



## Reaching the Children: The Relationship Between Title V and Part C

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### Introduction

Across the United States, two federally funded programs ensure the health and development of young children with special needs. Through Title V of the Social Security Act, states address the health needs of women, children and youth, including those with special health care needs. Through Part C of the Individuals with Disabilities Education Act (IDEA), states identify developmental delays in children age zero to three and coordinate early intervention services.

While the structure of these programs varies from state to state, Title V and Part C work together closely to address the health needs of children with disabilities. Because the legislation does not include specific provisions for this coordination, this report examines these partnerships in 20 states. As Congress reauthorizes IDEA in 2003, they have an opportunity to strengthen these programs and formally support their collaboration.

This report examines Title V and Part C partnerships in 20 states, highlights models of collaboration, documents barriers to collaboration and provides recommendations to Congress and the federal government to support this collaboration.

### Background

#### What is Title V?

Authorized by Title V of the Social Security Act, the Maternal and Child Health Services Block Grant supports the infrastructure for maternal and child health services in every state and territory. Consisting of the state Maternal and Child Health (MCH) and Children with Special Health Care Needs (CSHCN) programs, Title V supports efforts within both the public and private sectors to shape and monitor health-related services for women, children and youth. Title V programs provide resources, deliver critical screening services, and support preventive, primary and specialty care. If there are gaps in health-care services, Title V programs may support or provide those services to special populations. All Title V programs are administered by the state health agency, however in seven states the CSHCN program is located in another state agency or university.

The CSHCN programs are closely linked to early intervention programs. Children with special health care needs are defined as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition who also require health and related services of a type or amount beyond that required by children generally."<sup>1</sup>

The National Survey of Children with Special Health Care Needs estimates that 12.8 percent of all children in the U.S. younger than age 18, or 9.4 million children, meet this definition (excluding the at-risk population).

Compared with other state services, Title V programs often have the greatest expertise reaching special needs children, the strongest connection to networks of pediatric specialists, including the child's medical home, and the best data on the service needs of special needs families. Specifically, the Title V block grant provides funding for family-centered, community-based, coordinated-care for children with special health care needs. Many Title V CSHCN programs have expanded beyond direct services to care coordination and quality assurance. These programs also serve a gap-filling role, providing services not covered or available under other programs. In recent years, CSHCN programs have a history of commitment to family involvement by employing parents to increase outreach to parents of children with special needs, review block grant applications, serve on state policy panels, assist care coordinators and more. A recent survey found that 79 percent of CSHCN programs and 36 percent of MCH programs employ parents as staff, consultants or through contracts with parent organizations.<sup>2</sup>

These Title V programs are further bolstered by the President's New Freedom Initiative, which was developed to increase community integration for people of all ages with disabilities. The recently released "Action Plan for Children and Youth with Special Health Care Needs and their Families," contained in the New Freedom Initiative, outlines additional roles of Title V programs in such areas as medical home, family participation, reimbursement mechanisms and newborn screening. In addition, Title V programs are required to report annually on 18 national performance measures, six of which specifically relate to children with special health care needs.

#### What is Part C?

Part C programs facilitate statewide early intervention services for children younger than 3 with a disability or at risk for a substantial developmental delay. In 1975 Congress enacted legislation (P.L. 99-457), now known as the Individuals with Disabilities Education Act (IDEA), to provide a free appropriate public education for all students with disabilities above the age of five. In 1986, Congress established Part C (formerly Part H) of IDEA, known as the Early Intervention Programs for Infants and Toddlers with Disabilities.

States may choose not to participate in Part C, although currently all states and eligible territories do. While states have discretion to establish their own early intervention systems, all state systems have certain components, including (1) initial identification; (2) initial services coordination; (3) eligibility determination; (4) evaluation and assessment; (5) service coordination, including the development of an Individualized Family Service Plan (IFSP)<sup>3</sup>; (6) provision of services; (7) procedural safeguards; and (8) data collection.

Today Part C programs are experiencing serious growing pains, with greater calls for accountability, quality assurance and financial controls than ever before. In addition to ballooning state deficits, Part C programs face skyrocketing program costs, inadequate mental health services, and increases in the number of children requiring early intervention services, particularly children with autism. States are also experiencing difficulty accessing private insurance, transitioning children from Part C to Part B educational programs and complying with the natural environment requirements (see *Provider Availability, Training & Recruitment* section later in this paper).

## The Intersection of Title V and Part C

Title V programs play an important, if not always recognized, role in Part C programs. Indeed, Title V programs were instrumental in setting up Part C programs in their states when the legislation first passed. As one state mentioned, “In the early years of Part C, Title V supported Part C financially, when Part C was running a sizeable deficit.”

Title V programs have a statutory responsibility to “facilitate the development of community-based, comprehensive systems of care.” Since Part C is a part of this system, state Title V programs work closely with Part C programs on outreach and identification, care and service coordination, parental involvement, provision of services, and quality assurance. In nearly half of the states, Part C programs are housed in the state department of health,<sup>4</sup> often within the Title V program.

