states to reach out beyond the bounds of the typical Medicaid program to coordinate a broad range of activities and services necessary for the optimal functioning of a Medicaid client. Medicaid does not reimburse for activities involving non-Medicaid services such as subsidized housing, public assistance, or recreational programs.

A Medicaid TCM, due to its expansive definition, can include various kinds of collateral contact (such as telephone contacts, meetings including team meetings, and assistance with applications) as well as direct client "face to face" services. This category has been available to states since 1986, and is "housed" in section 1915 of the Social Security Act.

Under Part C, service coordination means the activities carried out by a service coordinator to assist and enable a child eligible under this part and the child's family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State's early intervention program. Part C requires the assignment of one individual to serve in this role for each child, working closely with the family.

TCM includes the provision of service or care coordination for eligible children. While CMS has not defined these services in regulations, the following four activities

are commonly understood to be allowable[71]. The Part C definition detail has been categorized under the appropriate activity and appears in *italics.*

1. Assessment of the eligible individual to determine service needs;
    a. *Coordinating the performance of evaluations and assessments*
2. Development of a specific care plan;
    a. *Facilitating and participating in the development, review, and evaluation of individualized family service plans*
    b. *Facilitating the development of a transition plan to preschool services, if appropriate*
3. Referral and related activities to help the individual obtain needed services; and
    a. *Coordinating the provision of early intervention services and other services (such as medical services for other than diagnostic and evaluation purposes) that the child needs or is being provided*
4. Monitoring and follow-up.
    a. *Coordinating all services across agency lines*
    b. *Serving as the single point of contact in helping parents to obtain the services and assistance they need*
    c. *Assisting parents of eligible children in gaining access to the early intervention services and other services identified in the individualized family service plan*
    d. *Facilitating the timely delivery of available services*
    e. *Continuously seeking the appropriate services and situations necessary to benefit the development of each child being served for the duration of the child's eligibility*
    f. *Assisting families in identifying available service providers*
    g. *Coordinating and monitoring the delivery of available services*
    h. *Informing families of the availability of advocacy services*
    i. *Coordinating with medical and health providers*

[71] See Appendix N to this Report for a copy of the January 19, 2001 State Medicaid Director (SMD) letter regarding TCM.

Case management under Medicaid does not include payment for the provision of direct services. The requirement for third party liability applies; that is, if the child is covered by another health care plan or state program which pays for this service, Medicaid wouldn't be responsible.

States typically have multiple TCMs covering a variety of populations, each with different service requirements. It is not uncommon for children to be enrolled in other programs with TCM in addition to Part C. This is particularly true for some children enrolled in Part C who may also be a client of the state's child protective or foster care system or Title V/Children with Special Health Care Needs (CSHCN). Appendix ME provides an expansive overview of that state's multiple TCMs, which illustrates the potential need for interagency agreements when children would likely be dually enrolled in Part C and at least one other program.

Due to the CMS preference to separate case management from direct therapeutic services, it is sometimes difficult to obtain Medicaid financing through TCM for state Part C systems using blended systems of service coordination (e.g., direct service providers who also perform service coordination). Part C systems using this approach to service coordination may consider organizing their reimbursement under EPSDT or HCBS where these services could be included as costs in the calculation of the provider's overhead expenses for direct services. Massachusetts is an excellent example where a designated percentage of the overall reimbursement is intended to cover the costs of service coordination including collateral contacts by telephone, travel and meeting time for off-site consultations and staff meetings.

Nevada's Part C system is moving away from having therapy practitioners also serve as service coordinators as their state Medicaid agency does not acknowledge these disciplines as qualified providers under that state's TCM. Developmental Specialists serve in both functions of service coordinator and special instruction provider. This state's Medicaid agency's recent opinion based on

federal regulation is that this is a conflict of interest. The Part C system is still using these individuals to provide both services, but are only able to bill for Rehab or TCM, not both. Nevada is implementing some dedicated service coordination, but has found that the blended model works best for families in this State. The dedicated model appears to be most appropriate for families receiving multiple services, or who have complex needs.

The Mississippi First Steps early intervention program is one of several states with TCM specifically for Birth-3 (Appendix MS). Their state plan amendment describes the rate methodology for public provider reimbursement.

Georgia's Babies Can't Wait system has had TCM for Birth-3 in place for several years. State policies and procedures are provided in Appendix GA that defines the services and the qualified providers, as well as the reimbursement methodology. This state's service coordination system is one in which there are identified individuals who meet the state's provider qualifications and serve only in the service coordination capacity. Providers are reimbursed on a monthly basis as long as the minimum level of service is provided.

North Carolina's recently approved TCM (Appendix NC) provides Medicaid reimbursement for service coordinators employed by the state lead agency for Birth-5 services. Oklahoma's Sooner Start early intervention system also utilizes public employees to provide service coordination through their Medicaid TCM.

Illinois utilizes a different approach for reimbursement for its TCM

services. The fee for service claiming is based upon a formula that incorporates caseload considerations, and also has performance incentive adjustments. (Appendix IL)

It is permissible by CMS for a child to have more than one case manager who is reimbursed by Medicaid, but these individuals may not be duplicating effort. Specific delineations of what each individual does should be articulated in state regulations to avoid denial of claims and duplication of service. Typically state Medicaid agencies pay the first TCM claim received within a given month. This can be problematic when children legitimately have more than one case manager; invoices from the second or subsequent case manager are denied when received by Medicaid. State Part C planners should address these issues when crafting interagency agreements, defining and clarifying their individual activities and clarifying how coordination will occur, thus avoiding duplication. The specifics of these interagency relationships for dually enrolled children should be detailed in the state's TCM. Reimbursement differentials could be established which would illustrate the difference in role and functions for those instances where service coordination is a shared responsibility.

Alaska is in the process of implementing TCM for their Part C system. This state plan amendment was recently approved and is the first of a planned sequence of TCM for other populations to be implemented. Service coordinators in Alaska come from a number of disciplines as this state does not have designated family service coordination positions. As other programs and services are added to this state's TCM initiatives, Part C planners will be investigating issues related to potential duplication and addressing these early. Alaska's resources are provided in Appendix AK.

One area that is increasingly important to Part C planners is each state's systems increased involvement with very young children through the CAPTA[72] amendments,

[72] CAPTA : Child Abuse, Prevention and Treatment Act, 42 USC 5105(a)(b)(2)(A)(xxi)

requiring states to develop procedures to ensure that all children with substantiated cases of abuse or neglect are referred to Part C for an evaluation for eligibility determination purposes. The delineation of responsibilities between Part C service coordinators and child protective/foster care case managers is important to clarify. With the exception of referrals to medical providers which is reimbursed by Title IV-E, these referrals under Part C for dually enrolled children are not billable to Medicaid.

Arrangements through interagency agreements which delineate responsibilities should be negotiated between the state's Part C lead agency and the state agency responsible for child protective and foster care. States must properly allocate case management costs between these two programs in accordance with OMB Circular A-87 under an approved cost allocation program. A portion of the state's services under Part C, as related to making referrals to medical care providers, would be able to be compensated through Title IV-E funds.

Reimbursement for TCM can be constructed in a variety of ways, including:

- A specific unit of measurement such as 15 minutes, weekly, monthly;
- Activity reimbursement (telephone contact, meeting, face to face contact); or
- Capitated fee (usually monthly).

Part C planners should be very well versed in the documentation requirements for TCM when reimbursed by Medicaid. Because the depth of service coordination through Part C could extend beyond what is Medicaid allowable, Part C systems will have to clearly define what is -- and what isn't -- Medicaid reimbursable for their state's participants, and create documentation protocols accordingly. Lack of appropriate documentation contributes to the majority of the audit findings involving recovery of federal Medicaid funds.

The West Virginia Part C system has developed statewide documentation requirements which are used for all children enrolled in WVBTT. These are provided in Appendix WV and

offer samples for service coordination documentation as well as other early intervention services including teaming. In this model, documentation is completed by the practitioner at the close of the visit and shared with the family who signs the document to indicate its participation and agreement with the statements. This form is on NCR paper. The original goes to the EI record, a copy is left with the family and the service provider maintains the other copy for his/her records. The information documented on this form is used in audit review to assure that the service provided was in accordance with the service that was authorized.

REHABILITATION SERVICES OPTION

Rehabilitation services are an optional Medicaid state plan benefit that must be recommended by a physician or other licensed practitioner of the healing arts, within the scope of practice under state law for the maximum reduction of a physical or mental disability and to restore the individual to the best possible functional level. The services may be provided in any setting (at the state's option) and can include occupational and physical therapy services, as well as mental health services such as individual and group psychological therapies, psychosocial services, and addiction treatment services. These services are also commonly referred to as the "rehab option."

The State Medicaid Manual developed by CMS describes in some detail what preventive and rehabilitative services may be covered if the State so chooses. Since the inception of the Medicaid program in 1965, it has covered "preventive" and "remedial" services under certain conditions. These services include those that:

- Involve direct patient care; and
- Are for the express purpose of diagnosing, treating or preventing (or minimizing the adverse effects) of illness, injury or other impairments to an individual's physical or mental health.

In order for a service to be covered, it must meet both of these elements.

An example of coverable preventive and remedial services that addresses broader social or environmental concerns is as follows:

- Preventive group counseling by a licensed practitioner of the healing arts can be covered when it allows direct, one to one interaction between the counselor and the individual recipient.

An example of non-covered services and non-medical services that addresses broader social or environmental concerns would be the dissemination of general information on prevention or rehabilitation approaches through the mass media which involves no direct patient care.

Rehabilitation services are often difficult to classify and may appear under another Medicaid service category, such as physical or occupational therapy. Consequently it is often difficult to distinguish what services would be covered under the Rehab Option. Appropriate documentation has been raised as an issue by CMS to several states operating under a Rehab Option. These concerns primarily are whether or not the planned services were actually delivered.

As earlier stated, states need to develop methods to ensure against double billing – either accidental or deliberate. Because many of the services included under the Rehab Option are covered in other Medicaid programs, data systems need to ensure that program billing is developed in such a manner as to identify if the same service for an individual child is billed under two different programs.

In summary, because rehabilitation services are an optional Medicaid benefit, not all states provide this Medicaid service. Those states that do provide rehabilitation services can define the scope of the benefit to include specific services and exclude others.

New Hampshire has utilized a Rehab Option for its Part C system for several years. This Medicaid SPA (Appendix NH) includes all Part C services with the exception of

service coordination, which is managed under a different Medicaid initiative for this population.

Nevada also utilizes a Rehab Option for its Part C system, and has had this in place since 1995. This Rehab Option has includes educators providing special instruction; reimbursement for therapy services and TCM are accessed through other Medicaid options. The lead agency is recognized by the state Medicaid agency as the early intervention provider and bills for all services directly. Nevada provides all of the early intervention services through the use of state employees and contractors, and compensates practitioners for their direct service time as well as travel time. Because Medicaid does not reimburse for travel time, revenue is lost due to the state's commitment to services in the natural environments because travel time is not reimbursable by Medicaid. The state lead agency bills directly for all services provided and have different rates depending upon the practitioner-type. This state has a line item budget that requires the lead agency to generate Medicaid revenue. If it fails to meet its target, this can result in budget reductions. Nevada is anticipating a change to a cost-based reimbursement structure which will permit incorporating administrative costs into the Medicaid reimbursement. The lead agency credits its success in Medicaid reimbursement for early intervention services to the fact that it is co-located in the same agency as the Medicaid program.

PARTNERSHIPS THROUGH INTERAGENCY AGREEMENTS

Medicaid regulations contain requirements and options for interagency agreements among the state Medicaid agency and a variety of partners in order to provide the services. States are mandated to have agreements with the State Title V/Maternal and Child Health agency and State Vocational Rehabilitation agency. They are also encouraged to have agreements with a wide variety of other agencies including Head Start, social services, case management and transportation agencies, mental health state agencies as well as Part C. The federal regulations governing this interagency agreement process is provided in Appendix R.

Title V

Title V is also a federal-state partnership and was established through the Social Security Act. There are several facets to the variety of Title V services that a state can sponsor through this federal block grant. These include preventive services, services targeted to children with special health care needs (CSHCN) (85% of the total appropriated amount), and targeted initiatives through SPRANS or Special Projects of Regional and National Significance (15% or the remainder of the federal appropriation). Additionally, MCHB is supporting a new initiative entitled Early Childhood Coordination Services (ECCS), providing funding to all states and territories in the advancement of coordinated and collaborative early childhood services.

A publication entitled Using the Title V Maternal and Child Health Services Block Grant to Support Child Development Services, authored by Rosenbaum, Proser, Schneider and Sonosky[73] in January 2002 provides an easy to read summary of these opportunities. Title V is administered by the Maternal and Child Health Bureau (MCHB) which is part of the Health Resources and Services Administration (HRSA) of the federal Department of Health and Human Services (HHS). States structure their Title V programs in very diverse ways due to the flexibility of state's use of this federal

[73] http://www.cmwf.org/use_doc/rosenbaum_titlev_481.pdf

block grant. The Title V program can act as a "bridge" for middle-income families with children with special health care needs, providing needed medical services for children above Medicaid eligibility but perhaps without any or adequate private insurance. Title V is obligated to utilize existing third party resources as they exist, including Medicaid and private insurance, and has the ability to implement a sliding fee scale at state discretion.

The Medicaid statute was amended in 1967 to require that states provide for agreements with Title V agencies to deliver Medicaid services. This language has been interpreted to place Title V in the position of payor of last resort, after Medicaid. The language also assures that Title V services can be billed to Medicaid for Medicaid-eligible children and offered free of charge to others. This provision, which is contrary to general Medicaid policy requiring payment for all services, has been used in Title-V-supported, school-based health programs. Additionally, some states have used the regulatory language to argue that Title V programs should receive cost-based Medicaid reimbursement. Federal Medicaid regulations provide additional requirements for Medicaid agreements with Title V. While federal statutes do not require states to coordinate, states clearly have the authority to do so.

MCHB provides leadership, partnership and resources to promote the health of women, infants and children through comprehensive, coordinated, family-centered culturally appropriate and community-based health care services. As such, Title V is already a partner to state Part C systems and is located in the same agency, if not the lead agency, for Part C in 28 states, 3 Territories and co-lead in two states.

In addition to the partnership offered through CSHCN services[74], another option for Part C planners to investigate for accessing Medicaid is through what is referred to as a "Title V Agreement" with their state's Maternal and Child Health agency. This approach was first implemented by Kentucky's First Steps system for Part C. Through a Title V agreement, the MCH state agency is designated as the Part C provider.

[74] Appendix S is the 2003 AMCHP Report on Title V and Part C Systems coordination offering several successful examples and recommendations for strengthened collaboration.

This structure permits the MCH agency, in partnership with Part C planners, to administer the state's Part C system for the purposes of accessing Medicaid reimbursement.

Under this opportunity, MCH becomes the provider for Part C in the eyes of the state Medicaid agency and, as such, can craft through the Interagency Agreement all aspects of the Part C system including eligibility, service definitions, provider qualifications, flexibility in site of service delivery, etc., as well as create reimbursement at full cost for these services. The Kentucky Title V approach, in place since 1992, has been highly successful and may be as a model for other state Part C systems. Appendix KY provides a variety of resource materials from this State. Kentucky elected to include service coordination in this State Plan Amendment (SPA) rather than create TCM. This approach eliminates some of the problems inherent in TCM where there is more than one case manager from a Medicaid billing perspective. The Part C system also is responsible for all monitoring and surveillance activities on behalf of Medicaid. Other Kentucky materials are located on their website.[75]

States may also have reciprocal agreements between the state Medicaid agency and the agency administering services for individuals with mental retardation or developmental disabilities. These agencies have long been in the forefront of Medicaid utilization for a variety of individuals with a variety of disabilities. Many of these agencies often set the "tone" for Medicaid configuration of waivers which may include the Part C population. Close coordination and communication between the Part C system and these entities is important – not only to ensure

[75] Kentucky policies and procedures (http://chfs.ky.gov/dph/pptablecontents.htm), provider qualifications (http://chfs.ky.gov/NR/rdonlyres/1F165174-F2CD-4941-A35F-71509A63179E/0/SectionIXPersonnelPolicies.pdf), central billing system information (http://chfs.ky.gov/NR/rdonlyres/008E88FB-7478-40F1-8780-19F15AA33CFA/0/SectionXIICentralBillingandInformationSystemManual041205.pdf), and information about coverage and payment (http://chfs.ky.gov/NR/rdonlyres/8D14E3A2-E0F7-4FEA-861A-6B12B444DF41/0/SectionXIVCoverageandPayment.pdf)

utilization of companion Medicaid opportunities, but to ensure a smooth transition to these agency services as appropriate for children and families as they exit Part C.

Supplemental Security Income (SSI)

The SSI program for children is a cash assistance program funded and administered by the federal government. The program became operational in January 1974, with its intended purpose to assist low-income individuals who are aged, blind or disabled, and was accompanied by modifications authorizing eligibility to children with disabilities under age 18. The Personal Responsibility and Work Opportunity Reconciliation Act (PRWORA) of 1996 renders many of these children ineligible for such assistance. It is estimated that 22% of children under age 18 lost SSI benefits as a result of these regulatory changes.

