

STATE STRATEGIES FOR CARE
COORDINATION, CASE MANAGEMENT,
AND LINKAGES FOR YOUNG CHILDREN: A
SCAN OF STATE MEDICAID, TITLE V, AND
PART C AGENCIES

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS	1
INTRODUCTION	2
Survey respondents	3
SIGNIFICANT FINDINGS	5
States are working to improve linkages at the primary care, service provider, and system-wide levels.....	5
States are using the medical home model as a strategy to improve linkages in primary care	5
States are using a wide variety of service provider partnership strategies, across all three agencies, to address linkages	8
States most frequently reported employing fax or report-back policies to forge better service provider partnerships.....	9
Systems change or cross-systems strategies involve HIT, data and information systems, and cross-agency planning.....	10
State Medicaid, Title V, and Part C agencies are using available tools to promote linkages for children in a variety of ways.....	11
Medicaid favors primary care strategies to support healthcare and community linkages ..	12
Title V Programs Focus on Communication, Outreach, and Other Cross-provider Connections	13
Part C agencies work closely with primary care to better coordinate services	13
Despite this myriad of efforts, barriers remain.....	15
SUMMARY	17
ENDNOTES	18

CHARTS AND FIGURES

Table 1: Scan respondents by state and agency.....	3
Table 2: States reporting use of the medical home strategy to improve linkages for children, by agency.....	5
Figure 1: The majority of states responding to the scan are using a combination of primary care, service provider partnership, and systems change or statewide strategies to address l inkages for children	6
Table 3: Provider partnership strategies used by agencies that responded to the scan, by agency	8
Table 4: Community strategies used by agencies that responded to the scan, by agency.....	10
Table 5: Most frequently reported strategies for improving care coordination, by agency.....	11
Table 6: Barriers to care coordination reported by responding states	15

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INTRODUCTION

Research has demonstrated that early childhood development is critical to school readiness, academic success, and overall well-being. Timely and effective services to prevent or address early developmental delay can reduce developmental and behavioral disorders. In turn these interventions for young children can save costs that would later be expended in the health, education, child welfare, and juvenile justice systems. States have responded to this research by promoting developmental screening and the early identification of children at risk for developmental problems. As a consequence, more children are being screened, and more pediatric primary healthcare providers have become skilled in identifying children with or at risk of these problems.

Once these children are identified, referral for further assessment and treatment is essential. However, accessing these services can be challenging for families. Many parents of young children find it difficult to navigate the various agencies and providers involved in publicly supported early developmental intervention – administered by Medicaid¹, Title V², and Part C of IDEA (Part C)³ – and many children are left with unmet needs. In addition, most primary care medical services are delivered through the private sector, while public health services often are delivered via public agencies. The variety of funding streams and the differences between public and private funding policies and practices can create additional difficulty in the coordination of services for families.

As developmental surveillance and screening practices recommended by the American Academy of Pediatrics (AAP) become increasingly standardized and more widespread, the need for better coordinated and systematized assessment, treatment and follow up for children has become apparent. For a more in-depth analysis of this topic, and for more information on the roles played by Medicaid, Title V, and Part C, see the National Academy for State Health Policy's (NASHP's) recent report, *Improving Care Coordination, Case Management, and Linkages for Young Children: An Opportunity for States* at <http://abcd.nashpforums.org/sites/abcd.nashpforums.org/files/temp/Commonwealth.pdf>.

As the next step in its Assuring Better Child Health and Development (ABCD) initiative, NASHP conducted a scan of states in order to better identify and understand what states are doing through variously funded early child health and development agencies to promote better care coordination, case management, and linkages to services⁴ for young children. The many and varied responses to this scan may help state policy makers become more aware of the potential resources and tools available to promote healthy development for young children and can provide states with strategies to more effectively coordinate resources and achieve better outcomes for their children.

METHODOLOGY

The state scan was guided by an advisory committee comprised of program directors from state Medicaid, Maternal and Child Health (Title V), and Early Intervention (Part C of IDEA; hereinafter Part C) agencies, as well as pediatric primary healthcare providers and other experts in child health and development. After pilot testing, the finalized scan was sent to all states, American Samoa, and Puerto Rico, and addressed to state Medicaid directors, state Title V directors, and Part C directors. NASHP chose these agencies because each has the potential to set policies that may influence the development of young children. State responses have been compiled and summarized, and are available at NASHP’s ABCD RFP website: http://abcd.nashpforums.org/sites/abcd.nashpforums.org/files/temp/ABCDIII_raw_data.xls

Design and limitations of the scan: The scan was intended to be a multiple choice review that could be completed quickly and would provide NASHP and the advisory committee with a timely overview of what actions states are taking to promote healthcare and community linkages for young children with or at risk of developmental delay. The quantity of data received, including extensive narrative information in addition to check-off questions, was unexpected, and this brief is a summary of this enthusiastic response.

The scan was designed to elicit strategies used by the three state agencies to improve healthcare and community linkages in three areas: within primary care practices; between primary care practices and other child and family service providers; and through systems or statewide strategies. Since Medicaid, Title V, and Part C have different resources and responsibilities, we provided each type of agency with a set of predefined strategies that each was likely to use. The scan was designed to produce a snapshot of activity within the state as a whole—not to compare activity across agencies within a state. NASHP did not seek to verify information, either for consistency within states or for accuracy. The information has been gathered and analyzed according to what might be useful for states as they contemplate further initiatives to coordinate care for young children.