Because these roles were not written in the original law, they have not always been understood. Reauthorization of the IDEA statute, including Part C, provides an opportunity to better coordinate programs for young children with disabilities and forge new partnerships among federal and state programs, such as Head Start, mental health and child care.

## Survey Methods

The Association of Maternal and Child Health Programs represents state public health agencies funded through Title V of the Social Security Act, including MCH and CSHCN programs.

To document the relationship between Title V and Part C programs, AMCHP conducted phone interviews with Title V MCH and/or CSHCN directors in 20 states. In most cases, directors or staff from the Part C program participated in the interview as well. These interviews were based on a questionnaire developed in consultation with the AMCHP Service Delivery and Financing Systems Committee.

The following states were interviewed: Alabama, Delaware, Georgia, Idaho, Illinois, Iowa, Kentucky, Massachusetts, Michigan, Minnesota, Nebraska, New Jersey, New York, Ohio, Oklahoma, Rhode Island, South Carolina, Utah, West Virginia and Wisconsin.

## Best Practices

The experiences of these 20 states, while instructive, do not necessarily represent the full range of relationships between Title V and Part C programs. The selection of states, while geographically diverse, is somewhat skewed to states where the Part C program is located within the health department. While all Title V and Part C programs share a common goal, there is a great deal of variability across states in eligibility (particularly in CSHCN programs), state resources and political environments.

## Location of Part C Programs

The location of Part C programs can have a significant impact on the extent of collaboration with Title V programs. Federal law allows the governor of each state to designate a lead Part C agency. In half of the states interviewed, Part C is located in the state health department. In eight of these 10 states, the Part C programs are located within either the Title V MCH or CSHCN program. (In Kentucky, the Part C program is located in the Title V CSHCN program, which is located outside of the health department.) In five states, the Part C program is located in the state department of education (although in Oklahoma, the education department contracts with the Title V MCH program to administer Part C). In the five remaining states, the Part C programs are located in another agency.

### Location of Part C Programs

State Dept. of Health	Title V MCH or CSHCN	State Dept. of Education	Other Agency
Georgia, Massachusetts, Nebraska, Ohio, New Jersey, New York, Rhode Island, South Carolina, Utah, West Virginia	Georgia, Kentucky (CSHCN not in Health Dept.), Massachusetts, Nebraska, Rhode Island, South Carolina West Virginia, New Jersey, Utah	Iowa, Minnesota, Michigan, Nebraska (co-leads with Health and Human Services) Oklahoma (contracts with Title V MCH to be service provider)	Alabama (Dept. Of Rehabilitation Services), Delaware (Health and Social Services) Idaho (Division of Family and Community Services, Dept. of Health and Welfare) Illinois (Office of the Assistant Secretary of Human Services), Wisconsin (Division of Disability and Elder Services, Department of Health and Family Services)

# Eligibility Criteria

The Part C statute requires participating states to provide services to both children “who are experiencing developmental delays, and those who have a diagnosed mental or physical condition that has a high probability of resulting in developmental delay. In addition, states may choose to serve children who are at risk of having substantial developmental delays if early intervention services are not provided.”<sup>5</sup> The majority of states interviewed described their eligibility criteria for Part C as “moderate” as compared to other states. Three states described their eligibility as “moderate to limited,” and four states described their criteria as “liberal.” Only two states interviewed (Massachusetts and West Virginia) serve at-risk children – those at risk of developing a disabilities or developmental delay.

According to National Early Childhood Technical Assistance Center (NECTAC), “The task of defining the eligible population has been a challenge for states. Eligibility criteria influence the numbers and types of children needing or receiving services, the types of services provided, and ultimately the cost of the early intervention system.”<sup>6</sup> Programs to identify eligible children, such as Child Find, are bringing increased numbers of children into the system. The budget crises that states currently face are further limiting resources. As a result, some states are being forced to impose greater restrictions on eligibility, potentially excluding children who were previously eligible.

Like Part C, states set eligibility criteria for special needs children who receive direct services under Title V. Because state dollars are limited, the eligibility criteria are often narrower than the broad federal definition of children with special health care needs. While the eligibility criteria for Part C and CSHCN may overlap, the statutory definition of special needs under Title V is broader than the Part C definition. This disconnect can raise problems in program coordination.

## Identification of Eligible Children

The age at which a child is referred to the Part C program is particularly crucial. The earlier a child can receive early intervention services, the greater potential for improved outcomes, so mechanisms to identify children eligible for Part C are vital. Federal law requires all state Part C systems to have a “Child Find” program to identify and refer eligible children. Child Find depends on newborn and early childhood screening, which is often administered by Title V.