SSI enrollment establishes more than the potential for the cash assistance. SSI provides each eligible child up to $484 per month in cash assistance. Some states supplement this amount in particular circumstances, and most states grant SSI children automatic eligibility for Medicaid coverage. To be SSI-eligible, a child must live in a family whose income is below a prescribed threshold and must meet SSI's disability definition for children. This definition was changed as a result of P.L. 104-193[76] which no longer linked to the definition of disability for adults.

Children who are eligible for SSI benefits must be referred to the state's CSHCN program which may provide a variety of services for this population. Additionally, even the smallest SSI payment may establish a child's eligibility for Medicaid.

In providing Medicaid[77] to individuals who are receiving SSI or deemed to be receiving SSI, states fall into one of three general categories:

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[76] The Personal Responsibility and Work Opportunity Reconciliation Act of 1966. See Appendix T to this Paper for the new definition of eligibility for children under SSI.
[77] http://www.cms.hhs.gov/medicaid/eligibility/criteria.asp; also see Appendix R to this Paper.

Section 1634(a) States

This terminology, referring to §1634 of the Social Security Act, means States have a contract with the Social Security Administration to determine eligibility for Medicaid at the same time a determination is made for receipt of SSI benefits. These 32 states and the District of Columbia also use the same Medicaid eligibility criteria for determining for their aged, blind and disabled SSI recipients as are used for the SSI program. State Part C planners should check with their state Medicaid administration to learn if they are a "1634 state," to better understand the implications and opportunities for the Part C system on an individual state basis.

SSI-criteria States

This means states that use the same Medicaid eligibility criteria for their aged, blind, and disabled SSI recipients as are used for the SSI program, but require that these individuals apply to the State separately from their application for SSI to determine their Medicaid eligibility based upon that application. There are seven (7) states and the Commonwealth of Northern Mariana Islands that are categorized as SSI-criteria States. State Part C planners should check with their state Medicaid administration to learn if they are one of these seven (7) states to better understand what this means for them.

Section 209(b) States

This means States that use more restrictive Medicaid eligibility criteria for their aged, blind and disabled recipients than are used in the SSI program in one or more eligibility areas and which were in place in the State's approved Medicaid plan as of January 1, 1972, although some §209(b) States do use SSI's definition of disability in determining the Medicaid eligibility of disabled individuals in their State. There are 11 States that are categorized as §209(b) States (CT, HI, IL, IN, MN, MO, NH, ND, OH, OK, VA).

Several state Part C systems actively participate in SSI referrals and in providing assessment information to assist in the eligibility determination process. Assisting families to access SSI would be considered a Part C service coordination function,

which then accesses Medicaid as a payor for early intervention and other medical and health care services that the child may require. This service could be reimbursed through either administrative claiming or TCM.

STATE CHILDREN'S HEALTH INSURANCE PROGRAM (SCHIP)

Overall, SCHIP has enjoyed widespread state and federal support and has successfully contributed to reducing the numbers of uninsured children. The "capped" financing approach permits the federal government to limit and predict its expenditures. The enhanced federal matching rate has provided incentives to states to expand coverage for children and, most recently adults. With this structure though, have come problems, which have led states to enact numerous legislative changes in the eligibility and design of their SCHIP. The funding formula does not recognize the variation in program costs based upon individual state design factors including scope of benefits, coverage levels, or participation rates. The result of this has been an unequal distribution of funds as compared to the efforts of many states to open enrollment and expand coverage. As state budgets become increasingly more constricted, coupled with the increase in uninsured children due to the changes in the landscape related to employer-supported insurance plans, it is likely that state efforts to control expenditures and the growth of SCHIP will continue.

Overall, state's efforts to implement SCHIP did not include efforts to reach out to the population of children with disabilities and their families. At least four states (CA, FL, MA, MI) had programs for children with disabilities already established prior to the passage of SCHIP or Title XIX. Two states were successful in having specific language unique to Part C included in SCHIP. Texas includes all federally mandated services as set forth in Part C to be provided within the context of their SCHIP program. Providers for this population are limited to those individuals and agencies recognized by the Texas Department of Assistive and Rehabilitative Services, Division of Early Childhood Intervention. Specific language is reflected in the SCHIP including, for example, the two-day federal referral requirement for all SCHIP providers. The IFSP is the plan of care recognized by SCHIP and particularly precludes the establishment of barriers to accessing services including the requirement for prior authorization for assessment.

Virginia was able to include referral language in their SCHIP program that requires SCHIP to inform families and facilitate referrals to the state's early intervention services system. A review of this state's CHIP contract does not appear to make any special provisions for Part C services beyond this although children with special physical and mental health care needs are considered a special population for enrollment purposes.

A total of 35 states have a joint application under Medicaid for separate SCHIP programs; states without this process include AK, AR, DC, HI, LA, MN, MO, NE, NM, OH, OK, RI, SC, TN, UT, WI. Most of these states do not have separate SCHIP programs.

The Urban Institute produced a paper[78] in May 2001 analyzing the early experiences of states serving children with special health care needs under SCHIP.

COVERAGE OF MENTAL HEALTH SERVICES FOR CHILDREN

While the positive development of each child's social and emotional skills has always been a focus for early intervention, Part C planners are recognizing the need for a more intentional focus on the early identification of children with mental health needs. This is due to at least three factors: 1) the increased relationship with children through the CAPTA and IDEA 2004 requirements for Part C referral, and 2) the increase in prevalence of children with diagnosed mental health disorders. The third influence is the increased emphasis on early intervention services to help prepare a child to be successful in public education, developing pre-literacy skills at an early age and using early intervention services to help support parent-child interactions which are the foundation for positive social-emotional health.

78 http://www.urban.org/Template.cfm?NavMenuID=24&template=/TaggedContent/ViewPublication.cfm&PublicationID=7300

Infant mental health initiatives are not new to most states, and many date back to the late 1970's. Infant mental health is the practice of promoting a positive parent-child relationship and is slowly being integrated into many state's Part C practices by a broad range of practitioners who come into routine and regular contact with families with very young children. Infant mental health has long been a priority of Early Head Start and Head Start agencies as well. ITCA produced a paper entitled: "Infant Mental Health and IDEA Part C" (July 2005) discussing the important role of mental health in the context of early intervention assessment and service delivery.

The National Governor's Association has published an Issue Brief[79] focusing on funding for children's mental health services in which it highlights the opportunities available to states through many of the Medicaid programs discussed in this paper, namely EPSDT, HCBS or TEFRA. The issue paper clearly states that early intervention for this population is most effective and less costly. It also discusses the actions that many families have taken in order to get services for their child, given the restrictive eligibility of most funding streams as related to income. This includes surrendering custody of their child to the state in order to access services for their child. It also includes a variety of employment and financial decisions that families are making, including selective unemployment and divorce, as some of the more drastic alternatives that families have been forced to take.

Florida's Agency for Health Care Administration, AHCA, in collaboration with the Louis de la Parte Florida Mental Health Institute, published an expansive study[80] of infant and toddler Medicaid funded mental health services. This excellent study provides a thorough research-based discussion of mental health issues and challenges for very young children from the early intervention perspective, and will be valuable to states interested in pursuing funding for this important service.

[79] http://www.nga.org/cda/files/0501childMentalHealth.pdf
[80] http://www.fmhi.usf.edu/institute/pubs/bysubject.html

The State of Maine has established Medicaid reimbursement for infant mental health services. Effective December 2002, Infant Mental Health Services are those services provided by agencies that have a contract, subcontract, consultant agreement, cooperative agreement with the Department of Behavioral and Developmental Services, for eligible children ages birth to age 2, and their families, that include screening, information, counseling and therapy. Infant mental health services reduce developmental and emotional delays; alleviate problematic behaviors; stabilize the family living environment; and minimize the necessity for out-of-home placement. Services assist parents and family members to understand the effects of the child's disabilities, and assist parents and family members to affect their child's developmental growth. (See Appendix ME for additional information.)

ENROLLMENT OF BENEFICIARIES IN GROUP HEALTH PLANS

In fiscally challenging times, states have looked to partner their Medicaid and State Children's Health Insurance Programs (SCHIP) with the private sector through premium-assistance programs. States have several options for implementing these programs, including:

- Medicaid—through §1906—Health Insurance Premium Payment (HIPP);
- SCHIP separate child health programs; or
- Section 1115 demonstration waivers or Health Insurance Flexibility and Accountability (HIFA) waivers.

Although most states have used SCHIP or waiver authority to implement premium assistance programs, at least 9 states[81] have adopted the HIPP model. The HIPP provision was added to the Medicaid statute in 1990. It required states to establish Medicaid programs to pay for the cost of health insurance premiums, coinsurances,

[81] GA, IA, MA, MO, PA, RI, TX, VA, WI

and deductibles for Medicaid-eligible people with access to employer-based insurance, when it is proven cost-effective for them to do so. Employer-based coverage is considered cost-effective if its costs are likely to be lower than the costs incurred by the state providing Medicaid coverage. The Health Insurance Premium Payment (HIPP) program is a Medicaid program that may pay for the cost of private health insurance premiums, when it is found to be cost-effective. The HIPP Program will determine if it would be cheaper to pay for the health insurance premiums instead of having Medicaid pay for all the medical bills.

The HIPP Program is advantageous to the state Medicaid agencies and to the taxpayer because it enables the Medicaid agency to shift some of the costs of care to liable third parties. Providers of medical care benefit from the HIPP program because insurance payments for the cost of care are usually more than what Medicaid would pay.

HIPP has potential significance for families with minor children under age 19 who qualify for Medicaid but whose parents have access to private insurance. If a child qualifies for HIPP and the family's private insurance plan also covers the entire family, the advantage is that parents and other siblings, who may not be directly covered by Medicaid, may also benefit. In such instances, the premium for the entire family is paid.

HIPP enrollees are entitled to all the states' Medicaid benefits, including those not included in the employer-based insurance plans. State Medicaid programs must cover certain services that are not covered by private plans.

Although the original 1990 provision was mandatory for states, a 1997 amendment made the program voluntary. This change may have been a response to the failure of many states to implement the HIPP program. According to a 1994 report by the Office of the Inspector General, at least 30 states had not implemented the provision at that point in time. Likewise, those states with active HIPP programs have struggled, experiencing very low enrollment, and achieving modest, if any, savings.

In 1997, the U.S. General Accounting Office (GAO) disseminated a report on the barriers states had experienced in enrolling beneficiaries to their HIPP plans. The major obstacles cited by the GAO included: difficulty in identifying eligibles, poor cooperation by employers to provide information regarding health insurance coverage offered, and difficulty enrolling HIPP eligibles within private health plans' narrow open-enrollment periods.

As state budgets become increasingly more challenging, state Part C planners may want to investigate their state's current activities under HIPP (or other premium subsidy efforts) and judge their applicability to Part C accordingly. Much of this will depend upon the state's Medicaid eligibility criteria coupled with the prevalence of private insurance coverage opportunities within the Part C eligible and enrolled population.

SECTION B: REFLECTIONS

1. Does your state serve any categorically needy populations under Medicaid that affect the Part C system?

2. Does your state serve any medically needy populations under Medicaid that affect the Part C system?

3. Does your state have pockets or areas of immigrants, migrant families, legal and/or illegal aliens? What is your state's Medicaid policy re: enrollment of these children in Medicaid?

4. How is your state's SCHIP program configured? Is it a ___ stand-alone, separate program, a ____ Medicaid expansion, or ____ both?

5. How are very young children, Birth-3, covered under SCHIP?

6. Does Part C have an interagency agreement with the state Medical program? If so, what is the basis of the agreement and the particular conditions (e.g., referral and outreach, shared monitoring, etc.)

7. Does Part C have an interagency agreement with the state SCHIP program? (e.g., referral, shared monitoring, etc.)

8. Does Part C have an interagency agreement with the state CSHCN program? (e.g., referral, service/care coordination, shared monitoring, etc.)

9. Who are enrolled, approved providers for Medicaid in your state?

Provider Type	Medicaid Enrolled/Recognized	SCHIP Enrolled/Recognized
Audiologists		
Family Therapists		
Nurses		
Nutritionists/Dieticians		
Occupational Therapists		
Orientation/Mobility Specialists		
Pediatricians and other physicians		
Physical Therapists		
Psychologists		
Social Workers		
Special Educators/Developmental Therapists		
Speech/language Pathologists		
Autism Specialists		
Para-professionals (type)		
Interpreter/Translators		

Other:		
Other:		
Other:		
Other:		

10. What are the unit configurations and rates for typical Part C services that your state's Medicaid agency pays for Medicaid and/or SCHIP?

Service	Medicaid Unit /and Rate	SCHIP Unit /and Rate	Current Part C covered service?
Screening			Yes/No
Assessment/Evaluation			Yes/No
IFSP Plan Development			Yes/No
Service Coordination			Yes/No
Assistive Technology/Durable Medical Equipment (DME)			Yes/No
Audiology			Yes/No
Family training, counseling and home visits (anticipatory guidance)			Yes/No
Health services			Yes/No
Medical services			Yes/No
Interpreter Services			Yes/No
Nursing services			Yes/No

Nutrition services			Yes/No
Occupational Therapy			Yes/No
Physical Therapy			Yes/No
Social Work services			Yes/No
Special instruction/education/ developmental therapy			Yes/No
Speech/language services			Yes/No
Transportation			Yes/No
Vision services			Yes/No
Other:			Yes/No
Other:			Yes/No
Other:			Yes/No
Other:			Yes/No

11. When and how were the rates for the above services last configured?
    a. Try to locate someone who can help you understand what the methodology and cost centers for this rate development were, if possible.

12. Has your state reduced Medicaid or SCHIP reimbursement rates in the last two years?
    a. Medicaid:
    b. SCHIP:

13. How does your state Medicaid agency require third party liability to be managed by providers?
    a. Providers must bill all third party resources first before accessing Medicaid. Must show proof of denial with claim submission to Medicaid.
    b. Medicaid pays providers first and then "chases" third party resources.

c. Medicaid doesn't require third party liability to be pursued for this population.

14. Does the state Medicaid agency have internal, state agency staff who conduct monitoring, utilization and review OR is this service, or any part of it, contracted out to a third party external to state government?

15. What is the rate of Medicaid enrolled children in the state's Part C system?
    a. How does this compare with the general enrollment of children Birth-3?
    b. Are there pockets or populations of children that are under-enrolled? If so, why? Where are they?

16. Does the state Medicaid agency forgo the utilization of third party resources under any circumstances?

17. What are the eligibility criteria for your state's Part C system?
    a. Developmental Delay: _____
    b. Medical conditions: _____
    c. Biological and/or environmental conditions: _____

18. Does your state's Part C system have a family cost participation/fee policy?

19. Does your state's Part C system require the use of private insurance?
    a. If so, how does the Part C system access this funding?

20. What about the state Medicaid program and Part C system is working right now?

21. What about the state Medicaid program and Part C system needs improvement?

22. Do these challenges affect other child- and family-serving programs beyond Part C? If so, who?

SECTION C. NEXT STEPS: CRITICAL INFORMATION NEEDED TO MAKE INFORMED PUBLIC POLICY DECISIONS

This Section of the Technical Assistance Paper provides a framework for:

- Identifying the right questions and issues to consider, and
- Offering a "road map" for state Part C planners to follow as they conduct fact finding and facilitate interagency and stakeholder discussions

There are considerable complexities in state Part C systems and within the diversity of Medicaid opportunities. State Part C planners will benefit from doing a careful landscape review, understand how Medicaid has been utilized for similar populations in the past (successes and failures!), and learn about the current scope and responsibility of their state's Medicaid system as they lay the groundwork for potential changes or expansions for early intervention.

With very few exceptions, Medicaid "maximization" efforts occurred in most states prior to the advent of Part C implementation. These efforts were largely spearheaded by state Mental Health/Mental Retardation (MHMR agencies in their quest to provide a comprehensive range of services to individuals with mental retardation, mental illness, and chronic mental health challenges. Due to the range in age and situations of their population, state MHMR agencies have had to work with diverse state agencies including education, corrections/juvenile justice, health and social services. The impact of OBRA'89 did not go unnoticed by many state educational agencies which now report that all states have established avenues for accessing Medicaid for special education services to some degree. These arrangements are very diverse and include the Part C population in at least two (2) states.

PURPOSE OF THIS SECTION

There are a variety of data and considerations to be identified and employed in defining how best to utilize Medicaid. There is typically more than one approach that can be used effectively by a state which will maximize Medicaid revenue without compromising the critical Part C vision and tenets. Management of any single or combination of diverse approaches needs to be carefully considered within the whole framework of Part C administration.

This Section provides a comprehensive discussion of the factors to be considered and weighed as states explore fund expansion or reorganization for Part C systems under Medicaid, and provide opportunities that support thoughtful decision making and plannedful outcomes. This Paper offers access to several state examples of successful state plan amendments, as well as Part C policies, procedures, billing codes and rates. Web site links and appendices are provided as appropriate throughout this Paper.

