

Title V Roles in Coordinating Care for Children with Special Health Care Needs

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Executive Summary

I. Introduction

Children with special health care needs and their families require a wide range of medical, psychosocial, educational, and support services (American Academy of Pediatrics, 1998; National Coalition of Family Leadership, 1995). Assisting families in coordinating these services is an important but challenging goal for health care providers, agencies, and managed care organizations in both the public and private sectors. What is care coordination and what can it be expected to achieve? How are care coordination services delivered? How can states assure adequate reimbursement for care coordination services? What are the key elements of successful programs? Answers to these questions are needed urgently to help shape the capacity of the nation's rapidly evolving health care system.

State Title V programs for Children with Special Health Care Needs (CSHCN) offer important insights into the challenge of providing and supporting care coordination. State programs have implemented diverse care coordination efforts, reflecting a variety of models, assumptions, and goals.

To gain insight into answers to critical research questions regarding care coordination, and to contribute to the understanding and ongoing development of Title V roles in coordinating care for CSHCN, Health Systems Research, Inc. (HSR) conducted a national study of Title V roles in coordinating care for CSHCN. This study was undertaken as an activity of the National Policy Center for CSHCN, which is funded by the federal Maternal and Child Health Bureau.

The study was conducted in two phases. In the fall of 1999, written surveys were mailed to each of the Title V/CSHCN agencies in the 50 states and the District of Columbia. A total of 46 surveys were returned over a period of several months, for a response rate of 90 percent. To obtain a more thorough understanding of the survey results and the ways in which different Title V agencies are carrying out their care coordination activities for CSHCN, HSR conducted follow-up telephone interviews with 14 states that responded to the written survey.

Both the survey and telephone interviews explored two levels of care coordination activities: the client level, where assistance in care coordination is provided to individual children and families, and the systems level, where coordination efforts are focused on linking and integrating policies and programs. This report presents the results of HSR's study.

II. Client-Level Care Coordination Services

A major focus of HSR's study addressed Title V roles in providing client-level, or what we also refer to as direct, care coordination services to CSHCN and their families. This section presents the study's results related to the provision of these services.

A. Title V Roles in Providing Care Coordination Services for CSHCN

Title V programs have a long history of providing care coordination services to the maternal and child population, especially CSHCN. Care coordination is an example of the enabling services category within the MCHB's MCH Pyramid model of resource allocation. This model illustrates how states focusing fewer resources on providing direct medical care services can increase the resources devoted to enabling, population-based, and infrastructure-building services.

In light of the MCHB's use of this model to reflect its focus on core public health services, HSR researchers assessed the degree to which Title V programs are currently involved in providing care coordination services to CSHCN and their families. The survey found that the majority of Title V agencies across the country are invested in providing and supporting this service—42 of

the 46 respondent states indicated that either Title V staff provide care coordination services to CSHCN or the Title V agency contracts for the provision of care coordination services to this population.

The survey also explored the ways in which state Title V care coordination roles had changed in recent years for states that are currently involved in providing direct care coordination services to CSHCN. Nearly two-thirds of the states indicated that they have increased the intensity or frequency of their care coordination services or changed in philosophy, direction, or approach. In particular, states noted three trends occurring in recent years: expanding eligibility to a broader population of CSHCN than in the past; providing a broader or more holistic set of care coordination services; and improving the quality of care coordination services. These changes are consistent with the MCH Pyramid Model.

B. Eligibility

Ideally, care coordination services will be available to all children with special health care needs. Unfortunately, not all states are able to meet this ideal. Fewer than half of the states responding to this study (18 states, or 43 percent of the states in which Title V provides or contracts for direct care coordination services) reported that Title V-supported care coordination services are available to all CSHCN.

Just over half of the states (24 states, or 57 percent of the states providing or contracting for care coordination services) fund care coordination services for only selected groups of children with special health care needs. These states have developed criteria to determine which children are eligible to receive services. Most often Title V agencies use diagnosis as a criterion for selecting which CSHCN are eligible to receive care coordination services. Following diagnosis, the categories of criteria most often used are family needs and functional status/severity of condition. Other criteria used by Title V agencies in several states are related to finances, such as ability to meet an income eligibility standard or ineligibility for Medicaid.

C. Providers

A central focus of this study's exploration of Title V roles in client-level care coordination was investigating who provides Title V care coordination services. For states that indicated providing care coordination services to CSHCN, the survey asked who provides these services: Title V staff and/or contractors. Of the 42 states that report providing care coordination services to CSHCN, 19 staff their care coordination programs with their own Title V employees. Ten states report providing care coordination entirely through contracts with outside agencies, including public health nursing agencies, health departments, non-profit organizations, hospital-based clinics, primary care clinics, and Early Intervention programs. Thirteen-states indicated providing CSHCN care coordination through both methods, Title V staff and contracts.

D. Processes and Procedures in Delivering Care Coordination Services

HSR's survey also explored aspects of the process through which Title V agencies and their contractors deliver care coordination services to CSHCN and their families, including the use of standard protocols, the scope of services coordinated, the mode through which care coordination services are delivered, and levels of care coordination.

- **Protocols.** The use of standard protocols or guidance can be an important tool for Title V agencies and their contractors to foster the consistent and systematic delivery of care coordination services. Twenty-four Title V agencies, slightly more than half, reported that they have written protocols or guidance outlining how care coordination services should be carried out. Title V agencies appear to be more likely to use protocols to facilitate the consistent provision of care coordination services when coordination is done by contractors rather than by their own staff. Among the 24 Title V agencies with protocols, 22 call for the development of a care plan for each client. Of these, 20 require that care plans include desired outcomes for the child and/or family.
- **Scope of coordinated services.** Title V agencies providing care coordination services to CSHCN, regardless of whether the services are provided by Title V staff and/or contractors, tend to provide a comprehensive approach to care coordination. Thirty-eight of the states coordinate seven or more different types of services (e.g., primary care services, specialty services, and ancillary therapies) for CSHCN and their families. The most common types of services coordinated

by Title V care coordinators are specialty medical services, Early Intervention services, primary care services, ancillary therapies, and family support services.

- **Mode of delivery.** Care coordination is delivered through a variety of means, including home visitation, clinic visits, and phone contacts, depending on the circumstances and needs of the child and his/her family. Most of the states in this study reported providing care coordination via all three modes.
- **Levels of care coordination.** While not addressed in the national survey, the telephone interviews found that several states have developed defined levels of care coordination that are used to match the intensity of care coordination services to the client's level of need. This approach can help to systematize the appropriate delivery of services, and also help to establish reasonable expectations about what care coordination can accomplish.

E. Financing

The survey examined several sources of financing for Title V care coordination services for CSHCN. The results revealed several important findings regarding national financing patterns for Title V care coordination services:

- **Title V funding.** The survey findings documented the critical importance of the Title V/MCH Block Grant in supporting Title V care coordination services. Of the 42 states with a role in providing or financing the provision of direct care coordination services to CSHCN, nearly all—40 states—indicated that they use MCH Block Grant funds to support care coordination services. Five of these states identified the MCH Block Grant as the only source of financing for these services.
- **Medicaid financing.** Medicaid is underutilized as a source of financing for Title V care coordination services. Thirty-five states indicated that they serve children on Medicaid. However, only 18 states reported receiving Medicaid reimbursement for care coordination services to CSHCN on Medicaid.

The survey also explored states' use of several different Medicaid reimbursement options to support Title V care coordination services to CSHCN. Targeted case management was reported as being used by 7 states, administrative case management by 10 states, EPSDT case management by 6 states, and waiver programs by 4 states. Four states noted that they obtain Medicaid reimbursement for care coordination services through alternative options. Eight states indicated using more than one of these financing options.

- **SCHIP financing.** Like Medicaid, SCHIP is also underutilized as a source of financing for Title V care coordination services for CSHCN. Of the 30 states

that indicated providing Title V care coordination services to children insured by SCHIP, only nine (less than one-third) indicated that the agency or its contractors receives reimbursement to support the delivery of direct care coordination services to CSHCN.

III Systems-Level Care Coordination Activities

Title V agencies have a critical function in fostering coordination of services by working at the broader systems level. In their role in helping to plan and develop the larger service systems of family-based, community-based, coordinated care for CSHCN and other MCH populations, Title V agencies influence the degree to which services will ultimately be coordinated for CSHCN and their families. HSR's study explored six categories of systems-level activities in which Title V agencies are engaged that affect the coordination of services for CSHCN:

- **Identifying CSHCN.** A critical element of an integrated system of care for CSHCN is its ability to identify these children and assure that their needs are assessed, planned for, and met. Our results indicate that the majority of Title V agencies are involved in screening children for special health care needs, with 35 states, or three-quarters of respondents, indicating their involvement in this activity. Most frequently states reported conducting newborn screening and screening for vision and hearing problems in school-age children. Twenty-six states reported being involved in the development or implementation of screening tools for identifying CSHCN. Also, 22 of the 46 respondents indicated their involvement in facilitating the development or implementation of policies for identifying CSHCN, such as through work with Medicaid and other agencies to influence policies and procedures for children within these systems.
- **Facilitating interagency coordination.** Coordination and communication among the various agencies that serve CSHCN can help to assure that services are provided seamlessly on the client level and lay the groundwork for coordinated responses to policy issues. The survey found that 33 states reported that they were responsible for spearheading efforts to improve coordination with other agencies serving CSHCN. In addition to Title V-led efforts, 39 states reported that their CSHCN program staff serve on interagency coordinating committees. Thirteen Title V programs reported that they fund staff positions (e.g., parent advocates, outreach or eligibility workers) in other agencies (e.g., Medicaid, Department of Education) to improve coordination.
- **Building structures to link CSHCN and their families to needed services.** Building and overseeing structures to ensure that CSHCN, their families, and providers have access to information about the services that are available and how to access them is a critical systems-level care coordination activity for Title

V agencies. Resource information (e.g., brochures, newsletters, resource directories, informational hotlines) regarding services for CSHCN for use by those caring for CSHCN is developed and/or distributed by 42 of the Title V agencies participating in this study. Maternal and Child Health staff, Medicaid managed care staff, or staff of health plans/case management organizations are trained in the needs of and resources available for CSHCN by 30 of the Title V agencies. Eleven of the Title V agencies reported directing or coordinating health services programming for children and adolescents in detention, mental health facilities, or foster care to ensure that CSHCN receive needed services.

- **Establishing standards and mechanisms to facilitate appropriate receipt of services.** Another important systems-level care coordination function performed by Title V agencies is the establishment of standards and mechanisms that help to ensure that CSHCN and their families obtain the array of services they need. Only ten states indicated having a role in authorizing care coordination services provided by another agency. In 17 states, Title V has a role in authorizing specialty medical services. Other than having a direct role in authorizing care coordination or medical specialty services, 15 Title V programs facilitate appropriate referrals by providing training to those who make such referrals (e.g., care coordinators working within managed care organizations). Finally, nine states noted their involvement in the development of contracts, such as those between Medicaid agencies and managed care organizations, that help to ensure children's access to specialty services.
- **Monitoring care coordination services.** Another systems-level role Title V agencies can play is that of oversight and monitoring of client-level care coordination services provided by Title V employees, contractors, and other agencies. Our survey found that 23 states conduct or are in the process of developing strategies to conduct evaluations of care coordination services, including chart reviews, site visits, and analysis of program data. Twenty-two states reported having a role in the development of standards for reporting and data collection from providers of care coordination. However, there remains no standard mechanism for measuring the quality, effectiveness, or cost-effectiveness of care coordination services.
- **Involving families in care coordination.** To provide the best coordination of care for children with special health care needs, experts agree there must be a partnership between families, health care professionals, and state agencies. Our survey explored how and in what capacity state Title V agencies support the inclusion of families in care coordination efforts on behalf of CSHCN. Thirty-eight states—or 83 percent—include families on advisory committees. Title V agencies offer forums, most commonly focus groups, to identify ways that services for CSHCN could be better coordinated in 36 states. In addition, 27 states employ parent consultants; the average number of parent consultants in a given state is 6.5.

IV Interpretation and Implications of Findings

This study documents the widespread role that Title V/CSHCN programs around the country have in coordinating care for CSHCN. At both the client and systems levels, Title V agencies across the country take a comprehensive approach to coordinating care for CSHCN and their families. At the client level, a broad array of services are coordinated and various modes of delivery (phone contacts and in-person visits) are used. At the systems level, Title V agencies are involved in an array of activities to foster improved program integration and coordinated policy responses.

Title V roles in each of these levels of care coordination are, furthermore, continuing to grow and change in accordance with the MCH Pyramid Model. Half of the states currently providing client-level care coordination for CSHCN anticipate that their role will continue to evolve, especially by broadening the population of CSHCN served and enhancing or expanding the scope of care coordination services. Similarly, 31 states indicated that they expect to increase broad systems development activities focused on improving coordination of care for CSHCN.

The study results also offer insight into the challenges faced by Title V agencies in conducting these activities, and ways that care coordination programs could be further strengthened. For example, one of the central findings of the study pertains to financing. At the client level, the study documents the underutilization of Medicaid reimbursement for Title V care coordination services. Title V agencies would do well to foster strong relationships with their counterparts in Medicaid and work to better understand and take advantage of available financing options. Utilizing financing options is a key component of efforts to obtain reimbursement, but if reimbursement rates are to be adequate, states must be able to define the components of Title V care coordination services along with the costs and benefits of these services. The study indicates that much progress remains to be made in states' ability to define the components, costs, and benefits of Title V care coordination services.

Financing is also a key issue when considering how to strengthen systems-level coordination. The broad array of agencies working to address the needs of CSHCN can partner in many ways

to improve systems of care for this population. One of these is identifying how funds from different sources can be applied and blended to address cross-system issues.

In addition to these ways of strengthening financing of care coordination activities, the study also suggests several key elements of states' approaches to care coordination that can contribute to their success in planning, organizing, and delivering client-level services. For example, an increased focus on identifying and monitoring the desired outcomes of care coordination services appears to be warranted, in particular on using these outcomes, rather than payment mechanisms, to drive the design of care coordination services. In addition, to promote the most effective use of available resources while being responsive to the changing needs of families, states may want to consider developing levels of care coordination that vary in comprehensiveness and intensity so that the intensity of the care coordination services can be matched to the level of care coordination need experienced by the child and the family.

The study also suggests several ways that Title V agencies can enhance their capacity to promote systems-level coordination. One activity to which Title V agencies are particularly suited, given their federal mandate to serve the entire maternal and child population, is convening the many agencies, programs, and systems that serve women and children, including CSHCN. These forums can serve to enhance programs' understanding of each other's roles and issues and, in turn, facilitate the coordinated development of policies and strategies for improving service delivery for CSHCN and their families. Furthermore, Title V agencies have a valuable opportunity to inform the many agencies serving CSHCN and guide efforts to better serve this population by sharing the valuable data collected about the CSHCN population, its needs, and available resources through its ongoing population-level activities such as the five-year needs assessment.

Assuring coordination of programs for CSHCN on the systems level, however, is a challenging task. Title V agencies, while statutorily and administratively well positioned to spearhead efforts to assure the coordination of programs and services, are not necessarily recognized as the natural leaders of these efforts. The development of strong interagency relationships, particularly with state Medicaid agencies, is often a major challenge to coordination at the

systems level. In addition, for Title V agencies, the ability to describe the population of CSHCN, to estimate their prevalence within Medicaid-funded and other systems of care, and to define a strategy for identifying them is both challenging and essential to the ability to persuade other agencies of the importance of care coordination.

While these and other challenges to coordination are significant, they are not insurmountable. The first step in establishing Title V's role in coordination of care for CSHCN, on either the client or the systems level, is developing an understanding of the specific components of care coordination and their value. It is hoped that this study can contribute to the ongoing project of defining and promoting Title V's role in the coordination of services for CSHCN and their families.

CHAPTER I

Introduction

Children with special health care needs and their families require a wide range of medical, psychosocial, educational, and support services (American Academy of Pediatrics, 1998; National Coalition of Family Leadership, 1995). Assisting families in coordinating these services is an important but challenging goal for health care providers, agencies, and managed care organizations in both the public and private sectors. What is care coordination and what can it be expected to achieve? How are care coordination services delivered? How can states assure adequate reimbursement for care coordination services? What are the key elements of successful programs? Answers to these questions are urgently needed to help shape the capacity of the nation's rapidly evolving health care system.

State Title V programs for Children with Special Health Care Needs (CSHCN) offer important insights into the challenge of providing and supporting care coordination. Their legislative mandate gives them a legislative foundation to assist in the development of coordinated service systems for all CSHCN and their families. As a result, state programs have implemented diverse care coordination efforts, reflecting a variety of models, assumptions, and goals. This diversity has yielded important lessons in understanding the challenges and outcomes in care coordination. Our report aims to identify some of these lessons by tapping the natural diversity in care coordination efforts implemented by state Title V programs.

We gathered information from a national survey of directors of state Title V CSHCN programs and follow-up telephone interviews with Title V leaders in selected states. The report examines two levels of care coordination:

- The client level, where assistance in care coordination is provided to individual children and families, and
- The systems level, where coordination efforts are focused on linking and integrating policies and programs.

In addition to describing our methods, results, and implications, we include brief vignettes to illustrate specific approaches to care coordination at both levels. Overall, this report captures current practices in the field and suggests how state Title V programs, other agencies, and managed care organizations can move forward in developing innovative approaches to care coordination for CSHCN and their families. First, we discuss the basic concepts underlying our discussion of care coordination at both the client and the systems levels.

CHAPTER II

Concepts of Care Coordination

Activities to coordinate care for CSHCN and their families may occur at two levels: at the individual client (or direct service) level, and at the systems level, both of which were explored by HSR's study. This section briefly discusses these different levels of care coordination and Title V agencies' historical roles in each.

A. Care Coordination at the Client Level

Care coordination at the client level generally involves the provision of assistance directly to individual children and families to help them gain access to the variety of services that they need. Care coordination is also referred to as case management or service coordination. In HSR's survey, the term "care coordination" was used, as this is generally the preferred term among Title V programs.

1. Defining Care Coordination

While the terms "care coordination", "case management", and "service coordination" are often used interchangeably, in practice they may reflect different principles or activities; indeed, the same term may be used differently within similar programs or agencies. This inconsistency in terminology reflects the unique philosophies and roles of care coordination providers. For example, while the aim of care coordinators in human service agencies may be to maximize clients' use of all needed resources, case managers in managed care organizations are likely to be focused on managing health care expenditures.

As care coordination becomes increasingly recognized as a critical service for CSHCN, the need to define care coordination has also increased in importance, and numerous definitions have been developed. Several examples of these are included in Figure II-1.

Figure II-1.
Sample Care Coordination Definitions.