A “medical home” is a critical referral source for special needs children and one of the most important elements of Child Find. This provides another opportunity for Part C to collaborate with Title V programs, which are required to ensure that children have a medical home.

The Child Find system also helps states identify unmet needs and service gaps. States report that children with mental health needs are increasingly being referred to Part C, but services are limited. Even more troubling, there are many children with behavioral health issues (e.g., Attention Deficit Disorder) who are not eligible for Part C but are in need of services.

Title V programs have considerable expertise designing and implementing outreach strategies. Federal law mandates that state Title V programs identify pregnant women and infants eligible for Medicaid and help them apply. Title V programs also maintain telephone hotlines to answer questions on prenatal care and provide referrals. Some states have similar hotlines for children with special health care needs. National surveys like the National Survey of Spe-

cial Health Care Needs, birth defects registries and EPSDT should help Part C and Title V programs identify children with special health care needs.

Eight states reported strong collaboration between programs in the area of newborn hearing screening, using the screening to identify referrals to the Part C program. Two states rely on Title V home visiting programs for referrals to Part C. Several states felt that pediatricians and primary care providers need further training to understand the relationship between medical homes and Part C programs and the importance of early referral.

**Tracking Child Find Referrals in Illinois:** The Title V MCH program worked closely with the Part C program to design quality indicators to evaluate the success of “Child Find” initiatives across the state. The state now tracks the number of referrals a local program makes to Part C, the age of the child at referral and the subsequent participation rate. These reports are shared with local programs. If referrals are low, especially for infants, local case managers receive additional training and technical assistance.

**Implementing Universal Newborn Hearing Screening in Ohio:** The Title V CSHCN program worked closely with the Part C program to pass legislation authorizing universal newborn hearing screening in Ohio. The two programs continue to work together to develop rules and implement the legislation.

**Serving Infants with Mental Health Needs in Utah:** The CSHCN and Part C programs are collaborating on an infant mental health initiative to develop preferred practice guidelines and to improve the Child Find process of identifying and referring infants and toddlers with mental health needs.

**Providing Nutritional Services in Wisconsin:** The Title V and Part C programs jointly developed a nutrition screening tool and follow-up process. County Part C programs will use this tool to assess if children need nutritional intervention within the context of the Part C program or if Part C should coordinate nutritional services from an outside provider.

**Integrating Screening Databases in Oklahoma:** Oklahoma passed legislation mandating universal newborn hearing screening in 2001. The Title V MCH program, in collaboration with CSHCN, trained staff in screening techniques and placed equipment in hospitals across the state. Through a SPRANS<sup>7</sup> grant, newborn metabolic screening and universal hearing screening databases were integrated and are used for follow-up and referral to Part C.

## The Importance of Collaboration

Public health programs are encouraged to “collaborate” so often that it can become an empty word. Nevertheless, collaboration forms the heart of the success of Part C and Title V programs. The majority of states interviewed reported strong relationships between their Title V and Part C programs, recognizing the important and unique role of each. Title V programs bring medical expertise to Part C, while Part C brings a developmental focus. Moreover, Part C programs have forged crucial links to the medical community and parent organizations. As one state said, “[Part C] would not have high numbers of kids without linkages with Title V.”

While Part C programs work with both MCH and CSHCN programs, the link to CSHCN is particularly important because of

the overlap in the children served. CSHCN programs can provide important mechanisms for collaboration with Part C, such as funding for direct services (e.g., spina bifida clinics, hearing aid devices) and infrastructure initiatives (e.g., developing a data system, expanding care coordination). Of the states interviewed, 16 provide some form of direct services to special needs children, and four states primarily fund infrastructure services.

States have the flexibility to design Part C programs that best suit their needs, as long as they provide multiple service sites. For example, service coordinators may be located in local agencies, health departments, early childhood centers, local school districts and other venues. Children may be evaluated at a number of sites, including clinics funded by Title V. In some cases, Part C may contract with Title V to provide services to eligible children.

A major factor contributing to collaboration is the location of the Part C program within the health department (and, even better, within the Title V program). These programs share staff (including family representatives), meet regularly and operate together as a set of services for special needs children. While Title V programs report collaboration even if the Part C program is outside of the health department, different departmental missions and funding streams limit the extent of collaboration. As one Title V director noted, “There is a separateness of services, more of a disconnect and less understanding about the importance of the health aspects of early intervention.” Indeed, some Title V directors noted a tension between the Part C program, which focuses on a narrow population, and Title V, which looks at the overall system of care. Nevertheless, collaboration can strengthen the mission of both programs.

**Helping Children Grow in Ohio:** In Ohio, the “Help me Grow” program and the Title V CSHCN program work together to identify dually eligible children and assure they receive the services they need. The Title V MCH and CSHCN programs run specialty clinics together for Part C children in underserved areas of the state.