EFFORT VS. OUTCOME

Federal and state Part C funds continue to be the first and second most significant fund sources used by states, as reported by 43 states and three territories (District of Columbia, Puerto Rico, Virgin Islands) in the ITCA National Survey. Medicaid is noted as third most significant resource utilized by states but not for the territories, given their federal funding limitations. Many states report that all Part C services are "covered services" by Medicaid[81]; assistive technology devices and services, medical services, nursing services, occupational and physical therapies, speech/language therapy, and transportation are reported as funded in all reporting states. States access these Medicaid funds using a variety of approaches with standard Medicaid being the most dominant approach reported. Very few states reported using only one approach to

[81] In addition to documents provided by several states expressly for this Paper, data was obtained from the ITCA National Survey, state Annual Performance Reviews, and CMS SPA documents.

access in Medicaid; in addition, few states as well reported administrative claiming agreements. At least eight (8) states reported that SCHIP was paying for Part C services including four (4) of these states reporting that special instruction was included in SCHIP reimbursement.

The methods, approaches and success of states in accessing Medicaid for Part C services range considerably. In most instances, relationships with the state Medicaid agency were crafted for individuals with disabilities before the implementation of Part C. Some states interviewed for this Paper stated that the existence of already developed models to access Medicaid served as opportunities for them to either "piggy-back" upon, or use as a vehicle to start discussions specific to Part C needs. Sometimes these historical relationships served the state Part C system well; other times, particularly if the prior relationship had problems, this didn't particularly help the state Part C system.

Several Part C and Medicaid administrators spoke of the importance of having a common language from which to speak. The "own-ness" in each of these situations to develop the common language, per report, was typically the responsibility of the state Part C system, who worked diligently to create cross-walks, definition comparisons, etc., in order to illustrate the potential for partnership with their state's Medicaid agency. Having a solid understanding of the current cadre of services and supports that the state Medicaid agency already had in place was essential to the success of the Part C system. In one state, the Part C Coordinator and staff developed a complex cross-walk that identified the elements of Part C and highlighted how other similar systems in the state (disability, mental health/mental retardation, social services, etc.) were accessing Medicaid for comparable services. This assisted the Part C planners to know first hand the similarities and differences between and amongst the populations, identify what was working well from both agencies perspectives, and also know about some trouble spots or weaknesses that were of concern to the Medicaid agency in preparation for dialogue.

The majority of individuals interviewed for this Paper cited the tremendous importance and impact of relationships upon the process. Sometimes having an advocate in the state Medicaid agency was all that it took to navigate to a successful partnership. In one state example, both agency representatives talked about how important it was to have knowledgeable individuals directly involved who had a level of authority from which to "speak and know" the other agency's needs. Some Medicaid agency administrators expressed appreciation for the understanding demonstrated by the state Part C planners to the reality of staffing limitations, time and (increasingly) budgetary limitations.

Some states reported that their partners in Medicaid welcomed Part C planners to guide the SPA development process, which included defining services, provider qualifications, documentation, quality indicators, etc. Personnel capacity in Medicaid was limited as was their knowledge and understanding of Part C. In many instances, Part C planners wrote state plan amendments for the consideration of their counterparts in state Medicaid agencies; from here, dialogue and discussion proceeded and progress was made without undue delays or disruptions due to personnel shortages.

Communication was key to success. In some instances, the importance of the confidentiality of the deliberations was important to participants. No one wanted to be pre-empted, embarrassed or misrepresented – particularly in public. Honoring state agency "protocols" and internal communications policies including the sensitivity to who signs the communications was important to ensuring collaboration and respectful dialogue. Joint letters to the field signed by both Medicaid and the Part C system leadership were recommended in order to give a unified position. And, as earlier stated, ensuring that each agency understands the terminology of the other helps to build confidence and avoid misunderstandings or misinterpretations.

Some state Part C planners talked about how "nothing happened" in terms of partnerships with Medicaid until a certain "key opportunity" presented itself. This might include administrative changes at the state Medicaid or Part C agency, the adoption

by the Governor's spouse of early intervention as a signature initiative (most typically, general early childhood services), or leadership provided by the State Interagency Coordinating Council membership. Once the opportunity appeared, time was of the essence and Part C planners needed to be able to respond quickly!

As the reader has seen in earlier Sections of this Paper, states have significant latitude and flexibility in defining services, identifying qualified providers and determining reimbursement. State Medicaid agencies must be diligent in providing services in the most effective manner; Part C systems share and appreciate the importance of the effective use of all available resources coupled with efforts to reduce – if not eliminate – duplication. Part C is an important service provider to each state's Medicaid agency. Due to the targeted nature of their services, Part C can help the state Medicaid agency to meet its federal requirements related to enrolling eligible children and ensuring the provision of needed services in conformance with the high standards of its early intervention system.

Because of the diversity of state populations as well as the way in which each state has chosen to implement its Medicaid systems, the individual considerations that will be reviewed next in this Paper may assume different proportions or importance from one state to another as Part C planners examine their Medicaid opportunities. The importance of understanding your state's landscape, particularly as the impact of federal and state budget cuts and program reductions take effect in the remainder of 2005 and into 2006 and beyond, cannot be understated.

As most states face the reality of tighter state budgets and growing numbers of children referred, Part C planners will want to understand the variety of funding options available, how can these "match" with the enrolled Part C population, philosophy and regulations, and what benefits partnering will provide. The clear and obvious advantage of Medicaid partnerships is that all states benefit from accessing Medicaid for this population, where the least they will benefit is 50 cents on every administrative or service dollar directed towards this population. The failure or inability of a state to access Medicaid means several things. One, the state is paying 100 cents on every

administrative or service dollar, and/or two, children and families aren't receiving the needed services, thus risking the state's continued participation in Part C. States without organized approaches to accessing Medicaid also risk not only duplication of service, but also the potential for duplicate billings to both systems.

The active involvement and commitment of leadership was cited as very important by several Part C planners through the course of verification for this Paper. In one state, expansive plans and draft state plan amendment documents related to Part C access to Medicaid had been "dormant" for several years when a new agency Commissioner came on board. During the orientation phase for this new administrator, the opportunity arose to present the need to resurface these plans for review and submission to CMS. Within six (6) months, significant Medicaid changes had been achieved for this state's Part C system.

Who's Eligible?

State Part C systems have been in operation for more than a decade, allowing most states to cultivate both experience and data that helps to guide decision-making. Each state Medicaid agency will be able to provide the Part C system with enrollment information, usually by age cohort (Birth-1, 1-2, 2-3) and county of residence. Comparing these data against state population figures will identify the state's average percentage of enrollment of children under the age of three in Medicaid. Given the relationship of poverty to disability, it is reasonable to estimate that there will be more children eligible and enrolled in Part C who are also Medicaid eligible. This number can be as high as 20% above the typical Birth-3 cohort depending upon the state's Part C eligibility and the variety of eligibility avenues that are afforded to very young children through Medicaid.

Some state Part C data systems collect a variety of family demographics including family income information. This information allows them to assist more families to access other financial and program resources with eligibilities that are typically income-based. It also informs Part C planners how many Medicaid-enrolled children there are in Part C,

by county/region/district and by age at enrollment as well. Knowing how many children are enrolled in Medicaid is important; understanding how long they are typically enrolled in Part C is vital. Child age and Federal Poverty Level (FPL) are two key indicators to have when projecting Medicaid enrollment for planning purposes. While children may enter Part C at an early age, differences in state eligibility may mean that these children lose their eligibility at age 1 or later. Further, anticipated changes in eligibility may mean that children beyond age 1 have a higher FPL for eligibility. Changes in EPSDT are very possible[82]; meaning that Congress may elect to reduce the cadre of services for this population including eliminating entirely the EPSDT provisions across the board.

Observing the growth, if any, in Part C enrollment over time, as well as changes in the enrollment by child age, will also be beneficial for Part C planners. Analysis of the Child Count over a four year period of time (2000-2003) indicated the following:

Eligibility Category Type	Child Count Increased	Child Count Remained the Same	Child Count Decreased
BROAD	23 states		6 states (DE, CO, FL, MS, NH, VA)
MODERATE	11 states	State (OR)	3 states (SC, TN, UT)
NARROW	6 states		2 states (AK, NV)

Figure 27: State Part C Eligibility in Relationship to Medicaid Growth, Source: Solutions Consulting Group, LLC based upon data from WESTAT

State planners will want to understand what causes fluctuations in the Child Count; some influences may be planned (such as a major Child Find campaign, changes in eligibility); others may be less evident and need probing.

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[82]Web site information related to potential Medicaid changes:
http://www.nga.org/cda/files/0506medicaid.pdf
http://www.nga.org/nga/legislativeUpdate/1,1169,C_ISSUE_BRIEF^D_8383,00.html
http://www.ncsl.org/statefed/medicaidactionpolicy1204.htm
http://www.cms.hhs.gov/media/press/release.asp?Counter=1266

Appendix S provides a chart illustrating some key data that will assist Part C planners to anticipate potential growth in Part C, and subsequent Medicaid enrollment, based upon the unique characteristics of their population. These data are readily available on the Internet through each state's Maternal and Child Health agency, and state health, education and human service departments.

Understanding the relationship between the Part C population and Medicaid enrollment also helps Part C planners to target areas of the state for more aggressive outreach and recruitment efforts. One example would be when state Part C planners identify that the enrollment of Part C children in Medicaid is at or less than the typical cohort enrollment within a given geographic area.

While the national average for Child Count is currently 2.3% (2003), state enrollment varies substantially (5.75% to .94%). Many states estimate that approximately twice this number of children are served in a one year period of time. For the most part, these variations do not seem to be influenced by the eligibility standard or the lead agency type. Within each state, there is typically diversity in the percentage of children served between individual county/region/district geographic areas. Some areas serve fewer than the state average; some more. This variation, similar to the national variation from state to state, is to be expected due to the multiple influences inherent within the individual location populations. For most, if not all states, it is to be anticipated that there should be continued growth in the Part C population and, for some states and locales, the percentage of potential enrollment is substantially more than 2.3% and may in fact be in the "double-digits."

Understanding the state trends for enrollment also includes the identification of the presenting needs of children and their families, providing rich information for projecting capacity needs by service type, training needs, and financial forecasting.

Covered Services

Impact of OBRA'89

For children enrolled in their state's Medicaid EPSDT program, OBRA'89 created the requirement of the state not only to provide periodic and inter-periodic screening across a wide range of developmental and health care needs, but also to provide appropriate treatment when a need is identified and diagnosed in a screening. Participation in EPSDT is not automatic; families must be informed about this opportunity, understand the benefits of enrolling their child, and consent to enrollment. This treatment or service must be provided even if it is not a covered service in the state plan, but on the listing of mandatory and optional services for Medicaid. (See listings in Section A, pages 57-58 and 59 respectively.)

The expansion of the definition of screening in OBRA'89 to include all of the developmental domains, including mental health, includes the variety of Part C services under the "Treatment" piece of EPSDT. Figure 28 (pages 158-160) provides a crosswalk between Medicaid and Part C services, starting with the definition of screening as required by EPSDT. (NOTE: This Figure does not present a full listing of optional Medicaid services.)

The approaches that states have taken to include early intervention services in Medicaid reimbursement reflect considerable diversity; one that appears to be more related to the historical approaches than states have used for other populations of individuals with disabilities.

Figure 28: Part C/EPSDT/Medicaid Services Crosswalk

Part C Service	Medicaid EPSDT Screening	Optional Medicaid Services
Evaluation means the procedures used by appropriate qualified personnel to determine a child's initial and continuing eligibility under this part, consistent with the definition of ``infants and toddlers with disabilities'' in Sec. 303.16, including determining the status of the child in each of the developmental areas in paragraph in (c)(3)(ii) of Section 303.322.	Comprehensive Health and Developmental History to include physical and mental health	Screening, Diagnostic Services
	Vision Screening	Optometrists' Services, Eyeglasses
	Dental Screening	Dental Services, Dentures
	Hearing Screening	Speech, Hearing and Language Therapy Services
Assessment means the ongoing procedures used by appropriate qualified personnel throughout the period of a child's eligibility under this part to identify-- (i) The child's unique strengths and needs and the services appropriate to meet those needs; and (ii) The resources, priorities, and concerns of the family and the supports and services necessary to enhance the family's capacity to meet the developmental needs of their infant or toddler with a disability.	Developmental Assessment	Preventive Services designed to address an area identified as a result of a developmental screening in one or more areas of development including but not limited to Medical Social Work Services, Psychologists' Services, Physical/Occupational/Speech-Language-Hearing Services
	Health education, anticipatory guidance and counseling	

Part C Service	Medicaid EPSDT Screening	Optional Medicaid Services
Physical Therapy Services, Assistive Technology Devices and Services, Special Instruction, Vision Services	Gross motor skills	Preventive Services designed to address an area identified as a result of a developmental screening in one or more areas of development including Podiatry Services, Physical Therapy Services, Durable Medical Equipment (DME) through the provision of home/health services, rehabilitation services and services which support independent living.
Occupational Therapy Services, Assistive Technology Devices and Services, Special Instruction, Vision Services	Fine motor skills	Preventive Services designed to address an area identified as a result of a developmental screening in one or more areas of development including Occupational Therapy, Prosthetic Devices, Durable Medical Equipment (DME) through the provision of home/health services, rehabilitation services and services which support independent living.
Speech-Language Pathology Services, Assistive Technology Devices and Services, Special Instruction, Vision Services	Communication skills or language development skills	Preventive Services designed to address an area identified as a result of a developmental screening in one or more areas of development including Speech, Hearing and Language Therapy Services, Durable Medical Equipment (DME) through the provision of home/health services, rehabilitation services and services which support independent living.

Part C Service	Medicaid EPSDT Screening	Optional Medicaid Services
Special Instruction, Physical/Occupational/Speech-Language Therapy Services, Health Services, Assistive Technology Devices and Services	Self-help and self-care skills (adaptive skills)	Preventive Services designed to address an area identified as a result of a developmental screening in one or more areas of development, Durable Medical Equipment (DME) through the provision of home/health services, rehabilitation services and services which support independent living.
Nutrition Services	Assessment of Nutritional Status	Preventive Services
Medical Services	Complete physical examination	Prescribed drugs, Clinic and/or Emergency Hospital Services, Nursing Services, Hospice Case Services, Respiratory Care Services
	Medical laboratory tests for lead screening, iron deficiency, cholesterol	
Service Coordination	Administrative Services	Case Management Services
Transportation	Transportation to be made available and provided as needed to and from services and health care visits	Transportation to be made available and provided as needed to and from services and health care visits; can include specialized transportation if needed
Family training, counseling and home visits – all disciplines including Special Instruction	EPSDT providers are required to provide anticipatory guidance, health education and prevention services within the context of their meetings with families/patients.	Personal care services, Private duty nursing (home health), rehabilitative services, ICF/MR services
Interpreter Services	Required to ensure that non-English speaking persons who are eligible gain access to Medicaid services. Usually has state provider qualifications; may be funded through administrative services or EPSDT.	Required to ensure that non-English speaking persons who are eligible gain access to Medicaid services. Usually has state provider qualifications; may be funded through administrative services or EPSDT.

Many state Part C planners report that they continue to experience problems in accessing Medicaid due to the delivery model that is employed by Part C – family centered, community based services, emphasizing typical routines and daily activities while working to enhance each family's capacity to meet the developmental needs of their child.

Special Instruction

Special Instruction has been a challenge for many Part C systems in terms of accessing Medicaid. In some states, this is a primary service for most – if not all – Part C children and families. While the amendments under OBRA'89 assisted many states tremendously, regional CMS offices have recently declined a state SPA with this service included even though a total of 22 states report[83] that Medicaid participates in the payment of all required Part C services including special instruction. Some states have termed this Part C service "developmental therapy" in order to achieve consistency with Medicaid terminology in EPSDT requiring a developmental screening.

Maine established reimbursement for developmental therapy, social work services and collateral services for Part C and Section 619 services by establishing a new EPSDT service entitled "Early Intervention Services." The State Plan Amendment (SPA) was first effective October 1, 1991; rules were promulgated on March 23, 1992. This SPA reflected inclusion of Part C services that were not already covered Medicaid services. Close collaboration with the state Medicaid agency and knowledgeable, committed Medicaid staff were pivotal to the success of this initiative, and to its continued operation. The development work to achieve this initiative took approximately 18 months of interagency discussions, research, collaboration and coordination. Services may be provided in a variety of settings including the home and other community settings. Maine utilizes standard Medicaid for other covered services which are required by Part C and Section 619 of

[83] ITCA National Survey database

IDEA. Services must be delineated in the IFSP or IEP, with the state's system – Child Development Services – identifying and credentialing providers, ensuring compliance through rigorous monitoring, and ensuring coordination of services through a Targeted Case Management Services option which was expanded to include this specific population.

Nevada utilized a Rehabilitation Services Option, which was originally established in 1985, to establish "rehabilitation therapy" for Part C children to be provided by professionals licensed by the State Department of Education as Child Development Specialists. Services may be provided in a variety of settings including the home and other community settings, with the IFSP defining the frequency, intensity, location and duration of services.

Texas recently established "developmental rehabilitation services" which are provided by the array of Part C providers, according to the IFSP. This SPA was approved by CMS in 2001 for services provided in 2000. This initiative was recommended in the 1998 Sunset Commission Review by that state's Legislature, and is a companion to other approaches to accessing Medicaid for ECI including a TCM, specialty services through EPSDT, and administrative claiming.