SURVEY RESPONDENTS

43 states and two territories responded⁵, including 26 Medicaid agencies, 22 Title V agencies, and 20 Part C agencies. 18 states sent back more than one response.

TABLE 1: SCAN RESPONDENTS BY STATE AND AGENCY

State	Medicaid	Early Intervention	Title V	State	Medicaid	Early Intervention	Title V
Alabama	•	•	•	Montana		•	
Alaska			•	North Carolina		•	
American Samoa			•	North Dakota		•	
Arizona	•			Nebraska			•
Arkansas	•		•	Nevada	•	•	
California	•		•	New Hampshire		•	
Colorado	•	•		New Jersey			•
Connecticut		•		New Mexico			•
Delaware	•	•	•	New York	•	•	•
District of Columbia	•		•	Ohio	•	•	
Florida	•		•	Oklahoma	•		•

TABLE 1: SCAN RESPONDENTS BY STATE AND AGENCY (CONTINUED)

State	Medicaid	Early Intervention	Title V	State	Medicaid	Early Intervention	Title V
Georgia			•	Oregon	•	•	
Hawai'i	•	•	•	Pennsylvania	•		
Idaho				Puerto Rico	•		
Illinois				Rhode Island		•	
Indiana				South Carolina	•		
Iowa	•			South Dakota			
Kansas			•	Tennessee	•		
Kentucky			•	Texas			•
Louisiana		•		Utah	•	•	
Maine				Vermont			
Maryland	•		•	Virginia	•	•	•
Massachusetts	•			Washington	•		•
Michigan			•	West Virginia		•	
Minnesota		•		Wisconsin			
Mississippi	•			Wyoming			
Missouri	•	•		Total (n=45)	26	20	22

SIGNIFICANT FINDINGS

States are clearly engaged and allocating time and resources to reducing service system fragmentation in the pursuit of healthy development for young children. A total of 68 distinct agencies in 43 states, Puerto Rico and American Samoa (a total of 45 state and territorial entities) responded to the scan. All respondents reported some activity aimed at improving or addressing care coordination, case management and linkage issues for young children. Many reported ongoing work in more than one state agency (Medicaid, Part C, Title V) to address healthcare and community linkages for young children.

States reported a diverse array of strategies, including inter-agency agreements to improve coordination across systems and co-location, and fax-back policies to promote communication between pediatric primary healthcare providers and other child and family service providers. There were, however, many common themes in the responses, and these are explored here.

STATES ARE WORKING TO IMPROVE LINKAGES AT THE PRIMARY CARE, SERVICE PROVIDER, AND SYSTEM-WIDE LEVELS

The scan asked states to identify their linkage activities in the following three categories:

- **primary care strategies** that transform the way pediatric primary healthcare practices are organized to deliver care;
- **service provider partnership strategies** that strengthen relationships between pediatric primary healthcare and other child and family service providers; and
- **systems change and cross-system strategies** that enhance or transform operations between health and other service systems at the state level.

Responses indicate that all three strategy categories are in use by states, with many states involved in more than one strategy area. (See Figure 1, next page)

STATES ARE USING THE MEDICAL HOME MODEL AS A STRATEGY TO IMPROVE LINKAGES IN PRIMARY CARE

The medical home model emerged from the state scan as one of the most commonly used strategies in the primary care setting to improve linkages for young children. Medicaid and/or Title V agencies in 25 states and Puerto Rico reported that they are currently implementing or plan to implement medical homes or medical home pilots to improve linkages (Table 2). Part C directors were not asked about medical home efforts.