**Evaluating Special Needs Children in Idaho:** CSHCN clinics evaluate children in the Part C program at no cost.

**Protecting the Fiscal Needs of Local Programs in Alabama:** The Part C program contracts with the Title V CSHCN program to act as fiscal agent for a number of local programs. The Title V program also provides early intervention services with Title V social workers acting as service coordinators.

**Joint Monitoring in Georgia:** Georgia is developing a joint monitoring process between Title V CSHCN and Part C programs. The programs have created joint policies and forms for collecting financial information and determining family costs. They will use the same intake process and forms as the statewide MCH programs.

**Integrating Care in Minnesota:** Minnesota has adopted a coordinated, multidisciplinary, interagency service system for all children with disabilities from birth to age 21 based on the Part C model. Up to 30,000 children will be served by this system once it is fully implemented. The system will simplify and streamline services to children, involve families and youth in directing their own care, improve communication among all parties, and serve as a single point of contact for families.

**Serving Autistic Children in Massachusetts:** To meet the needs of growing numbers of autistic children, Massachusetts created 10

specialty programs. Many children in these programs also receive early intervention services.

## Care Coordination and Service Coordination

Title V and Part C programs share a coordinating role. Title V programs provide “care coordination” to link support structures, services and resources for special needs families across multiple service delivery settings. Part C programs provide “service coordination” to meet the needs of the family as well as the child. Title V care coordination focuses on the health needs of children, particularly children with complex medical needs, while Part C service coordination focuses on the developmental needs of children.<sup>8</sup>

In reality, coordination services vary across states and even within states. In some areas, the same staff serve as both service and care coordinators, while in others, service coordination and care coordination are distinct and separate systems. A primary concern for both Title V and Part C programs is how to use both systems without duplicating services and confusing families. A number of states interviewed had developed, or were in the process of developing, a system that could use the strengths of both to fully help families while their children are eligible for Part C and to successfully transition beyond Part C. As one state Title V director noted, “Part C enhances Title V because of the intensity of service coordination and service delivery. Ideally, we would like to have service coordination [and the medical expertise of Title V CSHCN care coordinators] for all kids 0-21 with special health care needs.”

**Contracting Service Coordination in Iowa:** The Part C program in Iowa has the potential to contract with the Title V CSHCN’s care coordination program to provide service coordination to children with complex medical needs.

**Entering Part C Through Title V in New Jersey:** Title V care coordinators in county units serve as the entry point for Part C. To comply with the service coordination mandates in Part C, care/service coordinators are funded through Part C, state appropriations or Medicaid.

**Coordinating Across Programs in New York:** In New York, care coordinators and service coordinators are often the same people. For children with conditions that are expected to last into adulthood, Title V care coordinators are often assigned to ensure continuity beyond age 3.

**Providing One Care Coordinator in Ohio:** Children with special health care needs have Title V service coordinators that can provide coordination services as soon as the child enters either the Part C or Title V systems.

## The Medical Home

Closely related to care and service coordination is the concept of the medical home. A child with a medical home, according to the American Academy of Pediatrics, has a primary care physician who works with the child’s family to ensure that all their medical, non-medical, psychosocial and education needs are met in the local community. The medical home concept is particularly important for children with complex medical needs who may require a wide range

of medical and social support services. A medical home provides continuity of care and relationships with a health professional. As one state director noted, “We would like pediatricians to go beyond simply prescribing therapies and be active partners in implementing the [Individualized Family Service Plan].”

Part C provides an excellent opportunity to identify children lacking a medical home and help families determine the best medical home for their children. Nearly half the states interviewed reported promising partnerships on the medical home concept, with Title V CSHCN programs in leadership roles.

**Improving Communication in Ohio:** In Ohio, the Title V CSHCN system is working with all its partners to promote medical homes for children with special needs. In conjunction with the Part C program, there is a strong effort underway to educate service coordinators, providers and families. The Part C program is increasing the involvement of physicians in the program and strengthening communication between “Help Me Grow” (Ohio’s integrated 0-3 program), service coordinators and the child’s medical home.

**Involving Primary Care Physicians in Iowa:** The Iowa CSHCN program is planning an initiative supported by the Part C program to establish medical homes for special needs children in primary care practices. The initiative will improve physician practices in early childhood screening and medical home referrals. The initiative is an expansion of an existing pilot program in child health specialty clinics across Iowa.

## Provider Availability, Training and Recruitment

The growing number of children entering the early intervention system has strained the already limited number of qualified pediatric providers participating in the program. Many states report chronic shortages of physical therapists, occupational therapists and speech therapists, among others. Many of these providers have not received any specialty training in early childhood. States participating in the newborn hearing screening initiatives are having trouble finding audiologists with the necessary training. Other states report that they are competing with schools and hospitals for therapists, but they can’t always match the salaries because of lower reimbursement rates. In addition, an increasingly diverse population is fueling a need for hard-to-find bilingual providers.