Services to promote the effective and efficient organization and utilization of resources to assure access to necessary, comprehensive services for children with special health care needs and their families (Federal Omnibus Budget Reconciliation Act of 1989 legislation)

A collaborative process that assesses, plans, implements, coordinates, monitors, and evaluates the options and services required to meet an individual's health needs, using communication and available resources to promote quality, cost-effective outcomes (Case Management Society of America, 1995)

A process that links children with special health care needs and their families to services and resources in a coordinated manner to maximize the potential of the children and provide them with optimal health care [and which] occurs when a specified care plan is implemented by a variety of service providers and programs in an organized fashion (American Academy of Pediatrics, 1999)

A process designed to facilitate timely access to services and resources; promote continuity of care; provide family support and enhance family well being; improve health, developmental, educational, vocational, psychosocial, and functional outcomes; and maximize efficient and effective use of resources (Presler, 1998)

As illustrated by the sample definition by Presler (1998), one way of defining care coordination is by identifying the desirable goals or outcomes of the care coordination process. Defining desirable outcomes of family-centered care coordination for CSHCN was the specific focus of a project by the Center for Automation and Care Coordination Enhancing Service Systems in Maternal and Child Health (ACCESS-MCH), which in 1996 convened a group of parents and professionals to address this task. As described in the workgroup's final report (ACCESS-MCH, 1998), the participants identified 14 outcomes that are intended to guide the care coordination practices of programs and providers serving CSHCN. These outcomes emphasize the importance of care coordination services that address families' needs, goals, and preferences, and that place families at the center of the care coordination process. In another example, AAP's 1999 policy statement on care coordination for CSHCN emphasizes several

goals of the care coordination process, including: gaining access to and integrating services and resources; linking service systems with the family; avoiding duplication and unnecessary cost; and advocating for improved individual outcomes.

These definitions have been important contributions to the field of study on care coordination. Definitions are critical tools for clarifying the desired goals of care coordination and, in turn, for shaping the content of care coordination services.

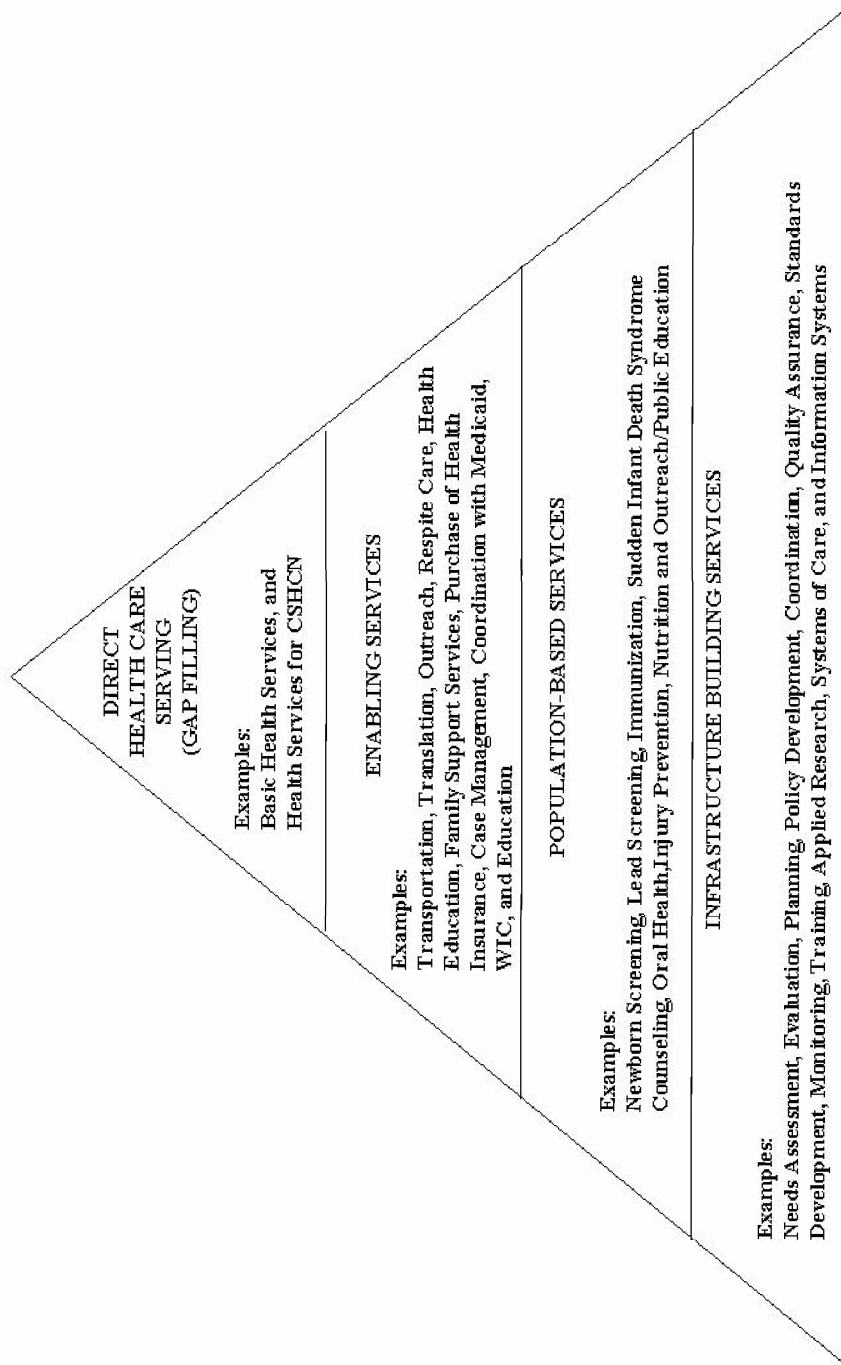
2. Title V Care Coordination

Client-level care coordination has long been the province of Title V CSHCN programs. Traditionally staffed by public health nurses and social workers, these programs have played an important role in providing or referring children to medical services, as well as coordinating a broader array of social and support services.

The advent of managed care, Medicaid expansions, and the State Child Health Insurance Program (SCHIP) have had the effects both of reducing Title V's role in the provision of direct medical care and of increasing interest throughout the health care system in care coordination. These changes reflect of a philosophical development at the federal Maternal and Child Health Bureau (MCHB) level that shifts emphasis away from direct health care services in favor of core public health services, including enabling services such as care coordination; population-based services; and infrastructure-building services, as illustrated by the MCHB's MCH Services Pyramid model shown in Figure I-2. (Health Resources and Services Administration, 1997).

Many state Title V agencies have developed or adopted definitions of care coordination, often as part of operational protocols. However, specific definitions of care coordination continue to vary across states and Title V programs, and often differ across programs and agencies within a state as well as across providers.

Figure I-2.
CORE PUBLIC HEALTH SERVICES DELIVERED BY MCH AGENCIES



Source: MCHB, 1997

While HSR’s study did not gather definitions of care coordination from Title V agencies nationwide, the study did identify several examples of Title V definitions of care coordination for CSHCN. While these examples typically stressed the need to link the family with the range of needed services, they varied in emphasis. For example, the definition of care coordination for CSHCN adopted by the New York State Department of Health highlights the centrality of the family:

Care coordination for CSHCN is a process of assisting families in organizing and coordinating the provision of comprehensive, accessible services for CSHCN and their families (that is) undertaken in a manner that centers on the concerns of the family, is sensitive to the family’s cultural values, and maximizes the resources of the community in which the family resides.

In Colorado, the definition of care coordination for CSHCN has greater focus on the health and functional status of the child:

Care coordination is the process of developing and implementing an integrated plan of action with each family, in cooperation with the Primary Care Provider, ensuring access to needed services and resulting in improved health and quality of life.

In light of such variations, state Title V programs have identified the need for a clearer definition of care coordination and its outcomes, especially to facilitate the establishment of reimbursement for care coordination services (Association of Maternal and Child Health Programs [AMCHP], 2000).

B. Care Coordination at the Systems Level

In addition to providing client-level care coordination services, action at the systems level to link and integrate policies and programs is another critical approach for fostering the smooth delivery of services to CSHCN.

The importance of systems-level activities in facilitating coordinated care is reflected, for example, in the National Association of Social Workers’ “Standards of Social Work Case Management” which identify both client-level and systems-level interventions as key components of service coordination. In these standards, the importance of systems-level

interventions such as agency policy formation, data collection, program evaluation, and quality assurance are linked to the capacity of agency and environmental systems to positively or negatively affect clients.

Title V agencies have a critical function in fostering coordination of services by working at the broader systems level. In their role in helping to plan and develop the larger service systems of family-based, community-based, coordinated care for CSHCN and other MCH populations, Title V agencies influence the degree to which services will ultimately be coordinated for CSHCN and their families.

HSR's study explored Title V agency roles in both client-level and systems-level care coordination activities for CSHCN and their families. The following chapter discusses the methodology employed in carrying out this study.

CHAPTER III

Methodology

This project was undertaken by Health Systems Research, Inc. (HSR) as an activity of the National Policy Center for Children with Special Health Care Needs. The Center, funded under a cooperative agreement with the Maternal and Child Health Bureau, is a partnership between Johns Hopkins University, HSR, and Family Voices. The Center's mission is to conduct policy research that will contribute to the availability and accessibility of comprehensive, community-based, culturally competent, and family-centered care to CSHCN and their families, especially in the context of a managed care environment.

The purpose of this study was to explore the different and changing roles that Title V agencies play in coordinating care for CSHCN. This report presents the results of this two-stage study, consisting of a national written survey and a series of follow-up interviews conducted with selected states.

A. Phase I: National Survey

The first and central phase of the study was the conduct of a national written survey of Title V agencies. This survey included two major lines of inquiry, with one set of questions related to Title V roles in the provision or support of client-level care coordination services to individual

CSHCN and their families, and the second set of questions exploring Title V roles in broader systems-level activities that affect the degree to which services are coordinated for CSHCN.¹

Under the client-level care coordination section, the following areas were examined:

- The current, past, and anticipated future involvement of the Title V agency in client-level care coordination services;
- Eligibility for care coordination services;
- The provision of care coordination services to CSHCN in Medicaid, SCHIP, and Part C/Early Intervention programs;
- The care coordination process; and
- Financing of care coordination services.

The second portion of the survey explored states' involvement in broader systems-building activities that affect the degree to which services for CSHCN are coordinated at the client level. States were asked about six major categories of systems-level care coordination activities, with each category encompassing several types of activities. These included:

- Identifying CSHCN;
- Facilitating coordination among agencies serving CSHCN;
- Building structures to link CSHCN and their families to services;
- Establishing standards and mechanisms to facilitate appropriate receipt of services;
- Monitoring care coordination services; and
- Involving families in care coordination.

A copy of the survey is included as Appendix A.

¹ HSR developed the survey with significant input from Johns Hopkins University and the Association of Maternal and Child Health Programs (AMCHP) Care Coordination Workgroup convened in 1999 to address care coordination issues.

In the fall of 1999, surveys were mailed to each of the Title V/CSHCN agencies in the 50 states and the District of Columbia. A total of 46 surveys were returned over a period of several months, for a response rate of 90 percent.²

B. Phase II: Follow-Up Interviews

To obtain a more thorough understanding of the survey results and the ways in which different Title V agencies are carrying out their care coordination activities for CSHCN, HSR conducted follow-up telephone interviews with a subset of states that responded to the written survey. Some states were selected to participate in comprehensive telephone interviews and some in more focused interviews, as discussed below.

1. Comprehensive Telephone Interviews

After preliminary analysis of survey results, HSR identified nine states representing different geographic areas and with varying approaches to delivering and financing client-level care coordination services for CSHCN to participate in comprehensive follow-up telephone interviews. Requiring from one and a half to two hours to administer, this in-depth interview protocol was designed to build upon the information in the written survey. The topics covered in the telephone protocol closely mirrored those addressed in the survey instrument, but were explored in greater detail. Comprehensive telephone interviews were conducted with the States of Alabama, Florida, Iowa, Massachusetts, North Carolina, Rhode Island, Texas, Utah, and Wisconsin. The interview protocol is included as Appendix B.

2. Focused Telephone Interviews

In addition to the nine states selected to participate in comprehensive telephone interviews, an additional five states were identified as having unique approaches to coordinating care for CSHCN, especially with respect to their systems-level activities. These were selected for more focused interviews. Instead of using the comprehensive interview protocol to conduct these

² The District of Columbia, Georgia, Indiana, New Hampshire, and Vermont did not respond to the survey.

interviews, HSR researchers concentrated questions on the topic of interest. Focused interviews were conducted with Title V representatives in the States of Arkansas, Colorado, Idaho, Missouri, and Pennsylvania.

The accounts from these 14 comprehensive and focused interviews³ are presented throughout the report as illustrative vignettes. Contact information for Title V/CSHCN officials from these highlighted states is included in Appendix C.

³ Information for the Michigan vignette was obtained through a 1999 study conducted by HSR under the National Policy Center for CSHCN, *Achieving Service Integration for Children with Special Health Care Needs: An Assessment of Alternative Medicaid Managed Care Models* by Hill et al.

CHAPTER IV

Client-Level Care Coordination Services

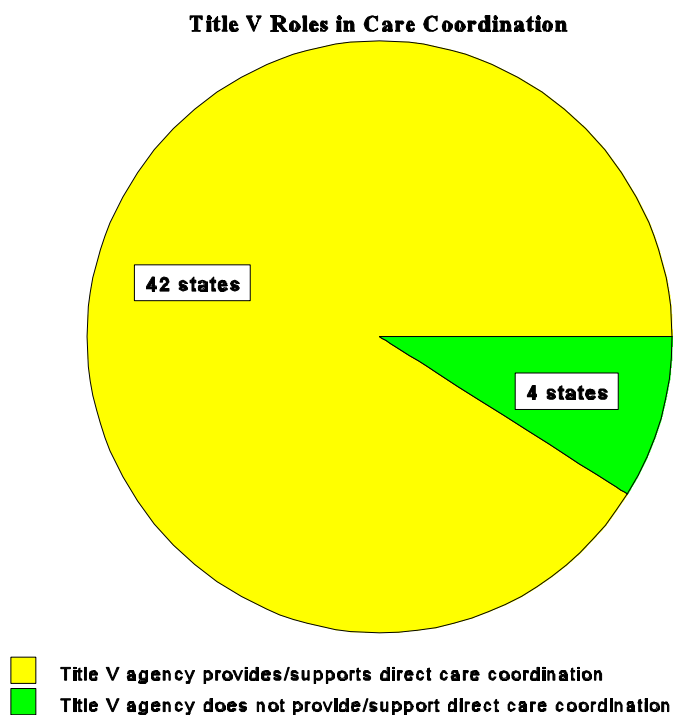
A major focus of HSR's study addressed Title V roles in providing client-level, or what we also refer to as direct, care coordination services to CSHCN and their families. This section presents the study's results related to the provision of these services.

A. Title V Roles in Providing Care Coordination Services for CSHCN

Title V programs have a long history of providing care coordination services to the maternal and child population, especially CSHCN. Care coordination is an example of the enabling services category within the MCHB's MCH Pyramid model of resource allocation. As discussed earlier, this model illustrates how states focusing fewer resources on providing direct medical care services can increase the resources devoted to enabling, population-based, and infrastructure-building services.

In light of the MCHB's use of this model to reflect its focus on core public health services, HSR researchers assessed the degree to which Title V programs are currently involved in providing care coordination services to CSHCN and their families. The survey found that the majority of Title V agencies across the country are invested in providing and supporting this service—42 of the 46 respondent states indicated that either Title V staff provide care coordination services to CSHCN or the Title V agency contracts for the provision of care coordination services to this population (see Figure IV-1 below).

Figure IV-1.



To understand how this current picture of Title V roles in care coordination for CSHCN has changed from that of recent years, the survey asked several questions. First, states that indicated that they do not currently have a role in providing or supporting care coordination services to CSHCN were asked if the Title V agency had been involved in this activity within the last ten years. Of the four states that are not now involved in care coordination for CSHCN, two—Pennsylvania and Minnesota—indicated that the Title V program had had this role in the past, but that it had been discontinued in the mid-1990s. Pennsylvania attributed this decision to the findings of a study indicating that care coordination services for CSHCN provided by the health department were duplicating services already available in the community, and Minnesota identified a combination of changing agency priorities and budgetary concerns as the factors behind the discontinuation of care coordination services. The other two states, Nevada and Alaska, had no former role in the provision or support of direct care coordination services to CSHCN.

The survey also explored the ways in which state Title V care coordination roles had changed for states that are currently involved in providing direct care coordination services to CSHCN. Specifically, states were asked if the agency's role in providing or supporting care coordination services for CSHCN had increased in intensity or frequency; decreased in intensity or frequency; or changed in philosophy, direction, or approach in recent years. The results indicate that Title V agencies' overall role in this area has grown. Nearly two-thirds of the respondent states indicated that they have increased the intensity or frequency of their care coordination services or changed in philosophy, direction, or approach. Comments provided by some states to this survey question indicate that Title V roles in client-level care coordination services for families with CSHCN have typically changed in three main ways:

- **Serving a broader population of CSHCN.** Three states noted that their care coordination programs serve children with a broader range of conditions than in the past. For example, Tennessee has extended care coordination services to children with a broader array of diagnoses than defines eligibility for medical services under the Title V/CSHCN program (e.g., care coordination services are now provided to children with developmental delays, autism, and less severe asthma than children receiving CSHCN medical services).
- **Providing a broader or more holistic set of care coordination activities.** Six states noted changes in their programs to expand the focus of care coordination services. For example, Alabama has shifted from coordinating medical services to also addressing children's broader service needs. In addition, South Carolina's Title V program has in recent years begun providing a broad set of family support services to families in the state's Medicaid managed care program.
- **Improving the quality of care coordination services.** Four states' comments reflected an increased focus on quality monitoring. For example, Massachusetts has increased its focus on accountability, data collection, and use of time-framed objectives within its care coordination activities. West Virginia is working to ensure that care coordination services are provided more systematically by introducing the use of standardized assessments and care plans.

The survey also assessed how Title V roles in providing care coordination for CSHCN are likely to change in the future. Half of the states currently providing care coordination for CSHCN anticipate that their role will continue to evolve, typically in the first two ways noted above,

broadening the population of CSHCN served and enhancing or expanding the scope of care coordination services.

These findings indicate that state Title V roles in providing direct care coordination services to CSHCN have changed, and are likely to continue changing, in ways that are consistent with the MCH Pyramid model. In both the written survey and the follow-up interviews, respondents confirmed that state Title V programs are shifting resources away from the provision of direct clinical services and focusing more resources on providing enabling services such as care coordination and related population-based services. The following vignette highlights Wisconsin's efforts to enrich and expand the reach of its care coordination program for CSHCN.

Wisconsin: Title V Care Coordination Role in Transition

Traditionally, the Wisconsin Maternal and Child Health Program has based its care coordination activities in its central office. Under this program, nurse consultants provided phone-based assistance to families with CSHCN to help them access needed services and provide limited financial assistance to families who met certain criteria. However, in the mid-1990s, in line with the MCHB's guidance to states to increase their focus on population-based activities, the Wisconsin MCH Program began to identify ways of shifting its CSHCN resources to reach a larger number of families. A major outcome of this re-evaluation was the MCH Program's establishment of five Regional CSHCN Centers in January 2000, one in each of the state's Division of Public Health's regions.

Through the implementation of the five Regional CSHCN Centers, the MCH Program hopes to create the infrastructure to increase the capacity of local communities to serve CSHCN in their home communities. The Centers will be responsible for providing information, referral, and follow-up services to all families of CSHCN and providers in the region, as well as developing parent-to-parent support networks.