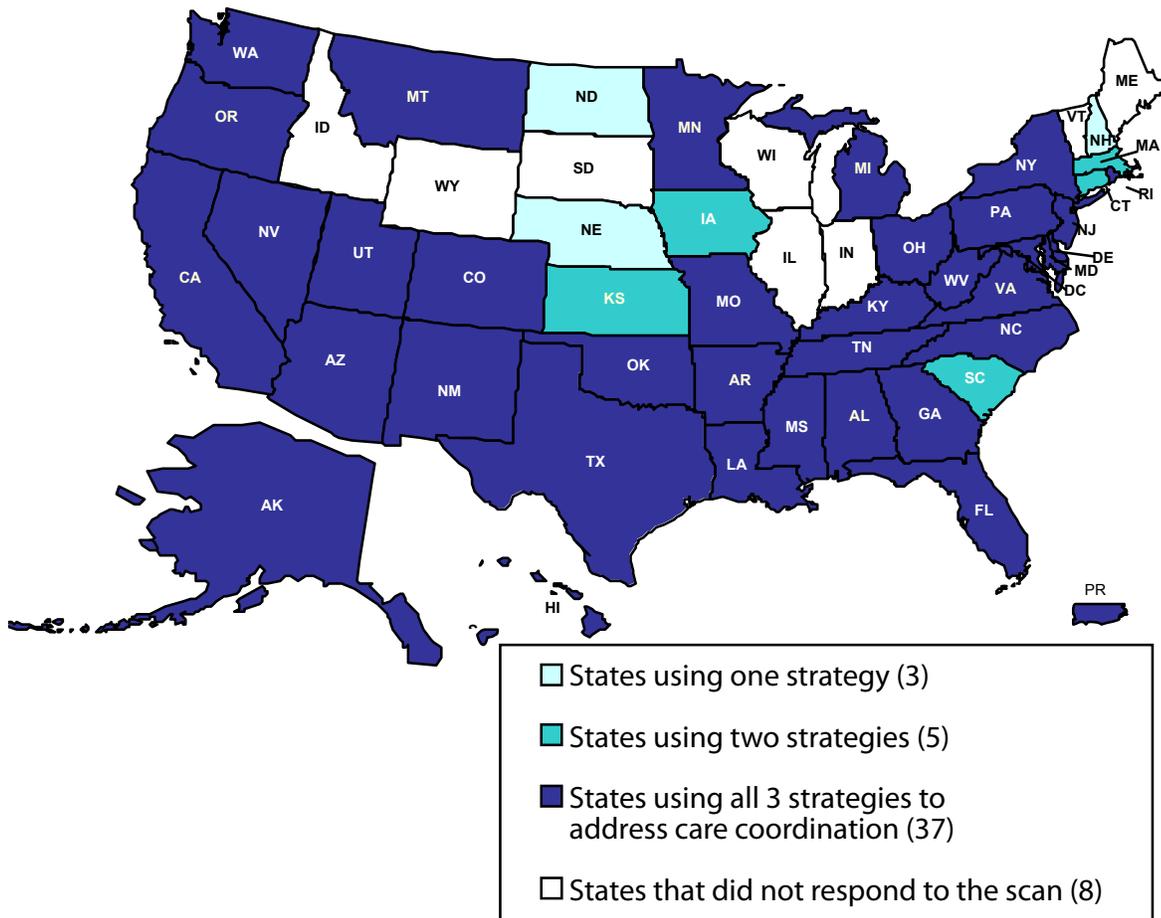
TABLE 2: STATES REPORTING USE OF THE MEDICAL HOME STRATEGY TO IMPROVE LINKAGES FOR CHILDREN, BY AGENCY⁶

States	Medicaid (n=26)	Title V (n=22)	States	Medicaid (n=26)	Title V (n=22)
Alabama	•		Missouri	•	NR
Alaska	NR		Nevada	•	NR
American Samoa	NR		New Jersey	NR	•
Arkansas	•		New Mexico	NR	•

TABLE 2 (CONTINUED): STATES REPORTING USE OF THE MEDICAL HOME STRATEGY TO IMPROVE LINKAGES FOR CHILDREN, BY AGENCY⁶

Arizona	•	NR	New York	•	•
Colorado	•	NR	Ohio	•	NR
Delaware	•	•	Oklahoma	•	•
District of Columbia		•	Oregon		NR
Florida		•	Pennsylvania		NR
Georgia	NR	•	Puerto Rico	•	NR
Hawaii		•	South Carolina	•	NR
Iowa		NR	Tennessee	•	NR
Kansas	NR	•	Texas	NR	•
Kentucky	NR		Utah		NR
Maryland			Virginia		
Massachusetts	•	NR	Washington	•	•
Michigan	NR	•	total	16	13
Mississippi	•	NR			

NR: state agency did not return a response to the scan

FIGURE 1: THE MAJORITY OF STATES RESPONDING TO THE SCAN ARE USING A COMBINATION OF PRIMARY CARE, SERVICE PROVIDER PARTNERSHIP, AND SYSTEMS CHANGE OR STATEWIDE STRATEGIES TO ADDRESS LINKAGES FOR CHILDREN

The medical home model for pediatric primary care, first advanced by the AAP in the 1960s as a way to provide continuous and coordinated care to children with special healthcare needs, has since been applied to a broader range of patients of all ages and care levels. States may differ on what they mean by the term “medical home.” According to the AAP, a medical home should be “accessible, continuous, comprehensive, family centered, coordinated, and compassionate.” In addition, the medical home should provide the following services:

- Provision of preventive care including, but not restricted to, immunizations, growth and development assessments, appropriate screening, healthcare supervision, and patient and parental counseling about health and psychosocial issues.
- Assurance of ambulatory and inpatient care for acute illnesses, 24 hours a day, 7 days a week, 52 weeks a year.
- Provision of care over an extended period of time to enhance continuity.
- Identification of the need for subspecialty consultation and referrals and knowing from whom and where these can be obtained.⁷

There has also been much recent state activity to support the medical home as defined in the “Joint Principles of the Patient-centered Medical Home.” In 2007, the four major associations representing primary care physicians (American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians, and American Osteopathic Association) jointly developed this common definition, which stresses core components including a personal physician, a physician-directed medical practice, a whole person orientation, and coordinated and/or integrated care.⁸

Because the scan was intended to provide a snapshot of state activities in broad terms, states were not queried as to how they interpret and implement the term “medical home.” The following sample responses provide some illustration of how states are using the medical home concept to advance healthcare and community linkages for young children:

- **Alabama** Medicaid uses the medical home model to better coordinate care for young children. Primary healthcare providers who agree to become medical home providers sign a participation agreement with a graduated per member per month payment schedule supporting medical home activities. Primary healthcare providers are trained how to establish and maintain a medical home for patients. A referral process ensures coordination of services across agency and provider lines.
- **Colorado’s** medical home model emphasizes a personal healthcare provider, a whole-person orientation, delivery within the context of family and community, and coordinated care across providers, conditions, and settings. Providers seeking the medical home designation must work with Colorado’s Assuring Better Child Health and Development (ABCD) program. Follow-up training is provided to practices on coding and billing to better incorporate the ABCD work into the daily life of the practice. The Colorado Department of Health Care Policy and Financing also monitors provider billing. This partnership has increased the use of code 96110 (developmental testing, limited) by 7000 percent in the nine months leading up to the scan.
- **Michigan** was selected to be part of the National Initiative for Children’s Healthcare Quality (NICHQ) Medical Home Learning Collaborative, a fifteen-month project to improve care for the growing population of children with special health needs. This initiative focuses on three practices in the state and assists them in completing a quality improvement process to provide medical homes to their patients with special needs. It also assists in building the capacity of Children’s Special Health Care Services

and other Michigan Health Department programs to support and extend this approach after the completion of the project.

STATES ARE USING A WIDE VARIETY OF SERVICE PROVIDER PARTNERSHIP STRATEGIES, ACROSS ALL THREE AGENCIES, TO ADDRESS LINKAGES

Since it is difficult to create connection and communication between providers, states frequently turn to service provider partnership strategies to address these challenges. Many states already have various linkage tools in place as a result of EPSDT, Part C, and Title V requirements, and they report using these tools to further improve the connection between pediatric primary healthcare providers and other child and family service providers (Table 3).

TABLE 3: PROVIDER PARTNERSHIP STRATEGIES USED BY AGENCIES THAT RESPONDED TO THE SCAN, BY AGENCY

Service Provider Strategies	Any responding agency in a state (n=45)		Medicaid agencies (n=26)		Title V agencies (n=22)		Part C agencies (n=20)	
	#	%	#	%	#	%	#	%
Adopted policies that facilitate reports back to pediatric providers from referral agencies.	26	58%	7	27%	12	55%	15	75%
Supported child care health and mental health consultants	24	53%	8	31%	11	50%	8	40%
Provided direct care coordination services	19	42%	NA		12	55%	8	40%
Developed provider training/technical assistance for information on referral agencies	18	40%	10	38%	13	59%	NA	
Financially supported co-location of community-based referral resources	16	36%	2	8%	8	36%	6	30%
Developed outreach to pediatric primary health care providers to inform them of Part C services	15	33%	NA		NA		15	80%
Developed hotlines to obtain information on referral agencies	14	31%	3	12%	7	32%	7	35%
Developed payment mechanisms	14	31%	NA		10	45%	7	35%
Used EPSDT outreach staff to assist providers and families in completing referrals	14	31%	12	46%	2	9%	NA	
Incorporated pediatric primary health care provider participation into early intervention individualized family service plans (IFSPs)	12	27%	3	12%	NA		11	55%
Developed ongoing advisory committees	11	24%	11	38%	NA		NA	
Made provisions for serving children who are found to be at risk but ineligible for Part C services	10	22%	5	19%	NA		6	30%
Contracted with public health programs for care coordination assistance	10	22%	10	38%	NA		NA	
Helped link Part C providers with pediatric primary health care providers in their service areas	10	22%	NA		NA		10	50%
Developed follow-up policies for children deemed not eligible for Part C services	9	20%	NA		NA		9	45%
Developed centralized referral systems	8	18%	6	23%	3	14%	NA	

TABLE 3 (CONTINUED): PROVIDER PARTNERSHIP STRATEGIES USED BY AGENCIES THAT RESPONDED TO THE SCAN, BY AGENCY

Service Provider Strategies	Any responding agency in a state (n=45)		Medicaid agencies (n=26)		Title V agencies (n=22)		Part C agencies (n=20)	
	#	%	#	%	#	%	#	%
Offered professional development for Part C service providers	7	16%	NA		NA		7	35%
Developed community or statewide registries of children served that link to other community or statewide data bases	5	11%	NA		NA		5	30%
Other	10	22%	5	19%	3	14%	4	20%

NA: Agency was not presented with this option on the scan.

Examples from Oklahoma, Ohio, and Florida illustrate the diversity of these service provider partnership strategies:

- **Care Management:** **Oklahoma** Medicaid's Care Management Department is comprised of Registered Nurses, Licensed Practical Nurses and Behavioral Health Specialists. These health professionals assist in coordinating medical services for Medicaid clients who need specialty care and provide ongoing care management services for children with complex medical conditions.
- **Provider Training and Technical Assistance:** **Ohio** provides training for pediatric and family medicine practices on general developmental and autism screening and care improvement. A learning collaborative includes monthly conference calls to assist practices in implementing structured screening and quality improvement in their practices. Among the training materials is the Physician Referral Tool Kit, which has a universal referral form based on the national AAP referral form template, and a checklist of community providers and services.
- **Co-location:** **Florida's** Title V Children with Special Health Care Needs Program supports the co-location of mental health providers within some pediatric practices, and has an interagency agreement with the children's mental health agency to offer assessment and intervention services for children with behavioral/mental health issues.