The federal requirement to use “natural environments” has resulted in a shift from traditional clinic-based services to family-centered sites, including the home and child care settings. This has placed a strain on some states, and, according to some parents, does not necessarily meet their needs. It is difficult for some states, especially those with large rural areas, to find therapists willing to work in natural environments. Adding to the problem in some states is inadequate Medicaid reimbursement for services provided in natural environments. As one state mentioned, “The low Medicaid reimbursement coupled with the travel time to reach the families makes participation in [early intervention] not worth the effort for many therapists.” Title V programs, with their links to providers and research institutions, are natural partners in training and recruitment initiatives.

**Training Students in Oklahoma:** The Part C program has teamed with the LEND<sup>9</sup> program at the University of Oklahoma Health

Sciences Center and the College of Allied Health to further train students in early childhood specialties by placing them in early intervention programs for a portion of their practicum experience.

**Using Alternative Treatments in Rhode Island:** To meet the increasing need for therapists, Rhode Island is exploring alternative treatments, such as group speech therapy.

**Certifying Autism Providers in New Jersey:** Title V and Part C programs are developing a paraprofessional program for autism that would provide state certification for graduates. Hopefully, this certification would result in Medicaid reimbursement, which only covers licensed providers.

**Giving Kids a Head Start in New Jersey:** Title V and the state’s Office on Child Care are working together to develop training and policies to make it easier for child care providers to serve children in the Part C program. Providers who serve special needs children get enhanced reimbursement through the Office on Child Care. Part C and Head Start have signed a Memorandum of Agreement to strengthen services for special needs children served through Early Head Start.

**Joint Training & Assessment in Nebraska:** Title V CSHCN and Part C programs routinely participate in joint training, especially to serve children with complex medical needs. To reach staff and providers in a largely rural state, the programs often use video conferencing. The programs have also completed a joint assessment.

**Expanding Provider Networks in Alabama:** The Title V CSHCN program, Children’s Rehabilitation Services (CRS), is expanding its provider network. In particular, CRS credentials individual therapists, who often work part-time and don’t have the time to handle Medicaid billing. CRS is helping the Part C system expand its provider network to ensure that local programs use only credentialed providers.

## Family Involvement

Both Title V and Part C programs work to include special needs families in all aspects of decision-making and system improvements. States say that they have learned from each other in ensuring greater parent involvement, with Title V taking the lead in some states and Part C in others. Several states noted that Title V’s experience involving parents has been helpful to Part C programs as they develop mechanisms for sustained parental involvement. In a number of states, the family staff member works with both Part C and Title V programs. Three Title V programs employ a part-time parent, funded by Part C.

**Expanding Family Involvement in Oklahoma:** The Title V MCH program employs a parent advocate who works with Part C to strengthen family involvement in policy and service development. Through support from MCH, parents in the Part C program receive the Oklahoma Family Voices Newsletter.

## Quality Assurance

In an era of increasing accountability and tighter budgets, state Part C programs face pressure to provide more reliable and informative quality assurance systems yet receive limited funding for these ac-

tivities. In particular, states are concerned that there aren't strong mechanisms to challenge the appropriateness of services and increase accountability of the Part C system. Because Part C doesn't require specific performance outcomes, it is difficult to monitor. Because Title V programs have statewide responsibilities for assessment and assurance, they are making great strides in measuring outcomes and monitoring systems. But there is still a need for an overall quality assurance system for children with special health care needs.

A number of states interviewed felt that the U.S. Department of Education doesn't provide enough funding or technical assistance for states to fully monitor their programs and were grateful that Title V, with its data expertise, could provide leadership and funding in these areas. Title V and Part C programs are partnering to develop quality indicators, practice guidelines and improved data systems. Some states have invested in quality assurance systems (using Title V dollars in some cases) to better monitor children and providers in Part C systems.

**Integrating Data in Kentucky:** The Part C program recently moved to the Commission for Children with Special Health Care Needs (the CSHCN program). These programs are in the early stages of integrating their data systems, including intake and eligibility, service planning, service delivery, and quality and outcomes.

**Researching Quality Improvement in Rhode Island:** With funding from the Title V, Part C and Medicaid programs, a fellow in early childhood development at Brown University is researching quality improvement issues affecting the three programs.

**Tracking Services & Referrals in Illinois:** As Illinois recently restructured its Part C program amid legal and financial troubles, Title V played a key role developing quality indicators to better determine the services children receive. The Part C program now collects information on what services children receive, how agencies and providers identify children, and whether agencies make appropriate referrals.

**Accessing Health Records in Utah:** Part C and Title V programs are working together on a large initiative for data development called the Child Health Advanced Records Management (CHARM) project. This system, funded by Title V, will give early intervention programs access to immunization records, newborn hearing screening results and newborn blood screening results.

**Creating Practice Guidelines in New York:** The Title V and Part C programs together have developed practice guidelines for six conditions, including autism. These guidelines are used by Part C programs and have been translated into informational booklets for providers, families and others. The next step is to create a quality assurance mechanism, through record review, to see if the guidelines are followed.