In addition, the Regional CSHCN Centers have a critical role in creating and supporting a community-based care coordination system for Wisconsin's CSHCN and their families. The Centers are responsible for coordinating regional efforts to build local capacity to provide service coordination, especially by working to enhance the capacity of local health departments, Early Intervention agencies, schools, and other agencies (all of which must meet the minimum requirements of the Medicaid targeted case management program) to provide service coordination activities.

Wisconsin: Title V Care Coordination Role in Transition (Cont'd.)

The Regional Centers are also responsible for reimbursing providers for delivering service coordination to the target population, defined as CSHCN who are not eligible for service coordination services through another program (e.g., Medicaid, Early Intervention). During the first grant period, 20 percent of the regional grant funds is earmarked for reimbursement of direct service coordina

Thus, through this reallocation of its CSHCN resources, Wisconsin's MCH Program is developing a community-based system of information, referral, parent-to-parent support, and service coordination that will significantly extend its reach to the state's CSHCN and their families.

B. Eligibility for Care Coordination Services

Ideally, care coordination services will be available to all children with special health care needs. A care coordination workgroup convened by the Association of Maternal and Child Health Programs (AMCHP) recommends that care coordination be proactively offered to all families of children with special health care needs from birth to age 21 (AMCHP, 2000). Unfortunately, not all states are able to meet this ideal. Fewer than half of the states responding to this study (18 states, or 43 percent of the states in which Title V provides or contracts for direct care coordination services) reported that Title V-supported care coordination services are available to all CSHCN. However, telephone interviews revealed that, even in states that indicated using very inclusive definition of eligibility for care coordination services, Title V-supported services are sometimes limited to children who are not eligible for other programs that offer care coordination services, including Medicaid and Early Intervention.

Just over half of the states (24 states, or 57 percent of the states providing or contracting for care coordination services) fund care coordination services for only selected groups of children with special health care needs. These states have developed criteria to determine which children are eligible to receive services. Most often Title V agencies use diagnosis as a criterion for selecting which CSHCN are eligible to receive care coordination services. Following diagnosis, the categories of criteria most often used are family needs and functional status/severity of

condition (see Table IV-1). Other criteria used by Title V agencies in several states are related to finances, such as ability to meet an income eligibility standard or ineligibility for Medicaid.

Table IV-1. Frequency and Percentage of Title V Agencies Utilizing Different Criteria to Define the Subsets of CSHCN Eligible to Receive Care Coordination Services		
Eligibility Criteria Category	Number of Title V Agencies Using this Category of Criteria	Percentage of Title V Agencies Serving Subsets of CSHCN Utilizing this Category of Criteria
Diagnosis	17	71%
Family Needs	14	58%
Functional Status/Severity of Condition	13	54%
Geographic Region	4	17%
Other Criteria	8	33%
More than One of Above Criteria	17	71%

Seven of the Title V agencies indicated using only one of the identified eligibility criteria categories. However, 17 of the agencies reported using more than one of these categories to define the subsets of CSHCN eligible for care coordination services.

Some states reported that they are moving toward a broader definition of the eligible population. The following vignette describes the broad definition used in North Carolina for its care coordination services for preschool CSHCN.

North Carolina: Care Coordination for Preschool CSHCN

North Carolina's Child Service Coordination (CSC) program offers care coordination to any child under age three who has one of a list of 40 risk factors, regardless of family income or categorical program eligibility. (Children between ages three and five must have one of twelve listed diagnosed conditions to be eligible for care coordination, and the service is not available to children over age five.) Most children are identified and referred through the newborn nursery. Other referral sources include prenatal providers and care coordinators, parents or family members, child care providers, health center and hospital staff, and other service providers. Local health departments are responsible for working with community agencies to provide education and outreach to assist them in identifying potentially eligible children.

A standard screening form is used by local health departments and newborn nurseries to identify children eligible for CSC. For children under age three, the eligibility criteria are broad. The screening form includes four categories of risk conditions :

- Parental/Family Conditions, including maternal age under 15 years, parental mental illness, parental substance abuse, lack of stable housing, and lack of familial and social support;
- Neonatal Conditions, including very low birth weight, preterm delivery, respiratory distress, asphyxia, and neonatal seizures;
- Postneonatal Conditions, including suspected visual or hearing impairment, lack of well-child care by six months, significant parental concerns, and suspected abuse or neglect; and
- Diagnosed Conditions, including developmental delay, atypical development, chromosomal anomaly or genetic disorder, metabolic disorder, or infectious disease.

The breadth of this list means that a significant proportion of the state's children are potentially eligible for the program. Local health departments serve as many children as they can, based on the resources available.

In addition, the CSC program provides care coordination to children eligible for Early Intervention services. If a child enrolled in CSC also enrolls in Part C, the CSC care coordinator also acts as the Part C coordinator and the CSC care plan is incorporated into the Individualized Family Service Plan.

C. Providers of Care Coordination Services

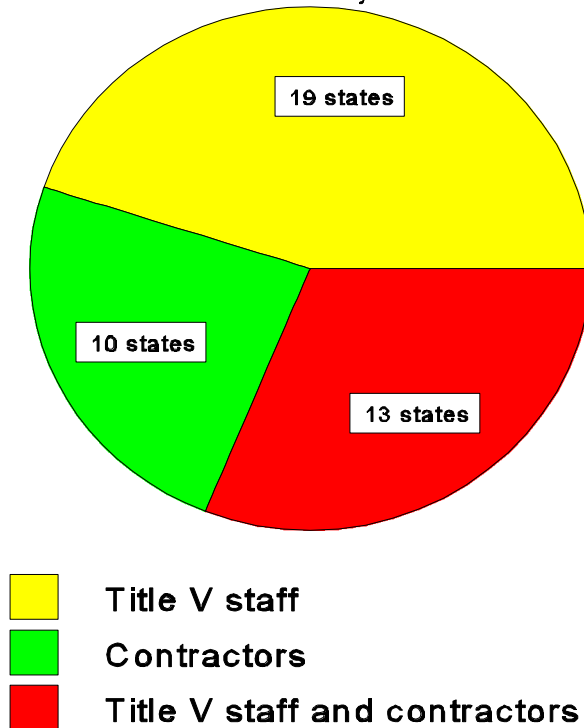
A central focus of this study's exploration of Title V roles in client-level care coordination was investigating who provides Title V care coordination services. For states that indicated

providing care coordination services to CSHCN, the survey asked who provides these services: Title V staff and/or contractors. The results are presented below and in Figure IV-2.

- **Title V staff.** Of the 42 states that report providing care coordination services to CSHCN, 19 staff their care coordination programs with their own Title V employees.
- **Contractors.** Ten states report providing care coordination entirely through contracts with outside agencies. Most states rely exclusively on public health providers, generally public health nursing agencies and health departments, to provide the care coordination services. Several states reported contracting with a variety of sources that include public health providers as well as non-profit organizations, hospital-based clinics, primary care clinics, and Early Intervention programs to meet care coordination needs.

Figure IV-2.

Provision of Care Coordination Services by Title V Staff and/or Contractors



- **Title V staff and contractors.** Providing care coordination through Title V staff and paying others to provide it are not necessarily mutually exclusive. Thirteen states indicated using both methods to best serve the CSHCN in their states.

The following vignettes illustrate how the States of Florida and Texas staff their Title V care coordination programs for CSHCN.

Florida: Title V Staff as Care Coordinators

Florida Children's Medical Services Program (CMS), administered by the Department of Health, has long been the cornerstone of the state's system of care for CSHCN. At the local level, CMS is administered through 20 area offices and two referral centers distributed across the state.

The CMS area offices play a central role both in managing local CMS provider networks as well as arranging for and providing needed services to enrolled families. Staff in the area offices are responsible for determining program eligibility; enrolling eligible children; identifying, recruiting, and credentialing CMS physicians; managing and staffing specialty clinics; purchasing health care services, and handling client grievances. Perhaps most importantly, local CMS office staff provide care coordination (called case management), a core CMS service, to enrolled families. Since the mid-1980s, CMS has been a Medicaid targeted case management provider and bills Medicaid on a fee-for-service basis.

CSHCN enrolled in the CMS Network receive care coordination primarily from locally-based state employees. Staff providing care coordination have at least a bachelors degree and at least a year of pediatric experience. Care coordinators are typically registered nurses; a few social workers also serve as care coordinators. All children are assigned to a care coordinator based on their needs and resources. Children are assigned to one of three levels of care coordination, with those assigned to Level III requiring the most intensive care coordination and those assigned to Level I requiring the least intensive care coordination.

Registered Nurse Specialists coordinate the care for those children who are identified as being in need of Level II or III care coordination. Children with medical and other complex issues are assigned to Level III; their case managers carry the smallest case loads: typically 50 children. Care coordinators caring for children and their families who are identified as requiring Level II carry a caseload of approximately 100 children. Senior Community Nurses care for children and their families classified as being in need of Level I care coordination. These nurses typically carry caseloads of more than 250 children.

Training was previously provided to all care coordinators through a contract with the University of Miami Mailman Center for Child Development. Now, due to limitations on staff travel, training will include distance learning opportunities.

**Texas: Title V Staff and Contractors
Providing CSHCN Care Coordination Services**

The Texas Department of Health's (TDH) CSHCN program operates a statewide system of case management (the state's term for care coordination) for CSHCN supported with Title V funding. Direct case management services are delivered to clients by a large corps of case managers, including employees of the Title V agency as well as those of contracted agencies.

Title V case management staff are located across the state's eight public health regions serving 254 counties. Approximately 80 case managers provide services to 55,000 CSHCN, as well as other populations eligible for Title V case management services. A large portion of the CSHCN in Title V-funded case management programs receive services from these regional Title V case managers. Title V staff in TDH's central office support the case managers through training, technical assistance, and quality assurance activities.

TDH supplements the capacity of its regional Title V staff to reach CSHCN by contracting with a range of locally-based case management agencies. Currently, TDH has contracts for the provision of CSHCN case management services with 15 contractors, including local health departments, hospitals, universities, and community-based non-profit organizations. These contracts support 57 full-time equivalent case management positions. In fiscal year 1999, these 15 contractors served approximately 20,000 children.

Title V CSHCN case management services are provided by staff with various types and levels of education and experience. Title V regional case managers consist primarily of licensed social workers, 60 percent of whom have masters degrees and 40 percent of whom have bachelors degrees in social work or a related area as well as a social work license. TDH recommends that contractual case management staff include social workers, registered nurses, family members of CSHCN, or other qualified individuals with experience in community programs serving CSHCN.

D. Processes and Procedures in Delivering Client-Level Care Coordination Services

HSR's survey also explored aspects of the process through which Title V agencies and their contractors deliver care coordination services to CSHCN and their families, including the use of standard protocols, the scope of services coordinated, the mode through which care coordination services are delivered, and the use of care coordination levels.

1. Use of Protocols

The use of standard protocols or guidance can be an important tool for Title V agencies and their contractors to foster the consistent and systematic delivery of care coordination services. Twenty-four Title V agencies reported that they have written protocols or guidance outlining how care coordination services should be carried out. The use of protocols among agencies using Title V staff to provide care coordination was compared to the use of protocols among agencies using contractors. Among the 19 agencies using Title V staff only, 47 percent use protocols; among the 10 agencies using contractors only, 70 percent use protocols; and among the 13 agencies using both Title V staff and contractors, 62 percent use protocols. Thus, Title V agencies appear to be more likely to use protocols to facilitate the consistent provision of care coordination services when coordination is done by contractors rather than by their own staff.

Protocols and guidance, however, are general guidelines. Since each child is unique, care must be tailored to meet the child's condition and psychosocial needs. Individualized care plans should be developed to ensure that services planned are appropriate for the client and address the client's needs. The American Academy of Pediatrics (1999) recommends that care plans include several specific components including: the goals of care coordination; the family's role in the care coordination process; the care coordination approach; the intensity of services to be provided; and the duration of services. Among 24 Title V agencies with protocols, 22 call for the development of a care plan for each client. In addition, 20 of the agencies require that care plans include desired outcomes for the child and/or family.

2. Scope of Coordinated Services

This survey also examined the types of services that care coordinators assist CSHCN and their families in receiving. As displayed in Table IV-2, most Title V agencies reported that care coordinators assist CSHCN and their families in receiving specialty medical services, Early Intervention services, primary care services, ancillary therapies, and family support services. Between 31 and 37 of the agencies reported care coordinators assist with coordination of

special education services, mental health services, transition planning for adolescents, and services provided under Medicaid managed care. In addition, 16 agencies reported

Table IV-2. Types of Services Care Coordinators Assist CSHCN and Their Families in Receiving by Frequency of Title V Agencies Offering the Service	
Type of Service	Number of Title V Agencies
Early Intervention Services	41
Specialty Medical Services	41
Ancillary Therapies	40
Family Support Services	40
Primary Care Services	40
Special Education Services	37
Mental Health Services	35
Transition Planning for Adolescents	33
Services Provided Under Medicaid Managed Care	31
Other Services	16

coordinating other services, such as services under private insurance, durable medical equipment, nutrition, home care, respite, transportation, translation, waiver services, schools, and camp. Title V agencies also noted their role in assisting CSHCN and their families with accessing other services and programs, such as food stamps, Temporary Assistance for Needy Families (TANF), and SSI.

Title V agencies providing care coordination services to CSHCN, regardless of whether the services are provided by Title V staff and/or contractors, tend to provide a comprehensive approach to care coordination. Thirty-eight of the states coordinate seven or more different types of services (e.g., primary care services, specialty services, and ancillary therapies) for CSHCN and their families.

3. Mode of Delivery

Care coordination is delivered through a variety of means, including home visitation, clinic visits, and phone contacts. The approach used will depend on the circumstances and needs of the child and his/her family. For example, high-intensity care coordination involving frequent home visits and clinic visits may be needed at such key times as release from the hospital, entrance into day care and school, transition into young adulthood, and when a change in health status occurs. At other times, care coordination may require fewer and less intense services, such as making a phone call or forwarding records. As seen in Table IV-3, most of the states reported providing care coordination via home visits, clinic visits, and telephone calls.

Table IV-3. Types of Methods Used to Provide Care Coordination Services by Frequency of Title V Agency Utilizing the Method	
Type of Method	Number of Title V Agencies
Telephone	41
Clinic Visit	39
Home Visit	38

4. Levels of Care Coordination

While not addressed in the national survey, the follow-up interviews explored another tool for the systematic delivery of care coordination services—the use of levels of care coordination as a strategy for matching the level of intervention to the client’s level of need. We found several states that use this approach in their care coordination programs, including Florida which was highlighted earlier. Additional examples of states using levels of care coordination are presented in the following vignettes.

Massachusetts: Promoting Consistent Case Management Services

The Massachusetts Division for Special Health Needs provides case management services to children with special health care needs through program staff located in six regional offices across the state. Case managers are responsible for coordinating the social and support services needs of children and their families, but are not involved in coordinating or arranging direct medical services.

Case management services are provided at two levels of intensity and involve five formal steps. The program's two levels are intended to assure that children receive services that meet their and their families' needs. The two major levels are:

- **Limited Service Coordination.** This service focuses on resolving a single issue or a few uncomplicated issues over a brief time period, generally three months (with one three-month extension available). This service is available to any child with a chronic or disabling condition that will last at least 12 months who has an identifiable need for services for which a case manager is needed. Approximately 60 to 70 percent of children in the program receive limited service coordination.
- **Extended Service Coordination.** This is a more intense level of service, lasting more than six months and addressing multiple needs. This level of service is available to children and families who meet at least two of the following criteria: the child has a life-threatening condition; the child is dependent on medical technology; the family faces a cultural, linguistic, or attitudinal barrier to service; or the family experiences complicated circumstances impeding service delivery. This level of service is used by 30 to 40 percent of CSHCN in the program.

Both levels of case management are provided through a consistent process that involves the following steps:

- **Step 1: Determination of Case Management Involvement.** In this step, an intake interview is conducted and the child is assigned to one of the two levels of case management.
- **Step 2: Assessment and Identification of Need.** Within two weeks of intake, a home visit is conducted to assess the needs of the child and family using a standard Needs Assessment Checklist. A packet of information is given to the family at this visit as well.
- **Step 3: Planning and Goal Setting.** An Individual Family Service Plan (IFSP) is then developed, using a standard form that includes a client profile, a catalog of the child's and family's resources, a history, and a service plan. The service plan lists the family's specific needs, goals, tasks necessary to achieve the goals, primary person responsible for the task, and time lines.
- **Step 4: Implementation and Evaluation.** The case manager and family then proceed with the action steps outlined in the IFSP, making ongoing contact by phone or in person at least once a month and conducting home visits as requested. This contact may include accompanying the family to school or Early Intervention meetings or to the hospital.

Massachusetts: Promoting Consistent Case Management Services (Cont'd.)

- **Step 5: Formal Reassessment of Case Management Involvement.** At the end of the agreed-upon time period, an evaluation and supervisory review are conducted to assess the effectiveness of the care coordination service. In addition, the Needs Assessment Checklist is completed to evaluate the family's need for continued involvement. The IFSP is updated and signed by the parent, and, if the family's needs have been resolved, the case is closed.

Idaho: A Tiered Care Coordination Approach

Idaho's Children's Special Health Program (CSHP), the Title V CSHCN program located within the Department of Health and Welfare, contracts with seven regional health departments to organize specialty care clinics and provide care coordination to CSHCN. Through these contracts, the state has recently instituted a system whereby each child served by the regional programs is assigned to one of three tier levels related to the complexity of the child's needs.⁴

The child's assignment to a care coordination tier level is determined by the overall mix of tier level assessments within eight different categories addressing both the child's health care and family functioning issues.⁵ These categories include: the child's medical needs, the level of medical management required, the family's need for education and training, the family's required level of assistance to use resources appropriately, and the family's financial status, problem-solving skills, support systems, and ability to cope. For each of these categories, a tier level is assigned, ranging from the least intense level of care coordination (Tier I) to the most intense level (Tier III).

To guide staff in conducting the tier level assessments, short definitions have been developed for the three tier levels within each of the eight categories. The tier with the most points indicates the child's overall care coordination tier level. This tier level assessment is adjusted as the child/family's circumstances change. Based on the assessment of the child's and family's needs, a care plan is developed for each child. If the child is in the Part C/Infant Toddler Program and CSHP has been identified as the care coordinator for that child, the care plan will serve as the Individualized Family Service Plan.

In addition to developing the tiered assessment scheme, the Title V agency has also developed guidelines regarding the types of care coordination activities that correspond to the different tier levels. Within each tier level, guidance is given regarding the care coordinator's role in making referrals to other service providers, collaborating with other agencies serving the child, the type and frequency of contacts, and the frequency of reassessment. For example, the guidelines indicate that care coordinators should have face-to-face or telephone contacts with families with children receiving Tier I care coordination at least quarterly; that Tier II clients should receive at least monthly contacts from their care coordinators and that these contacts should include face-to-face visits with telephone contacts as needed; and that care coordinators have face-to-face and telephone conferences with Tier III clients as often as necessary.