At least two other states have approved state plans and have implemented early intervention services that are defined differently and encompass the range of early intervention practitioners or providers. This approach has helped to move the Part C system away from what has been perceived as a "medical model" and more towards developmentally appropriate practices. Services are defined more generically and include:

- Developmental Monitoring
- Eligibility Determination
- Evaluation and Assessment
- Service Coordination
- Developmental Intervention and/or Therapeutic Intervention
- Teaming
- Collateral Contacts
- Assistive Technology Devices and Services

Depending upon the specific financing approach being used with the state Medicaid agency, many states have been able to craft language that incorporates all of the key Part C principles including the use of the IFSP and team to define services on an individualized basis, the importance of services emphasizing daily routines and typical activities, etc.

One challenge that many states have identified is the difficulty accessing reimbursement for "teaming" activities, as well as reimbursement when more than one provider is conducting assessment services or participating in collaborative family training. Increasingly, states have included "collateral" contact in that state's SPA to include "face-to-face contact by a therapists with other professionals, caregivers, or others included in the treatment plan to seek information or discuss the recipient's case and to achieve continuity of care, coordination of services, and the most appropriate mix of services for the recipient." Collateral contact in at least one state cannot be billed when provided on the same day that direct services are provided.

Through these definitions, which were established by the Part C system in accordance with the Medicaid interagency agreement, reimbursement by all partner funding sources including Medicaid is ensured for the variety of teaming activities that are performed throughout the Part C process.

As another example, Kentucky crafted their services, in addition to service coordination, through a Title V collaborative agreement, to include:

- Evaluation
- Service Assessment
- Treatment
- Integrated Disciplines/Center-Based
- Collateral Services
- Assistive Technology

Increasingly, the state's early intervention system is the enrolled Medicaid provider and responsible for a wide range of responsibilities (establishing provider qualifications, provider recruitment and credentialing, monitoring, training and technical assistance) as well as establishing comprehensive regulations including reimbursement approaches that are implemented through their partnership with Medicaid.

In addition to establishing Medicaid partnerships through a Title V Agreement, the use of the "Organized Health Care Delivery System"[84] is another vehicle available to state Part C systems. Medicaid regulations establish the option for an entity to receive Medicaid payments directly for the provision of at least one covered service in the state's Medicaid plan or help the state to implement a waiver program. At least one state utilized this approach for it's Part C system. This structure permitted the state's lead agency to be the Medicaid provider for early intervention services, and to enroll providers under the "umbrella." This state implemented its Part C system with consistent or "universal" provider certification, enrollment, service definitions, monitoring, etc. for all services irrespective of their funding source(s).

[84] http://www.cms.hhs.gov/manuals/45_smm/sm_02_2_2080_to_2089.9.asp

New Mexico's Family Infant Toddler (FIT) Program also has implemented Medicaid reimbursement through EPSDT, which it has titled "Special Rehabilitation Services." Approved and implemented effective 1995, three (3) specific initiatives were approved (Service Coordination, Early Intervention and Comprehensive Multidisciplinary Evaluations) to assist this state to obtain Medicaid reimbursement for Part C services. Regulations are promulgated by the Human Services Department governing the Medicaid - Special Rehabilitation services. Billing for special rehabilitation services matches the scope of services through the Department of Health, FIT Program and common rates are utilized by both programs. Rates for early intervention are based on four location billing codes. Negotiations between the state and regional Medicaid officials consumed several years before this SPA was approved.

The diversity of approaches that states have taken to configure Medicaid funding for Part C services indicates that many state Part C systems, in collaboration with the state Medicaid agency, have been able to develop and have approved SPA's that recognize the unique characteristics of the Part C legislation and regulations. States have broad flexibility in establishing provider qualifications that include traditional as well as nontraditional providers for these Medicaid funded services. Many states successfully include the variety of Part C components within Medicaid reimbursement structures, including monitoring and supervision, Child Find and public awareness, training and technical assistance, etc. Several states include all of the Part C services as well as special instruction (termed "anticipatory guidance") and collateral contacts for all services as Medicaid funded activities.

Part C Service Delivery Models

Discussions with state Part C planners revealed that many states are moving towards, if not seriously considering, a greater emphasis on alternative models of service delivery in Part C. While there is no "one size fits all," the consultative or primary coach model does offer states the opportunity to structure increased family-centered, developmentally appropriate supports and resources to enrolled families. These models, as well as transdisciplinary or interdisciplinary models, provide a range of supports and resources to the family that are adjusted as progress is made and family priorities and/or needs change. The emphasis is placed on supporting families, caregivers and the community resources in responding to the child's developmental needs rather than the provision of hands-on, direct therapies.

Concurrent in any of these model approaches is the need for training and teaming, which – at least initially – is an intensive, time consuming commitment. Every state Medicaid agency is not only committed to "doing the right thing" – but also doing it in the most cost effective way possible, with the best outcomes. Part C planners interested in implementing these model options will need to develop a comprehensive data-based research approach in order to collect the type and intensity of information that is required to persuade Medicaid agencies to do business differently. What are the savings? When do they occur? How do these models compare with traditional therapies in terms of resulting in positive developmental outcomes? What are the short- and long-term effects upon families?

One state's effort to demonstrate the effectiveness of alternative service delivery approaches has been multi-faceted. They modified their IFSP to better capture the amount of time spent and number of disciplines involved in "teaming" activities so that delineation can be made between face-to-face time with a child and family, co-treatment visits and teaming. They also will compare the services by intensity and frequency between those children and families who receive services in a more traditional model against these new data.

This state is also going to families to obtain feedback from them specifically related to their outcomes and impressions (e.g., increase inclusion, competence, ability to support their child, satisfaction, etc.). In addition to family feedback, they will also monitor the progress and attainment of IFSP outcomes for children in both models.

Cost is a consideration for this state as they move forward, and they are having their local entities report to them how much they are spending specifically to support MDT facilitation, teaming, and coaching activities that are not reimbursed by other fund sources.

Because of the flexibility already offered through many Medicaid options, State Part C planners and their partners in Medicaid have the opportunity to reflect a variety of service delivery models within the Medicaid reimbursement. By combining provider definitions and qualifications together with service descriptions, states have already been able to incorporate a number of different service approaches that reflect best practice under Part C. It is likely that these kinds of approaches will become more accepted and recognized by Medicaid agencies once the right kind of data (cost and outcome) are provided to them.

Amount, Intensity and Duration of Services

The individualized nature of Part C requires that services are determined through the multidisciplinary process, emphasizing a strengths-based approach to enhancing each family's capacity to respond to the developmental needs of their child. State Medicaid agencies, increasingly, have established "caps" or limits on service frequency and/or intensity which poses particular problems for Part C planners when IFSP recommendations exceed the Medicaid "cap" for an enrolled child. While service limits cannot be imposed under EPSDT, they may be a part of an approach such as an HCBS or Rehabilitation Option to manage costs. Caps or limits on care are certainly prevalent in the managed care (MCO) environment. Typically where service caps or limits exist, there is a system for appeal or prior authorization which can be utilized as necessary to exceed the prescribed limit(s).

The existence of "caps" or limits to services can also come into play when accessing private insurance when the child is also enrolled with Medicaid. In these cases, private insurance is utilized first to the maximum degree available and the provider switches to Medicaid for reimbursement after the cap or limit is exhausted.

Very few state Part C planners report that they have developed formal or informal service "guidelines" that are intended to help prevent over-utilization in Part C by all participating fund sources. The experiences in at least two (2) states where specific service limits were established, including prior authorization in cases where the limits needed to be exceed as a result of the IFSP team decisions, were that IFSPs tended to "hover" around the service limits for the majority of children with the request for prior authorization to exceed these limits rarely if ever utilized. As one state Part C planner said, teams "rose to the occasion" and met the cap. As most state systems continue to address appropriate service models and options, as well as appropriate service frequencies, the individualized nature of the early intervention system suggests that caps or service limits are not compatible with the regulations and/or the philosophy of Part C. State Part C planners reported utilizing data more frequently as a method for identifying issues and targeting interventions when the level of service appeared to be problematic.

Medical Necessity

A review of many approved SPAs revealed that the IFSP was frequently cited as the method for determining both medical necessity as well as meeting any Medicaid requirement for prior authorization. Professional assessments, together with the identification of family concerns, priorities and resources, produce a series of outcomes with needed service(s) identified. The participation of multidisciplinary teams in the assessment and IFSP development process has met the requirement, if one exists.

Many state licensure boards for physical, occupational and speech-language therapy require physician prescription for services. This requirement is inconsistent from state to state. In several states, physician prescription is needed for evaluation and service delivery; in other states, just for service delivery. In still other states, physician

prescription is needed for some disciplines, by function, and not for others. Physician prescription is not a Part C requirement nor is it a Medicaid requirement; it becomes a practice for children enrolled in Medicaid due to the relationship of using a licensed service provider and is usually limited to physical, occupational and speech-language therapy services. The function of obtaining the prescription from the physician is typically performed by the service provider, but in some cases is identified as the responsibility of the service coordinator or the family. The frequency with which physician prescription is required is also determined by state licensure and ranges from quarterly to annually, as well as varying in purpose.

Several states cite this licensure requirement as a concern, while acknowledging that it has to be completed in order to meet state licensure requirements for the individual provider. Even though it is not a Part C requirement, it can become labor intensive and cause unnecessary delays in providing Part C services. Physicians often legitimately require that they see the child before authorizing a particular service, particularly if they haven't seen the child recently. This can result in cost to the family which some Part C systems do pay for. Some provider agencies address this requirement by having a physician consultant whose responsibility it is to conduct chart review and issue prescriptions for services. This practice, particularly for young children, bypasses the medical home concept and risks contraindicated care particularly for those children with multiple needs. The American Academy of Pediatrics understands these issues and challenges and has conducted research on physician practices, which is summarized in a publication entitled "Policy versus Practice: Comparison of Prescribing Therapy and Durable Medical Equipment in Medical and Educational Settings"[85] (June 2005). They have also distributed a document, Appendix W, entitled Best Practices related to Medical Necessity.

In several states, medical necessity has been met by having the physician's signature on the IFSP. Indiana has successfully employed this practice for several years. Indiana notes that this practice has helped to

[85] http://pediatrics.aappublications.org/cgi/content/abstract/114/5/e612

bridge communications between the medical community and their First Steps system. In this state, service coordinators are responsible for this requirement, ensuring that the child's primary physician has a copy of the IFSP or a summary statement in the process. Physician prescription is required for some services and is the responsibility of the provider to obtain and retain on file.

Idaho requires either a physician's signature on the IFSP or another written "order" for services which will be reimbursed by Medicaid. They will accept a letter from the physician or a prescription or a particular form developed by their Healthy Connections (Medicaid managed care) unit. This option became important because the provider found they couldn't always wait for the physician's signature on the IFSP to start services as this sometimes became a reason for not meeting the 45 day timeline or a reason for having service implementation delays. Idaho strongly encourages physician involvement for all children in Part C but do not require this.

In Connecticut, state Medicaid regulations require physician participation in the review of the determination of eligibility and in the IFSP. (Appendix CT) For eligible children, the Part C system obtains the physician's signature on the IFSP which includes the services and the child's ICD-9 code. For children who are not eligible, a form is sent to the physician for signature just for the evaluation since there won't be an IFSP.

The implementation of medical homes for CSHCN has highlighted the importance of the relationships between Part C systems and primary care, and may contribute to some states' rationale for physician signature on the IFSP, or the requirement to send a service summary to the child's primary care physician.

Provider Qualifications

For more than a decade, federal Medicaid has been a leader in supporting state and federal efforts to reduce institutionalism and support the successful integration and participation of persons with disabilities in their communities. The unfolding of Medicaid waiver programs, particularly Home and Community-Based Services (HCBS), has helped many states to create a continuum of support for individuals in their community that has allowed considerable expansion of the inclusion to consist of a variety of non-traditional providers and services. This opportunity is not limited to HCBS or other waiver programs; many Part C systems have been successful in incorporating individuals, including educators, as qualified providers for Medicaid covered and reimbursable services under EPSDT/Rehab Options.

State Medicaid agencies and Part C systems routinely defer to the state licensure boards for establishing the licensure and credentials for certain specialty providers. For Part C, this is reflected in the federal requirement for the "highest entry level standard" of provider qualifications. When there is no licensure board to establish these qualifications, the responsibility typically goes to the state lead agency to identify the qualifications, training requirements and credential obligations for certain provider-types such as educators and service coordinators.

In addition to establishing provider qualifications for these functions, most state Part C systems have been able to establish different levels of provider qualifications within the recognized provider standards. Sometimes referred to as "para-professionals," these individuals are often described as "Associates" (versus Specialists), "Aides," "Assistants," etc. This flexibility allows states to expand their provider capacity with appropriately qualified and supervised individuals. Supervision is provided by a licensed or otherwise recognized individual and is sometimes a Medicaid reimbursable service. Depending upon state licensure criteria, the use of aides sometimes extends to physical and occupational therapy aides or assistants, and, infrequently, speech-language aides. In these instances, the licensure board will have defined "supervision" and often requires "on-site" supervision for these individuals. This requirement makes it difficult for Part C to

then reasonably utilize these individuals due to the home and community-based delivery methods of early intervention services and the questionable cost efficiencies of paying for two people. Some states restrict the activities of these individuals, prohibiting them, for example, from conducting assessments or participating alone in the IFSP team.

Often provider recognition or enrollment is a time consuming process, preventing the timely delivery of services in the IFSP if there are provider shortages and discouraging individuals from participating in their state's Part C system. South Carolina's model of a "streamlined provider agreement for non-traditional Medicaid providers" [86] could be a model for Part C planners in reducing the time involved in provider identification and enrollment/recognition, as well as in expanding the provider capacity overall.

Documentation and Record Keeping

Documentation, which is sometimes termed "excessive," is an issue raised frequently in the Part C provider communities throughout the country. When a diversity of fund sources are accessed, it often means that providers must complete multiple or different methods of documentation in order to meet funding requirements. Since provider documentation is rarely included in the development of rates for reimbursement, duplication of effort becomes as concern as does the issue of an audit finding should appropriate documentation be lacking.

Several states have been successful in achieving common documentation, allowing providers to complete one set of paperwork that meets the requirements of Medicaid and Part C. This sometimes means additional documentation of elements beyond what is required by the Part C lead agency. One example of this would be the Medicaid requirement under some funding approaches to document the specific amount of time used to provide a service. Some states including West Virginia have incorporated the "start" and "finish" time on their documentation of services in order to meet this requirement. A copy of this summary is left with the family at the close of the

[86] http://www.cms.hhs.gov/promisingpractices/scspa.pdf

visit. The summary is signed by the family as additional verification of the receipt of services. (See Appendix WV for this resource.)

Texas ECI developed an on-line training module[87] concerning documentation and progress notes. This module discusses what elements should be included in a progress note, how to write a progress note as part of a developmental services or therapy visit, and how to document service coordination and targeted case management contacts. At this time, all progress notes are kept in each child's (physical) folder at the individual program that serves the child and family.

Site of Service Delivery

Part C federal regulations required that services be provided "To the maximum extent appropriate to the needs of the child, early intervention services must be provided in natural environments, including the home and community settings in which children without disabilities participate." (Sec. 303.12 Early intervention services). Sec. 303.18, Natural environments further states: "As used in this part, natural environments means settings that are natural or normal for the child's age peers who have no disabilities."

For the purposes of this discussion, this Paper uses the federal term "Natural Environments" or NE. This term is intended, however, to mean more than a physical location. Early intervention services emphasize the important role that the child's family, caregivers, and community environment play in promoting developmental gains. Part C focuses on enhancing the family's capacity to respond to the developmental needs of their child and helps to build responsive and receptive communities along the way through collaboration with services and programs in which families of very young children tend to participate. NE is more than a place; it is the emphasis of the daily routines and typical activities in which the child and family, or caregivers at the family's

[87] http://www.enspire.com/apps/eci/documentation/movie.html

selection, choose to participate and are reflective, many times, of the family's culture, beliefs and values.

Florida has developed a position statement related to the Natural Environments (NE)[88];

Virginia[89] has recently developed clarification as to what constitutes family support services in an effort to move towards more of a developmental service delivery model than a historical "treatment" or medical model.

This is not a situation unique to either of these states; Part C systems across the country have been challenged to not only implement the NE provisions, but often, to defend them. Many states report that coupling the federal requirement for Part C services to be provided in home and community settings with Medicaid reimbursement has been and, for some, continues to be challenging. Early efforts by some states to access Medicaid through existing programs established for other populations of individuals with disabilities also may have resulted in noncompliance with Part C requirements related to service setting because some states "piggy-backed" upon existing Medicaid opportunities which had requirements that were contrary to the NE provisions.

Frequently the use of home health agencies is cited by state Part C planners as particularly problematic due to the fact that these agencies, established under long-term care initiatives in states, are primarily medical in orientation and often have higher reimbursement rates than other similar services. If the state's existing Medicaid program(s) have some restrictions about "site of service" then sometimes home health agencies are identified as a resource for some early intervention services in order to receive Medicaid reimbursement for these services.

