

IMPROVING CARE COORDINATION,  
CASE MANAGEMENT, AND LINKAGES  
TO SERVICE FOR YOUNG CHILDREN:  
OPPORTUNITIES FOR STATES

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— APRIL 2009 —



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## EXECUTIVE SUMMARY

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**A**s pediatric primary health care providers increase appropriate developmental screening and early identification of developmental delays in young children, the weak linkages among providers of services to children and families become increasingly apparent. Young children often fall through the cracks between pediatric primary health care providers and providers of mental health, early intervention, child welfare, and early care and education services.

Currently, there is a call for better linkages that support families in securing appropriate care and services. Five major types of barriers limit these linkages:

- Constraints on primary care provider capacity to refer to and link to other community resources;
- Inadequate service capacity for early childhood developmental and mental health services;
- Gaps between programs and service delivery systems, including eligibility criteria;
- Insufficient payment/financing for time spent in referral and coordination efforts; and
- Different practice cultures and customs.

States can play an important role in removing barriers and providing support as communities move toward more integrated services. Federal programs can support state efforts to improve linkages. Medicaid, through its Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program; Children's Health Insurance Programs (CHIP); Title V Maternal and Child Health and Children with Special Health Care Needs programs; and programs implemented under the Individuals with Disabilities Act (IDEA), especially Part C Early Intervention Programs, provide a way to finance care coordination/case management (CC/CM) for health and related services.

Strategies to improve CC/CM and strengthen linkages include primary care practice-based strategies, service provider linkage strategies, and systems change and cross-system strategies. This report uses a framework that illustrates the intersection between these three levels and the various roles states can play to facilitate and support CC/CM and linkages as illustrated in Table 1.

States can review existing policies of key programs to identify barriers and opportunities for improvement. In particular, review of case management/care coordination rules and payments is critical. This paper provides key questions for reviewing state policies and financing strategies that support cross-system linkages and care coordination/case management (C/CM). Areas for action within each of the state's fiscal and administrative support roles are provided.

**TABLE 1: LINKAGE AND CC/CM STRATEGIES TO PROMOTE COORDINATION BETWEEN MEDICAL PROVIDERS AND COMMUNITY REFERRAL AND RESOURCE AGENCIES**

	<b>Primary care practice-based strategies</b>	<b>Service provider linkage strategies</b>	<b>Systems change and cross-system strategies</b>
<b>Role of State Fiscal and Administrative Support</b>	<i>Strategies that transform the way pediatric primary care practices are organized to deliver care</i>	<i>Strategies that strengthen relationships between pediatric primary care and other providers</i>	<i>Strategies that enhance or transform operations between health and other service systems at state level</i>
<b>Support for strategies that maximize use of personnel in linkages and CC/CM</b>	<ul style="list-style-type: none"> <li>• Medical homes that use care planning and care coordination approaches.</li> <li>• Staff assigned to assure referrals and linkages, including onsite care coordinators.</li> </ul>	<ul style="list-style-type: none"> <li>• Community-based staff that assist providers and families in completing referrals and linkages.</li> <li>• Co-location of primary health care and other service providers (e.g., child development, social work, mental health).</li> <li>• Resource and referral strategies to help medical providers and families learn about/link to resources, including parent-to-parent approaches.</li> </ul>	<ul style="list-style-type: none"> <li>• Care coordination utilities that operate across a state (e.g., EPSDT coordinators statewide, coordination networks).</li> <li>• New structures to organize CC/CM personnel and programs (e.g., public health nurses, community social workers, MCO staff, CSHCN coordinators).</li> <li>• Health and mental health consultants in early care and education programs who provide referral and linkages to other providers.</li> </ul>
<b>Support for quality improvement initiatives and other mechanisms for assuring and monitoring quality</b>	<ul style="list-style-type: none"> <li>• Quality improvement efforts within clinical practice settings which can address gaps in knowledge and behavior (e.g., introduce new tools, quality measurement).</li> </ul>	<ul style="list-style-type: none"> <li>• Quality improvement initiatives that engage networks of providers in measuring and changing performance.</li> <li>• Monitor and provide incentives for quality of care coordination, including completion of referrals, care plans, etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Shared or common standards, definitions, and protocols across systems (e.g., common referral forms, shared definitions of special needs or special risks).</li> <li>• Public-private payer quality initiatives.</li> <li>• Cross-system professional training.</li> </ul>
<b>Support for data, information, and technology that facilitates linkages and communication among families and providers</b>	<ul style="list-style-type: none"> <li>• Adoption of technology such as electronic medical records that facilitate linkages and CC/CM</li> <li>• Practice-based follow-up systems (e.g., practice registries, tracking systems).</li> </ul>	<ul style="list-style-type: none"> <li>• Data, information, and technology strategies that support linkages (e.g., common referral forms, telephone consultation, telemedicine).</li> <li>• Electronic medical/health records that support patient-centered care.</li> </ul>	<ul style="list-style-type: none"> <li>• Macro data and information strategies (e.g., surveys, early childhood information systems, shared resource data bases) that guide planning for early childhood health and related services.</li> <li>• Strategies to reduce administrative barriers for sharing information.</li> </ul>
<b>Support for individualized care plans and cross-systems planning</b>	<ul style="list-style-type: none"> <li>• Individualized care plans used by primary care providers/medical homes.</li> </ul>	<ul style="list-style-type: none"> <li>• Care plans that incorporate multiple provider perspectives and recommendations.</li> <li>• Part C Individualized Family Service Plans (IFSP) that link to pediatric primary care providers.</li> </ul>	<ul style="list-style-type: none"> <li>• Planning for improved integration of early childhood services and systems with support for local implementation (e.g., early childhood comprehensive systems initiatives).</li> </ul>