⁴ Care coordination activities carried out by the regional health departments are primarily directed to the uninsured population; children in other insurance programs are considered to have access to care coordination. For example, children in Medicaid receive care coordination from their primary care providers and EPSDT care coordinators.

⁵ The tiered care coordination model used in Idaho was adapted from the model used by Oregon's Title V *CaCoon* care coordination program for CSHCN.

E. Financing of Client-Level Care Coordination Services for CSHCN

The survey examined several sources of financing for Title V care coordination services for CSHCN. These included the MCH Block Grant, Medicaid, SCHIP, Part C/Early Intervention, and other sources of funding used by Title V to support these activities. This section will focus in particular on the findings related to the MCH Block Grant, Medicaid, SCHIP, and other funding sources identified by states.⁶

1. MCH Block Grant

The MCH Block Grant plays a critical role in supporting the activities of Title V agencies, especially those for CSHCN. In light of this fact, the HSR survey asked respondents if the state Title V agency uses MCH Block Grant funds (including federal and/or state funds) to support the provision of client-level care coordination services for CSHCN.

The results indicate, not surprisingly, that the MCH Block Grant is an important source of financing for Title V care coordination services. Of the 42 states with a role in providing or financing the provision of direct care coordination services to CSHCN, nearly all—40 states—indicated that they use MCH Block Grant funds to support care coordination services. In fact, five states identified the MCH Block Grant as the only source of financing for these services. In many of the other states, MCH Block Grant funds provide a base operating budget for the care coordination program, which is supplemented by other sources of reimbursement.

The survey also asked states to indicate if they have a specific portion of the Title V budget (i.e., a budget line item) specifically allocated for direct care coordination services for CSHCN. While not necessarily related to the state's MCH Block Grant funding, this question was included to assess the degree to which states have committed Title V funds to care coordination

⁶ Analysis of the results related to the use of Part C/Early Intervention funds were not conclusive. In reviewing survey results, it was not clear if states noting a role in providing care coordination to children in Part C or receiving Part C funds were referring to Title V roles related to being the lead agency for Part C, which was not the focus of this study.

activities. In fact, 27 states indicated that they have a budget allocation for care coordination services for CSHCN, indicating widespread commitment among Title V agencies to this important category of services.

2. Medicaid

Due to several factors, particularly the extension of Medicaid coverage to children in working poor families, combined with many states' implementation of Medicaid expansions as part of their SCHIP programs, an increasing number of CSHCN are eligible for Medicaid. Therefore, Medicaid reimbursement is an important avenue of financing for Title V agencies that provide care coordination services to Medicaid-eligible CSHCN. In fact, the appropriateness of a role for state MCH programs in providing care coordination, or case management, services to Medicaid-eligible children, and being reimbursed for this and related activities, is specifically noted in Medicaid regulations (HCFA, 2000).

States were asked to indicate whether or not they provide care coordination services to children in their state's Medicaid program. Thirty-five states indicated that they serve children on Medicaid. More specifically, 25 states indicated that they serve children in Medicaid risk-based managed care arrangements, 31 states noted their involvement in serving children in Medicaid fee-for-service arrangements (including primary care case management), and 21 states indicated that they serve children in both types of arrangements.

Given the large number of state Title V agencies that provide care coordination services to Medicaid-insured CSHCN, Medicaid could be an important source of financing for these services. However, only 18 states reported receiving Medicaid reimbursement for care coordination services to CSHCN on Medicaid. Thus, there appears to be significant opportunity for Title V agencies that are serving CSHCN on Medicaid but not getting reimbursement for care coordination services to explore options for obtaining Medicaid reimbursement.

In the majority of states, responsibility for serving Medicaid clients has been contracted, at least in part, to managed care organizations. In these cases, Title V agencies may find working

directly with these organizations to be an important avenue for reaching Medicaid-enrolled CSHCN who need care coordination services. The following vignette illustrates the Colorado Title V agency's approach to marketing its CSHCN care coordination services to health maintenance organizations in the state.

The discussion following this vignette focuses on the range of reimbursement options available to Title V programs providing care coordination services to Medicaid-eligible children, including CSHCN, and the survey's results regarding how many states use each of these options. These include targeted case management (used by 7 states), administrative case management (used by 10 states), EPSDT case management (used by 6 states), and waiver programs (used by 4 states), all of which were explored within this survey.

**Colorado: Marketing a Public Health Model of
Care Coordination to Managed Care**

Traditionally, Colorado's Health Care Program for Children with Special Needs (HCP) has delivered care coordination services to CSHCN through a well-established system of 13 regional and 45 local public health agencies. However, in response to the implementation of Medicaid managed care and, more recently, the state's Child Health Insurance Plan known as CHP+, HCP had seen a shift in the demand for services placed on the program. Specifically, fewer children were without a source of funding for direct clinical services but, due to the increasing complexity of the state's health care system, more families with CSHCN were being identified as needing assistance in coordinating needed services.

In light of these changes, and with the support of the state agency administering CHP+, HCP began marketing its expertise in the provision of care coordination services, as well as its established relationships with providers and families with CSHCN, to health maintenance organizations (HMOs) serving CSHCN in public health insurance programs.

To sell their expertise in the delivery of care coordination services to HMOs, HCP realized the importance of marketing care coordination as a high-quality and cost-saving product. Toward that end, HCP developed a marketing packet that provides a detailed description of the Title V care coordination process.

**Colorado: Marketing a Public Health Model of
Care Coordination to Managed Care (Cont'd.)**

As part of the marketing packet, HCP proposed prices for the delivery of care coordination services to CSHCN over a one-year period, with three prices given for families with different levels of need for care coordination services as determined by the HCP Care Coordination Acuity Tool: \$138 per year for families with needs of low complexity; \$299 per year for families with needs of moderate complexity; and \$596 per year for families with needs of high complexity.

In addition to marketing care coordination services to managed care, HCP also found it had to market the idea of a partnership with managed care to its regional and local agencies providing the care coordination services. Thus, education of both managed care and public health officials regarding the benefits of a public health-managed care partnership was a necessary component of the marketing process.

As of early 2000, HCP had signed a contract to provide care coordination services to CSHCN, regardless of whether publicly or privately insured, with one HMO serving an eight-county area, and two more contracts with other HMOs were pending. Under the signed contract, which is in its early implementation stages, children may be identified for care coordination services by either the HMO, public health agencies, or through the joint Medicaid/CHP+ application which includes a question aimed at identifying CSHCN.

A two-way referral form has been developed that can be used either by the HMO or public health agency that identifies a child potentially in need of care coordination services. Children who the HMO and public health agencies agree need care coordination services will be assessed to determine the appropriate level of care coordination, and the established combination of telephone contacts and in-home visits for that level of care will be provided to the child and family over the coming year.

HCP officials are clearly excited about their new partnership with HMOs to ensure that CSHCN receive care coordination services. In addition to being a wonderful opportunity in itself, HCP hopes that these new relationships will lead to additional collaborations to benefit CSHCN and their families.

a. Targeted case management

Targeted case management (TCM) is defined in Medicaid statute (Social Security Act, Section 1915(g)) as “services which assist individuals eligible under the (Medicaid) Plan in gaining access to needed medical, social, educational, and other services...(including those) not included in the Medicaid State Plan.” Given this broad definition, TCM is an intriguing option for Medicaid reimbursement for services provided to CSHCN, as the service needs of these children

clearly extend beyond the medical care services included within the Medicaid benefit package.

Examples of reimbursable activities under TCM include:

- Conducting an assessment of needs;
- Referring or arranging for needed services; and
- Following up to ensure that services were received, regardless of whether these services were medical in nature or not.

TCM is an optional Medicaid service that states may elect to include in their state Medicaid plans if they receive federal approval to do so. As a regular service, the state is eligible for the same matching rate from the federal government as for other services; in Federal Fiscal Year 2000, federal matching rates range from 50 percent in wealthier states to 75 percent in poorer states. However, unlike other Medicaid services, TCM was exempted by Congress from the statutory requirements regarding statewideness and comparability, meaning that states can limit TCM services to certain high-risk populations such as CSHCN or to specific geographic areas.

States set the criteria that a provider must meet to be a TCM provider, but Medicaid recipients retain the right to choose among qualified providers. However, an exception to clients' freedom of choice among Medicaid TCM providers exists for Medicaid-eligible persons with developmental delay or chronic mental illness; in these cases, states are permitted to limit the range of TCM providers, for example to a state agency. To obtain reimbursement from the Medicaid agency, TCM providers generally have to track the services they deliver and submit claims. This administrative requirement is an important consideration for Title V agencies considering the feasibility of alternative Medicaid reimbursement options.

HSR's survey asked states that receive Medicaid reimbursement to identify which Medicaid options they use to receive this reimbursement. Of the 18 states that receive Medicaid reimbursement for providing care coordination services to CSHCN, TCM was noted as being used by seven states. One of these, highlighted below, is the State of North Carolina.

North Carolina: Targeted Case Management

North Carolina's Child Service Coordination (CSC) program is supported by a combination of Title V and Medicaid funds. The Title V budget provides general operating support for the program, and Medicaid reimbursements are paid directly to the local health departments, supplementing their base budgets and allowing them to serve more children.

Medicaid reimburses for services provided to eligible children under the Targeted Case Management option. (Approximately 60 percent of CSC children have Medicaid coverage.) Eligible providers, including local health departments, community and migrant health centers, and area mental health agencies, are paid a capitated rate of approximately \$80 per child per month, a rate that was developed based on local agencies' costs; each year, the rate is calculated based on the cost of the care coordinators' time, plus travel and indirect costs, divided by the program's caseload.

In addition to the capitated rate, there is a cost settlement process each year in which differences between costs and payments are accounted for.

The Medicaid rate, while generous, is not adjusted in any way for each child's complexity or level of risk. Thus, the payment structure provides an incentive to enroll as many low-risk children as possible. State officials are concerned that these incentives create artificially large caseloads and limit the intensity and quality of the care coordination services that can be provided to each child. State Title V officials are currently working with the Medicaid agency to develop a more comprehensive care coordination system and to address the program's fiscal incentives.

b. Administrative case management

Administrative case management (ACM) is typically seen as the primary alternative to TCM, as some of the same services can be reimbursed under either option. However, the ACM definition is more limited than that of TCM. ACM activities are defined in Medicaid statute as those that are "necessary for the proper and efficient administration of the State Plan." That is, unlike TCM, which covers activities that relate to services that may or may not be covered under the Medicaid State Plan, ACM activities must relate directly to Medicaid. Activities that would be reimbursable under the ACM option would include, for example:

- Outreach to persons potentially eligible for Medicaid;
- Medicaid eligibility determinations and redeterminations; and
- Prior authorization for Medicaid services and utilization review.

Whereas the TCM definition allows a broader range of activities likely to be needed by CSHCN to be reimbursed as compared to ACM, the ACM option offers more varied and potentially higher reimbursement rates. There are two tiers of reimbursement for ACM activities:

- ACM activities are generally reimbursed at a 50 percent match rate. While this rate may be lower than a state's regular match rate, since many Title V agencies engage in activities that could be reimbursed under this option but are now being supported with general revenues, obtaining this 50 percent match rate for these activities could result in a significant source of new revenue for these states.
- An enhanced 75 percent match is available for administrative activities that must be performed or supervised by skilled medical professionals, as is often the case when caring for CSHCN. Services eligible for the enhanced match rate include those that must be performed by physicians, dentists, nurses, and other specialized personnel with medical care education and training.⁷

In addition to the reimbursement potential of this option, another advantage of ACM is that it is not subject to federal approval, as is the case for TCM. All that is needed for a state to implement ACM is an interagency agreement between the Medicaid agency and the agency performing the ACM activities.

Of the Medicaid options investigated by the HSR survey, administrative case management was the one most frequently reported as being used by state Title V agencies. Ten states indicated that the Title V agency received reimbursement for care coordination services provided to Medicaid-eligible CSHCN under this option.

c. EPSDT case management

Another reimbursement option for care coordination services to Medicaid-eligible children is case management under the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) program, the portion of the Medicaid program designed to promote early identification and treatment of conditions in children.

⁷

The enhanced rate is not available for nutritionists and social workers.

HCFA's Medicaid State Manual notes that care coordination has always been an integral component of EPSDT and, in fact, that the case for providing care coordination within the context of the EPSDT program was strengthened with passage of OBRA-89. This legislation required that all medically necessary services be provided to children to address problems identified during an EPSDT screen.

States have several options for reimbursing medically necessary care coordination services, including as a component of an existing service, through the TCM option, or as an ACM activity; in fact, HCFA notes Title V as an agency that would appropriately provide EPSDT case management through ACM. The multiple reimbursement options for EPSDT case management illustrate how the various Medicaid reimbursement options for care coordination discussed in this section may overlap; that is, they are not mutually exclusive.

HSR's survey found that six states utilize the EPSDT case management option to reimburse the Title V agency for providing care coordination for Medicaid-eligible CSHCN.

d. Home and community-based services waivers

The final Medicaid reimbursement option for care coordination services addressed in HSR's survey was the waiver option. While not specified in the survey, a type of waiver very likely to be used for CSHCN is the home and community based services (HCBS) 1915(c) waiver. This type of waiver allows states to cover Medicaid services for persons in their homes and/or communities who would otherwise only be eligible for Medicaid if they were institutionalized. HCBS waivers may be targeted to persons with disabilities, developmental disabilities, mental retardation, or mental illness. A group of people with a specific illness or condition, such as technology-dependent children, may be appropriately targeted for this type of waiver.

In addition to the usual scope of Medicaid services, waivers allow states to provide additional services to support the person's ability to live within their home/community rather than in an institution. Case management is one of the services identified as appropriately provided through HCBS waivers.

Four state Title V agencies responding to HSR's survey indicated that they obtain Medicaid reimbursement for care coordination services for CSHCN through waiver programs.

e. **Other Medicaid reimbursement options**

Four states responding to HSR's survey noted that they obtain Medicaid reimbursement for care coordination services through options other than those discussed above. Rhode Island uses the Medicaid rehabilitation option, Alabama includes care coordination along with many services reimbursed through a bundled clinic encounter rate, California is reimbursed on a fee-for-service basis for care coordination activities, and South Carolina referenced its Family Support Services program through which Title V is reimbursed for support services provided to families in the state's Medicaid managed care program.

Another important findings of relevance to state Title V agencies' use of Medicaid reimbursement options is that eight states indicated using more than one of the above financing options. This finding, supported by the telephone interviews conducted with selected states, suggests that once Title V agencies have established financing arrangements with their counterparts in Medicaid, it is more likely that additional financing options will be explored and implemented. In fact, Title V officials pointed out in their interviews that Medicaid officials were often extremely helpful in identifying alternative and improved Medicaid financing options for care coordination and other services provided by Title V to Medicaid-eligible persons, emphasizing the importance to Title V agencies of establishing strong relationships with their state Medicaid programs.

A summary of Title V agencies' use of the various Medicaid reimbursement options available for care coordination is presented in Table IV-4.

**Table IV-4.
Title V Agencies' Use of Medicaid Options
to Support Care Coordination Services**

Medicaid Option	Number of States Using this Option
Administrative case management	10
Targeted case management	7
EPSDT case management	6
Waiver program	4
Other options	4
Two or more of above options	8

Rhode Island: Conflict with Medicaid

In Rhode Island, the Title V CSHCN program, housed in the state Health Department's Division of Family Health, provides education, family support, and service coordination to CSHCN through a contract with the Child Development Center at Rhode Island Hospital in Providence. The Health Department's Division of Family Health is, in turn, under contract with the state Medicaid agency to provide Child Development Center services for Medicaid-eligible children with special health care needs. Under this contract, the Department of Health provides the state share of the cost of these services and receives the Federal Medicaid match. However, the hospital's multidisciplinary team cannot bill Medicaid for care coordination services provided to Medicaid-eligible children.

This prohibition is rooted in an essential difference in philosophy between the state's Title V and Medicaid programs. Title V's goal is to build and maintain a system of high-quality care, including multidisciplinary assessment and care coordination, for CSHCN that is accessible to children regardless of payer. The Medicaid agency, on the other hand, believes in the value of competition, and prefers to separate service delivery from care coordination. In its effort to encourage the development of new sources of care coordination, the Medicaid agency has prohibited the Title V contractor from billing for this service.

The Title V program continues to serve children who are enrolled in RItCare, the state's Medicaid managed care program. However, the program cannot bill Medicaid for services provided to these children, and is therefore forced to absorb their cost.

Utah: Utilizing Medicaid Financing to Support Title V Case Management for CSHCN

In Utah, the Title V/CSHCN program and the Medicaid program have worked collaboratively to establish and expand Medicaid funding for Title V roles in serving Medicaid-eligible CSHCN.

Earlier in the decade, the Title V/CSHCN program operated a federally-funded demonstration project under which case management services were provided for technology-dependent children, adults and elderly persons. When this program ended, Title V and Medicaid worked together to establish Utah's Home and Community-Based Services Waiver for technology-dependent children, which began in February 1995. This program strives to keep children with complex medical conditions in the community by offering respite care, case management, and other services needed by this population.

The Title V/CSHCN program is responsible for a variety of case management-related activities under the waiver (e.g., screening applicants for eligibility, conducting an in-home initial assessment of participants' needs, authorizing needed waiver services). These services were once billed in 15-minute increments as Medicaid targeted case management. However, as discussed below, they are currently reimbursed under an administrative case management agreement with Medicaid.

While the targeted case management option once worked well for case management services for children in the waiver program, the Title V agency found it challenging to meet the administrative requirements of this option for children served in the state's broader CSHCN clinical program. For these children, the documentation requirements for obtaining Medicaid reimbursement for both clinical and targeted case management services exceeded available staff resources.

To both minimize the required paperwork and to maximize Title V reimbursement, in 1997 Title V and Medicaid entered into an administrative case management contract. This contract expanded Title V's role in serving Medicaid-eligible CSHCN by providing Medicaid reimbursement for a variety of activities to ensure that Medicaid-eligible CSHCN receive timely and appropriate access to needed Medicaid services. This contract also included reimbursement for case management services provided to children in the waiver program. Thus, administrative case management replaced the targeted case management approach previously used for children in the Title V/CSHCN and waiver programs.

The advantages of the administrative case management contract reported by Title V officials include not having to bill for services (reimbursement is based on time studies); being reimbursed for an expanded array of activities; and obtaining the enhanced 75 percent matching rate permitted under this financing option.

Utah's Title V/CSHCN officials emphasized the value of the program's strong relationship with Medicaid. As they noted, this relationship has greatly facilitated the program's ability to make use of Medicaid financing to support Title V roles in coordinating care for CSHCN.

3. State Children's Health Insurance Programs

Given the growing number of children insured through State Children's Health Insurance Programs, this survey also inquired about Title V roles in providing care coordination for children in SCHIP programs.

Thirty states indicated that Title V provides care coordination services to children insured by SCHIP. However, only nine of these states, less than one-third, indicated that the agency or its contractors receives reimbursement to support the delivery of direct care coordination services to CSHCN. Of the nine states receiving SCHIP reimbursement for care coordination services provided to enrolled CSHCN, two have implemented Medicaid expansions. Of the remaining seven states, four have established separate state SCHIP programs, and three have used a combined approach.