STATES MOST FREQUENTLY REPORTED EMPLOYING FAX OR REPORT-BACK POLICIES TO FORGE BETTER SERVICE PROVIDER PARTNERSHIPS

Pediatric primary healthcare providers may not be aware of all the resources available for young children with or at risk of developmental delay, and therefore may not appropriately refer families. But even when families do receive appropriate referrals, these referrals may not be completed. Barriers to successful referrals may include language difficulties or concerns about cost that may prevent the family from calling for the recommended appointment, lack of transportation or child care, and lack of consistent communication pathways between the referring physician and the community provider that can prevent important health information from being shared.

States are working to address these basic yet complex coordination and linkage issues through variations on report-back or fax-back policies intended to standardize communication between providers and facilitate successful referral.

- **Hawaii** utilizes a Central Point of Contact for referrals to Part C (called HI Keiki Information Service System or H-KISS). All referrals for Part C services go through the H-KISS system. After a pediatric primary healthcare physician or other service provider makes a referral for early intervention services, they receive a letter thanking them for the referral and information as to which early intervention program the family was referred. This information is given to the referring provider.
- **Virginia** uses a referral and consent form (http://www.abcdresources.org/get_file.php?file_id=394) to initiate referrals from pediatric primary healthcare providers to community referral resources. This form assures that referrals are completed, provides feedback from community referral resources to pediatric primary healthcare providers and helps integrate information received back from referral resources into ongoing care.

SYSTEMS CHANGE OR CROSS-SYSTEMS STRATEGIES INVOLVE HIT, DATA AND INFORMATION SYSTEMS, AND CROSS-AGENCY PLANNING

States are looking to technology to enhance healthcare and community linkages. Within the pediatric practice, the use of electronic medical records is being encouraged. Across service provider systems, shared databases and other information technologies are being developed. Fifty-eight percent of responding Medicaid agencies reported that they are promoting healthcare and community linkages through the use of electronic medical records and health information technology, while slightly more than half of the states reported the implementation of data and information-sharing strategies. Additionally, 20 states reported that they are working to establish better coordination and partnering among child-serving agencies in state government as a systems level strategy.

TABLE 4: COMMUNITY STRATEGIES USED BY AGENCIES THAT RESPONDED TO THE SCAN, BY AGENCY

Community strategies to support care coordination	Any responding agency in a state (n=45)		Medicaid agencies (n=26)		Title V agencies (n=22)		Part C agencies (n=20)	
	#	%	#	%	#	%	#	%
Implemented data and information sharing strategies	25	56%	14	54%	10	45%	8	40%
Improved coordinated care planning across state agencies	20	44%	10	38%	12	55%	9	45%
Supported electronic medical records and health information technology	15	33%	15	58%	NA		NA	
Adopted common definitions of special needs or special risks	13	29%	5	19%	6	27%	5	25%
Conducted surveys on care coordination	13	29%	5	19%	7	32%	4	20%
Supported shared care planning	7	16%	NA		NA		7	35%
Developed uniform standards for care management plans	5	11%	5	19%	NA		NA	
Expanded the MCH toll-free phone line to promote coordination of resources	3	7%	NA		3	14%	NA	
Other	10	22%	3	12%	5	23%	3	15%

NA: Agency was not presented with this option on the scan.

States are looking at ways to use new or existing health information strategies to share information across systems:

- **Shared databases:** The **New York** State Early Intervention Program maintains an information management

system for children in the program. New York matches data at the aggregate level between the state's Part C information system and other statewide databases that include lead screening, congenital malformations, newborn screening, and other health information, to identify ways to improve local referral, follow-up, and treatment practices.

- **Connections to primary care:** **Utah** is working on an IT data-sharing project to connect primary healthcare providers to information from various Health Department programs. When the program is fully implemented, the primary healthcare care provider will be able to connect to a database that will provide information on the disposition of referrals and other early intervention information.

In addition to health information technology strategies, states are also working at the system-wide level to establish formal and informal agreements among their agencies to support local implementation of health-care linkage strategies.

- **Florida's** Department of Children and Families, the Department of Health, the Agency for Persons with Disabilities, and other state entities signed a memorandum of understanding (MOU) that formalizes interagency collaborations at the local level through Local Review Teams. The MOU was developed to better serve children who need services from more than one agency or system, and supports a "champion" for those children in need of cross-agency coordination.
- **Minnesota's** Local Interagency Early Intervention Committees mirror the state Interagency Coordinating Council. Committees must include representatives of local health, education, and county human service agencies, county boards, school boards, early childhood family education programs, Head Start, parents of children under age 12 with disabilities, child care resource and referral agencies, school readiness programs, current service providers, and may include representatives from other private or public agencies and school nurses. The committees are charged with coordinating a comprehensive service array at the local level across agencies.

STATE MEDICAID, TITLE V, AND PART C AGENCIES ARE USING AVAILABLE TOOLS TO PROMOTE LINKAGES FOR CHILDREN IN A VARIETY OF WAYS

Medicaid, Title V and Part C, while all engaged in promoting the healthy development of young children, have different program objectives and focus on distinct, if interconnected areas. How these state agencies approach the challenge of coordinating care across systems differs, but with significant overlap. States are using the varied expertise and resources of these programs to coordinate care for young children.