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**AREAS FOR STATE ACTION:**

1. *Support for strategies that maximize use of personnel in assuring effective linkages and CC/CM.* For example:
  - Financial incentives and supports for medical home providers that use care planning and CC/CM approaches (e.g., enhanced reimbursement for certified primary care providers).
  - Financing for care coordinators and other co-located professionals in primary care settings (e.g., direct or indirect reimbursement for primary care settings that add capacity through co-location).
  - Financing for care coordination utilities such as EPSDT coordinators in every county.
  - Support for information or service centers designed to improve linkages and CC/CM.
2. *Support for quality improvement initiatives and other mechanisms for assuring and monitoring quality related to referrals, linkages, and CC/CM.* For example:
  - Incentives for quality improvement in clinical practices and among networks of providers.
  - Structures for monitoring and reporting quality of referrals and CC/CM.
  - Interagency agreements supporting common standards, definitions, and protocols across programs and providers.
3. *Support for data, information, and technology that facilitates linkages and communication among families and providers.* For example:
  - Financing and other incentives for electronic health records for children.
  - Structured referral processes, forms, and accountability.
  - Integrated child information and data systems that provide information for use by families and providers.
  - Interagency agreements designed to reduce barriers to information sharing among providers and systems.
4. *Support for individualized care plans and cross systems planning.* For example:
  - Incentives and supports for individualized, patient-centered care plans in primary care/medical homes.
  - Review and reorganization of existing CC/CM programs, using a tiered approach to maximize available staff capacity (e.g., from community health workers to advanced practice nurses).
  - Structures that maximize the impact of Individualized Family Service Plans through systematic involvement of pediatric primary care providers, specialty care providers, child welfare programs, early intervention programs and other services.
  - Early Childhood Comprehensive System plans that include explicit strategies to link health and public health and other services and supports.

The Assuring Better Child Health and Development (ABCD) initiative intends to focus state attention on improving CC/CM and linkages that can improve child development as the result of screenings. With this report, NASHP provides a foundation for a third ABCD Consortium that will help state agencies, especially Medicaid agencies, build and strengthen systemic linkages between pediatric primary health care providers and other child and family service providers to promote and support the healthy development of young children.