4. Other Sources of Financing

Numerous states indicated that they receive funding from sources other than the MCH Block Grant and Medicaid to finance care coordination services to CSHCN. In most cases, this other source of funding was noted as being state general revenues, as was the case for seven states. Two states noted the existence of trust funds for persons with catastrophic illness that helps to support care coordination services to CSHCN. One state noted receiving funding from the child welfare agency (which is matched with Medicaid funds) to support care coordination services for children in foster care.

CHAPTER V

Systems-Level Care Coordination Activities

In this survey, HSR sought to explore the various types of systems-level activities in which Title V agencies are engaged that affect the coordination of services for CSHCN. These include identifying CSHCN, facilitating interagency coordination, building structures to link CSHCN and their families to needed services, and various other activities, each of which is discussed in turn below.⁸ Table V-1 provides an overview of the types of activities within each of these categories explored by the survey, as well as the number of states reporting to be involved in each. More detailed discussion of each category is provided below.

A. Identifying CSHCN

A critical element of an integrated system of care for CSHCN is its ability to identify these children and assure that their needs are assessed, planned for, and met. Part of this process involves assuring that CSHCN are assigned to providers who are trained and experienced in caring for children with complex needs. Without mechanisms for systematically identifying CSHCN and assessing their needs, systems of care are crippled in their ability to anticipate and provide these children and their families with the numerous and diverse services they often need to achieve optimal functioning (Hill, et al., 1999.).

⁸ In developing the survey questions on this different areas, researchers found the publication, *Public MCH Program Functions Framework: Essential Public Health Services to Promote Maternal and Child Health in America* by Grason and Guyer of the Johns Hopkins University Child and Adolescent Health Policy Center (1995) to be a particularly helpful resource.

**Table V-1.
Title V Systems-Level Care Coordination Activities**

Activity	Number of States
Identifying CSHCN	
Screen children for chronic illnesses and disabilities	35
Facilitate the development or implementation of screening tools for identifying CSHCN	26
Facilitate the development or implementation of policies for identifying CSHCN	22
Facilitating interagency coordination	
Spearhead efforts to improve coordination with other agencies serving CSHCN	33
Serve on interagency coordinating committees	39
Fund staff positions in other agencies to facilitate interagency coordination	13
Building structures to link CSHCN and their families to needed services	
Develop resource information about services available for CSHCN	42
Train staff serving CSHCN about available services	30
Direct health service programming for children in detention, mental health facilities, foster care to ensure CSHCN receive needed services	11
Establishing standards and mechanisms to facilitate appropriate receipt of services	
Authorize care coordination services provided by another agency/provider	10
Authorize medical specialty services	17
Facilitate appropriate referrals by providing training to those who make referrals	15
Develop model contracts to provide managed care enrollees access to subspecialists	9
Monitoring care coordination services	
Evaluate care coordination services for CSHCN	23
Standardize data collection/reporting on care coordination services	22
Involving families in care coordination	
Serve on advisory committees to improve coordination of services for CSHCN	38
Provide forums for families to ID ways services for CSHCN can be better coordinated	36
Employ parent consultants to provide ongoing family input on issues related to serving CSHCN	27

HSR's survey asked about three different types of activities in which Title V agencies may be engaged to help identify CSHCN:

- Screening children for chronic illnesses and disabilities;
- Facilitating the development or implementation of screening tools for identifying CSHCN; and
- Facilitating the development or implementation of policies for identifying CSHCN.

Our results indicate that the majority of Title V agencies are involved in screening children for special health care needs, with 35 states, or three-quarters of respondents, indicating their involvement in this activity. Most often, states indicated their involvement in newborn screening, typically for metabolic, genetic, and/or hearing problems. Screening of children in schools, typically for vision and hearing problems, was also commonly reported. Examples of screening activities being used by respondent states to identify children with health problems include:

- North Dakota operates a Birth Review Program, under which parents may request their child's birth certificate to be reviewed for risk factors for special health care needs.
- Wyoming will pay for a diagnostic evaluation by a specialist to be conducted on a child suspected of having a special health care need.
- Rhode Island offers a universal screening program to identify at-risk newborns and, for children found to be at risk, provides linkages to services as well as home visits.

Twenty-six states reported being involved in the development or implementation of screening tools for identifying CSHCN. Several notable examples identified in the survey responses included:

- Tennessee's Title V program assisted in the development of a tool to be used by schools to identify children in need of assistive technology. Title V is also participating on a TennCare committee to develop vision, hearing, and

developmental/behavioral pediatric assessment tools to be used by TennCare providers as part of EPSDT exams.

- Florida's Title V program was instrumental in the development of the application for the state's CHIP program, *Healthy Kids*, which includes a question to identify CSHCN.
- Oregon's Title V program collaborates with the state's Medicaid agency to conduct family surveys designed to identify CSHCN.

A large number of states, 22 of the 46 respondents, also indicated their involvement in the third category of activities, facilitating the development or implementation of policies for identifying CSHCN. Numerous states mentioned their work with Medicaid and other agencies to influence policies and procedures for children within these systems. For example, in Nebraska, the Title V program worked with Medicaid to develop a CSHCN screening tool to be used to facilitate the appropriate matching of clients with managed care plans. In addition, New Mexico's Title V program is working to assist Medicaid managed care organizations in identifying CSHCN and effectively responding to their needs.

Several states also noted other ways that the Title V agency works to facilitate the identification of CSHCN. For example, Iowa indicated that the Title V program is participating in the development of a population-based household telephone survey which will include questions aimed at identifying CSHCN. In all of these ways, Title V agencies are playing an integral role in identifying CSHCN who can then, in turn, be linked with the services that they need.

Texas: Identifying CSHCN in Medicaid Managed Care

The CSHCN Division within the Texas Department of Health, the state's Title V agency, is a key partner in a statewide effort to develop and pilot test a process for identifying CSHCN enrolled in the state's Medicaid managed care system. This effort was spurred by the Texas State Legislature's passage in 1997 of Senate Bill 1165, which directed the Health and Human Services Commission (HHSC) to develop a definition of CSHCN, develop a process to ensure their identification within Medicaid managed care, and identify strategies for ensuring the delivery of high-quality services to this population. In response to this legislative mandate, HHSC organized the SB 1165 Workgroup including representation from advocacy groups, parents of CSHCN, state agencies including the CSHCN Division, and managed care organizations.

It was within this context that the Texas Center for the Study of Children with Special Health Care Needs, based at the University of Texas Health Science Center, applied for and received a SPRANS grant from the federal MCHB to facilitate the state's effort to better identify and serve CSHCN within Medicaid managed care. With this SPRANS funding, and working in partnership with the Texas Title V program, the Center has supported the work of the SB 1165 Workgroup in addressing its mandated goals.

The results of the Workgroup's efforts to date include the development of a definition of children with complex special health care needs (CCSHCN) and the development and pilot testing in the San Antonio/Bexar County service delivery area of a process for identifying children in Medicaid managed care who meet this definition. The six-month pilot test, which concluded in April 2000, tested a two-step process of screening and identification facilitated by the state's Medicaid managed care enrollment broker, Maximus:

- **Screening.** Potential CCSHCN candidates are identified at the time of enrollment in Medicaid managed care. Maximus sends new enrollees a packet of information that includes a health status screening tool. Three of the questions on this tool pertain specifically to CSHCN. A positive response to any of these three questions for a child enrollee, including children identified through the Medicaid recertification process or through referrals to the program, triggers a follow-up contact by Maximus staff for administration of the CCSHCN identification tool.
- **Identification.** Maximus staff administer an eight-question identification tool to identify children who meet the definition of CCSHCN for purposes of the pilot. (This tool was adapted from the CSHCN screening tool developed by the Foundation for Accountability.) The tool is administered primarily via telephone or face-to-face contact, although if a candidate cannot be reached, the form will be mailed. Children who are confirmed as CCSHCN are identified to the managed care plan in which they are enrolled. The plan, in turn, is responsible for providing care coordination services to ensure that the child receives appropriate care and referrals. Data from the pilot test will be assessed over the summer of 2000 to evaluate the effectiveness of this process in identifying CCSHCN in Medicaid managed care.

B. Facilitating Interagency Coordination

An essential element of coordination on the systems level is coordination among the various agencies that serve CSHCN, including Title V, education, mental health, developmental services, and possibly most important, Medicaid. Coordination and communication among these agencies can help to assure that services are provided seamlessly on the client level; moreover, interagency coordination can lay the groundwork for coordinated responses to policy issues and create a structure for addressing problems in a coordinated fashion.

Title V's role in facilitating coordination among these agencies can take many forms. Our survey specifically asked if Title V agencies supported interagency coordination through the following activities:

- Spearheading efforts to improve coordination with other agencies serving CSHCN;
- Serving on interagency coordinating committees; and
- Funding staff positions in other agencies to facilitate interagency coordination.

In response to this question, 33 states reported that they were responsible for spearheading efforts to improve coordination with other agencies serving CSHCN. Examples of these efforts include the following:

- New Jersey's Title V program leads the Medicaid Managed Care Alliance, a family and interagency effort to develop a tool to assist families with CSHCN in navigating the Medicaid managed care system.
- Washington State's Title V program convenes a CSHCN communication network including program contractors, the Part C agency, Medicaid, and family organizations, which meets bi-monthly to identify and address common issues.
- Delaware's Title V program is leading the Medical Home Project 2000, which works with the Division of Social Services (the state Medicaid agency) and the state chapter of the American Academy of Pediatrics to develop a system to assure that all CSHCN have a medical home.

In addition to Title V-led efforts, 39 states reported that their CSHCN program staff serve on interagency coordinating committees. These include Part C Interagency Coordinating Councils, councils for children with behavioral and delinquency problems, councils addressing issues related to the transition from adolescence to adulthood, and advisory councils on state CHIP programs. Officials in these states report a number of ways that their participation in these committees has improved the coordination of care for children. These include:

- Building relationships among agencies (especially between Title V and Medicaid);
- Increasing coordination between the medical and educational communities;
- Developing joint programs, such as cross-training efforts, and locating Medicaid eligibility workers in Title V clinics;
- Assuring that referrals are made to the proper agency or provider;
- Improving levels of screening at birth and more consistent referrals to and from Early Intervention programs; and
- Helping to facilitate specific projects, such as funding for a program for parents of CSHCN (in New Mexico) and a formal transition program for adolescents (in Mississippi).

Thirteen Title V programs reported that they funded staff positions in other agencies to improve coordination. These staff positions include parent advocates, outreach workers, eligibility workers, coordinators, and consultants on CSHCN, and the agencies and organizations in which they are housed include Medicaid, the Department of Education, the Department of Economic Security (the state welfare agency), Family Voices, a hospital, and a city health department.

Examples of these positions include the following:

- Massachusetts used funding from an MCHB SPRANS grant to support a staff person in the state Medicaid agency who worked to develop a pilot program to provide enhanced case management for CSHCN.
- Illinois funds outreach workers at the Shriners' Children's Hospital in Chicago. These workers act as liaisons between the hospital and the Division of Specialized Care for Children (the Title V CSHCN agency).

- Pennsylvania's Title V program supports a Special Needs consultant in the Philadelphia Department of Health and in each of the state Department of Health regional offices.
- Several state Title V agencies support staff positions in family advocacy organizations: Rhode Island supports parent paraprofessionals in the state's Family Voices chapter, Maryland funds a parent advocacy group with regional family representatives, and Utah contracts with three parent organizations for consultation.

Among all of the agencies that Title V programs work with, the state Medicaid agency may be the most critical in assuring the coordination of services for CSHCN. Medicaid is a primary payer for medical services for CSHCN, and Medicaid's policies often play a significant role in determining whether services are accessible to families. In addition, as discussed above, Medicaid may support care coordination through its Targeted Case Management, Administrative Case Management, and EPSDT programs. When these services are provided by Title V staff or contractors to Title V agencies, a productive working relationship between the two agencies is essential.

Among the state officials we interviewed, relationships between Title V and Medicaid agencies vary from positive and productive to antagonistic. Title V officials who have good relationships with their state Medicaid agencies report several key elements that contribute to this relationship. These include the ability to demonstrate the effectiveness of Title V services, as well as less objective elements such as a cooperative, rather than adversarial, approach and an appreciation of the two agencies' shared responsibility.

The following vignettes illustrate creative interagency arrangements established in two states for strengthening services to CSHCN.

Missouri: Supporting Inclusion of CSHCN in Child Care Settings and Schools

Like many other states, Missouri's Title V/CSHCN program has witnessed a decrease in the need to fund direct services for CSHCN as more children are covered through public health insurance programs. With this change, the program has been able to redirect its funding resources to support activities that can reach the state's broader population of CSHCN. Notably, the state has included among these activities initiatives to support inclusion of CSHCN in child care settings and better management of special health care needs for children in mainstream school systems.

Efforts to Support Inclusion of CSHCN in Child Care. By blending funds from the Title V/MCH Block Grant and Child Care and Development Fund, the Title V program and the Bureau of Child Care within the Department of Health have supported a range of innovative activities to address the lack of adequate child care options for families with CSHCN. The Department has contracted with the Missouri Child Care Resource and Referral (R&R) Network to offer enhanced child care resource and referral services for families and child care providers of CSHCN. The R&R Network employs 11 inclusion coordinators, including three mothers of CSHCN, who offer the following services: (1) contact with child care providers to determine vacancies and their level of experience caring for CSHCN; (2) ongoing education for families, child care providers, and the community regarding quality child care standards, the benefits of inclusion, child care providers' responsibilities under the Americans with Disabilities Act, and community resources; (3) development of a plan with the family and child care provider selected to determine the supports needed to create a successful child care experience; and (4) referrals for families to other systems that support individuals with special needs (e.g., Early Intervention, special education, mental health). The Department also supports the provision of consultation to child care providers on issues related to caring for CSHCN and collaborates with many agencies to assure that training for child care providers addresses the needs of CSHCN. One important outcome of this interagency collaboration has been the Department of Social Services' decision to increase subsidies paid to child care providers for serving CSHCN.

Education and Training of School Health Nurses. The Title V program's efforts to enhance the capacity of professionals to work with CSHCN also includes the training and education of school nurses. The rationale behind this approach is that, if school nurses are better informed about and equipped to deal with students' special health needs, parents will be more comfortable sending their children to school and attendance will improve. Toward this end, the Title V program funds the University of Missouri School of Nursing to provide training for nurses in local health departments and private/parochial schools to develop materials and conduct trainings on issues related to school-age CSHCN, including asthma, diabetes, and seizure disorders. All school nurses are expected to develop individualized health plans for students with special health care needs that affect the educational process. This continuing education increases their ability to work with students and parents in determining how students needs will be managed within the school environment. Funding is also available to purchase equipment and supplies, such as wheelchairs and assistive technology devices, to assist children in functioning well in school.

Alabama: Nurse in Foster Care Program

In Alabama, Children's Rehabilitation Service (CRS), the Title V CSHCN program, is a part of the Alabama Department of Rehabilitation Services. CRS recently initiated an innovative approach to supporting and enhancing the care coordination provided to CSHCN in foster care in Alabama.

An interagency agreement between CRS and the Department of Human Resources (DHR), the child welfare agency in Alabama, was developed and signed effective 1 January 2000. Under the agreement, CRS has placed a nurse with over ten years of experience supporting CSHCN in the DHR office to provide training, consultation, referrals, and care coordination support to children in foster care with special needs. The nurse participates in the Individualized Service Plan and brings the medical perspective to the discussion. The nurse reviews children's records, sits in on staff case reviews, and once a week meets with staff from CRS to discuss cases. The nurse serves as a link between the DHR social worker, the foster family, the child and CRS or the specialized medical community.

Before this agreement, CSHCN in foster care were not receiving the level of care coordination to support their special needs. The nurse has been involved with children of all ages around feeding issues, lupus, renal problems, autism, seizures, and many other special needs. Since the collaboration began, foster families have given their overwhelming support to the project and DHR social workers have embraced this new resource. Cross training has improved both systems and supported a renewed level of understanding related to CSHCN in foster care.

C. Building Structures to Link CSHCN and their Families to Needed Services

In this report we have described various aspects of comprehensive care coordination systems for CSHCN. One of the most essential elements to a care coordination system is the capacity to link CSHCN and their families to needed services. Building and overseeing structures to ensure that CSHCN, their families, and providers have access to information about the services that are available and how to access them is a critical systems-level care coordination activity for Title V agencies. Examples of these structures include information hotlines, training programs for staff who work with CSHCN, and systems for producing and distributing updated written and electronic resource materials about available services.

Resource information regarding services for CSHCN for use by those caring for CSHCN, such as care coordinators, families, and providers, is developed and/or distributed by 42 of the Title

V agencies. Title V agencies reported developing and distributing written materials, such as brochures describing services, information sheets, newsletters and resource directories for families and providers of CSHCN. Resource information from other programs, such as the Social Security Administration, social services, and family support are also distributed. Toll-free hotlines are also used to disseminate information. Parent Networks also provide a forum for sharing information.

A few states are using computer technology as a means to share information. E-mail is often used to communicate with CSHCN and their families. In addition, one state reported that they are developing a web page which will provide information on services available.

Training staff serving CSHCN about available services facilitates linking CSHCN to those services. Maternal and Child Health staff, Medicaid managed care staff, or staff of health plans/case management organizations are trained in the needs of and resources available for CSHCN by 30 of the Title V agencies. The trainings include presentations, inservices, and assistance via the state hotline. Title V agencies reported providing ad hoc training as well as continuous training. Quarterly and annual training sessions were reported.

Children with special health care needs in detention, mental health facilities or foster care may not receive care coordination services unless a special effort is made to locate these children, assess their needs, and provide services. Eleven of the Title V agencies reported directing or coordinating health services programming for children and adolescents in detention, mental health facilities, or foster care to ensure that CSHCN receive needed services.

Pennsylvania: The Special Kids Network

Until 1995, the Pennsylvania Department Maternal and Child Health Supplemental Security Income Disabled Children's Program provided care coordination to CSHCN, but the care coordination was discontinued after a study indicated that this service duplicated care coordination services already being provided by other agencies. Currently, the Title V agency does not provide direct care coordination services to CSHCN.

However, a statewide study of service delivery to CSHCN found that families often didn't know where to obtain services and there was a lack of coordination among services. The Special Kids Network (SKN) was developed to address these issues.

The Special Kids Network, supported entirely by Title V funds, is a statewide information and referral system developed to make services more accessible. The mission of SKN is to connect families with a broad range of services. Families are assisted with assessing their unique needs and provided with access to resources to improve the child's and the family's quality of life. The Special Kids Network was developed to help locate the following services:

- Health care products (e.g., adapted clothing, standing and walking aids, wheelchair repair);
- Recreation and leisure (e.g., recreational and therapeutic camps, Special Olympics and wheelchair sports, and playgrounds with adaptive equipment);
- Social services and counseling (e.g., adolescent, child or family counseling; child abuse counseling; bereavement counseling; respite care; money management counseling; Hospice care; foster care and adoption services);
- Support and advocacy services (e.g., legal counseling, parent and sibling counseling, special education advocacy, and legislative advocacy); and
- Therapy (e.g., physical, occupational, and art therapies).