**Partnering on Quality in Delaware:** The Part C program funds a CSHCN staff member to focus on quality issues and help the programs work together on respite care, traumatic brain injury, medical homes and child care for children with disabilities.

**Recording Early Intervention Data in Alabama:** Alabama's Part C program conducts joint monitoring with teams from both the Part C and CSHCN programs. All providers, regardless of agency, can

record early intervention data in the program's data system.

**Linking Local Providers to the State in West Virginia:** West Virginia's Part C system is locally administered by community-based agencies acting on behalf of the state. The local agencies link to the state's data system of all patient forms including Individualized Family Service Plans. The state also receives all billing for authorized, appropriate services to Part C participants, including Medicaid, regardless of the family's payor status. A quality assurance team monitors all Part C providers, matches the IFSP to services rendered, confirms provider credentialing and tracks other chart review requirements. The quality assurance unit reports directly to the MCH program.

## Program Funding

While the interview didn't include specific questions on funding, budget issues certainly impact a state's ability to deliver early intervention services. In some states, the Part C program is significantly larger than the CSHCN program, while in other states the opposite is true. Some states have invested significantly beyond the federal Part C funding, while other states have invested more in their CSHCN programs. For these states, the state budget shortfalls will obviously impact the extent of their programs.

Title V and Part C programs differ in their federal and state funding. The Title V budget is composed of federal, state matching, local maternal and child health (MCH), and other funds, as well as program income. For every \$4 of federal funds, the state must match at least \$3 with state and local funds. In FY 2001, the federal government's portion of this partnership equaled \$592 million, with grants ranging from \$1.3 million in Wyoming to \$44 million in California. The state match totaled \$2.3 billion for the 50 states and nine jurisdictions. If states exhaust the block grant money, they must request additional funds from the state legislature.

Part C programs work like entitlement programs — they must serve all infants and toddlers meeting the eligibility criteria, regardless of available resources. However, Part C is not a true entitlement program, because states may opt out of participating in Part C and families may contribute to the financing through private or public insurance, co-payments, deductibles, or sliding fee scales.<sup>10</sup>

Title V and Part C programs face their greatest financial threat in years as states confront the worst budget crisis since World War II. Nearly all states interviewed emphasized budgetary pressures as their most significant challenge, and many worry that they'll be forced to cut services and personnel. This situation is exacerbated by the fact that Congress has never fully funded the IDEA program, Part C has never been permanently authorized and Part C is a state option. Currently, the federal government contributes only 17 percent of the funding authorized by law.

## Financing

The financing of Part C services is perhaps the most critical issue facing states as budget deficits coincide with increasing participants. Part C was originally designed as early intervention "glue" money, intended to facilitate coordination among state agencies. In practice, however, states have not been completely successful in leveraging the money necessary to fund the program adequately. Financing for Part C programs varies widely across states depending on state resources, politics and the needs of the population. States' ability to sustain and expand their programs is dependent on Med-

icaid reimbursement, commercial insurance and appropriate reimbursement levels for Part C providers.

Because statute establishes Title V as a payor of last resort for Part C services, Title V has a vested interest in sound financing structures for Part C. This is especially true at a time when state Title V programs are playing a decreasing role in direct services and a greater role in public health care coordination. Title V programs have extensive experience with the intricacies of Medicaid billing and reimbursement. Furthermore, Title V care coordinators in some states have greater experience and training than service coordinators in the funding and reimbursement issues for special needs children.

### **Relationship with Medicaid**

While Part C programs interviewed reported generally good relationships with their state Medicaid counterparts, this is not the case for all Part C programs. Even in states with good relationships, Medicaid funding and reimbursement for Part C services remain a problem. Not all state Medicaid programs cover all early intervention services, or the reimbursement rates are too low to encourage enough providers to participate in the program. Many states that receive Medicaid coverage for all Part C services find they still need additional funds. In addition, state Medicaid programs have not always acknowledged the multidisciplinary approach of many Part C programs. Some of this reluctance may be due to the skyrocketing costs of the Medicaid program.

States also point to a lack of federal leadership in ensuring consistent Medicaid and early intervention policies. For example, some states report difficulty getting Medicaid to reimburse rehabilitation services in natural environments, because Medicaid cannot bill for services outside of hospitals. In addition, some states report that Medicaid is changing the parameters for serving children under Medicaid Home and Community Based Waivers (which have no income requirement) due to rising costs. This is of particular concern to families of autistic children who can only access the intensive services they need through the waiver. States vary widely in their use of Medicaid EPSDT<sup>11</sup> for diagnostic evaluation and referral of children into Part C.

Covering Developmental Services in South Carolina: The early intervention program, under the leadership of the Title V CSHCN program, is working with Medicaid to develop reimbursement for a package of developmental services.