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## ABOUT THE AUTHORS

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### **Kay Johnson, M.P.H., M.Ed.**

Kay Johnson has been a leader in child health policy for 25 years. Since 1984, she has been active in Medicaid and children's health policy at the federal level and served as an advisor to 40 state health and/or Medicaid agencies. Her expertise encompasses a wide range of maternal and child health issues. Ms. Johnson is a Research Assistant Professor of Pediatrics at Dartmouth Medical School and a Lecturer in Health Policy at the George Washington University. She also is president of Johnson Group Consulting. Formerly, she was the national policy director at March of Dimes; and a senior staff member at the Children's Defense Fund. Prior to her policy work, Ms. Johnson trained as an educational child development specialist and provided direct services to low-income families in child care and child development programs from 1975-1983.

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Jill Rosenthal is a Program Director at the National Academy for State Health Policy (NASHP). For the past nine years at NASHP, Ms. Rosenthal has provided policy analysis and technical assistance to states, directed programs, and authored reports on emerging state health policy issues, focusing primarily on health care quality, patient safety, and child health and development. Prior to coming to NASHP, Ms. Rosenthal worked for the state of West Virginia in various capacities on health promotion and rural health issues. She has a background in public health and health planning with a focus on health policy development and analysis and health promotion.



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## INTRODUCTION AND BACKGROUND

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All children need health care that monitors their growth and development. Based on knowledge about the importance of healthy development to early school success and awareness of the gaps in achievement between low-income children and their more affluent counterparts, families, professionals, and policymakers have given increased attention to early childhood development. Increased poverty among young children raises the stakes for success.<sup>1</sup> A growing body of evidence suggests that prevention and early intervention are substantially less costly than life-long special education and treatment.<sup>2</sup> Through early identification and intervention, providers and parents can influence young children's development and readiness to learn at school, their risk of certain adult diseases, and their future social and economic productivity.<sup>3</sup>

Across the country, states, providers, and communities have undertaken efforts to identify young children in need of early interventions by increasing the number who receive appropriate, objective standardized developmental screening. Early childhood developmental screening—at appropriate intervals with valid instruments—can identify the majority of children who have developmental risks and concerns. Studies show that screening with an objective tool more reliably identifies problems and increases referrals.<sup>4</sup>

Although screening is critical to the developmental surveillance pediatric primary health care providers conduct, it does little good for a child unless accompanied by effective referral and follow up and appropriate interventions. As providers conduct more screening and identify more children in need of follow-up services, the weakness of the U.S. child-serving systems and inadequacy of linkages among providers becomes increasingly apparent. It is clear that more must be done to assure access to the diagnostic assessment and early intervention services essential as follow up to screening.

Promising approaches for improving follow up and strengthening linkages are underway at the practice, community, and state levels.<sup>5</sup> Many such projects and initiatives aim to help families benefit from screening and surveillance in pediatric primary care by connecting them and their children to services and supports they need.<sup>6</sup>

States play an important role in removing barriers and providing support as communities move toward more integrated services. This paper outlines the opportunities to better connect children and families to services, barriers that hinder effective coordination and linkages, and strategies that states can use to promote coordination between primary health care providers and follow-up medical and developmental services in their communities. It sets the stage for a new ABCD initiative to focus on care coordination and linkages to support healthy child development.

### ACCESS TO DEVELOPMENTAL SERVICES IS UNEVEN AND INEQUITABLE

Not all families receive the services they need to identify developmental and behavioral issues in early childhood. In the National Survey of Early Childhood Health, less than half of parents of young children reported that their pediatric primary care provider offered thorough “anticipatory guidance” related to their child's health and development, and only 57 percent reported their child's development had ever been assessed at a pediatric primary care visit.<sup>7</sup> The survey also identified racial/ethnic disparities in pediatric primary care providers' patterns for discussing selected topics with parents. Parents of African-American and Hispanic children report higher rates of unmet need for early childhood development

advice and services in pediatric primary care.<sup>8</sup> African-American and Hispanic parents are more likely to say their concerns about development were not adequately addressed.<sup>9</sup>