TABLE 5: MOST FREQUENTLY REPORTED STRATEGIES FOR IMPROVING CARE COORDINATION, BY AGENCY

Effort focuses on:	Strategy	Agencies reporting use of strategy	
		Number	Percent
Medicaid agencies (N=26)			
Primary Care	Developed and monitored performance standards	16	62%
Primary Care	Initiated a medical home strategy that supports care coordination	16	62%
Community or system-wide	Supported electronic medical records and health information technology	15	58%
Primary Care	Assessed quality and/or implemented quality improvement initiatives	15	58%
Primary Care	Developed payment mechanisms	15	58%

TABLE 5 (CONTINUED): MOST FREQUENTLY REPORTED STRATEGIES FOR IMPROVING CARE COORDINATION, BY AGENCY

Community or system-wide	Implemented data and information sharing strategies	14	54%
Title V agencies (N=22)			
Primary Care	Initiated a medical home strategy that supports care coordination	13	59%
Service Provider Partnerships	Developed provider training/technical assistance for information on referral agencies	13	59%
Community or system-wide	Improved coordinated care planning across state agencies	12	55%
Primary Care	Developed universal referral or consent forms	12	55%
Service Provider Partnerships	Adopted policies that facilitate reports back to pediatric providers from referral agencies.	12	55%
Service Provider Partnerships	Provided direct care coordination services	12	55%
Part C agencies (N=20)			
Service Provider Partnerships	Adopted policies that facilitate reports back to pediatric providers from referral agencies.	15	75%
Service Provider Partnerships	Developed outreach to pediatric primary health care providers to inform them of Part C services	15	80%
Service Provider Partnerships	Incorporated pediatric primary health care provider participation into early intervention individualized family service plans (IFSPs)	11	55%

MEDICAID FAVORS PRIMARY CARE STRATEGIES TO SUPPORT HEALTHCARE AND COMMUNITY LINKAGES

Medicaid is one of the largest payers of medical services for young children.⁹ Through the Early Periodic Screening Diagnosis and Treatment (EPSDT) program, state Medicaid agencies play a major role in the policy and financing of children's primary health care.¹⁰ State Medicaid agencies use this important payer position to strengthen care coordination, particularly at the practice level, through strategies including the medical home model, quality improvement and performance standards, and the use of electronic medical health records.

Medicaid	
Most frequently reported strategies to improve linkages	
Developed and monitored performance standards	Initiated a medical home strategy that supports care coordination

In addition to medical home initiatives discussed earlier, state Medicaid agencies frequently use performance standards and quality improvement tools, often implemented through managed care contracts, to measure and improve referral and care coordination practices. For example:

- **Maryland:** As part of the EPSDT Program (MD Healthy Kids), providers are monitored through medical record reviews for compliance with preventive care delivery standards, including developmental and mental health assessments.

Where a provider suspects or diagnoses a problem, referrals for appropriate services are also monitored by the MD Healthy Kids Program. MCO performance in the area of developmental and mental health assessments are monitored by an External Quality Review Organization using the same standards established and used by the MD Healthy Kids Program.

- **Ohio:** The Ohio Department of Job and Family Services requires managed care plans to have a Quality Assessment and Performance Improvement Program to address coordination of care. This plan is reviewed and approved annually.

TITLE V PROGRAMS FOCUS ON COMMUNICATION, OUTREACH, AND OTHER CROSS-PROVIDER CONNECTIONS

Title V is a state/federal partnership that provides block grants to fund state maternal and child health efforts. Title V programs are required to work with other state/federal programs—such as the Medicaid EPSDT benefit—to coordinate care and provide outreach to families with children. In describing the interrelated roles of Title V and Medicaid, one HRSA publication states: “One of Medicaid’s critical roles is to provide financial coverage for important preventive and primary care services and specialty services

Title V Most frequently reported strategies to improve linkages	
Initiated a medical home strategy that supports care coordination	Developed provider training/technical assistance for information on referral agencies

for those eligible; Title V is essential to help translate those funds into a system of care that is accessible.”¹¹ As a result, common care coordination efforts of state Title V programs involve making connections and working with Medicaid to facilitate access. Data from the scan also shows that Title V agencies play a key role in educating providers, especially those who serve Medicaid beneficiaries.

- **New Jersey’s** Title V program collaborated with the New Jersey Academy of Pediatrics and their Pediatric Council on Research and Education (PCORE) to develop a medical home teaching module. Content includes training on the appropriate referral of children to community-based resources and covers topics such as children with special health needs, case management, and early intervention services.