Improving Therapy Reimbursement in Wisconsin: In 2002, Wisconsin enhanced the Medicaid reimbursement rate for therapy services for Part C children. A therapy provider receives \$21.50 over their regular reimbursement rate per child per visit per day to reflect the costs of providing services in natural environments. They also simplified the prior authorization process for therapy services; a therapist now needs prior authorization only once for each child as long as the child participates in the Part C program.

Using EPSDT as a Referral Source in West Virginia: In West Virginia, EPSDT (which is administered by the Office of Maternal and Child Health) serves as a referral source for Part C and Title V CSHCN programs, among others. The EPSDT workforce encourages pediatric medical providers to refer to Birth to Three and CSHCN for assessment and evaluation. If the child is eligible for either Part C or CSHCN, they are enrolled and provided appropriate service. All children referred to Part C or CSHCN receive assis-

stance selecting a medical home.

Providing Technical Assistance to Part C Providers in Iowa: The Title V program recently played a large role working with Part C and the state Medicaid program to gain Medicaid coverage for early intervention services. In the implementation phase, the Title V program will provide technical assistance to Part C providers and service coordinators in Medicaid billing procedures.

### **Commercial Insurance**

Under federal law, states are responsible for identifying and coordinating all available resources for early intervention services within the state, including federal, state, local and private resources. Further, Part C is the payor of last resort, especially when children have private insurance. However, insurance can only be accessed with parental consent. Families are understandably reluctant to use private insurance because of lifetime caps on expenditures. Some states, Massachusetts in particular, have mandated that insurance companies cover services available under Part C and disallow lifetime financial caps on special needs children. Two of the states interviewed are developing similar legislative language, and others mentioned strong interest in such legislation.

Legislating Insurance Coverage in Massachusetts: Massachusetts law mandates that commercial plans cover early intervention services, including developmental therapy, up to \$3200 annually without impacting a child's lifetime expenditure cap.

### **Financing Structure**

The financing structure of Part C can impact the program's ability to monitor services. A number of states have changed, or have considering changing, from a contract structure, where agencies receive grants or contracts, to a fee-for-service system. These changes resulted in part from concerns of fraudulent billing through the contract system and a desire to better track the services a child receives. Because of high reimbursement rates, one state noted, there is no incentive for providers to carefully consider costs.

Redesigning the Payment System in West Virginia: The state Part C program, under the leadership of Title V, recently redesigned its payment system as part of an overhaul of the entire Part C program that involved consumers, providers and other stakeholders. While Medicaid already covered early intervention services, the high reimbursement rates for center-based care were a disincentive for natural environments. Now, under a new Medicaid state plan, the program has a central financing system with all billing (from all sources of payment) coming through the Title V program. According to Title V leaders, providers are paid more quickly and families receive the services in a more timely fashion. Through an integrated data system connected to the billing process, Part C administrators can determine if children are receiving the services they need.

## Recommendations

The many partnerships between Title V and Part C point to the enormous potential and benefits of collaboration. While Part C provides services for children in their early years, Title V can continue to serve them throughout childhood and as they transition to adulthood.

The following recommendations for state programs, federal agencies and Congress will foster greater collaboration and ensure the health and well-being of special needs children and their families.

## For State Title V and Part C Programs

- Form interagency workgroups (with strong parent representation) to address critical issues in the special needs populations, such as autism and infant mental health; develop practice guidelines; strengthen early identification guidelines; increase service capacity and reduce duplication of services.
- Develop mechanisms to track all children referred to Child Find, particularly those with special needs who are not eligible for Part C services, so they don't get lost in the system.
- When children are dually eligible for Title V CSHCN care coordination and Part C service coordination, develop mechanisms to integrate the care plan and the Individualized Family Service Plan.<sup>12</sup>
- Strengthen data sharing and capacity between programs. Title V programs should share current, state-specific information from the National Survey of Children with Special Health Care Needs.
- Use the President's New Freedom Initiative and Title V performance measures to integrate systems of care.
- Develop joint training for pediatricians and other providers on topics such as Medicaid billing, medical homes and Part C referrals.
  - Work jointly with Medicaid to maximize the role of EPSDT in identifying and evaluating children referred to Part C.
  - Develop seamless transitions for children moving from Part C to Part B. Title V should have a more visible presence in schools to assist with transitioning to Part B and, later, to adult health care.
- Provide incentives for people to pursue careers in early childhood specialties, such as therapists and child care providers.

## For the Maternal and Child Health Bureau, U.S. Department of Health and Human Services

- Continue to provide funding for states to build and strengthen partnerships in areas such as Healthy Child Care America, Early Childhood Comprehensive Systems Grants and Newborn Hearing Screening.
- Work with the Department of Education and other agencies within HHS to provide incentives for more people to pursue careers in early childhood specialties.
- Continue to provide federal leadership, and partner with the American Academy of Pediatrics, to train doctors in the medical home concept and in the early intervention referral process to help pediatricians be active members of IFSP teams.