Parents and providers are encouraged to call an 800 number which automatically routes calls to a telephone counselor at the nearest of six regional offices throughout the state. Counselors using a computerized resource directory of local and statewide health and social services provide information, referral, and advocacy to families.

Outreach for the network historically has been through a statewide television campaign encouraging parents to call the toll-free number. Additional outreach methods continue to be explored. Currently, SKN is targeting rural areas through a pilot program in which classified advertisements are placed in daily and weekly rural newspapers. In this pilot outreach program SKN is testing whether including a statement about health insurance increases program participation in this area.

The state continuously evaluates the network. At the regional level, users of SKN are contacted in an evaluation of the resources and the information provided by the counselor.

D. Establishing Standards and Mechanisms to Facilitate Appropriate Receipt of Services

Another important systems-level care coordination function performed by Title V agencies is the establishment of standards and mechanisms that help to ensure that CSHCN and their families obtain the array of services they need. HSR's survey asked states if they were involved in several activities relating to this goal, including authorizing care coordination services provided by another agency, authorizing medical specialty services, providing training in how to make referrals appropriately, or developing model contracts to provide managed care enrollees access to pediatric subspecialists.

Only ten states indicated having a role in authorizing care coordination services provided by another agency. For example, the Texas Title V program authorizes extended medical case management services for children in EPSDT. In 17 states, Title V has a role in authorizing specialty medical services. In some of these states, the services involved are supported with Title V funds. In other states, such as Arkansas and Utah, which are highlighted in the following vignettes, Title V is involved in authorizing specialty services paid for by other agencies.

Other than having a direct role in authorizing care coordination or medical specialty services, 15 Title V programs facilitate appropriate referrals by providing training to those who make such referrals. For example, in Maryland, Title V is involved in training care coordinators working within managed care organizations. North Dakota provides detailed guidance on the referral process within the care coordination standards provided to county public health staff.

Finally, nine states noted their involvement in the development of contracts that help to ensure children's access to specialty services. For example, the Texas and Utah Title V programs were involved in the development of Medicaid managed care contract language addressing this important access issue.

Utah: Authorizing Home-Based Services for Technology-Dependent Children

Utah's Medicaid Home and Community-Based Services Waiver for technology-dependent children is administered by the state's Title V program. In addition to the regular Medicaid services for which enrolled children are eligible, the waiver covers several types of services that are needed to facilitate the child's care within the home environment. Among the activities for which the Title V/CSHCN program is responsible under this waiver include authorizing these home-based services:

- Respite care: A service provided to relieve the primary caregiver from the stress of providing continuous care;
- In-home respiratory care: Assessment and treatment provided by a licensed respiratory therapist to help maximize respiratory function;
- In-home family counseling: Provided to families of individuals served under this program to help them cope with the stress that goes with the daily care of a seriously ill child;
- Nutritional evaluation and in-home treatment: A specialized diagnostic and treatment service provided by a multidisciplinary team to help the child who cannot get adequate nutrition through ordinary means; and
- Portable oxygen: Provided for non-medical transportation and activities outside the home setting.

Arkansas: Establishing Medical Necessity for Therapy Services

In Arkansas, the Title V CSHCN program currently provides only limited direct care coordination services for Medicaid-eligible children. Formerly, care coordination was a major activity of the program. More recently, the program has taken a lead role in developing system-wide standards for establishing the medical necessity of therapy services, and Title V staff are now involved in utilization management for Medicaid using a prior authorization system guided by these standards. These activities are described in more detail below.

- In 1997, the Title V agency convened an expert consensus process to develop standards for the authorization of physical, occupational, and speech therapy services. These standards, which were based on accepted clinical practice guidelines, were intended to guide providers of targeted case management in determining the number of units of service to authorize for children with various diagnoses. Additional units of service may be authorized when medically necessary.
- Title V also employs nurses to conduct utilization management by prior-authorizing these therapy services for Medicaid. Using the clinical guidelines, these nurses review, establish medical necessity and authorize therapy services. Additional units of service beyond the amounts suggested in the guidelines may be authorized when the rationale for establishing the medical necessity of the plan is offered.

In addition, the Title V agency provides training to case managers from a variety of agencies who serve CSHCN in the range of services (beyond therapies) available to these children.

State officials are careful to distinguish their program's role in the development of guidelines and management of utilization from direct care coordination. The goal of the program is to assure that children receive the appropriate therapy services needed in an environment of limited resources and increasing pressure to contain costs. By setting standards that are clinically and scientifically sound, and by devoting CSHCN staff resources to review and authorize these therapies, Arkansas officials hope to integrate their program's strengths with Medicaid managed care's goals.

E. Monitoring Care Coordination Services

Another systems-level role Title V agencies can play is that of oversight and monitoring of direct care coordination services provided by Title V employees, contractors, and other agencies. This can involve direct evaluations of care coordination programs as well as responsibility for standardizing data collection and reporting mechanisms from these agencies, with the general goal of using these data to monitor the services provided. Our survey explored

two types of monitoring activities: evaluation and monitoring of care coordination activities, and standardizing data collection and reporting across agencies that provide care coordination services.

Twenty-three states reported that they conducted or were in the process of developing strategies to conduct evaluations of care coordination services. These efforts can take many forms, including chart reviews, site visits, and analysis of program data. Examples of the evaluation strategies reported include the following:

- Tennessee conducts site visits to the local health departments that provide care coordination on a regular basis, reviews client charts, and reviews agencies' overall compliance with care coordination guidelines;
- Oregon conducts periodic evaluations of its Title V care coordination program, including focus groups of families and satisfaction surveys; and
- New Jersey's 21 county case management units are monitored by state Title V staff at least monthly by telephone, as well as through bi-annual site visits and quarterly reports of program and financial activities.

Most of these states reported that their evaluation efforts were limited to oversight of care coordination conducted by Title V staff and contractors. However, a few states also reported that they had responsibility for monitoring care coordination provided by other agencies. Texas, for example, oversees Medicaid's medical case management services, which are provided by both Title V and Medicaid staff, and Rhode Island's Title V program is responsible for evaluating Early Intervention services, special hospital clinics for CSHCN, and school-based health centers.

Title V agencies may also be involved in the development of standards for reporting and data collection from providers of care coordination. Twenty-two states reported having a role in these activities, including the following:

- New York asks local health units to report the number of children enrolled in care coordination, their diagnoses, and their insurance status.

- Tennessee uses a patient information system database to document the amount of time spent and activities conducted with clients, and can periodically aggregate and analyze this information.
- North Dakota requires care coordinators to report their activities by 15-minute time increments; from this information, quarterly and annual reports are generated, and annual quality assurance reviews are conducted.

Despite all of these various efforts, however, there remains no standard mechanism for measuring the quality, effectiveness, or cost-effectiveness of care coordination services. While state officials may monitor the number of clients seen or the amount of time spent per client, they have no agreed-upon standard to which to compare these statistics. Thus, quality monitoring is generally a matter of assuring that care coordination services are provided as outlined in the state's protocols and manuals. In the absence of standards for the process of care coordination, however, an alternative is to monitor the success of these programs through focus groups and surveys of the families who use their services. In this study, however, only Oregon and Florida reported using parent satisfaction as a measure of the quality of care coordination services. In Florida, a family survey instrument was developed by the state Family Voices coordinator and is administered by the county Children's Medical Services offices. The survey has found that more than 90 percent of families are satisfied with the care coordination services they receive.

Surveys can also be used to measure the outcome of care coordination for the family. (For example, Family Voices recently conducted a national survey, in conjunction with Brandeis University, on the health care experiences of families of CSHCN, including their experiences with care coordination.) Although it may never be possible to measure the direct effect of coordination on children's health or functioning, surveys can assess whether this service has improved children's access to care and parents' sense of control and decreased families' level of stress—outcomes which may, in fact, be the ultimate goals of care coordination.

Two states' efforts to monitor Title V care coordination services are highlighted below.

Iowa: Utilizing an Abstract Form to Monitor Care Coordination Services

Iowa Child Health Speciality Clinics, Iowa's Title V program for children with special health care needs, monitors care coordination activities provided by care coordinators who are Title V staff for clients. The primary monitoring activity is completion of a care coordination abstract by a care coordinator or a secretary. Data gathered on the care coordination abstract summarizes the extensive care coordination activities noted in the patient's chart that are not part of usual clinic-related activities. Information gathered includes the following:

- The services provided (e.g., initiating care coordination, resource and referral information, and home visits);
- The type of care coordination service (e.g., clinical patient, hemophilia, nutrition, autism, and diabetes school re-entry);
- Diagnosis;
- Disposition (e.g., call or recall to clinic);
- Care plan, including services arranged or facilitated (e.g., finances, transportation, residential care); and
- Providers (e.g., county relief, WIC, and respite care agency).

The abstract information is coded into a patient data base to provide a more complete record about the patient in the data base and to enable statistical reporting of extensive care coordination services, not otherwise reported.

F. Involving Families in Care Coordination

To provide the best coordination of care for children with special health care needs, experts agree there must be a partnership between families, health care professionals, and state agencies. The family is a constant in the child's life, monitoring the child's condition on a daily basis and making crucial decisions about the child's well-being. Often times, the most progress is made when health professionals recognize families as a valuable source of information and support. Professionals should strive to put families at ease, to include them in decision-making, to take into consideration their concerns, and to arm them with as much information as possible (Haas et al., 1992).

Idaho: Monitoring Regional Care Coordination Activities

Idaho's CSHCN care coordination activities are executed by seven regional health departments. In addition to the benefits of community-based care coordination, a state approach would be prohibited by the small size of the Children's Special Health Program (the state's Title V/CSHCN program), which has only two professional staff persons. In determining how to best use these limited staff resources, the staff agreed that an important focus would be to improve the quality of the state's care coordination program for CSHCN.

The implementation of the state's tiered care coordination approach is an important example of state's efforts toward this end and, more specifically, a move toward a more uniform care coordination approach across the state.

In addition to implementing its three-tiered model of care coordination about two years ago, the state at the same time instituted several activities to improve the state's capacity to monitor the delivery of care coordination services by the regional health departments. Chief among these has been the introduction of intensive chart audits conducted on an annual basis.

During these reviews, state staff check that charts include all required documentation, that children have been assigned to a tier level, and that services are being provided in accordance with the care plan. Feedback is provided to health department staff by the state reviewers through a written report highlighting the strengths and weaknesses of the departments' charting practices.

Other monitoring/quality improvement activities include the submission of quarterly reports by the health departments to the state agency, quarterly conference calls among regional program coordinators and state staff to identify needs and share information, and an annual meeting to bring staff together for more intensive information-sharing, training, and discussion than is feasible during the quarterly conference calls.

State CSHP officials emphasize that all of these activities are conducted in a collaborative spirit with the regional health departments, with the focus on improving the consistency and quality of the care coordination services.

Our survey explored how and in what capacity state Title V agencies support the inclusion of families in care coordination efforts on behalf of CSHCN. States were queried regarding their involvement in such systems-level activities as involving families on advisory committees and forums and in employing parents as consultants to the agency:

- **Advisory committees.** The survey inquired as to whether families serve on advisory committees as a strategy for improving the coordination of services for CSHCN. Thirty-eight states—or 83 percent—include families on such committees. Families serve on committees at local, regional, and state levels. The types of committee can include parental advisory committees, maternal and child health advisory committees, and Medicaid managed care committees,

among others. The number of family members included on a given committee also varies. In Michigan, for example, on special committees required by health plans serving CSHCN, 50 percent of advisory committee members must be family members of CSHCN. Most states, however, employ far fewer family members on committees.

- **Forums.** Respondents were asked whether their Title V agency provides parents with a forum to identify ways that services for CSHCN could be better coordinated. Thirty six states—or 76 percent—indicated that they provide such forums. Focus groups were overwhelmingly the most common forum cited. Surveys and parent networks were also mentioned as ways in which states seek input from families.
- **Parent consultants.** The survey also asked States whether the Title V agency in respondent states employs parent consultants to provide ongoing family input on issues related to services for CSHCN. As shown in Table V-2, the results indicate that 27 states employ parent consultants, and that many states employ five or more (the average number of parent consultants in a given state is 6.5). Several states that maintain just one parent consultant indicated that this employee may work part-time or may share time among several agencies. Parent consultants work at all levels—local, regional, and state, with the majority placed at the local and regional level.

Table V-2.	
Title V Agency Employment of Parent Consultants	
Number of Parent Consultants	States
1-4	7 states (15%)
5-10	6 states (13%)
10 or more	6 states (13%)
* Note: States do not add up to 27, as not all states specified how many parent consultants are employed.	

Several respondent states indicated that they have other ways of involving parents in the care coordination process, such as contracting with parent support and information organizations for input on issues and services related to CSHCN.

The following vignettes describe strategies used by the States of Florida and Michigan to integrate parents of CSHCN in ongoing policy development and program operations decisions.

Florida: Parent Consultants

Florida's Children's Medical Services Program (CMS) has a history of involving parents of CSHCN in advisory and advocacy positions for services for CSHCN. At the state level, parent consultants act in an advisory role. Parents serve on a network advisory council aimed at improving the coordination of services for CSHCN and help to shape the policy development and implementation process on matters pertaining to CSHCN.

At times the Title V agency has funded parents to act as advocates for other parents. In each of the 22 regions, parents have provided advocacy and support for other parents of CSHCN. The parents may also act in a role similar to a care coordinator. Children's Medical Services anticipates expanding parent roles as it moves toward capitation in the Medicaid program.

Michigan: Family Involvement in Managed Care

The Michigan CSHCS program has a long history of involving parent consultants in the oversight of its programs and of developing and supporting networks of families of CSHCN. The parent consultants were instrumental in the design of the Special Health Plans model, the voluntary capitated system, and one of their major contributions was the inclusion of a Family Centered Care Coordinator (FCCC) within each plan. The role of the FCCC in each plan (both of whom are themselves parents of CSHCN) is to function at the policy and systems levels to assure that the plans' services are family-centered and to assure that the plan's policies meet families' needs. Examples of the activities of the two family-centered care coordinators include:

- Assuring that the plan's written materials are clear and are written with respect for the role of families in their children's care;
- Training customer service staff to address families' needs appropriately;
- Assuring that the plan's grievance and appeals process is family friendly;
- Educating individual families to identify their children's needs and assure that these needs are met;
- Participating in the plan's utilization management program;
- Training providers, school district staff, local health department, and enrollment broker staff in the plan's system; and
- Developing protocols for coordination with other community agencies, including local health departments, community mental health agencies, school districts, and Early Intervention programs.

CHAPTER VI

Interpretation and Implications of Findings

This survey has provided a wealth of information about the roles of state Title V CSHCN programs in providing and overseeing care coordination services to individual children and their families, as well as their efforts to assure coordination of programs and services on the policy level. In this final section, we attempt to draw together and interpret these findings and provide some preliminary recommendations for building successful care coordination efforts on the client and system levels.

A. Continued Role for State Title V Agencies

In this study, HSR asked states about expected changes in their role in client-level and systems-level care coordination activities. As discussed earlier in the discussion of Title V roles in client-level care coordination services, half of the states currently providing care coordination services anticipate that their role in this area will continue to evolve. In particular, states often noted that the reach of their care coordination services will be broadened to a more diverse population of CSHCN and that the scope of care coordination services will become more encompassing or holistic in nature.

HSR also asked states if they anticipate any increases in their role in broad systems development activities focused on improving coordination of care for CSHCN. Thirty-one states indicated that they do, in fact, anticipate an increase in such activities. In discussing the impetus for this shift in activities, states noted several factors, including the increased focus of Title V programs on systems-level activities in accordance with the MCH Services Pyramid, as well as the need to reduce fragmentation across agencies and programs, especially as it affects families enrolled in multiple care coordination programs.

Several states indicating that an increase in systems-level activities was planned noted that this activity is focused in specific areas. For example:

- South Carolina is working to strengthen the Title V program’s partnership with tertiary care hospitals to facilitate the availability of community-based services;
- Mississippi is planning to add a parent consultant to its staff and also develop a separate parent advisory committee; and
- Iowa is implementing shared management protocols for CSHCN enrolled in managed care organizations.

Thus, the role of Title V agencies in both client-level care coordination activities, as well as systems-level activities to facilitate the delivery of coordinated care for CSHCN, is not only well established but continuing to evolve and grow.

B. Direct Care Coordination

In the introductory chapter of this report, several research questions were laid out as being valuable to efforts to better understand and document the value of direct care coordination services for CSHCN. In this section, we return to these and related questions, presenting the survey’s contribution to our understanding of direct care coordination services and our recommendations to state Title V agencies for enhancing their client-level care coordination services to CSHCN and their families.

1. What is care coordination and what can it be expected to achieve?

Defining care coordination is an essential step in designing, implementing and evaluating any care coordination effort. As we have discussed, Title V programs, managed care organizations, Early Intervention programs, and primary care providers offer a wide variety of services, from utilization management to assessment and referral to medical and support services, all under the general rubric of “care coordination” or “case management.” Therefore, it is important to develop definitions of these services to distinguish them from each other and to clarify the critical elements, including the scope, intensity, and goals, of each. Moreover, the definition of

the service provided forms the basis for the development of cost estimates, for the description of the service presented to potential payers, and for the development of appropriate measures of quality of care.

Despite the critical importance of a clear definition of care coordination, few Title V programs reported that their programs included a formal definition of the service. Nonetheless, in our telephone interviews, state officials were more likely to report that their care coordination programs had explicit goals rather than formal definitions. Several states appear to have omitted the development of a definition in favor of the development of goals for care coordination, which they use to form the basis for their effort to monitor and evaluate the program's success and the quality of its services. While this approach is practical, it limits states' ability to describe the service consistently to clients and potential payers. Moreover, it is difficult to determine the goals of the service if the service itself cannot be defined.

In discussing their goals, it is important to note that state officials generally did not report that they expected their care coordination programs to demonstrate improvements in children's health or functional status. While a care coordinator may be able to link children to services that will lead to improvements in health outcomes, it is close to impossible to attribute changes in children's health specifically to the activities of a care coordinator. Thus, states' goals reflect the recognition that the outcomes of care coordination are unlikely to be health outcomes *per se*; rather, they are more likely to focus on increasing access to care or improving the functioning of the family. For example:

- **Increasing access.** The Title V care coordination program for CSHCN in North Carolina, the Child Service Coordination program, has as its goal “to collaborate and cooperate with families to assure identification of and access to preventive, specialized and support services for themselves and their children.”
- **Family empowerment.** While Massachusetts' case management program does not have explicit goals, program officials describe the program's expected outcomes as emphasizing the education and empowerment of the family; as state officials explain, “making skills available to the family is part of good case management.”

These states provide good examples of the types of outcomes that can be realistically expected from care coordination programs. In most cases, however, states have not formally defined the results that they expect to see from care coordination, and few have systems in place to monitor their success at achieving these goals.

2. How are care coordination services delivered?

This survey explored the delivery of care coordination services to CSHCN through Title V agencies. The findings show that, in nearly all states in the nation, Title V agencies are involved in delivering care coordination services to CSHCN. In recent years, Title V roles in providing care coordination have increased as Title V funds have been redirected away from clinical services and toward enabling services. It appears this trend will continue.