- The **Oklahoma** University Child Study Center’s State Implementation Grant for Integrated Community Systems for Children and Youth with Special Health Care Needs supports implementation of a medical home in primary care practices by providing a practice improvement facilitator to help primary care providers as they implement medical home concepts. Much of this work focuses on establishing evidence-based screening and referral procedures.
- **Florida’s** Title V program uses the Bright Futures curriculum in its primary care training. Bright Futures is a national initiative spearheaded by the American Academy of Pediatricians. The project has resulted in a series of materials, toolkits, and guidelines—now in its third edition—that are developmentally focused and designed for use in a number of child health settings.¹²

PART C AGENCIES WORK CLOSELY WITH PRIMARY CARE TO BETTER COORDINATE SERVICES

Part C of IDEA provides an entitlement for children from birth to age three who have or have a high probability of developmental delays. In order to receive federal funding, states must have Part C plans in place

Part C: Most frequently reported strategies to improve linkages	
Adopted policies that facilitate reports back to pediatric providers from referral agencies.	Developed outreach to pediatric primary health care providers to inform them of Part C services

that adhere to specific federal requirements. These requirements, such as a comprehensive Child Find system to locate, assess and refer children, a centralized directory of services, training for primary referral sources, and development of interagency agreements, are well-suited to promote healthcare and community linkages for young children with or at risk for developmental delays. State Part C agencies most frequently focus their efforts to improve linkages on bettering the flow of

information between Part C providers and primary care providers.

- **New York's** municipalities are responsible for the administration of its Early Intervention Program. Municipalities are engaged in outreach with hospitals, community health centers, and pediatric primary healthcare providers to inform them of the Early Intervention Program, promote developmental screening and developmental surveillance in pediatric practices, and ensure that children are referred for early intervention services when concerns about development arise. The New York State Department of Health supports these activities through training on six evidence-based guidelines for providers, parents, and primary referral sources¹³. DOH also sponsors training on the Early Intervention Program, specifically targeting healthcare providers, with activities such as grand round sessions on developmental disabilities and the importance of early intervention.
- **West Virginia** Part C programs coordinate with Health Check- EPSDT Program Specialists to ensure that all EPSDT providers are knowledgeable about Part C (West Virginia's Birth to Three Program) and know when and how to make referral.
- **Ohio** has developed a referral follow-up form that must be sent to the referring provider within a required time frame.

SCAN RESPONSES INDICATE THAT CERTAIN STRATEGIES MAY REPRESENT UNDERUTILIZED RESOURCES FOR STATES

Many of the care coordination strategies outlined in the NASHP scan are complicated undertakings that can involve the development of new service delivery models, or require complex funding arrangements. Co-location, for example, is a strategy that very few states are currently employing to improve healthcare linkages for young children, perhaps due in part to the complexity of individual practice and funding requirements. In contrast, other strategies may be more readily implemented, since they involve adapting or expanding existing resources to achieve more effective linkages across systems.

Expansion of Maternal Child Health Hotlines

All states participate in the Title V program, and since 1989, Title V regulations require state programs to include a toll-free number for parents seeking information on maternal and child health and related concerns. A 2004 report supported by The Commonwealth Fund found that 41 percent of states supplement Title V funding for these hotlines with other state funds, including funds from Medicaid, SCHIP, and Part C¹⁴. Joint funding notwithstanding, only three states (**New York, Oklahoma, and Washington**) report that they have expanded these toll free lines to promote care coordination. **Hawaii** uses its Part C information system (HKISS) as both a parent information resource and a centralized referral mechanism for

pediatricians and other service providers. This could serve as a model for other states in expanding MCH hotlines to support care coordination.

Electronic or web-based referral strategies

Most state are using web-based technology to provide information to Medicaid recipients, explain benefits, promote public health messages, and alert citizens to programs available through state agencies. However, only a few states are making use of their web capacity specifically to promote better care coordination across state agency or provider sectors. Of responding states, only six report they are currently using web-based technology, in particular through Part C programs, to promote care coordination for young children. For example:

- **Missouri:** Primary referral sources (including primary health care providers) can enter referrals into the Missouri Early Intervention program online. The referral is automatically routed to the System Point of Entry (SPOE) office based on the zip code of the child/family.
- **Oklahoma:** Through a toll-free phone line and website, the Oklahoma Area-wide Services Information System (OASIS) provides information, referral and assistance to Oklahomans, including families with young children with disabilities and special health care needs. The service maintains a large resource directory that includes available community services around the state and is accessible to providers as well as families.

DESPITE THIS MYRIAD OF EFFORTS, BARRIERS REMAIN

States are clearly working on many different fronts, using many different resources, to overcome barriers to healthy early childhood development caused by insufficient healthcare and community linkages. Notwithstanding the many and varied initiatives identified through this scan, states also cite numerous and consistent barriers that challenge state policy makers as they try to improve the referral and service system for young children with or at risk of developmental delay.

TABLE 6: BARRIERS TO CARE COORDINATION REPORTED BY RESPONDING STATES

Barriers identified by state agencies	Number of responding states reporting barrier (n=44)
Funding/resources/reimbursement	17
Fragmentation/silos in funding, rules, eligibility, communication across responsible agencies	14
Workforce issues: caseloads, scarcity of providers	12
Lack of comprehensive system/care coordination/Part C partner	11
CMS regulations	11
Lack of communication/understanding of PCP community/provider training	10
Lack of good data-sharing data across systems	8
HIPAA/FERPA	8
Unclear service responsibility between acute care health plans and behavioral health plans.	4

Transportation	3
Administrative burdens	3
Transition to other systems	2
Lack of referral resources	2

States report the lack of resources makes it difficult for providers to engage in necessary healthcare linkage activities. Other major barriers include the challenges of siloed funding, regulations, and communication throughout state agencies. States also report that working through the intricacies of the Health Insurance Portability and Accountability Act (HIPAA) and the Family Education Rights and Privacy Act (FERPA), both of which include restrictions on sharing health information between providers and across systems, presents its own challenges. Respondents noted:

- “Currently, the greatest barrier to care coordination and communication is lack of sufficient funding to fully support the medical home and comprehensive care coordination.”
- “Because there are many agencies involved in the provision of services for children, communication is difficult and we don’t seem to be working in coordination with one another.”
- “The biggest barriers to comprehensive system-building for children lie in the fragmented nature of reimbursement and grant systems to fund services, and the ‘siloed’ aspects of governmental programs.”