- Work with the Department of Education to ease confidentiality rules between health and education records to promote better data sharing and child tracking between the Title V and Part C programs.

- Encourage state and local involvement at the policy level in State Interagency Coordinating Councils (SICCs) and Local Interagency Coordinating Councils (LICCs).

## For the U.S. Department of Education

- Promote the important role Title V plays in Part C programs.
- Work with the Centers for Medicare and Medicaid Services (CMS) to promote standardization across states for Medicaid reimbursement for early intervention services, particularly those in natural environments.
- Work with CMS to promote stronger federal guidance about the responsibilities of EPSDT in diagnostic screening and evaluation.
- Provide more technical assistance to states in the area of data surveillance and integrated data systems.
- Examine the paperwork requirements for Part C at the state and local level where they may be burdensome and counterproductive.
- Revise the federal rules governing the Part C programs to place a stronger emphasis on outcome rather than process measures.
- Provide mechanisms for states to evaluate IFSPs to ensure that health needs are addressed and the recommended therapies are appropriate.

## For Congress

- Fully fund IDEA Parts B, C and D.
- Permanently authorize IDEA Part C.
- Formalize the connection between Title V and Part C in newborn hearing screening.
- Formalize the partnership of Part C and Title V programs in mechanisms like Child Find to identify children lacking a medical home and help families determine the best medical home for their child.
- Provide incentives for states to broaden Part C eligibility.
- Align and/or remove barriers for public and private insurers to cover Part C services.

# Endnotes

<sup>1</sup> McPherson, M., Arango, P., Newacheck, P.P., Perrin, J.M., Shonkoff, J.P., and B. Strickland. "A New Definition of Children with Special Health Care Needs." *Pediatrics*. Vol. 102. No. 1. July 1998.

<sup>2</sup> Families in Program and Policy: Interviews with State MCH and CSHCN Programs. A Presentation of Preliminary Data. Betsy Anderson and Nora Wells. AMCHP Annual Conference. March 11, 2003.

<sup>3</sup> An IFSP integrates the comprehensive needs of the client in the context of the needs of the family as a whole. School-age children receive an IEP (Individualized Educational Plan), which is individual and does not look at the family context but rather the person as a student and only relates to educational needs.

<sup>4</sup>Source: NECTAC List of Part C Agencies (May 2002)

<sup>5</sup>Source: NEC\*TAS Paper: State and Jurisdictional Eligibility Definitions for Infants and Toddlers with Disabilities under IDEA p. 1

<sup>6</sup>Ibid

<sup>7</sup>Special Projects of Regional and National Significance. Funded through the Title V MCH Block Grant and administered by HRSA's Maternal and Child Health Bureau.

<sup>8</sup>The Association of Maternal and Child Health Programs convened a working group to address goals of Title V care coordination and its relationship with other programs. Two documents were published: *Care Coordination for Children with Special Health Care Needs and Their Families in the New Millennium: Principles, Goals and Recommendations Developed by the AMCHP Working Group on Care Coordination* (2000) and *Meeting the Needs of Families: Critical Elements of Comprehensive Care Coordination in Title V Children with Special Health Care Needs Programs* (2002)

<sup>9</sup>Leadership Excellence in Caring for Children with Neurodevelopmental and Related Disorders

<sup>10</sup>Part C of Individuals with Disabilities Education Act (IDEA): A Unique Federal-State Partnership. Susan Mackey Andrews and Maureen Greer. Sprans Chapter One: Overview of Part C, IDEA, July 8, 2000.

<sup>11</sup>EPSDT refers to Medicaid Early and Periodic Screening, Diagnosis and Treatment services for children.

<sup>12</sup>State CSHCN and Part C programs have a limited number of children who are eligible for services under each program. In most cases, these are children with both a physical disability and a developmental disability, such as a child with spina bifida who has some developmental delay or a child with Downs' syndrome who also has congenital hearing or heart problems.

# Thanks to reviewers:

**Sharon Walsh**, Government Relations Consultant, Division for Early Childhood, Council for Exceptional Children and Infant and Toddler Coordinators Association

**Bonnie Strickland**, Chief, Integrated Services Branch, Division of Services for Children with Special Health Needs, Maternal and Child Health Bureau, Health Resources Services Administration, Department of Health and Human Services

**Richard Roberts**, Director, Early Intervention Research Institute, Utah State University

**Linda Goetze**, Senior Research Scientist, Center for Persons with Disabilities, Early Intervention Research Institute, Utah State University

The Association of Maternal and Child Health Programs is the national organization representing state public health leaders and other interested individuals and organizations working to improve the health and well-being of women, children, youth and families, including those with special health care needs.



Association of Maternal and Child Health Programs  
1220 19th Street NW, Suite 801 • Washington, DC 20036 • (202)775-0436 • fax: (202)775-0061