Low-income families-whose children face higher risk for health and developmental problems and thus may need more services-often face greater barriers to care. National survey data indicate that low-income families seeking care for their children are more likely than middle/high income families to have a “big problem” getting necessary care (2.4 vs. 1.0 percent) and have trouble getting a referral to a specialist (11.5 vs. 5.3 percent).<sup>10</sup>

Even children with identified conditions may not receive prompt intervention. The Part C Early Intervention Program is the primary source of evaluation and treatment for infants and toddlers with developmental delays and those who have a diagnosed mental or physical condition that has a high probability of resulting in developmental delay. On average, a problem was detected early for children served through Part C but program services were not systematically provided for approximately half of the child’s life (Table 2). The average time between an expressed concern and entry into program services was 8 months.<sup>11</sup>

**TABLE 2. AGES FOR EVENTS RELATED TO IDENTIFICATION AND ENROLLMENT IN PART C**

Event	Mean age in months
Age at which someone first expressed concerns about the child’s development	7.4
Age at diagnosis	8.8
Age at referral to Part C	14.0
Age at formal entry into Part C entitlement services	15.7

#### STATES ARE POISED TO IMPROVE LINKAGES TO PROMOTE HEALTHY CHILD DEVELOPMENT

The Assuring Better Child Health and Development (ABCD) program, supported by The Commonwealth Fund and administered by the National Academy for State Health Policy (NASHP), has sponsored two state learning consortia and a screening academy dedicated to improving the delivery of child development services to young children who are Medicaid beneficiaries. The program has two goals. First, ABCD is attempting to create models of service delivery and financing which promote good quality services supporting children’s healthy development for Medicaid eligible children, birth to three, especially those with less intense needs (those who need only preventive care and those who are identified as “at risk” or in need of low-level early intervention). The second goal is to develop policies and programs that assure health plans and pediatric health care providers serving these children and their parents have the knowledge and skills needed to provide health care to support a young child’s healthy development.

More than half the states have participated in the ABCD program. Collectively, the ABCD learning consortia states have changed state statutes, regulations, contracts, provider manuals, web sites, and other documents that define state policies aimed at improving the delivery of child development services. These states also clarified and modified benefits coverage, improved claims processing approaches, conducted quality improvement projects, and helped providers better understand new and existing policies. Results show states can improve identification of developmental delays by increasing effective and appropriate screening by pediatric primary health care providers.<sup>12</sup>

In addition to screening, many states that have participated in the ABCD initiative focused on improving referral and linkages. Despite recognition of the importance of this issue, states that have participated in

the ABCD initiative have found documenting referral and treatment for children in need of follow up to be one of their greatest challenges and a barrier to improving children's healthy development. Building on current research and best practices from across the country, opportunities exist for states to improve linkages among services to promote healthy child development.

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## CARE COORDINATION, CASE MANAGEMENT, AND SERVICE LINKAGES

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Currently, there is a call for better linkages that support families in securing appropriate care and services. Providers of various early childhood services are offering developmental screening and need to make appropriate referrals for follow up evaluation, diagnostic assessment and intervention. Because effective developmental interventions generally involve more than one provider or system of care, linkages among medical providers, as well as between medical care and other providers (e.g., public health, mental health, family support, and early care and education), are critical to assuring that young children and their families receive the services they need. Care coordination and/or case management (CC/CM) and other linkage strategies can help close gaps and reduce barriers described below.

### BARRIERS HINDER EFFECTIVE LINKAGES

When a developmental problem is suspected, young children often fall into the gaps between different health coverage plans, health care providers, and mental health, child development, and early childhood education programs.<sup>13</sup> Screening might occur in a doctor's office, child care center, WIC nutrition site, health department immunization clinic, nurse home visit, or early intervention program office. Since more than 80 percent of young children had a well-child visit within the past year,<sup>14</sup> developmental problems can be detected at visits to a pediatric primary care provider for most children.<sup>15</sup>

When pediatric primary care providers identify a concern through developmental screening, they need information about where to refer a child for further diagnostic assessment and intervention; however, they may have limited knowledge of community resources.