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[88] http://www.doh.state.fl.us/cms/EIPFocusWrkGrp/PosPprProvEIP.doc
[89] http://www.infantva.org/documents/fam-SupportServices.pdf

To be "homebound" generally means that the individual cannot leave home without excessive effort such as but not limited to requiring the aid of supportive devices (i.e. crutches, canes, wheelchairs, and walkers), the use of special transportation, the assistance of another person, or if he or she has a condition which is such that leaving his or her home is medically contraindicated. Absences from home must be infrequent, or of short duration, or to get medical attention. Any absence of an individual from the home attributable to the need to receive health care treatment, including regular absences for the purpose of participating in therapeutic, psychosocial, or medical treatment in an adult day-care program that is licensed or certified by a state, or accredited, to furnish adult day-care services does not disqualify an individual from being considered to be confined to his home. It is expected that in most instances absences from the home which occur will be for the purpose of receiving medical treatment.

However, occasional absences[90] from the home for non-medical purposes, e.g., an occasional trip to the barber, attending a religious service, a walk around the block, or a drive would not necessitate a finding that the individual is not homebound so long as the events are undertaken on an infrequent basis or are of relatively short duration and do not indicate that the patient has the capacity to obtain the health care provided outside rather than in the home.

Applying the homebound standard to the majority of Part C children, depending upon an individual state's eligibility criteria, appears to be inappropriate for this population. However, in order to ensure the provision of services and/or to access Medicaid funds, utilization of home health providers for some states has become a necessity.

One problem cited by Part C planners for this Paper that results in the utilization of home health agencies is that they are then obligated to pay the higher fee should this provider serve a non-Medicaid enrolled child; these fees are often dramatically higher than other therapeutic or health care services due to the requirements of home health

[90] The Social Security Act -- Sections 1814(a)(2)(C) and 1835(a)(2)(A), as amended by Section 4615 of the Balanced Budget Act of 1997

itself. Other states cited the difficulty in ensuring that home health providers were consistent with the Part C requirements, including family centered care. These challenges vary from state to state and often reflect the design of the Part C provider delivery system more than the direct impact of Medicaid regulations.

A review of federal Medicaid regulations identified no federal restrictions on site of service. In fact, recent efforts by the CMS have emphasized the flexibility of the federal Medicaid program to support individuals in their communities to live independent and productive lives through a variety of initiatives. Their advocacy of HCBS waivers is direct evidence of their commitment to ensuring appropriate and individualized care for recipients of all ages. As discussed earlier, federal Medicaid does require that services be delivered in a cost effective manner; recent waiver submissions have required documentation that the cost of the waiver services will not exceed – and possibly be less than – what is currently spent by Medicaid for that population and/or service.

When asked about compensating for services in the natural environment, a few states reported that they have developed different alternatives. More than one state has been successful in incorporating NE considerations into their overall rate of reimbursement, using travel time and cost as one "center" in their cost allocation plan. Other states have concurred with their state Medicaid agency that travel time and cost is NOT a component of the existing Medicaid rate and established an "add on" that is paid either by Medicaid (for their recipients) or by the Part C system for non-Medicaid recipients. One state reported reimbursing providers for their time spent in travel, and has them add this time into their reported units of service delivery which is then compensated at the state Medicaid rate.

State Part C planners reported that there is still much work to do to successfully accomplish services in the NE. Many reported that the perception is that they have been successful simply in moving "therapy to the living room." Other states felt that they were a little farther along; no state reported feeling that they had achieved the level of quality and focus intended by the NE provisions and most are working diligently on this. Some Part C planners reported that, while achieving a 100% or slightly less

success rate in services in the NE, questions remain about the specific nature of these services, the degree to which families are actively involved in the service delivery effort, and the overall incorporation of daily routines and typical activities into the IFSP services.

The success of many states to identify the location of Part C services for Medicaid reimbursement in home and community settings through EPSDT serves as an example to others in crafting this language.

Reimbursement for Medicaid Covered Services

As the discussion in this Paper has unfolded, the tremendous impact of OBRA '89 on Part C has been routinely referenced. Because of this landmark legislation, states have an enormous opportunity to craft specific initiatives that reflect the principles and beliefs of the Part C system as Medicaid covered service(s). Children under age 21, particularly those very young children under age 3, are populations where prevention and early intervention clearly make a difference in a number of ways.[91] This flexibility lends itself to alternative approaches to determining reimbursement rates, which provide the opportunity for Part C planners to include a variety of what may seem to be "nontraditional" costs in the rate methodology approaches that are required for each State Plan Amendment (SPA).

CMS does not approve the specific rate that states develop for the variety of covered Medicaid services; they do approve the rate methodology. Each SPA requires a statement as to how the rate will be configured.

Because of the construct of Part C, which incorporates as many fund sources as possible into the "mix" of resources, there are four (4) components to cost identification and participation that need state Part C planners' attention. These are:

1) Allowability of costs
2) Allocability of those costs

[91] See Bibliography for resources

3) Claimability
4) Satisfaction of the "match" requirement

Cost allocation is a process by which a variety of cost centers are identified and isolated for the purposes of documenting the cost of a function. This is accomplished through the following steps:

1. Proper identification of the total allowable cost in accordance with OMB circular A-87. (The OMB Circular No. A-87[92] was revised in June 2004.) State Part C planners should also become familiar with EDGAR[93] – the Education Department Guidelines and Regulations which provide guidance for definitions and is specific to the requirements of program income related to Part C.
2. Proper allocation of costs on the basis of a beneficial relationship between expenses and the function to which they are assigned.

Coupled with cost allocation is the identification of cost that is claimable back to a particular funding source where multiple sources are used for a single cost objective. The basis for Medicaid cost distribution involves identifying the respective eligible and enrolled population as a percentage of the total enrolled population in Part C. Medicaid requires that adequate non-federal "match" is available as a condition of drawing down the Federal Financial Participation (FFP).

A cost allocation plan is probably needed by most, if not all, state Part C systems because costs are attributable to more than one cost objective, which is defined as a function, organizational subdivision, contract, grant, or other activity for which cost data are needed and for which costs are incurred. Most Part C systems fit this requirement since some operate systems beyond age 3, supporting positions or functions of more than one cost objective; or where a variety of fund sources come

[92] http://www.whitehouse.gov/omb/circulars/a087/a087-all.html (Also enclosed as Appendix X to this Paper.
[93] http://www.ed.gov/policy/fund/reg/edgarReg/edgar.html

together to support a common activity for Part C. It is important for state Part C planners to determine which functions programs and personnel are performing so that the appropriate accounting and assignment of costs can be determined, up front.

Depending upon the organization of the state's reimbursement system, the cost allocation plan may be required at the state level, the local level or both. For those states utilizing a central finance system, state level cost allocation is required. For those states utilizing administrative claiming as well as other, more locally driven methods of accessing Medicaid, both the state and local cost allocation plans will be needed. For those states without administrative claiming and operating a totally locally driven billing access for Medicaid, local cost allocation plans will be necessary.

States are utilizing different approaches to accounting when accessing Medicaid. Some states are implementing random moment sampling; others are utilizing full time reporting. Still others are using cost settlement while a couple of states reported prospective rate approaches. When individuals in early intervention provide multiple functions, it is important to ensure that appropriate allocations of time and effort are documented so that costs can be apportioned accurately. Examples of this include: when the same individual provides service coordination and a direct service, when an individual provides some degree of assessment services or direct services as well as administrative duties.

These requirements, however necessary they are, can place an additional paperwork and administrative burden upon providers and agencies. It is essential that administrators at all levels understand and appreciate the importance of whatever documentation and cost validation process has been established for the state, and that they take this obligation seriously. The failure to achieve a 100% commitment to accuracy can jeopardize the Part C system at all levels, and subject it to an audit finding(s) resulting in financial recovery or recoupment. Iowa is one of many states where the Part C staff provides training and audits local programs to identify documentation programs as a preventative way to avoid recovery or recoupment.

Impact of the Health Insurance Portability and Accountability Act (HIPAA)

The Health Insurance Portability and Accountability Act requires that the U.S. Department of Health and Human Services (DHHS) develop a series of rules governing health information. In general these rules are intended to standardize the communication of electronic health information between the health care provider and health insurer. Similar to FERPA, the Federal Education Rights and Privacy Act, these rules are intended to protect the privacy and security of personally identifiable information. HIPAA was passed by Congress in 1996 and was designed to simplify the health care administrative processes in five (5) administrative areas:

- Electronic Data Interchange (EDI)
- Code Sets
- Identifiers
- Security
- Privacy

Each state's Part C system must operate under the confidentiality provisions of both Part C of IDEA and FERPA – the Family Education Rights and Privacy Act 1994[94] which together provide parents whose children receive Part C services with the right to inspect and review their child's early intervention records, the right to seek to amend those records, and to limit unauthorized disclosure of personally identifiable information from those records. FERPA applies to the records required to be maintained by educational institutions that are the recipients of funds from the U.S. Department of Education.

In addition to consumer privacy, HIPAA provides requirements for the security of health information, national standards for electronic healthcare transactions, and national identifiers for providers, health plans, and employers. The Office of Civil Rights, under

[94] *[1] http://www.ed.gov/policy/gen/reg/ferpa/index.html*

the U.S. DHHS, governs HIPAA and has a variety of simple and straight-forward fact sheets which define patient rights, confidentiality and provider requirements.[95]

State Part C planners may want to engage the legal counsel for both the Part C system as well as from the agency responsible for the implementation of HIPAA within the state. Their dialogue would help to clarify individual state understandings and agreements related to the application of FERPA and HIPAA and provide written direction to all key stakeholders.

HIPAA is instituting a system of national standardization[96] throughout the health care industry which includes uniform code sets to document the procedures conducted during health care encounters. This largely eliminates many of the "local" codes that states had previously used for services that were not defined in the existing CPT-4 codes. HIPAA goals are to result in the development of a Health Care Common Procedure Coding System (HCPCS or "hic-pics") which includes procedure and modifier codes, their long and short descriptions. These codes, which are established by CMS's Alpha-Numeric Editorial Panel, primarily represent items and supplies and nonphysician services not covered by the American Medical Association's CPT-4 codes.[97] The relationship between HCPCS and CPT codes is discussed in a National Health Policy Forum document[98] dated January 2002.

As this Paper was prepared for distribution, the Commonwealth Fund published a paper entitled: "How Medical Claims simplification Can Impede Delivery of Child Developmental Services." This paper, written by Anne Markus, Sara Rosenbaum, Alexandra Stewart and Marisa Cox with the George Washington University School of Public Health and Health Services, examines the HIPAA administrative standardization and the process of modifying the standardized codes. It assesses the implications of HIPAA standardization for payment of Medicaid-covered early childhood preventive

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[95] http://www.hhs.gov/news/facts/privacy.html
[96] http://aspe.hhs.gov/admnsimp/faqcode.htm)
[97] Current Procedural Technology
[98] http://www.nhpf.org/pdfs_bp/BP_Coding_1-02.pdf

and developmental services, drawing on findings from a 50-state, point-in-time review of readily available state HIPAA compliance documents conducted in December 2004. This paper is provided as Appendix Y and observes that HIPAA standardization has inadvertently resulted in reduced Medicaid coverage for child development services. Even with the HIPAA standardization, there remains variation in payment coding. The authors make several recommendations including allowing payment coding to be customized to accommodate unique coverage standards.

Examples of current Part C reimbursement codes are provided for state Part C planners in various state Appendices to this Paper. These can vary widely depending upon how the state system for Medicaid participation in Part C is constructed, and each state's historical preferences related to diagnostic, procedure and billing codes.

Medicaid "Match" Approaches

Earlier sections of this Paper discuss the requirement of state Medicaid match in order to "draw down" FFP (Federal Financial Participation) according to the individual state's Federal Medical Assistance Percentage (FMAP). This match not only varies state by state, but can vary by the type of service provided or type of provider. Match is basically having non-federal funds that can meet the match requirement. These funds largely come from state general fund appropriations either to the Medicaid agency or to the state agency responsible for implementing services. Currently the majority of states report some degree of state funding specifically for Part C.[99] Thirteen (13) states[100] and the District of Columbia report that their state Medicaid agency covers all of the state match for Medicaid covered Part C services; five (5) states[101] report that the Part C system covers all or a portion of the state match for some covered Part C services. Seven (7) states[102] report that Medicaid provides the state match for service coordination for Part C.

[99] Review of Annual Performance Reports (APRs) and individual state annual narrative reports.
[100] CA,GA,ID,IL,IN,KY,MA,NM,OH,OR,SC,VA and WV
[101] CA,DE,MO,TX,VT
[102] GA,OH,ID,NM,TX,VA,WV

For those states utilizing a school-based health services approach to accessing Medicaid for early intervention, Part C services, the regional or local school district typically certifies the match requirement from state allocations and locally generated revenue. However, this is not necessarily true for all states with this Medicaid funding option.

Increasingly, Medicaid match is a "hot topic." In the past, most Medicaid state agencies acknowledged their responsibility to provide services to young children under the EPSDT and standard Medicaid requirements. When earlier partnerships were cultivated, the state Medicaid agency typically provided the match for services while requiring the Part C agency to provide the match for new initiatives specific to the administration or responsibilities of the state's early intervention system (e.g., administrative agreements, service coordination). The argument in having the state Medicaid agency continue to provide the match was that, absent Part C, the obligation to serve would still be theirs.

Some state laws require that the "sponsoring"[103] state agency provides the match irrespective of the service. In the Part C system, interagency opportunities for match are significant. Establishing new initiatives requires additional match. Legislatures may appropriate general funds specifically for these purposes, or state agencies may have sufficient funds within their current allocations to meet the match requirements.

Other funds may be used to meet the match requirement, including locally-raised taxes, county or community appropriations, monies earned through private fund raising, grants, fees, etc. The key here is that federal funds may not be utilized for Medicaid match. State Part C planners need to apportion their non-federal funds accordingly for match, ensuring that – as the population of enrolled, Medicaid covered children changes – the changing match obligation is available and sufficient to draw down the federal funds. State Part C planners also need to track the amount of service provided for the same reason. Match is based upon 100% of a qualified activity, adjusted by the

[103] Meaning the state agency or program proposing Medicaid reimbursement, not the state Medicaid agency.

percentage of Medicaid enrolled individuals (of the total population) who received or benefited from the service(s).

Match can be managed in several different ways.

1. State funds are appropriated to the state Medicaid agency and used, in conjunction with FFP, to pay the submitted invoice in full to either the state agency or provider of record.
2. State funds are appropriated to the state agency and transferred to the state Medicaid agency, usually proportionate to the amounts invoiced. One state described the mechanism whereby it receives full reimbursement from the state Medicaid agency and, on a quarterly basis, returns the state match share received to the state Medicaid agency.
3. The participating state agency has adequate non-federal funds and "certifies" these funds to the state Medicaid agency. As services are provided, they are billed to the state Medicaid agency which only then reimburses the FFP.

Local agencies including school districts have local non-federal funds and "certify" these funds to the state Medicaid agency, under the same payment structure as described in item 3, above.

Due to the interdepartmental, collaborative nature of Part C, it is not uncommon for other agencies to provide the match for Medicaid-covered Part C services that they will provide and be reimbursed for, either directly or through their contracted providers. Leveraging Medicaid FFP through appropriate methods reflected in state and local partnerships has long been a supported practice by state Medicaid agencies. The historic use of certification of match has been successful in securing needed services for eligible populations and maximizing state Medicaid opportunities without necessitating the transfer of funds to the state level, which may be regarded as politically unacceptable in many instances.

Few states have a local "share" requirement for Part C. Exceptions to this are states (particularly birth-mandate states) operating through local public schools, as discussed earlier, where school-based Medicaid services include the Birth-3 population. New York

and Pennsylvania are also two (2) notable exceptions, where local municipalities (county health or mental health departments) are responsible for a 50% or 10% local share respectively. These funds are generally locally raised revenue or direct state appropriations. Other states, such as Ohio with its largely county based system, are reported to have substantial voluntary local contributions but these are not tracked or quantified.

On December 12, 1991, the Medicaid Voluntary Contribution and Provider-Specific Tax Amendments of 1991 was signed into law (P.L. 102-234). In general, the provisions of the law became effective January 1, 1992. Under the provisions of the law, the Health Care Financing Administration (HCFA) (now CMS) was authorized to deduct from a state's Medicaid expenditures, before calculating the federal payment, funds raised from provider-specific taxes or donations deemed impermissible by the Act. The final rule was published in the August 13, 1993 Federal Register.

Briefly, a permissible tax must be: (1) broad-based - apply to all providers; and (2) uniform - applied to all providers on the same basis and at the same rate. States are prohibited from establishing programs that would have the effect of offsetting or reducing the impact of the tax on providers or taxpayers. This prohibition is called the "holdharmless" provision.

In December 1994, HCFA notified several state Medicaid Directors that their state had one or more "impermissible taxes" and was in danger of having their Medicaid allotment reduced. These letters listed the impermissible taxes HCFA had identified and asked the Medicaid director to provide information to support the permissibility of the identified taxes. There has been minimal follow-up to these communications, but CMS has issued a “State Medicaid Director” letter, which may be of interest to Part C planners, clarifying the conditions under which provider taxes or fees can be assessed.