Findings from the survey illustrate other trends in care coordination services among Title V agencies. They appear to be moving toward serving a broader population of CSHCN, providing a more holistic set of care coordination activities, and improving the quality of care coordination services. For example:

- **Eligibility for Title V care coordination.** Title V agencies use a variety of categories of eligibility criteria to identify CSHCN eligible for care coordination services. In recent years, numerous states have expanded eligibility for Title V care coordination services to children with less severe diagnoses than those used to define eligibility for medical services under the state's Title V/CSHCN program.
- **Scope of care coordination services.** The focus of care coordination activities in recent years has shifted in many states from a focus on coordination of medical services to more comprehensive activities. Title V agencies report coordinating a diverse array of services, including mental health, special education, family support, and Early Intervention services.
- **Quality of care coordination services.** Finally, agencies are moving toward improving the quality of care coordination services, such as by focusing on defining and meeting objectives for care coordination.

Survey responses indicate that Title V agencies expect that these trends, especially the first two, will continue over the coming years. However, more attention to the third area, improving the

quality of care coordination services delivered by Title V agencies, appears warranted. Two strategies that Title V agencies can use to facilitate this goal include establishing care coordination protocols and defining levels of care coordination.

- **Care coordination protocols.** Protocols, or written guidance regarding how care coordination services can be carried out, can facilitate the consistent and systematic delivery of services. Furthermore, protocols provide a standard against which the delivery of services can be assessed. However, only half of Title V agencies reported using protocols, with agencies that provide care coordination through contractors somewhat more likely to have these guidelines in place. More widespread use of protocols could be an important tool for Title V agencies seeking to more firmly establish their role as CSHCN care coordination providers.

Protocols should be flexibly implemented to ensure that the unique needs of each client and family are addressed. Survey responses illustrate Title V agencies' recognition of this. Nearly all agencies using care coordination protocols call for the development of a care plan for each child and, of those that require care plans, almost all require that care plans address outcomes desired by the child and family.

- **Levels of care coordination.** Our study also found that numerous states have developed defined levels of care coordination that are used to match the intensity of care coordination services to the client's level of need. Not only can this approach help to systematize the appropriate delivery of services, it can also help to establish reasonable expectations about what care coordination can accomplish.

Finally, our survey findings suggest that, if Title V agencies are to establish a niche in the delivery of care coordination services to CSHCN, especially within the Medicaid managed care environment, agencies must clearly outline the components of their services. An explanation of care coordination services that outlines costs, as supported by data, as well as benefits, will be of significant importance in agencies' efforts to convince insurers of the value of Title V care coordination services for CSHCN.

3. How can states assure adequate reimbursement for care coordination services?

In order for Title V programs to sustain direct care coordination services to CSHCN and their families, they need to meet three conditions. First, they need to know the costs of providing the

care coordination services. Second, they need to obtain reimbursement rates that reflect the costs of providing these services; otherwise, without a source of supplemental funding, the Title V agency will be unable to continue providing them. This is true regardless of who is paying for the care coordination services (e.g., the state Title V agency, Medicaid, or managed care plans). Finally, states need to utilize available financing options to obtain adequate reimbursement rates.

In interviewing states, HSR found that states' knowledge about the costs of providing care coordination services was inconsistent. Furthermore, on the issue of reimbursement rates, HSR's study found that reimbursement rates for Title V care coordination services are in some, but not all, cases, based on the actual costs of providing these services.

- **Care coordination reimbursement rates based on costs.** Several states with which we conducted telephone interviews indicated that reimbursement rates for Title V care coordination are based on the costs of providing this service. For example, Medicaid reimbursement rates for Title V care coordination services in North Carolina, Florida, and Utah, for example, have been developed based on time studies used to estimate the direct cost of delivering care coordination services. In addition, the Texas Title V agency reimburses its case management contractors based on the contractors' costs of providing the services, in accordance with budgets submitted by the contractor and audits conducted by the Title V agency. The actual reimbursement rates in these states vary widely. In North Carolina, local health departments receive a base amount of funding from Title V and an additional \$80 per member per month to provide care coordination services to Medicaid-eligible children. In Texas, reimbursement rates average \$275-\$300 per child per year.⁹
- **Care coordination reimbursement rates based on rates established for similar services.** Other states have developed Title V care coordination reimbursement rates based on established rates for similar services, rates which may or may not have been based upon costs and which, even if they are cost-based, are not necessarily the same as Title V care coordination services. A case in point is Colorado, which is marketing Title V care coordination services for CSHCN to managed care organizations. To develop the rates for their three-tiered care coordination services to CSHCN—\$138 per child per year for families with needs of low complexity, \$299 for families with needs of moderate

⁹ The reimbursement paid by the Texas Title V agency to any individual contractor varies depending on the degree to which the contractor has other resources to support its infrastructure. For example, local health departments typically have other sources of funding to support the infrastructure needed to provide care coordination services, whereas community non-profit agencies are more likely to need Title V funds to support this infrastructure.

complexity, and \$596 for families with needs of high complexity—the Title V agency looked at the reimbursement rates paid by Medicaid for related, albeit different, services (e.g., nurse case management for women’s health, physician consultations). Local agencies consulted on the adequacy of these rates agreed that the rates were not sufficient to cover the full costs of providing these services; however, given the lack of cost, efficacy, and outcome data regarding the unique Title V care coordination services, the Title V agency felt it could not justify asking for higher reimbursement rates at this time. Title V funds will be used to supplement these rates until better data are obtained, ideally through experience providing care coordination services under the new managed care contracts.

The use of time studies and other methods to determine adequate rates for care coordination services in some states is a promising finding. However, the variation in care coordination rates across states, combined with the minimal data available on the costs of providing a public health model of care coordination services, supports the importance of more clearly elucidating the costs, especially in relation to the benefits, of Title V care coordination services.

The issue of how these services are financed was explored more extensively by the national survey. The results revealed several important findings regarding national financing patterns for Title V care coordination services:

- **Title V funding.** The survey findings documented the critical importance of the Title V/MCH Block Grant in supporting Title V care coordination services. Nearly all states involved in providing these services reported using MCH Block Grant funding as a source of financing.
- **Medicaid financing.** Medicaid is underutilized as a source of financing for Title V care coordination services. Only about half of the states that reported providing care coordination to children on Medicaid receive Medicaid reimbursement for these services.
- **SCHIP financing.** Like Medicaid, SCHIP is also underutilized as a source of financing for Title V care coordination services for CSHCN. Given the enhanced matching rate for SCHIP as compared to the regular Medicaid program, exploring financing options under SCHIP is also important.

The possibilities for financing Title V care coordination services are varied and depend on the particular circumstances of the state. However, a basic step that would benefit all Title V

programs is becoming more educated about the various financing options, and creative about utilizing and blending funding sources to support care coordination services for CSHCN. Furthermore, developing a clear definition of the care coordination services being provided is fundamental to Title V efforts to determine the entailed costs and justifying reimbursement requests.

4. What are the key elements of successful programs?

While HSR's study did not set out to answer this question directly, as by measuring outcomes of Title V care coordination programs, the study does shed light on this critical research question. In gathering information from state Title V agencies about their evolving roles with respect to care coordination services for CSHCN and their families, several key elements that contribute to success in the planning, organization and delivery of these services emerged. While these elements are described separately below, they are closely connected; for example, a focus on the child and goals for families will be strengthened by the purposeful involvement of families. The weaving together of these elements by the Title V agency and others involved in CSHCN care coordination can contribute to a statewide system of appropriate, quality care coordination services for CSHCN and their families.

- **Focus on child and family care coordination outcomes rather than on payment mechanisms.** The design of care coordination services is frequently driven by the mechanism to pay for the service rather than by the care coordination needs of the children and their families. The development of child and family-focused outcomes for care coordination—such as reduced family stress or improved access to services—should be an integral aspect of the care planning process, and these goals should be clearly stated and agreed to by families, policy-makers, providers, and payers. Mechanisms for monitoring the quality of the care coordination services should be developed to measure and assure attainment of the identified outcomes.
- **Coordinate at both the direct service and system levels.** Care coordination services may be organized and implemented by states in a variety of ways according to the specific needs of children and their families and other factors such as financial eligibility and age of the child. However, at both the direct service level and the systems level, mechanisms for coordination need to be in place to assure the seamless delivery of care, to smooth the transition from one program to another as needed, and to ensure the effective use of all available sources of funding.

- **Involve families purposefully.** Many states reported the involvement of families in their Title V care coordination activities, but some were not clear about the outcomes expected from parental involvement. Involvement of families in the planning and delivery of care coordination services should be deliberate and goal oriented. This involvement not only informs and enriches the design of care coordination services but also acts to develop and organize a constituency for care coordination services that meets the needs of CSHCN families.

- **Identify and creatively use available funding sources.** The underutilization of Medicaid financing to support care coordination was a major finding of the study. The development of waivers and the potential to include services in State Medicaid Plans should not be overlooked. In addition, since a variety of jurisdictions, including health, education, and social services, may be involved in providing care to CSHCN, opportunities to blend funding can also be pursued. This approach can assist each of the partners in fulfilling their respective mandates and maximize the effective use of their individual resources. Blending of funding also facilitates and supports the linkage of services, allowing for a more seamless delivery of services to families.

- **Establish levels of need and match with appropriate level of intervention.** CSHCN are not a homogenous category of children in regard to their care coordination needs. Also, the ability of families to coordinate the care for their special needs children may vary over time depending upon the child’s health and developmental status and the family’s resources. Therefore, consideration should be given to developing levels of care coordination that vary in comprehensiveness and intensity so that the intensity of the care coordination services can be matched to the level of care coordination need experienced by the child and the family. This approach promotes the most effective use of available resources while being responsive to the changing needs of families.

In the complex and dynamic world of health and human services, state Title V agencies— in partnership with the myriad agencies and groups concerned with the organization and delivery of services to CSHCN and their families— can play a leadership role in assuring the availability, accessibility and responsiveness of the care coordination services needed by these children and their families.

C. Systems-Level Care Coordination

In addition to providing insight into Title V roles in the delivery of direct care coordination services to CSHCN, this study contributes significantly to the knowledge base regarding the

ways in which Title V agencies work to promote coordination of care for CSHCN and their families at the systems level. Drawing upon these findings, this last discussion highlights several overarching strategies that appear likely to facilitate successful systems-level coordination by Title V agencies, as well as challenges that Title V agencies are likely to encounter in these efforts.

1. Strategies for Successful Systems Coordination

Title V agencies are well positioned to facilitate coordination of care for CSHCN at the systems level. The following strategies, drawn from insights gained through the survey and telephone interviews, suggest some specific ways that Title V agencies can enhance their capacity to promote systems-level coordination.

- **Convening systems partners.** The Title V program is the only federal program solely devoted to improving the health of all mothers and children. This mandate to serve the entire MCH population places Title V agencies in a uniquely strong position to bring together the many agencies, programs, and systems that serve mothers and children, including CSHCN. By convening these partners around shared concerns, Title V can provide a forum for enhancing their understanding of each other's roles, shared issues, and the benefits of coordination to clients and programs alike. In turn, Title V agencies can play a central role in facilitating the coordinated development of policies and strategies for improving service delivery to CSHCN and their families.
- **Using funding creatively.** A major advantage of Title V efforts to build strong relationships among systems partners is the potential to identify issues of shared concern and address them through a coordinated, jointly funded response. Medicaid is a natural partner to consider in funding strategies to improve services for CSHCN, as Medicaid is a primary payer of medical services for CSHCN. However, as CSHCN require a broad range of services in addition to those of a more medical nature, funding partners can and should be sought in these broader arenas, as well. Missouri's success at blending funds from the Title V/MCH Block Grant and the state's Child Care and Development Fund to improve child care options for CSHCN is an excellent example of how funds can be blended to address the needs of CSHCN and their families. Funding of staff positions in other agencies, as was reported by 13 states, is another strategy that can improve coordination at the systems level.
- **Sharing data obtained through population-level activities.** Title V agencies have broad responsibility to create comprehensive, community-based, high-quality systems of care for CSHCN and their families. This mandate is carried

out through a variety of population-level activities including assessment, policy development, and quality assurance. In each of these roles, Title V agencies gather data that can inform the various programs and agencies serving CSHCN and, in turn, be used to guide efforts to better serve the population. For example, an integral responsibility of Title V agencies receiving MCH Block Grant funds is the conduct of a comprehensive needs assessment of the MCH population every five years. In carrying out this responsibility, each state's Title V agency gathers a wealth of information regarding the CSHCN population (e.g., who the state's CSHCN program encompasses, how many CSHCN there are, the particular health care conditions they have) and their needs (e.g., resources that exist to meet their needs, as well as gaps in services). By sharing the data gathered by this ongoing investment in needs assessment and, furthermore, helping systems partners to interpret and use this data, Title V agencies can facilitate the accomplishment of its mission to improve systems of care for this vulnerable population.

- **Creating and utilizing structures to obtain ongoing family input and involvement.** In order to create and improve any service or product that is responsive to its target audience, it is critical to obtain ongoing feedback from its consumers. This same argument can be made for Title V efforts to develop and continually enhance the system of care for CSHCN. In fact, in this case, “feedback” may be an insufficient concept; as families are at the center of children’s lives, the perspective of families with first-hand knowledge of what having a CSHCN involves is best integrated into the Title V infrastructure for CSHCN policy and program development, implementation, and monitoring. Furthermore, just as is true for the sharing of data gathered through needs assessments and quality assurance activities (which are likely, themselves, to include input from families), sharing of the family perspective across agencies and programs serving CSHCN, including training programs for persons working with families of CSHCN, can help to foster the family-centered characteristic that the MCH community continually strives to infuse into the broader system of care for CSHCN.

2. Challenges to Successful Systems Coordination

Assuring coordination of programs for CSHCN on the systems level is a challenging task. Title V agencies, while statutorily and administratively well positioned to spearhead efforts to assure the coordination of programs and services, are not necessarily recognized as the natural leaders of these efforts. The specific challenges involved in organizing and leading efforts to coordinate services for CSHCN are described in more detail below.

- **Building relationships.** The development of strong interagency relationships, particularly with state Medicaid agencies, appears to be the major challenge to

coordination at the systems level. Bridging the differing philosophies and orientation of Title V and Medicaid agencies can be a significant challenge. This issue is further complicated if the Title V agency is also a provider of direct services, as there may be confusion between the agency's role in policy development and its role as a service provider.

- **Possessing key information and data.** Information is critical to establishing Title V's role in systems coordination. Title V CSHCN agencies must be able, first, to demonstrate the need for their involvement in systems development and planning, and then to establish the value of their contribution, both on the direct service level and on the policy level. For example, information on the cost of care coordination services is necessary to establish adequate reimbursement rates. Again, few Title V agencies are able to evaluate their services in these terms.
- **Identifying CSHCN.** A critical element of a system of care for CSHCN is, of course, a definition of this population and a method for operationalizing this definition in both public- and private-sector systems. For Title V agencies, the ability to describe the population of CSHCN, to estimate their prevalence within Medicaid-funded and other systems of care, and to define a strategy for identifying them is both challenging and essential to the ability to persuade other agencies of the importance of care coordination.
- **Monitoring.** Title V agencies may be able to establish a role in setting standards for care coordination and referrals as well as in training care coordinators from a range of agencies. A logical extension of this role would be the monitoring and oversight of these care coordinators, in order to assure the quality and consistency of the services they provide; however, the lack of consensus on the outcomes of care coordination and the absence of data in many states poses a major barrier to the adoption of this responsibility. In addition, as mentioned above, Title V's role as a provider of direct services may pose a conflict with its role in monitoring the quality of the services provided by other agencies.

Finally, the development of the infrastructure for systems-level coordination efforts can be hampered by the simple fact of the impermanence of government structures. On one hand, collaborative efforts depend on the interpersonal relationships among high-level officials, but it is these officials who are most vulnerable to political change. Thus, it can be difficult to build commitment to a process that may not outlast the current administration.

While these challenges are significant, they are not insurmountable. The first step in establishing Title V's role in coordination of care for CSHCN, on either the client or the systems level, is

developing an understanding of the specific components of care coordination and their value. It is hoped that this study can be the first step in the ongoing project of defining and promoting Title V's role in the coordination of services for CSHCN and their families.

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Appendix A: National Survey

Title V Roles in Care Coordination for Children with Special Health Care Needs

A Survey by
The National Policy Center for Children with Special Health Care Needs
October 1999

Who is conducting this survey and why? This survey is being conducted by the *National Policy Center for Children with Special Health Care Needs* (CSHCN), a partnership between the Johns Hopkins University, Health Systems Research, Inc., and Family Voices funded by the Maternal and Child Health Bureau, to explore the different and changing roles that Title V agencies play in coordinating services for CSHCN.

What will be the outcome of this survey? The outcome of this survey, as well as follow-up telephone interviews to be conducted with selected states utilizing a range of care coordination strategies for CSHCN, will be a document that presents a menu of options—illustrated with examples identified by our research—that state Title V agencies have for improving the coordination of services for CSHCN. This document will be shared with all Title V agencies, members of the Association of Maternal and Child Health Programs' recently-convened care coordination committee, and other key partners.

What does this survey explore? Specifically, this survey addresses the “enabling services” category within the MCH Services Pyramid with respect to care coordination for CSHCN. The survey seeks to identify the range of activities included under a broad definition of “enabling services” that directly or indirectly affect the degree to which services for CSHCN are coordinated. These activities include the provision of care coordination services (alternatively known as case management or service coordination) directly to clients, as well as broader systems development activities such as developing tools to identify CSHCN and link them to needed services; convening or participating on interagency committees that facilitate coordination among agencies serving CSHCN; and defining standards or outcomes for care coordination services.

Please note that, while many Title V agencies have lead responsibility for Part C/Early Intervention, this survey is NOT focused on Part C responsibilities.

Who should complete this survey? This survey should be completed by a high-level CSHCN program official with a broad understanding of the Title V agency's roles and how its policies and programs are operationalized.

Please return survey by *NOVEMBER 15, 1999* to: Beth Zimmerman, Health Systems Research, Inc., 1200 18th St., NW, Suite 700, Washington, DC 20036, or Fax (202) 728-9469 *Any questions?* Contact Beth at (202) 828-5100 or bzimmerman@hsrnet.com.

Thank you very much for your participation in this study!

STATE _____
Name _____
Title _____
Department _____
Agency _____
Address _____

Phone _____
Fax _____
E-mail _____

For all questions, check all responses that apply. Note that questions in italics require short written responses (use back of page if necessary).

A. Direct Care Coordination Services

This first series of questions relate to the provision of direct care coordination services to CSHCN and their families. These services may be provided by Title V staff or provided by staff of another organization that is funded by the Title V agency to deliver direct care coordination services to CSHCN and their families. For each question below, check all responses that apply. Please include additional explanatory notes as needed.

1. Does your Title V agency currently provide care coordination services to CSHCN either directly (i.e., by Title V staff) or by paying others to provide care coordination services (e.g., through contractual, fee for service, or other arrangements)? Check all that apply. (Please note that this survey is *not* addressing Part C responsibilities.)