SUMMARY

The deficiency in healthcare and community linkages for young children with or at risk of developmental delay has been identified by states as an issue requiring state attention and intervention. The majority of states are actively pursuing strategies that promote better coordination and communication across systems for young children and their families, and they are working in the primary care setting, among providers, and at the systems and statewide level to address these challenges.

States are using the existing resources of Medicaid, Title V, and Part C programs to promote linkages in the arenas typically served by these programs. State Medicaid agencies tend to focus on primary care, using the medical home model and managed care contracting components such as performance standards and quality improvement initiatives. Title V agencies report a focus on outreach and other community-based efforts, and Part C agencies similarly focus on bringing critical information into the pediatric practice from community-based resources.

States reported few efforts that build on existing Maternal Child Health hotlines – an area that may represent an underutilized resource that some states may want to add to their care coordination strategies. In addition, states reported surprisingly few web-based referral strategies, which, given the many states that have well-developed web capacity, may be another care coordination improvement that presents a low barrier option for states.

Finally, states acknowledge that barriers remain in addressing healthy child development through better healthcare and community linkages. Funding and reimbursement mechanisms are inadequate, communication and data barriers exist, and siloed infrastructure prevents community resources from effectively addressing children's development and health needs in a coordinated way. Planning and implementation of new state initiatives to improve development and health outcomes for young children through better linkages should anticipate these barriers. Programs may want to explicitly address these common challenges at the outset, and describe how they will be managed through program design.

However, the breadth of activity revealed through this scan indicates that states do not view existing barriers as insurmountable. States are working within and across their Medicaid, Title V, and Part C agencies to improve healthcare and community linkages so that young children with or at risk of developmental delay can better access the resources they need.

ENDNOTES

- 1 Medicaid is a state and federally-funded health care program, administered by states, that provides health insurance for low income and disabled adults and children. For a brief overview of the Medicaid program and links to additional information, see: <http://www.cms.hhs.gov/Medicaidgeninfo/>
- 2 Title V of the Social Security Act created the Maternal and Child Health Bureau of the U.S. Department of Health and Human Services. The Bureau, in partnership with Maternal and Child Health agencies in all fifty states, administers the Title V program. Title V focuses on improving the health, safety, and well-being of mothers and children through public health and direct service programs. For more information on Title V, see <http://ftp.hrsa.gov/mchb/titlevtoday/UnderstandingTitleV.pdf>
- 3 The Program for Infants and Toddlers with Disabilities (Part C of IDEA) is the federal grant program that works with states to offer a comprehensive set of intervention programs and services for young children, birth through 2. For further information on Part C, see <http://idea.ed.gov/explore/view/p/.root,statute,I,C>,
- 4 The terms “care coordination” case management” and “linkages” have been variously defined, and can often have distinct meanings and usages. For simplicity’s sake, this paper will use the term “healthcare and community linkages” to signify all three activities.
- 5 Hereinafter, the word “states” is used to mean both the states and the territories that responded to the scan.
- 6 The scan did not offer Part C agencies ‘use of medical home’ as a defined choice. Therefore that agency is not included in table 2.
- 7 <http://pediatrics.aappublications.org/cgi/content/abstract/90/5/774>
- 8 <http://www.pcpcc.net/content/joint-principles-patient-centered-medical-home> ; a recent NASHP paper also discusses this topic in depth and can be found at: http://www.nashp.org/_docdisp_page.cfm?LID=980882B8-1085-4B10-B72C136F53C90DFB
- 9 http://www.kff.org/uninsured/upload/7698_02.pdf
- 10 “The Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) service is Medicaid’s comprehensive and preventive child health program for individuals under the age of 21 . EPSDT was defined by law as part of the Omnibus Budget Reconciliation Act of 1989 (OBRA ‘89) legislation and includes periodic screening, vision, dental, and hearing services. In addition, Section 1905(r)(5) of the Social Security Act (the Act) requires that any medically necessary health care service listed at Section 1905(a) of the Act be provided to an EPSDT recipient even if the service is not available under the State’s Medicaid plan to the rest of the Medicaid population.” From: <http://www.cms.hhs.gov/medicaidearlyperiodicscrn/>
- 11 ftp://ftp.hrsa.gov/mchb/IAA/B_State_MCH_Medicaid_Chapter1.pdf
- 12 More information on Bright Futures can be found at <http://brightfutures.aap.org/faqs.html>
- 13 http://www.health.state.ny.us/community/infants_children/early_intervention/memoranda.htm
- 14 http://www.amchp.org/publications/ChildrensHealth/Documents/787_Booth_dialing_for_help_issue_brief.pdf