Provider taxes, particularly for those Part C systems without the ability for administrative claiming, may be an option to help off-set what are expensive costs for training, provider enrollment, credentialing and monitoring. The CMS ruling limits the provider tax to the actual cost expended by Part C to provide these functions. These funds

could then be used to augment state match, thus expanding the capacity of the state to draw down FFP. Much of this would depend upon the size of the provider pool and the extent to which the Part C system was actively involved in personnel development and provider credentialing.

Inadequate match will limit a Part C system's access to Medicaid – no matter where the shortfall of funds is located. States must be confident that they have sufficient resources to commit match from the Part C system, which can mean (depending upon the methods used to access Medicaid) complex budget planning and management. States have taken different approaches to interpreting the federal maintenance of effort and non-supplanting requirements of Part C. For some states, these requirements are limited to the federal Part C funds; for others, legislation has been implemented which applies these same standards to state Part C funds. While it appears reasonable for the state's Part C system to provide match when accessing Medicaid for new, Part C-oriented services (such as TCM or administrative claiming), it could be interpreted as supplanting if a Part C system were to provide state match for Medicaid covered services that were already established and, but for the presence of the Part C system, would have been offered and provided to Medicaid eligible children.

As budget issues continue to escalate at the federal and state levels, issues of match will likely escalate proportionately.

Reimbursement Rates

Depending upon the approach(es) used to access Medicaid, many -- if not most -- state Medicaid rates for reimbursement were developed prior to the advent of Part C and, as such, may not include some of the required federal components of the law – such as services in the natural environment. One important question for Part C planners to ask their colleagues in the state Medicaid agency is: what cost considerations were included when this rate(s) was developed?

Most Medicaid rates are developed based upon the identification and quantification of considerations that, together, define "cost" from the financial side of the service or

program. Cost is generally defined to include both cash and non-cash outlays (such as depreciation) and must always have a descriptor of what the cost represents (e.g., cost of Part C personnel for Fiscal Year 2003). Reimbursement is what happens when these costs, and sometimes profit, are converted and restated in terms of the payment basis and/or time. Cost is specific; reimbursement is essentially cost restated in terms of the basis of payment. The collective of this process contributes to the identification of a "rate" for payment – no matter how the reimbursement is organized.

This Paper hasn't specifically discussed the importance of the Part C vision and mission in crafting a system of services to very young children with disabilities or developmental delay and their families. Practically speaking, perhaps nowhere else does the essence of each state's vision and mission statement play a more important role than in helping to configure rates that will support the delivery of appropriate, high quality and individualized early intervention services. Part C planners can sincerely believe in and promote family centered principles of care, through high quality, individualized services, emphasizing daily routines and typical activities, building communities of care that will be there for families and children as they grow and develop. Realistically, it is difficult if not impossible to promote these principles if providers can't meet their expenses, or if the rates fail to be sufficiently competitive so as to attract and retain providers.

In identifying the cost considerations for Part C, states have benefited most when involving a diverse group of stakeholders including family members, state agency administrators, local administrators and providers themselves. By combining the perspectives and opinions of each of these major stakeholders, the articulation of "what is important" crosses the spectrum of the interest groups, and has a higher likelihood of being successfully marketed and defended through the SPA process.

This participatory process also assists in local implementation, and helps to inform providers as well as engage them in understanding any new requirements.

Some considerations identified in the process of determining rates include, but are not limited to, the items presented in Figures 29 and 30 (pages 188-189).

Figure 29: Related Activities

RELATED ACTIVITIES	Family-centered service delivery
	• Services in the "natural environment:
	  o Travel to/with family
	  ▪ Time
	  ▪ Distance
	  o No show/cancellations
	• Training to best practices including diversity, cultural competence
	
	Teaming
	• Evaluation for eligibility
	• Assessment for service planning
	• IFSP development
	• IFSP review, monitoring and annual evaluation
	• Problem solving
	• Transdisciplinary/interdisciplinary models/approaches
	• Resource development activities
	
	Staff meetings
	
	Administrative activity
	• Data entry, reports required to the Part C regional/state level
	
	Documentation
	• Report writing
	• Information gathering, EI record development and maintenance
	• Service documentation
	• Billing
	  o Depending upon the state's system, may be complex and time consuming, requiring providers to invoice private insurance first before accessing state Medicaid reimbursement

Figure 30: Cost

COST	Salary & Benefits • Sick/Vacation time • Supervision • Recruitment/retention efforts Facilities and capital Improvements Vehicles Equipment Materials and supplies Utilities Insurance Food Limited In-Kind Administrative costs Miscellaneous expenses Annual Inflation factor

Depending upon what cost centers were included in Medicaid rate development, state Part C planners may have some options. First, they may build the "case" for the state Medicaid agency to revisit an already existing rate given new considerations, available data and a well thought-out argument. This would include the special characteristics of the target population, Part C federal requirements, etc. Second, in building rates for new Medicaid services or for new populations, Part C planners can articulate the cost centers based upon the service definition and provider qualifications as well as the special considerations for the target population.

In determining rates, there are a number of considerations regarding the structure of reimbursement rates that state Part C planners will want to include in their deliberations. These may include:

- Service oriented vs. discipline based rates
  - Supervision
  - Considerations for the use of para-professionals to include supervision
  - Caseload

- Service coordination
  - Intake
    - Caseload
  - Ongoing
    - Caseload

- What is the definition of a rate?
  - Unit increments
    - 15 minutes, or some other measurable period of time
  - Episodic – which may be capitated regardless of the service
    - Monthly
    - Quarterly
    - Annually
  - Capitated

- What defines a "service?"
  - Face to face contact time
  - Teaming
  - Family present
  - Family not present
  - Screening
  - Assessment
  - IFSP Development
  - IFSP review, monitoring, annual evaluation
  - Collateral contact – in person
  - Collateral contact – phone
  - Collateral contact – documentation for a specific purpose (eligibility for another program or service)
  - Transition planning and facilitation
  - Transition planning/services

- Service delivery approaches
  - Group vs. individual service approach
  - Consultation
  - Primary service provider/primary coach model

- Interagency Activities

- Child find, public awareness

- Training or credential requirements of the Part C system

There are some mitigating factors that need to be considered, as well. Typically, there are no real regional differences in the cost reimbursement structure. What a rural area demonstrates in terms of travel and distance considerations, the metropolitan or urban areas make up for in terms of the volume of children receiving services. Some states have identified that it is not so much the travel distance as it is the time – traffic delays included. Many states report that they have been unable to renegotiate Medicaid rates to include travel considerations and that this continues to be a detriment to provider recruitment and retention irrespective of the area to be served.

Many state systems have cultivated providers who serve children and families, or other populations, beyond the Part C early intervention population. For this reason, it is next to impossible for these Part C systems to establish caseloads. "Contained" systems, with identified agencies and/or providers serving only Birth-3 often can accomplish this. For many states, caseloads have become important in determining adequate provider capacity as well as contributing to the rate discussion and, to some extent, to monitoring and supervision requirements.

In configuring approaches to Medicaid access, it is not uncommon for state Medicaid agencies to want to quantify or otherwise control expenditures – whether these are by individual provider, service type or for the individual program or system as a whole. Maximum caseload is one vehicle to have some degree of quality control over the provision of services. This approach is frequently observed in service coordination reimbursement, where there is a defined level and frequency of contact, specific requirements that comprise the service definition, etc. that is more universal for all children than the individualization of other service recommendations in the IFSP process.

In order to ensure that services are provided to children and families in a timely manner, there may be a need to handle some service delivery outside of the fee system if extreme situations make service delivery using the fee structure impossible. Many states struggle with provider capacity problems; rates should promote the development of sufficient numbers of qualified providers and not be a deterrent to this goal. Low

rates may actually promote higher service levels in the IFSP that are inappropriate for very young children, and that do not support family-centered supports and services.

Medicaid requires providers to accept the Medicaid rate as payment in full. No additional charges can be levied to the Medicaid recipient/family for Medicaid covered Part C services. However, it is permissible for either the Medicaid agency or Part C system to complement the existing Medicaid rate based upon Part C requirement(s) which are not already included or exceed the cost centers of the existing rate methodology. Part C planners will need to have documentation and data to support those items that are not included in the rate methodology developed by Medicaid. Several states reported that they had arrived at agreements to complement or accompany the existing Medicaid rate, not to augment or supplement the rate however. This is typically related to travel considerations and training or credential requirements for Part C practitioners. Sometimes these costs are borne by the Medicaid agency, other times, by the Part C system. Careful documentation of these efforts and agreements should be developed and maintained so as to avoid any audit findings or challenges of supplementing the Medicaid rate at a later time.

Increasingly, states are configuring their Part C reimbursement in concert with or consistent with Medicaid rates, so that there is no disincentive in accessing third party resources.

Reimbursement is a complex issue. Some Medicaid options, such as Title V agreements, permit cost-based reimbursement. This is also typical with school-based health services initiatives under EPSDT/rehabilitative services option. Cost settlement practices are increasingly more common, including states where prospective rates have been established. State Part C planners need to be armed with accurate, timely and comprehensive information and data that displays their needs and supports their recommendations. Understanding how other similar program rates have been established helps to frame this planning. Rates are not frequently “re-visited” although inserting this as a condition in an interagency agreement may be an excellent idea.

Reimbursement rates need to be fair and equitable, reflecting a reasonable consideration of "cost" but also balancing cost with other criteria that promote best practice. States report that defining the reimbursement rate to include desired activities, sometimes at a higher rate of reimbursement, promotes best practices – such as teaming, services in the natural environment, etc. Most states have rates which separate "individual" from "group" reimbursement, with typically a higher rate for "individual" service. While well intentioned, at least two states commented that this approach was not achieving the desired effect of promoting the use of community-based facilities as originally intended, but tended to be used to maintain special purpose programs. One state Part C planner shared an interesting perspective that all Part C services should be individualized, therefore "group" rates were unnecessary since the specific location of the service could be in a group but would be focused on the child, and not on the "group." New Mexico, for example, recently added a community group rate for IDEA Part C in an early care or education setting (child care, Early Head Start, etc.).

Some Part C planners have looked ahead to identify reimbursement issues that will be important to consider in future years, as Part C systems mature and become even more refined. Provider recruitment is a huge issue for most states; retention is increasingly becoming even larger. Some state Part C planners are discussing potential approaches to use to support higher provider retention, particularly given their costs related to provider training, credentialing and focused monitoring. Some states may consider a differential which would offer a higher rate to providers who "grow" within the Part C system, achieving advanced training or certification in needed specialty areas (e.g., autism spectrum disorders). Several states currently have provider "levels" (Supervisor, Specialist, Associate, Para-professional) which have established rate differentials and offer a financial impetus to individuals to participate in a variety of personnel development activities, offering a career ladder for advancement.

For many Part C planners interviewed for this Paper, concerns about the adequacy of service coordination and special instruction reimbursement are very real. While other disciplines, largely due to longevity and the existence of "trade" organizations that help

to advocate on their behalf, have been able to establish adequate compensation – these two disciplines appear to have been left by the wayside. In one state example, it was reported that the state's association for a specific therapy provider went directly to the state Legislature and was successful in getting a bill passed that provided a rate enhancement to that provider group only for Part C services.

This imbalance in power, representation and visibility can result in an undue reliance on "therapies" rather than special instruction for eligible children and their families if there are not sufficient early childhood development resources to tap for Part C.

Service coordination is even a larger problem, as reported by many Part C planners. As the "linchpin" of the Part C system, these providers are often the most poorly compensated individuals in Part C and are often reportedly not "seen" as professionals by other members of the team. Further, some states experiencing compliance problems report that they have tracked these issues back to inadequate service coordination. While compensation may not be the only issue related to building and sustaining a high quality service coordination system for Part C, it certainly can be used to leverage or cultivate other service coordination components such as participation in training, improving IFSP team facilitation and monitoring, linking families to existing community resources and working on an interagency basis to identify and fill gaps identified across the spectrum of early childhood, family needs.

(For more information on Part C rate development, please consult the ITCA website for the publication entitled: "A Resource and Technical Assistance Paper For Reimbursement Methods In IDEA Part C.")

Relationship to Private Health Insurance Coverage

Depending upon the state's Medicaid eligibility and economy, an individual child may be dually enrolled in both a private insurance plan and the state's Medicaid program. Part C planners should identify the number of dually enrolled children currently in the Part C system, as well as the projected enrollment based upon state demographics, as they do their overall financial planning. Depending upon the state's policies and

procedures related to family cost participation, utilizing Medicaid for dually covered children may be problematic in that it may result in costs to the family that compromise their "inability to pay." Part C policy options related to family cost participation are discussed in the ITCA paper entitled: "Part C System of Payments: Family Cost Participation."

In most states, providers are responsible for billing Medicaid directly and receiving this revenue. In a small number of states, the state share of the total payment is withheld and the provider receives only the FFP. If there is a third party present, many states require the provider to locate, bill and receive a rejection before submitting this bill for services to the state Part C system. Usually, third party reimbursement is more than the Medicaid reimbursement so many providers don't voice difficulty with this secondary payment approach, despite the time that is often involved between the delivery of service and the payment.

Often, private insurance will have established "caps" on services (and, more recently, "caps" on total expenditure by service within a given period of time). When these "caps" are realized, it opens the door for Medicaid reimbursement.

State Medicaid agencies can elect to forgo third party recovery (TPR) under certain, limited circumstances. Several state administrators report that this type of agreement exists for their state with respect to Part C. Under federal Medicaid regulations, states may forgo pursuing third party resources if they can justify that the cost for doing so will exceed the reimbursement.

Quality Assurance/Surveillance, Utilization and Review

Both the state Medicaid agency and Part C have considerable requirements for monitoring and supervision of providers and services for eligible children and their families. Sometimes called "continuous quality improvement" (CQI), the outcome for either agency's oversight activities is to promote not only compliance with federal and state regulations, but also to ensure the timely delivery of quality services to the eligible population. These activities can range from simply collecting data that indicate: "did it

happen?" which links the IFSP with the services provided, including the review of progress notes, to judge "what happened?" and "did it make a difference?" Routine auditing starts with the expenditure of funds and tracks this back through the invoicing, IFSP and team discussion of why this particular service responded to the need. In most state environments, the first level of auditing or monitoring makes sense and is easily performed.

The next levels – those of quality and tying into reimbursement – are more intense but also important. It simply isn't sufficient to say that something happened; we have to take that more than one step forward and be prepared to speak to "why," "what" and now, "so what."

Several state Part C systems have been able to negotiate agreements with their state Medicaid agency to conduct the monitoring and surveillance activities as required by Medicaid. These agreements have culminated in the utilization of common documentation and procedures that help to consolidate efforts and improve services. Many Part C systems provide their own state monitoring, sharing these results with the state Medicaid agency and investigating situations as appropriate. This agreement helps to ensure against duplication of effort.

Working With Managed Care Networks

The introduction of managed care was accompanied by a flurry of concerns that it would deprive infants and toddlers (and other populations) of the appropriate type, level or diversity of services that they would benefit from. Consequently, many states decided to "carve out" the Part C population from Medicaid managed care participation, maintaining these children in the historic fee for service system. State Part C planners interviewed for this Paper spoke of current managed care discussions within their own states and expressed concerns about the impact upon the Part C population should this effort move forward.

Some states report fairly positive relationships with their Medicaid managed care entities, although these are in the minority. State Part C planners cite difficulties in

joining the "network," getting physician referrals, and the inadequacy of reimbursement as barriers to managed care participation. For those states reporting successful relationships, it was essential to get involved early and be visible so that their contribution and participation was assumed, early on, rather than as an add-on. Collaboration with Part C can be a significant advantage to the managed care organization's (MCO) marketing ability with enrollees. Part C offers a well defined system of care, defined by federal law, which can respond immediately to the MCO's enrollees' needs with little if any investment or effort by the MCO. Rate negotiation for managed care services should be constructed similarly to those negotiations for fee for service reimbursement.

Virginia is one state where Medicaid managed care has been in operation for several years, through which Part C services are provided and reimbursed. Enrolled provider agencies negotiate a local rate, by service type. They are now implementing a system of prospective rates which is a change from the former cost settlement approach. This is not necessarily associated with managed care; it is a rate system for all providers. This state has encountered several problems with their participation with MCOs, most notably in three major areas. First, they lost many Part C providers when the MCOs were instituted, which has strained their service delivery system considerably. The State Part C office had to strongly encourage providers to enroll in local MCO networks. If order to remain early intervention providers, they had to become providers in MCO networks and accept capitated rates instead of fee-for-service rates that were higher, in most cases. Secondly, many provider agencies didn't understand the rate methodology process sufficiently, resulting in rates that were sometimes significantly less than their cost. Working initially under a "capped" rate structure was a dramatic shift from earlier funding approaches, resulting in a continued loss of providers. Efforts to renegotiate rates were not successful; providers were not accustomed to negotiating in the managed care environment. Efforts to include some level of reimbursement for services in the natural environment were not successful either. As a consequence, Part C assists providers to offset these costs with Part C funds. Thirdly, the rates range dramatically, contributing to a lack of consistency in what locales were doing, and

resulting in some local measures to manage costs which may have compromised the Part C principles and requirements.