 Yes, provided by Title V staff (Skip to Question #3)
 Yes, by paying others to provide care coordination services (hereafter referred to as “contractors”) . *Who do you pay to provide these care coordination services?* (After responding, skip to Question #3)

 No (Go to Question #2)
2. Did the Title V agency have a role in providing or paying for direct care coordination services within the last 10 years?

 Yes *When and why was this role discontinued?* (After responding, go to Part B, page 5)

 No (Go to Part B, page 5)
3. Is Title V-supported care coordination available to all CSHCN or, alternatively, to subsets of CSHCN?

 All CSHCN (Skip to Question #5)

- Subsets of CSHCN (Go to Question #4)
4. Which of the following criteria define the subsets of CSHCN who receive direct care coordination services? Check all that apply.
- Diagnosis
- Functional status/severity of condition
- Geographic region
- Family needs
- Other criteria. *Please describe:*
5. Does your Title V agency use MCH Block Grant (federal and/or state funds) to support the provision of direct care coordination services for CSHCN? Yes No
6. Does your Title V agency have a portion of its budget specifically allocated for direct care coordination services for CSHCN? Yes No
7. Does the Title V agency or its contractors provide care coordination to children in the Medicaid program? Check all that apply.
- Yes, to children in Medicaid risk-based managed care arrangements (Go to Question #8)
- Yes, to children in Medicaid fee-for-service arrangements, including Primary Care Case Management (Go to Question #8)
- No (Skip to Question #9)
8. Does the Title V agency or its contractors receive Medicaid reimbursement for providing direct care coordination services to CSHCN in Medicaid? (Check all that apply.)
- Yes, through targeted case management
- Yes, through administrative case management
- Yes, through EPSDT case management
- Yes, through a waiver program
- Yes, through other case management options. *Please describe:*
- No
9. Does the Title V agency or its contractors provide care coordination to children in the State Children’s Health Insurance Program (CHIP)?

- Yes (Go to Question #10)
- No (Skip to Question #11)

10. Does the Title V agency or its contractors receive CHIP reimbursement to support the delivery of direct care coordination services to CSHCN in CHIP? Yes No

11. Does the Title V agency or its contractors provide care coordination to children in the Part C/Early intervention program?
 Yes (Go to Question #12)
 No (Skip to Question #13)

12. Does the Title V agency or its contractors receive Part C funds or reimbursement to support the delivery of direct care coordination services to CSHCN in Part C/Early Intervention? Yes No

13. Does the Title V agency or its contractors receive funding from any other sources to support the provision of direct care coordination services to CSHCN?

- Yes. *Please specify:*
- No.

14. Which types of services do the Title V agency’s coordinators/case managers, or those employed by its contractors, assist CSHCN and their families in receiving? Check all that apply.

- | | |
|--|--|
| <input type="checkbox"/> Primary care services | <input type="checkbox"/> Transition planning for adolescents |
| <input type="checkbox"/> Specialty medical services | <input type="checkbox"/> Mental health services |
| <input type="checkbox"/> Ancillary therapies | <input type="checkbox"/> Special education services |
| <input type="checkbox"/> Early intervention services | <input type="checkbox"/> Family support services |
| <input type="checkbox"/> Services provided under Medicaid managed care | <input type="checkbox"/> Other services. <i>Please identify:</i> |

15. Through which methods are care coordination services provided to CSHCN? Check all that apply.

- Telephone
- Clinic visit
- Home visit

16. Does your Title V agency have written protocols or guidance outlining how care coordination services should be carried out?

- Yes. **(Please include a copy with your completed survey.)** *Please describe:*

No (If no, skip to Question #19)

17. Do the protocols/guidance call for the development of a care plan for each CSHCN?

Yes No

18. Do the protocols require that care plans include desired outcomes for the child/family?

Yes No

19. Has the Title V agency's role in providing or supporting care coordination for CSHCN changed significantly in recent years (e.g., increased its role such as by providing care coordination services under a Medicaid managed care contract, decreased its role by reducing the populations to whom care coordination services are provided, changed its orientation by utilizing different types of staff), or stayed fairly constant? Check all that apply.

Increased in intensity or frequency

Decreased in intensity or frequency

Changed in philosophy/direction/approach. *Please define:*

No significant changes

20. Are there plans to change the role of the Title V agency in delivering care coordination services to CSHCN from the current level?

Yes. *In what ways is the Title V agency's role expected to change?*

What is the impetus for this anticipated change in the program's care coordination role?

How and over what time frame do you envision this will be done?

No

B. Broader Care Coordination Services

Defined broadly, enabling services can entail a range of systems-building activities that affect the degree to which services for CSHCN are coordinated. This second series of questions pertains to these types of activities.

1. Do your Title V agency staff play a role in coordination of different agencies that serve CSHCN by (check all that apply):

Spearheading/initiating/leading efforts to improve coordination with other agencies serving CSHCN (e.g., mental health agency). *Please describe:*

Serving on interagency coordination committees.

What issues do these committees address?

Please briefly note any significant ways in which these committees have improved the coordination of care for CSHCN.

Funding staff positions in other agencies to facilitate interagency coordination.

What type of position(s) are funded?

In what agency/agencies are these positions funded?

Other activities. *Please describe:*

Not applicable.

2. Does the Title V agency help to identify CSHCN through such activities as (check all that apply):

Screening children for special needs. *Please describe:*

___ Facilitating the development or implementation of *screening tools* for identifying CSHCN (e.g., by working with health plans/provider networks and other child/family-serving systems like education, social services, etc.) *Please describe:*

___ Facilitating the development or implementation of *policies* for identifying CSHCN (e.g., by working with health plans/provider networks and other child/family-serving systems like education, social services, etc.). *Please describe:*

___ Other. *Please describe:*

___ Not applicable.

3. Whether or not you provide or fund direct care coordination services, does your Title V agency help to link CSHCN and their families to needed services by (check all that apply):

___ Informing families (directly or through a contracted agency) about services for CSHCN provided by other agencies (e.g., informing SSI beneficiaries about transition services available through the vocational rehabilitation agency).

___ Developing and/or distributing resource information regarding services for CSHCN for use by care coordinators, families, providers, etc. *Please describe:*

___ Training staff of MCH or Medicaid managed care hotlines or staff of health plans/case management organizations in the needs of and resources available for CSHCN. *Please describe:*

___ Directing or coordinating health services programming for children and adolescents in detention, mental health facilities, foster care to ensure that CSHCN receive needed services. *Please describe:*

___ Other. *Please describe:*

___ Not applicable.

4. Does your Title V agency have a role in determining or approving referral patterns with respect to care coordination and/or specialty services for CSHCN through any of the following activities (check all that apply)?

Authorizing care coordination services provided by another agency/provider.
Please describe:

Authorizing medical specialty services (e.g., long-term care facilities, CSHCN home and community-based home services). *Please describe:*

Providing training in how to make referrals appropriately. *Please describe:*

Developing model contracts to provide managed care enrollees access to pediatric centers of excellence and office/clinic-based pediatric subspecialists.
Please describe:

Other. *Please describe:*

Not applicable.

5. How are families involved in your care coordination efforts on behalf of CSHCN?
(Check all that apply.)

Families are involved in the development of care plans for their children with special needs

Families serve on advisory committees to improve coordination of services for CSHCN. *Please describe:*

___ Title V provides forums for families to identify ways that services for CSHCN can be better coordinated (e.g., focus groups of families, providers, and/or care coordinators). *Please describe:*

___ Title V employs parent consultants to provide ongoing family input on issues related to serving CSHCN. *How many?*

___ Other. *Please describe:*

___ Not applicable.

6. Does your Title V agency have responsibility for monitoring care coordination services for CSHCN such as by (check all that apply):

___ Conducting evaluations/monitoring of care coordination services for CSHCN. *Please describe:*

___ Standardizing data collection/reporting methodologies with regard to care coordination services. *Please describe:*

___ Other. *Please describe:*

___ Not applicable.

7. Are there discussion about or plans for increasing the role of your Title V agency in broad systems development activities (including but not limited to those identified in Part B of this survey) focused on improving coordination of care for CSHCN?

___ Yes. *What is the impetus for this re-evaluation of the program's care coordination role?*

Are there any specific areas or activities in which your agency is planning on (or thinking about) focusing in particular?

Over what time frame do you envision changes will be implemented?

No.

8. Would your state be willing to participate in a follow-up interview about your activities if selected as appropriate for further research and possible inclusion as a case study in our final report?

Yes

No

THANK YOU VERY MUCH
FOR YOUR TIME AND PARTICIPATION!

PLEASE RETURN SURVEY
BY *NOVEMBER 15, 1999* TO:

Beth Zimmerman
Health Systems Research, Inc.
1200 18th St., NW, Suite 700
Washington, DC 20036

Any questions?
Contact Beth at (202) 828-5100 or
bzimmerman@hsrnet.com.

Appendix B: Interview Protocol

TITLE V ROLES IN CARE COORDINATION FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

Follow-up Telephone Protocol

This protocol will be used to get a more in-depth understanding of the different strategies that Title V agencies are using to coordinate services for CSHCN. These questions build on the information provided in the national survey and are being posed to a selected number of states.

Section I pertains to states in which Title V has a role in the direct provision of care coordination services for CSHCN. Section II pertains to states that facilitate coordination of services for CSHCN in ways other than the provision or funding of direct care coordination services.

II. DIRECT CARE COORDINATION SERVICES TO CSHCN

A. Overall Status of Title V Agency in Care Coordination

1. *Probe to survey questions 19 and 20:* The written survey asked about how your state's role in providing or supporting care coordination to CSHCN has changed in recent years and plans to change the role of the Title V agency in delivering care coordination services to CSHCN. I'd like to find out a little more about that as a context for our interview.

Please describe the role that your agency has traditionally played in providing direct care coordination services to CSHCN.
How has this role changed in recent years?
How do you anticipate things will change in the future? What factors are spurring these changes?

B. Administration/Staffing

2. *For states responding yes to survey question 1:* Please describe how your care coordination program for CSHCN is administered. For example:

Do state employees provide care coordination to CSHCN from a central location? If so, how does this work?
Do local health department staff provide care coordination with Title V funds?
How many LHDs provide care coordination to CSHCN?
Does the Title V agency contract with other organizations to provide care coordination to CSHCN? If so, with what types of organizations do you contract (e.g., private non-profit organizations, private for-profit organizations)? How many contractors do you have?

3. What level of education/training do your CSHCN care coordinators have?

Do you have staff at the masters, bachelors, and/or associate degree levels?

Are lay workers used?

Do parents of CSHCN serve as care coordinators?

What kind of supervision do the care coordinators receive?

4. Do you provide any training to your care coordinators? Please describe content and length of training, curricula used, etc.

C. Eligibility for Care Coordination

5. *Probe to survey questions 3-4: Which CSHCN are eligible to receive care coordination services? To which populations are care coordination services targeted?*

How is eligibility determined (upon what criteria)?

Who determines if a child is eligible for care coordination services?

D. Care Coordination Process

6. Does your state Title V program have a formal definition of care coordination services for CSHCN? If so, what is that definition?

7. What are the primary goals of your care coordination services?

8. *For states that answered yes to survey question 16: I understand that you have written protocols or guidance to indicate how care coordination services should be carried out.*

Please describe these.

How are they used?

When were they last updated?

Can we get a copy (if we haven't already)?

9. Please describe the process of care coordination for a typical client (*includes probes to survey questions 14-15 and may relate to questions 17 and 18*):

How are clients referred to and enrolled in care coordination?

Are any standard assessments done? How is this information used?

How are clients assigned to a care coordinator?

Is a care plan developed? What are the components of the care plan? How often are care plans checked to see if revisions are needed?

What services are standardly provided to all clients as part of care coordination?

Are there additional services that may be provided as appropriate?

What is the typical mode of contact between care coordinators and their clients (phone, clinic visit, home visit, other)? How is the appropriate mode of contact determined?

How frequent are these contacts?

When are care coordination services ended?

10. Are different types or levels of care coordination provided for different groups of CSHCN (by age, condition, level of function, income, etc.)? Please describe these standards and the distinctions among levels of need.

How were these levels (the schema) determined?

11. Do caseload sizes vary significantly among care coordinators (e.g., care coordinators with clients with intensive needs may be assigned a smaller number of cases)? If so, please describe.

For each level of care coordination, what is the average caseload size?

E. Care Coordination to CSHCN in Medicaid Managed Care/CHIP/Part C

12. *For states responding yes to survey question 7a:* You indicated in the survey that your Title V agency has a role in providing care coordination to CSHCN in Medicaid risk-based managed care:

What was the impetus and process for establishing a role for the Title V agency and/or its contractors to provide care coordination to CSHCN in Medicaid managed care?

Please describe the negotiations process with the Medicaid agency and/or managed care plans.

How are eligible children identified within the plans?

How do Title V care coordinators (or Title V-contracted care coordinators) work with/relate to plan personnel, including case managers and primary care providers?

Who has responsibility for authorizing services (e.g., those identified as being needed in the care coordination care plan) to be provided to children enrolled in the plans?

13. *For states responding yes to survey question 9:* You indicated in the survey that your Title V agency has a role in providing care coordination to CSHCN the state's CHIP program:

What is this role?

What was the impetus and process for establishing a role for the Title V agency and/or its contractors to provide care coordination to CSHCN in CHIP?

How are eligible children identified within CHIP?

What services do these children receive from Title V or its contracted care coordinators? (Confirm that it is the same service described above and, if not, clarify the distinctions.)

14. *For states responding yes to survey question 11:* You indicated in the survey that your Title V agency has a role in providing care coordination to CSHCN in the state's Part C/Early Intervention program:

What is this role?

What was the impetus and process for establishing a role for the Title V agency and/or its contractors to provide care coordination to CSHCN in Part C?

How are eligible children identified?

What services do these children received from Title V or its contracted care coordinators? (Confirm that it is the same care coordination service described earlier and, if not, clarify the distinctions.)

F. Linkages with Other Systems

15. How do care coordinators coordinate with other care coordinators that serve their clients, such as those from the special education and mental health systems?

Do multiple care coordinators routinely discuss clients they have in common? In what forum does this occur (e.g., informal contacts, formal case conferences)?

Is a primary care coordinator designated when a child has multiple coordinators? How is this person chosen—is there a protocol, or does the family choose?)

Is training coordinated in any way with training provided to care coordinators in other agencies that serve CSHCN (e.g., is the same curriculum used, are care coordinators from different agencies trained together)?

- r. Are there any other strategies used to facilitate the ability of care coordinators to bridge multiple systems serving CSHCN?

G. Financing

16. How are Title V care coordination services paid for (do you pay a percent of salaries of a staff of care coordinators, or do they bill for units of service, or are contractors paid a capitated rate for a range of support services, or is there some other arrangement?)

How are your payment rates determined?

What are the rates?

17. Do you have data on the cost of providing care coordination services? (e.g., per unit costs, by child, by diagnostic grouping, etc.)

If yes:

What are the specific cost elements included in that estimate? How do you calculate the costs?

How do you use these data (e.g., to readjust rates)?

If no:

Do you need this information?

How would you use it if you had it?

What prevents you from gathering this information?

18. *For states responding yes to survey question 8: I understand that you receive Medicaid reimbursement through the (targeted case management/administrative case management/EPSTD case management/waiver program/other case management) option(s):*

Can you provide any insight into why these particular options were exercised to allow Title V or its contractors to receive Medicaid reimbursement?

Are there any particular advantages or disadvantages between these different options?

Do you have any lessons to offer other states in obtaining reimbursement through these options?

19. *For states responding yes to survey question 7a: On the survey you indicated that your Title V agency provides care coordination services under contract to Medicaid managed care plans:*

How are you paid under these contracts (fee-for-service reimbursement or capitation?)

If capitation:

– What is included in that rate?

How was the capitation rate determined?

What are the rates that you receive?

Do the rates cover the costs of providing the care coordination service?

Are rates regularly reviewed?

Please describe the negotiations process. What information did you provide to the plans to demonstrate the value of your services?

If fee-for-service:

– How was the rate schedule arrived at?

At whose initiative were these contracts developed?

Please describe the negotiations process. What information did you provide to the plans to demonstrate the value of your services?

20. *For states responding yes to survey question 10: On the survey you indicated that your Title V agency receives reimbursement to support the delivery of direct care coordination services to CSHCN in CHIP:*

How are you paid (fee-for-service reimbursement or capitation)?

What are the rates that you receive? How were these determined?

Do the rates adequately cover the costs of providing the care coordination services?

Were there any particular challenges you had to overcome to establish CHIP as a reimbursement source?

21. *For states responding yes to survey question 12: On the survey you indicated that your Title V agency receives reimbursement to support the delivery of direct care coordination services to CSHCN in Part C:*

How are you paid (fee-for-service reimbursement or capitation)?

What are the rates that you receive?

Do the rates adequately cover the costs of providing the care coordination service?

Were there any particular challenges you had to overcome to establish Part C as a reimbursement/funding source?

22. *For states responding yes to survey question 13: On the survey you indicated that your Title V agency receives reimbursement from sources other than those identified in the survey to support the delivery of direct care coordination services to CSHCN:*

What is this source of funding?

How did it become a source of funding for care coordination services for CSHCN? What factors helped to leverage this funding source for this purpose?

23. Do you have any lessons to offer to other states in obtaining funding/reimbursement to support the provision of direct care coordination services to CSHCN?

G. Monitoring and Evaluation

24. What process measures do you track to assess the performance of your care coordination services (e.g., number of children served, number and types of services provided, percent of clients receiving a home visit, etc.)?
25. What outcome measures do you track to monitor the impact that your care coordination services are having (e.g., decrease in costs, reduced hospital visits, family satisfaction, etc.)?
26. Who does ongoing monitoring of the care coordination services for CSHCN?

How is this done?

How is the information used?

27. What strategies do you use for ensuring that your care coordination services are known to providers, accessible to families, and responsive to family needs?
28. Have any evaluations been done of the care coordination services your agency provides to CSHCN?

II. BROADER CARE COORDINATION SERVICES: Systems-building activities (other than direct care coordination) that affect the degree to which services for CSHCN are coordinated

For states noting significant activity under Part B of the survey. Specific activities to be explored through these questions are to be identified for states prior to their scheduled interviews.

1. As the survey only provides a general sense of what you are doing, please provide a more detailed description of the activity. *(Develop probing questions as appropriate to the area of focus.)*

2. What factors led to the Title V program's involvement in this activity?

When did it begin?

3. With what other partners (state agencies, state and local organizations/groups, etc.) did you work to establish this activity?
4. With what other partners do you continue to work with on carrying out this activity?
5. How does this activity help to ensure that services for CSHCN are coordinated?
6. Can you give any examples of changes in programs or systems that came about as a result of these efforts (e.g., changed policies, procedures, programming, etc.)?
7. How is it funded?

8. What staff are involved in this activity?

What level are these staff?

What disciplines do involved staff represent?

What functional area within the Title V agency do they represent?

9. How were/are families involved in the development, implementation, and/or oversight of this activity?

Appendix C: Contact Information for Highlighted States

Contact Information for Highlighted States

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