For example, a physician may not be aware of the Part C Early Intervention program or may not know how to make a referral to them. The primary care provider may make the referral but not receive important follow-up information such as whether or not the family completed the referral, the status of evaluations, and type and frequency of additional services provided. If a family receives screening through Part C, they may be referred directly for evaluation and intervention services without efforts to involve or inform the child's pediatric primary care provider.

Similarly, results of screening at an early care or education program (e.g., child care, Head Start, Early Head Start, pre-kindergarten program) may not be shared with the pediatric primary care provider. If the concern is about the child's social-emotional/mental health development, linkages for referrals and follow-up interventions may be even more difficult to complete, due to a shortage of early childhood mental health providers. In any of these cases, the family may need support to carry through on referrals for follow-up testing or treatment.

Five major types of barriers limit linkages. These include:

- 1. Constraints on primary care provider capacity to refer to and link with other community resources.** Barriers at the practice level include time constraints, staff capacity (e.g., having a staff person whose time can be dedicated to linkages), and a lack of familiarity or history of poor communication with non-medical services, which may translate to a reluctance to refer. While a majority of pediatricians have staff to help with care coordination for medical conditions (e.g., chronic disease), pediatricians generally report concerns about their ability to address developmental problems of children, given their training and a reimbursement system that values procedures. Schor has described: "The dissonance between the needs of patients and the capacity of the health care system is ... pronounced for preventive pediatric care and developmental services,"<sup>16</sup>

- 2. Inadequate service capacity for early childhood developmental and mental health services** (i.e., insufficient provider capacity to provide services for identified problems). Across the country, the supply of developmental services for young children is limited, particularly intervention services for children with mild to moderate delays and early childhood mental health services. There are also long wait times at academic health and specialty centers for assessment for potentially serious delays and autism.<sup>17</sup> Children with Medicaid coverage or those who are uninsured may face additional barriers. Such limits in service capacity can make physicians reluctant to screen for developmental risks or delays, since a basic tenet in health care is to not screen unless the physician can treat the problem or is aware of the appropriate referral resources.<sup>18</sup>
- 3. Gaps between service delivery systems.** Gaps between delivery service systems are generally driven by policy, program design, or categorical funding. For example, providers may be confused about when to refer an infant to a Title V program for Children with Special Health Care Needs (CSHCN), Neonatal Intensive Care Follow-up, or Part C Early Intervention. Varying definitions of “special health care needs”—across states and among programs—are a barrier. Some states include only a narrow range of chronic conditions in their Title V CSHCN definition and have a separate definition for those with special needs who are exempt from Medicaid managed care enrollment. In some areas of the country, child development centers or early intervention centers operated (and primarily financed) by education systems may be the primary referral resource, yet may not be connected with pediatric primary care providers. Part C Early Intervention programs more often link to and provide physical, occupational, and speech-language-hearing therapies than mental health or medical services. Even among children referred for evaluation and found eligible in a service system such as Part C or children’s mental health, communication with pediatric primary care providers may be limited or ineffective.
- 4. Insufficient payment/financing for care coordination/case management (CC/CM).** Although many pediatric primary care providers want to be a medical home for their patients, the cost of care coordination and other supports delivered in pediatric practice settings is substantial and often uncovered by payers.<sup>19</sup> Having staff assigned to provide care coordination in the community (e.g., based in local health departments) also is costly and not routinely covered by health plans. Medicaid financing for case management has never been clearly defined and has become more complex following changes to law in the Deficit Reduction Act of 2005 (DRA). The definition of CC/CM varies across programs. Partitioned funding makes it possible for one family to have multiple care coordinators/case managers without effective coordination or a family-centered approach. Where states have adopted approaches using case managers or care coordinators focused on pediatric care, there may be only one per county.
- 5. Different practice styles and customs.** Variations in professional practice are another challenge. Differences in practice cultures are important barriers at the community level. For example, both health care and early care and education providers play a central role in promoting child development but perceive their role and engage with families differently. Early care and education providers tend to think in terms of assessment (through observation) and intervention (through education) or referral, while health care providers tend to think in terms of identification, diagnosis and referral and/or consultation. Similarly, while many public health and human services organizations expect staff to work in teams or in interagency meetings, few health providers have the time or inclination to work this way. In addition, physicians are accustomed to getting written feedback when they refer to or seek consultation from other physicians (i.e., a letter detailing the findings

of a specialty evaluation), but other service providers may not routinely provide such feedback or provide it in a format that is not immediately useful to health care providers. In fact primary health care providers reported that among various referral resources, they were least likely to receive the results of referrals made to non-medical community organizations.<sup>20</sup>