One state's Part C program operates a health plan within the waiver which "carves-out" Part C services from medical health plan services. Children eligible for Part C and the §1115 waiver program are enrolled into the Part C "carveout" health plan. Part C services delivered to children who are Medicaid certified as disabled are billed by procedure or visit on a fee for service basis. At least half of the §1115 waiver and Medicaid fee for service reimbursement is for service coordination. The §1115 waiver began several years ago, but the Part C system wasn't able to initiate the capitated reimbursement until recently. The Memorandum of Agreement indicates that the Part C system pays 100% of the state match; the federal share of the §1115 waiver payments from the Medicaid State office are made directly into a Special Fund that was set up by the legislature for early intervention. This state also participates in a Medicaid fee-for-service payment system for Part C for other children who don't meet the §1115 waiver requirements.

In the District of Columbia, the Medicaid agency and Part C system have been working together for the past seven (7) years to coordinate financing of early intervention services in a managed care system. In 1998, OSEP provided funds to some states to support the development of a financing team; this helped to support and serve as an impetus for DC's development of a task force in conjunction with the State Interagency Coordinating Council (SICC). In the inception of the task force, a variety of key stakeholders (family members, providers, state agency administrators) met bi-monthly to identify and resolve barriers. This group has moved to quarterly meetings, which are held over a "brown bag" luncheon with additional involvement of MCO administrators, case managers and supervisors. Each meeting hosts a targeted presentation designed to inform other members. MCO administrators and staff are now participating in Part C-sponsored trainings through the CSPD system.

DC works currently with four (4) MCOs. In the MCO, service coordination is a shared responsibility between the MCO and the EI system which usually results in no

reimbursement for EI for this service. The public system does reimburse Part C service coordinators for services whether the children are Medicaid enrolled or not. All Part C services with the exception of special instruction are covered. Reimbursement for IFSP team meetings was recently added. A comprehensive interagency agreement has been drafted and is close to formal signatures, and is the "template" for planned application with other programs and services.

DC utilizes other avenues to access Medicaid as well. Both agencies do monitoring of the providers, resulting in some duplication and provider complaints. Both agencies are working closely to monitor and quickly resolve complaints. DC feels strongly that the continuation of their workgroup is vital to ensuring continued improvements in the utilization of MCO for early intervention.

Certainly a strong partnership with the state Medicaid agency can help to pave the way for positive MCO relationships. State Medicaid planners typically conduct routine meetings with MCO officials which are great opportunities for Part C to provide education and information about their services, discuss linkages, and also participate in problem solving. DC's resources are found in Appendix DC.

Some Part C planners interviewed for this Paper discussed their state's plans to implement managed care initiatives in the coming years, as one mechanism to manage costs and still provide a basic level of health care for residents. Discussions about "carving in" and "carving out" likely will resurface. Bachman and Burwell in the March 1997 publication[104] entitled: "Medicaid Carve-Outs: Policy and Programmatic Considerations," have identified five (5) managed care enrollment options for recipients with disabilities:

- Mainstream managed care plan enrollment
- Specialized plans
- Service carve-outs

[104] Medicaid Carve-Outs: Policy and Programmatic Considerations, Sally Bachman, Ph.D., and Brian Burwell, for the Center for Health Care Strategies, Inc., Princeton, N.J., March 1997 (commissioned by the Robert Wood Johnson Foundation)

- Population carve-outs
- Exclusions to fee-for-service

How a state chooses to pursue managed care for the Medicaid population depends significantly upon identifying what the purpose of the carve-out is. The decision is likely to generate considerable discussion amongst stakeholders. Earlier decisions to carve-out the infant-toddler population from Medicaid managed care in many states may be revisited in the coming years. Part C planners will benefit from preparing thoroughly, well in advance, if this is likelihood for their state. There are a number of resources which are particularly informative for Part C planners in Appendix I.

Challenges and Barriers to Collaboration

Interagency Relationships

This Section has described many of the opportunities and challenges to states in accessing Medicaid to support Part C systems and services. State Part C planners report that enormous amounts of time and energy are needed to cultivate and maintain interagency relationships. With the many changes to Part C reporting and accountability, these competing demands have – by report – resulted in reduced interagency efforts. This was the issue raised most frequently by individuals who were interviewed for this Paper as a barrier to accessing resources across the agencies, not just Medicaid, to support Part C systems.

These same pressures are upon state Medicaid agencies, perhaps even more so as efforts towards cost containment and budget reductions from the federal and state level become further actualized. Several Part C planners reported that their early discussions with the state Medicaid agency were not fruitful until they started taking the lead, writing draft concept papers, providing a crosswalk to illustrate the comparability of provider types between Part C and Medicaid, or a crosswalk to organize Part C services in a way that made sense to Medicaid planners. In several instances, the Part C system developed the State Plan Amendment with input and guidance from the state Medicaid agency. They worked together to involve CMS in draft review and discussions so as to preempt any opportunity for delays or challenges. It is likely that this kind of "give and take" will be essential in the years to come.

Several Part C planners interviewed for this Paper commented that it would be helpful to have more articulated at the federal level related to interagency relationships to facilitate the appropriate utilization of all resources, Medicaid included. The perceived lack of direction contributes, according to several interviewed, to the continuous repetition and duplication of effort that states engage in while trying to identify and coordinate a variety of disparate resources. Added to the complexity of this is that Part C systems are required to report financial data in the Annual Performance Reports concerning all sources of funds accessed to support children and families. This task is

next to impossible for many states when these fund sources operate and are accessed outside of the formal Part C system.

Relationship-Based

Part C is a system that is deeply relationship-based. Part C providers cultivate relationships with families and colleagues, building teams to address the provision of supports, resources and services to families and enriching communities where children and families live, learn, work and play. The interagency nature of the system is relationship-based, working across agency lines and boundaries to develop what many call "seamless" or transparent systems of care and support for young children and those who care for them.

Many state Part C planners spoke of state agency level personnel changes as a double-edged sword. Sometimes, the changes resulted in having personnel at another agency with similar interests, commitment or vision; other times, valuable initiatives were vulnerable because of the lack of history and personal connection. Interagency agreements are helpful in many situations, such as when state leadership changes and the effects of this "ripple" down to various degrees within the state administrative structures. Interagency agreements cannot effectively communicate the process and dialogue that occurred to arrive at agreement; the process itself built understanding and commitment.

Routine informal and formal communications between parties was cited as essential. Waiting until a problem crops up to talk with a colleague risks establishing what one Part C planner called the "whining syndrome," being perceived as always finding fault rather than recognizing success.

Building Systems; Not Silos: Turf as a Challenge to Collaboration

"Turf" was highlighted by many interviewed as being a tremendous barrier to collaboration. Establishing a common communication and terminology was essential to reducing the "threat" by others that some reported they felt when initiating discussions about Medicaid reimbursement – on both sides. Each system has its own

language, its own alphabet soup – filled with acronyms that can be, at best, intimidating, if not disrespectful. As this Paper has identified, there is tremendous commonality in purpose for both the states' Part C and Medicaid agencies. The importance of finding the "right" person or people to talk with and taking the time to educate and become educated cannot be understated.

The issues of "turf" also were discussed during interviews for this Paper relating to agencies beyond Medicaid. Several Part C planners discussed the "silos" that individual programs and services in their state had cultivated; often operating in parallel ways rather than collaboratively. Not only does this make it difficult to access the variety of resources intended by Congress for Part C systems through collaboration and interagency partnerships, but these "silos" can make it very difficult for families to access needed and appropriate services.

"Turf" comes is many shapes and sizes from the perspective of Part C planners. While the essence of Part C legislation is to promote collaboration and coordination of systems, the reality is that – in tight budgetary times – human beings have a tendency to pull back, retreat and protect what is important to them - hardly a fertile environment to promote collaboration! Rather than competing for limited resources, the opportunity for coalition-building with the disability community including special education, early childhood programs and state prevention initiatives may be the key to ensuring that reasonable, sound and defendable priorities are identified. These collaborative efforts would ensure that at least a foundation of support and resources for families – irrespective of their own special considerations – is in place during these challenging times.

Next Steps and Activities

State Part C planners are positioned in a potentially very powerful and influential way to guide the articulation of meaningful public policy that determines the allocation of resources. Children and families in Part C often participate in other public systems, depending upon their own personal circumstances and special considerations. As such, Part C planners at the state and local levels interface with a variety of disability, education, social service, prevention and community service agencies which also – in one way or another – "touch" this same population.

Part C planners bring to this discussion a "system" perspective which includes all of the "business" components required in an accountable, viable and successful operation. Outreach and engagement (marketing), quality assurance, financial controls, methods to resolve disagreements – are just some of the critical components (see page 92, Section B of this Paper) that not only constitute the Part C system, but are or should be critical components of other human service delivery systems. Each of these business components is reflected in the state Medicaid agency's state plan application which is required in order to ensure the receipt of federal funds to support the provision of quality services to their recipients.

Part C planners also recognize that "resources" mean more than financial when people are collaborating and coordinating efforts. It may mean co-locating in a building with other early childhood programs, cost-sharing a training event, or having the Part C system "advertised" on another program or service brochure. At the state level, it may mean sharing data in order to obtain a more broad understanding of the landscape, priorities and resources. The partnership between state Medicaid agencies and Part C Child Find is one example of effective use of resources. During their outreach and engagement efforts for Part C, states often provide information to families about Medicaid enrollment and may assist them in making an application. These efforts, as well as many others, are recognized through administrative agreements between the two systems.

Robert Quinn, in his book entitled: "Deep Change," defines a team as follows:

An enthusiastic set of competent people
who have clearly defined roles, associated in a common activity,
working cohesively in trusting relationships, and exercising personal discipline
and making individual sacrifices for the good of the team.

Quinn's definition will guide the discussion of next steps for Part C planners as they take what they have learned from this Resource Paper in the review and potential revision of their state's approach to accessing Medicaid for the Part C system. This final Section of the ITCA Medicaid Resource and Technical Assistance Paper provides some basic "next steps" to Part C planners in organizing information, cultivating support and creating a process to investigate options for partnership with Medicaid that will respond to identified state and local needs. Depending upon the state's unique situation, these steps may not be sequential. Not everything may be necessary or appropriate for an individual state. The detail provided reflects the sum of comments and experiences reported by more than 20 state Part C planners throughout the course of the development of this Paper.

Creating the Case: Identifying the Problem(s) or Situation Statement(s)

The first step is typically identifying the situation at hand – what is happening now, what needs to happen, and what could happen? This is the start of an ongoing process of data and information collection that is used to frame the need as well as evaluate any initiatives that are developed subsequently. Reflections have been provided in previous sections of this Paper to guide the collection of information from the Part C planner's perspective, designed to better understand what is going on, how it is working and what could be better? Individual state examples or options are provided, focusing on successful state initiatives between Part C and Medicaid. Using these resources and completing the Reflections will provide a thoughtful start to these deliberations.

Fourteen steps follow, guiding Part C planners through a series of outcomes with individual activities that have been successful for several Part C systems.

Strategic Outcomes:

- Develop and implement strategies to identify, collect and utilize local and state data, as well as national data, to identify and define the scope of the situation/problem.
- Study and learn about the unique factors and stakeholders who are or could/should be involved in the situation/problem.
- Identify the political and economic circumstances that affect the situation/problem and could affect or influence the solution.

Step One:

A SWOT analysis, sometimes referred to as an environmental scan, defines the strengths, weaknesses, opportunities and threats that may involve economic or demographic issues, political and/or fiscal realities, cultural or historical influences, etc. For the purposes of this Paper, there may be more than one issue or question present, perhaps including one or more of the following:

- What is the current "state of affairs" of the state's budget including Medicaid expenditures?
- What effect, if any, will upcoming local or state elections have upon the political landscape? Are there likely to be personnel changes at the state level which would influence – either positively or negatively – Part C planners' efforts?
- How can Part C appropriately access Medicaid for all Part C services?
- How can Medicaid access be streamlined to promote this as a viable resource for providers and family members who currently may not be accessing this resource for IFSP or other Part C services?
- How is the Part C "way" supported (team based, family-centered, developmentally appropriate services) with what is essentially a medical insurance program?

- How can services be configured to support changing practices away from a medical model to one that is more reflective of Part C requirements, best practices, etc?

- How can some of the Part C services and providers be "recognized" for reimbursement purposes?

- How can more consistent state-wide access to Medicaid be achieved for eligible Part C children and families?

Learning from history is an important step in the SWOT process. What have other similar populations or programs done in the past to access, or attempt to access Medicaid? What were their barriers and challenges? Locate some historians in the state and talk with them. Understanding what went on before can provide clues to how to proceed now, including identifying key people, strategies, allies, etc., to link up with.

Identify and collect data, creating a baseline that tells the story of what is currently happening. The baseline starts to form "what is" and is critical as implementation of any change occurs in order to inform key stakeholders with facts, essential to promote effective proposals; and to be able to effectively and reliably measure progress and effectiveness.

In collecting information, opinion, or "soft data," is often just as important as are hard data. Some Part C data systems are unable to provide state Part C planners with key data that they need in either a complete way, a timely manner, or with accuracy and statewideness. Relying upon partners including the state Medicaid agency to provide information helps to engage them, and raise the issues to a higher level of awareness and visibility.

In the absence of data, perception typically becomes fact. Conducting informing sessions, public forums, surveys, key stakeholder interviews helps to "round out" the picture and inform not only what the numbers tell, but the likely barriers and opportunities that will present themselves as opinion or perception.

Washington State reports considerable success of its interagency workgroup, promoted by the State Interagency Coordinating Council, in terms of identifying the issues related to Medicaid utilization. This group meets every 6 weeks, and has completed the process of landscape review or SWOT analysis, developing strategies and moving the issues to the next level of administrative response.

Step Two:

Take this information forward. The next level of application is state and local level informing and engagement essential to build commitment.

Activities to consider include:

- Assess and understand the political climate – what are the economic, political and social competing **or** compelling issues? Think broadly.
- "White papers" or concept papers also provide the opportunity to double-check that the information is complete and that all perspectives are reflected, factually.
- Multiple "audience" materials may be appropriate to target the varying levels of involvement, understanding, background and impact appropriately.
- Make sure that all materials are dated and sources properly cited.
- Share information with identified key stakeholders to inform and engage, creating "buy in" and commitment. Cast the "participation net" as tightly or widely as you think appropriate.
- Engage people on their "turf" – recognize that private meetings may often allow for important information to be shared that may be inappropriate or not timely for more public distribution.

- Discuss shared principles, concerns and opportunities.
- Be certain that key people within the lead agency have been informed; identify and involve individuals who can support and assist the task.
- Engage state advocacy groups early-on.
- Keep notes of these discussions, send these notes – clearly marked "draft" to stakeholders to summarize the conversation. Elicit "next steps" and ideas.

Strategic Outcomes:

- Identify, engage and recruit appropriate partners to address concerns, opportunities. The more stakeholders are involved, the more momentum the issue gathers and the greater the chance for visibility and success. Depending upon the current environment, this may or may not be desirable.
- Implement the necessary organizational "mechanics" to ensure that the workgroup has appropriate supports and resources, no matter what its group size, its anticipated assignment, or estimated length of existence.

Identifying and engaging appropriate stakeholders is the next important step in the process of creating the environment for discussion and shared problem solving. Building broad-based coalitions with diverse stakeholders at multiple levels of management and responsibility, including consumers, from the state and local levels is one way to foster the dialogue and working together will identify problems **and** creative solutions that will work locally. Solutions will benefit substantially from broad based input, which helps to establish buy-in and commitment.

Step Three:

Figuring out the WhIIFM – what's in it for me – for each of the potential participants is important and may be key to engaging them in a positive, productive manner. Depending upon the configuration of a

state's Part C system, "who" is at the table may vary, particularly when considering local representatives. Initiatives can always grow in size and representation; it is often difficult to reduce a stakeholder group once it has been initiated unless the group is disbursing into small, topical workgroups and reducing the meeting frequency of the large group.

Depending upon the individual state situation, the group being identified and assembled may be very small – state agency Part C and Medicaid representatives. In other instances, such as in Washington State, a larger workgroup has proven successful. Common issues or challenges to participation or progress may include:

- In some states, the Part C system is perceived as having sufficient federal resources to meet their federal requirements.
- For local program or agency administrators serving other populations, expanding or changing Medicaid access for Part C may be perceived as reducing revenue, or competing for limited state and federal resources.
- For consumers, there may be an identified need to ensure covered services for targeted populations of children – perhaps children with autism, or those with assistive technology needs.

During challenging economic times, efforts to improve the access to Medicaid may be threatening to some people for different reasons. For some state administrators, already under severe pressure to curtail state spending, participation in such an effort may be prohibitive due to time and circumstance. In one state, the Part C planner reported that the SICC was successful in going to the Secretary to gain participation in examining Medicaid and other third party resources for early intervention; they left the meeting with not only a commitment – but the name and telephone number of the individual the Secretary of the agency had assigned to represent him and report back on a regular basis.

Part C planners interviewed for this Paper repeatedly discussed the importance of relationships to successful planning and negotiations related to Medicaid coverage for

Part C services and system support. Relationships should be cultivated with a variety of public and private entities, forming partnerships at the state and local level. Key participants identified by some Part C planners included: community agencies, advocates, consumers, health insurance companies, receiving institutions (like the public schools), children's mental health services, Head Start/Early Head Start, child care, legislative representatives, etc.

Step Four:

In laying the foundation for effective coalitions, there are several options that Part C planners spoke of being successful. If utilizing a more expansive approach, one option is to "piggy-back" with an already existing entity, such as the SICC, to provide leadership. Another approach is to start a new group with representatives from existing entities such as the SICC, the state's Medicaid advisory committee, etc. Both approaches have been successful. Smaller interagency discussions, commonly used as a "starter" to the dialogue between Part C and the Medicaid agency, should include a discussion of the role and involvement of each system's advisory group, leadership and key constituents.

Step Five:

Sufficient staffing is critical to ensure the success of any group, regardless of its size. Staffing is needed for meeting logistics, the development and dissemination of meeting agendas, minutes, and other materials as well as routine member communications. Logistical planning makes sure that the meeting space is accessible to people with disabilities, that there is sufficient parking, that the room is large enough – with sufficient sitting and working space for participants and observers. Staff support ensures that meeting agenda are developed and disseminated well prior to the meeting; perhaps calls 2-3 days before the meeting are made to participants to "remind" them; e-mails may be another avenue if everyone has this ability. Creating the meeting notes or minutes and posting them for review and comment in a timely manner, closest to the meeting day, helps to avoid misunderstandings or misreports. Timely posting of meeting materials also speaks to the importance of the initiative, and recognizes the value of the time and effort contributed by each participant.

Workgroups often "break out" into smaller topical working committees; staffing continues as a need – perhaps more so as these groups tend to focus on intense investigation or discussion for short periods of time, involving research, verification, and the development of materials comprehensive enough to relay their results to the rest of the workgroup.

Having sufficient staffing is key to effective communications. These tasks require substantial time, depending upon the size of the group and frequency of meetings. They will be most effectively performed when they are part of someone's job description as compared to "additional job responsibilities" of an already overcommitted individual. Perhaps these functions could be parceled out to one or more participants. One example might be that meeting note responsibility could be rotated amongst members. Responsibility for meeting notes is not only time consuming, but it can lend an impression to other partners of "control" which may not be intended.

Step Six:

In terms of logistics, some Part C planners have commented that having a consistent meeting location was more reliable for participants. Others noted that meeting in different places provided equal opportunity for all participants to "host" a meeting. Part C planners should examine their own state's culture and determine which approach would work best. Sometimes a meeting "off site" in a neutral location is needed in order for interruptions to be minimized.

Step Seven:

Additional "tips" to organizing and managing the workgroup or task force environment:

- Organize workgroup or task force strategically – have regular meetings, agenda widely circulated in advance.
- Provide informational sessions as part of the routine agenda.
- Widely publicize meeting minutes and encourage observers and contributors throughout the process.
- Timing of the meetings – at the start of a day works well; you will lose fewer people's participation overall. The end of the day is also an option, but sometimes people are tired at this time of day and it isn't their greatest creative time!

  - Make sure that the meeting time is appropriate to the agenda – leaving things "undone" and undermine progress and create a feeling that the work is overwhelming, impossible or that the group isn't capable of the task at hand.

- Importance of food – at least beverages, for participants – can't be underestimated. Minimally ensure that there is a facility close by where participants can purchase a beverage and perhaps a snack. Depending upon low long the meeting is scheduled to last, this can become particularly important to some participants.
- Remember the "sunshine" laws of state government; deliberations are open to the public as are meeting agendas and minutes or notes. Consider having a website where these materials, including meeting dates in advance, are posted to ensure that those who want or need to know can locate this information easily.
- Figure out leadership. Someone should chair the meeting and be responsible for its smooth and professional operation.
- Creating a trusting environment by establishing, early on, ground rules which prevent or reduce the opportunity for unprofessional conduct, sharing of misinformation, attacks or negative, hostile behavior against fellow members OR people not in the room.
- Importance of consistency of representation. Having different people from an agency or program often invites delays encountered by having to repeat discussions for those not previously present, introductions, etc. Try to reinforce the importance of consistency in being there with all partners.
  - Regular attendance is also central to ensuring productive and positive outcomes. Often calling ahead a few days before the meeting can alert to potential absences, and create the opportunity to minimize these as best as possible.
- Why are we here – Create a mission statement together.
- What do we wish to achieve – vision statement.
  - Who are they "working for" (who will hear and hopefully act upon their recommendations? how informing will happen?
- Clarify the level or degree of authority, if any, that the workgroup or task force has.
- Create a statement of purpose, anticipated outcomes and timelines.
- Who belongs to the group (membership, roles and responsibilities).
- Discuss and determine how decisions and/and recommendation will be made and approved by the group (consensus vs. voting).

A variety of different perspectives and opinions from stakeholders provides a comprehensive set of information and options for decision makers to consider meaningful solutions. State Part C planners may determine that their approaches to working on Medicaid opportunities will best be addressed through small interagency meetings; others may decide to take a more broad approach by involving a variety of stakeholders for informing and strategic development sessions. Each state's ecology and governmental structure will help to determine the appropriate pathway. Whether a Part C planner employs a large or small group to pursue the Medicaid opportunities available, these reminders are helpful to follow to ensure productive meetings with positive outcomes. If a small planning group approach is utilized, the ideas of public informing sessions, "white" papers and other methods of sharing the drafted plans are very appropriate to gain additional validation and support once the basic planning and negotiation work is completed.

Strategic Outcomes:

- Utilize existing information to inform partners, and expand the information base through their individual and collective contributions and knowledge.
- Cover all the bases – consider and include opportunities for public input, review and comment at regular and routine opportunities throughout the process.
- Identified the range of needs and outcomes; select something initially "do-able" within a short period of time.

Getting started in the engagement and informing process is an art. Participants often enter into discussions with information that sometimes is based upon old or faulty information, misconceptions or fear. Taking time to frame the issue is critical. Equally important is taking the time to learn about each other <u>from</u> each other; don't assume anything! This includes avoiding the assumption that everyone understands the challenge or issue, terminology, the other participants at the table, the history, etc.

Step Eight:

Sharing information at the onset is important as it helps to ensure that everyone is on the same foundation, and this foundation is documented in meeting notes or minutes.

- Provide the forum for presentations by members and others that provides information about their program, agency, etc.
- Provide a framework for people to organize their materials in – this helps to make sure that consistent information across all participants is provided, not left up to the individual creating the presentation.
- Pose some common questions or request data that helps to guide the presentations.
- Create formal informing sessions for key policy makers, legislators, decision makers at agencies, etc.
- Engage relevant "in house" decision makers; don't leave them uninformed.
- There are many excellent references and resources available via the Internet (see the Bibliography and Internet Listings as Appendices to this Paper). Consider forming a small group around topical areas of interest, with each participant responsible for reading one article. Come together to discuss what each individual learned and how this has application to your state needs.
- Check with states located in your state's CMS region; learn what successes and challenges they have experienced. This will help Part C planners to better understand the relevant examples and also the history of early intervention and the CMS region.

Step Nine:

The next step is agreeing to the work scope which involves two steps: arriving at consensus on the problem/situation(s), and identifying or prioritizing together how to proceed. Everyone at the table wants to be successful. Depending upon the agreed-upon priorities, which may be considerable, each group will want to carve out a couple of activities that will offer the opportunity to test their abilities together. Some Part C planner suggestions include:

- Be comprehensive.
- Engage public feedback on outcomes, recommendations of the group.
- Inform key stakeholders and interested persons accurately, in a timely manner. One Part C planner noted that more energy and time goes into correcting mis-information than it takes to get accurate information out first!

- Work to identify what this means for individuals, constituent groups and make sure that they are properly informed, engaged and have indicated support, identified problems or barriers, etc. beforehand.
- Work together to focus the emphasis on planning vs. crisis management.

Brush fires are often distractions to major forest fires! Crises are, unfortunately, a natural part of daily life for most Part C planners and their partners in Medicaid. Hopefully, early on in the planning process of the SWOT, some of these challenges were identified and they are incorporate them into considerations related to time, energy, motivation, etc.

Preparing for effective strategic planning is always a challenge! Calendars don't often allow the luxury of scheduling blocks of time for tackling strategic planning, which is usually the most productive and effective approach. Some planners have to settle on planning which takes place in short periods of time interspersed into already busy schedules. Staffing comes into real consideration here. Several Part C planners reported that their Medicaid agencies "were swamped" and asked them to prepare white papers, crosswalks, state plan amendments, develop and review financial impact statements, etc., as a way to keep progress moving forward.

In the ideal world, time and money are no object. Here are some ideal world ideas recommended by Part C planners that, in whole or in part, may be utilized to create the opportunity for successful strategic planning.

- Identify meaningful baseline data which not only frame the problem(s), but will define progress or successful resolution of a problem(s).
- Meet – if not retreat -- away from office, cell phones and pagers.
- Make efficient use of time.
- Start on time, stay on time, and stop on time.
- Have a planned agenda and stick to it!
- Record the proceedings and get these notes out to participants in a timely manner.
- Mark everything "draft for discussion only", ensure that it is dated and marked, if appropriate, "confidential, not for reproduction or distribution".
- Have an agreed upon schedule of meetings in advance, committed on calendars, that can be relied upon for work time.

- Provide for relaxation, time to get to know one another. This may be a luncheon, a dinner or, in the luxury of time, recreational activities that break up the pace of work.
- Establish goals or outcomes, objectives, strategies, timelines and methods to be used to monitor or measure effectiveness or completion.
- Recognize the interconnectedness of events, watch for the "domino" effect and plan for it.
- "Pick your ducks" for success.
- Starting "small" with one outcome that can be fairly of not easily achieved, in a short period of time, contributes to energy and commitment.
- Identify your resources – in kind, duplication of effort, system fragmentation, lack of coordination or communication, how you use what you currently have or do what you currently do (if behavior is the change desired).
- Be open to identifying what doesn't work, acknowledge changing standards or practices.
- Think creatively!

Step Eleven:

Moving from planning to action happens next. Implementation takes all forms and approaches – target realistic and meaningful implementation that takes into consideration the energy needed to not only start new initiatives – but maintain programs and current activity. Depending upon the level or degree to which "outreach" and engagement has been done already in terms of informing the broad array of stakeholders, including families as consumers, further efforts to inform the public may be in order. This need, coupled with the very real need to validate the plan and develop meaningful and reasonable implementation strategies, can serve as the impetus for plan distribution, dissemination and input sessions. These may be done on a regional basis, or by population (e.g., providers, family members, public schools). Several states reported tremendous buy-in when the plan was presented with a series of questions for public input:

- What are, from your role/perspective, the benefits of the plan(s) proposed?
- What are, from your role/perspective, the concerns or potential problems of the plan(s) proposed?
- Solicit ideas and recommendations for implementation, including:

  - Pilot sites or statewide implementation of selected "targeted" components of the overall plan.
  - Solicit volunteers! Who would like to take leadership....?
  - Assess whether change saves time, effort and isn't burdensome to stakeholders.
- It may be necessary to highlight the trade-offs if additional time in training, documentation, time studies, data collection, etc., are required.
- Actively "market the plan" by obtaining feedback and buy-in from a diversity of stakeholders at multiple levels within the state's system. Visibility of the planning and product efforts makes it much less likely for the implementation plan to, as one Part C planner noted, "become shelf paper."

Step Twelve:

Manage the plan. Every strategic plan needs to be implemented and managed; this doesn't happen spontaneously! The best ideas on paper stay on paper unless they have been moved into action and evaluated, using a baseline that indicates from where you started, to illustrate over time the progress being made. Plan management involves setting timelines and responsibilities against individual task assignments, and then following through to 1) make sure these activities were performed, 2) confirm the timeliness of the actions, and 3) evaluate the outcome. Plan management helps to ensure that implementation problems or barriers are identified early on and addressed before things get out of control or become truly problematic or endemic.

Plan management is most effective when coupled with plan evaluation on a routine basis. Evaluation of the plan and activities is essential to maintaining visibility and confidence, participation and buy-in. Plan management and evaluation is essential to maintaining credibility, which is instrumental in maintaining positive and productive relationships.

- Establish a method, timeline and routinely evaluate, reassess and modify the plan from your successes, your challenges, the changing landscape, effectiveness, etc.
- "Fess up" if something goes wrong, early on -- and then fix it.

- Focus on a "progressive evaluation" – make sure that you are looking for reasonable and not premature progress based upon the workscope and intensity of the endeavor.
- Watch for unanticipated outcomes – talk about them, incorporate them into the plan, learn from them.
- Make progress public, or the lack thereof.
- Provide routine reports that are easy for the diversity of stakeholders to obtain and understand.
- Use the baseline to apply data demonstrating change or improvement.
- Don't be afraid of modifications to the data!
- Historical data may be incomplete; definitions might have been incompatible, etc.
- The use of data typically helps to improve the collection of data.

Step Thirteen:

Celebrations are important. The completion of a plan is a celebration – recognize the effort, hard work and contributions of those who were instrumental. Working together to identify and implement early victories helps to keep excitement, involvement and commitment. Display data and celebrate success, in whatever form or measure it comes. Use small successes to build future initiatives.

Step Fourteen:

State Part C planners, throughout the course of the interviews, stated the importance of continuity and commitment of leadership to accessing Medicaid for early intervention systems. This is a dynamic process that can mature over time, involve different stakeholders, and cover a variety of issues and situations. Part C planners need to make certain that the expansion of funds supports, rather than compromises, the foundation of the Part C system. As regulations and research change practice, Part C planners will need to be able to use data to demonstrate need and direction for change. Some of the states that could be considered "successful" have spent years cultivating relationships, proposing change and dealing with delays due to changing administrations, competing populations, a simple lack of time or visibility of Part C. These planners were diligent in pursuing Medicaid opportunities, rewriting state plan amendments, reengaging former partners

and informing new ones. It was difficult for many to identify that one moment or factor that resulted in success; everyone did agree though that preparation and readiness to respond was ongoing and constant.

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http://www.cms.hhs.gov/manuals/45_smm/sm_02_2_2080_to_2089.9.asp

Medicaid regulations governing Organized Health Care Delivery Systems

http://www.cms.hhs.gov/medicaid/schools/macguide.pdf

School Based Medicaid Claiming Guide

http://www.cms.hhs.gov/glossary/default.asp?Letter=ALL&Language=English#Content

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CMS – EPSDT web site

http://www.healthlaw.org/pubs/mc1997checklist-epsdt.html

EPSDT Checklist for Medicaid Managed Care and Children with Special Needs

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IDEA Early Intervention and Special Education Laws and Information

http://www.nectac.org/partc/partc.asp

Early Intervention Program Resources at NECTAC

http://www.ed.gov/about/offices/list/osers/osep/index.html

OSEP - Office of Special Education Programs, U.S. Department of Education

http://www.ideadata.org/

IDEA data and resources

Other National Resources

http://medicaid.aphsa.org/members.htm

Medicaid Physical Therapy, Occupational Therapy, and Services for Individuals with Speech, Hearing and Language Disorders.

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Childrens Health Matters, for individual on individual state Medicaid and SCHIP programs

http://www.ssa.gov/notices/supplemental-security-income

Social Security Administration

http://www.acf.hhs.gov/programs/add/

Administration on Developmental Disabilities

http://www.ichp.edu/cshcn

State Maternal Child Health Agency contacts

http://www.ncsl.org/programs/health/medicaidsnapshot.htm

National Council State Legislatures Medicaid 'primer"

http://www.nectac.org/

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http://www.dec-sped.org

Division of Early Childhood of the Council For Exceptional Children

http://www.acf.hhs.gov/programs/hsb/

Head Start and Early Head Start

http://www.zerotothree.org

Zero to Three: National center for Infants, Toddlers & Families

http://www.naeyc.org

National Association for the Education of Young Children

http://www.iamyourchild.org

Parents' Action for Children

http://www.familiesusa.org/site/PageServer?pagename=Medicaid_Index

Families USA – information on Medicaid and Children

http://www.familycenteredcare.org

Family-Centered Care

http://www.clas.uiuc.edu

Culturally Appropriate Early Childhood Practices

http://www.aap.org/policy/re9753.html

Culturally Effective Pediatric Care

http://www.healthinschools.org/coe.asp

The Center for Health Care in Schools

www.medicaidforeducation.org.

National Alliance for Medicaid in Education

http://www.naphacc.org

National Association of Pediatric Home and Community Care (NAPHACC)

http://www.healthlaw.org/library.cfm?fa=detail&id=48378&appView=folder

National Health Law Program – recent publications

http://www.healthlaw.org/index.cfm

National Health Law Program – home page

http://www.nasmhpd.org/

National Association of State Mental Health Program Directors

http://www.ssa.gov/notices/supplemental-security-income

Information on Supplemental Security Income (SSI)

www.ssa.gov/disability/professionals/bluebook/ChildhoodListings.htm

Information on children's eligibility for Supplemental Security Income (SSI)

http://www.acf.hhs.gov/programs/add/

The Administration on Developmental Disabilities

http://www.ichp.edu/cshcn

Directory for state Title V programs

http://www.firstsigns.org

First Signs website (comprehensive early childhood resources focusing on early identification and intervention)

http://www.colorado.edu/slhs/mdnc

Marion Down National Center for Infant Hearing

http://www.infanthearing.org

National Center for Hearing Assessment and Management (NCHAM) at Utah State University

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