### CARE COORDINATION/CASE MANAGEMENT (CC/CM) PROVIDES AN OPPORTUNITY TO ASSURE CHILDREN AND FAMILIES ARE CONNECTED TO NEEDED SERVICES

Efforts to assure young children and their families receive needed services and support includes, but is not limited to, care coordination. (Antonelli et. al., 2008) In terms of children’s health, “care coordination” and “case management” are terms used to describe an array of activities that help to link families to services, avoid duplication of effort, and improve communication between families and providers. While some sources make a distinction between these two terms, and some have advocated replacing the term case management with care coordination,<sup>21</sup> the meaning of these terms varies depending on the provider, program, or payer. In practice today, the terms care coordination and case management are used interchangeably, without clear and distinct usage.<sup>22</sup> For example, while most public health programs and pediatric primary care providers emphasize care coordination, Medicaid has traditionally paid only for services identified as case management. (The federal Medicaid statute and implementing regulations do not contain a “care coordination services” category.<sup>23</sup>) A pediatric primary care provider practice, public health nurse, managed care organization staff, or others, including a family member, may provide CC/CM. Such providers may work inside a medical home, for a managed care plan, for a children’s hospital, or in a local health department.

CC/CM is commonly used to support access to appropriate health services for two groups of children: 1) children with special health care needs, including chronic conditions and disabilities, and 2) children who experience problems with access to care related to barriers such as language, culture, low health literacy, or geographic distance. Both groups of children are disproportionately represented in the population covered by publicly subsidized health coverage ( e.g., Medicaid and CHIP).

These groups overlap in some instances. For families who need assistance with access to care, a care coordinator/case manager might be more involved in securing adequate health insurance, transportation or providing training in health literacy. Care coordination for CSHCN is defined by the AAP as “a process that links children with special health care needs and their families to services and resources in a coordinated effort to maximize the potential of children and provide them with optimal health care.”<sup>24</sup> For families with children who have special health care needs, CC/CM typically focuses on implementing care plans and promoting communication among multiple providers, including referrals, authorizations, specialty care appointments, and so forth. In either case, improved communication with or linkage to primary care providers is part of the function.

A number of studies show significant benefits of CC/CM to both families and payers;<sup>25</sup> however, CC/CM is not available to all families who need support. Low-income families are more likely than their more affluent counterparts to be affected by access barriers, to have children with special health needs, and to face challenges in communicating effectively with the provider.<sup>26</sup> Children less likely to have a medical home with care coordination include those who are uninsured, have low income, and are African American,<sup>27</sup> as well as those with disabilities and limitations of function.<sup>28</sup>

A systematic review of care coordination strategies prepared for the Agency for Healthcare Research and Quality (AHRQ) recommended:

- increased support for standardized efforts to identify case management;
- expanded efforts to evaluate care coordination interventions;
- improved performance standards for managed care plans; and
- linking development of care coordination programs to emerging practice and health system reforms.<sup>29</sup>

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## KEY FEDERAL/STATE PROGRAMS FINANCING HEALTH AND RELATED SERVICES

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States increasingly recognize that service linkages and CC/CM are essential to young children's health and development. State efforts can be supported by a variety of federal-state programs. Medicaid, through its Early Periodic Screening, Diagnosis, and Treatment (EPSDT) program, State Children's Health Insurance Programs (SCHIP), Title V Maternal and Child Health programs, and programs implemented under the Individuals with Disabilities Act (IDEA) each provide ways to finance linkages and CC/CM between health and related services.

### MEDICAID AND EPSDT

Medicaid provides coverage for approximately one out of every three children under age five, making it an important source of financing for direct services, as well as for CC/CM.

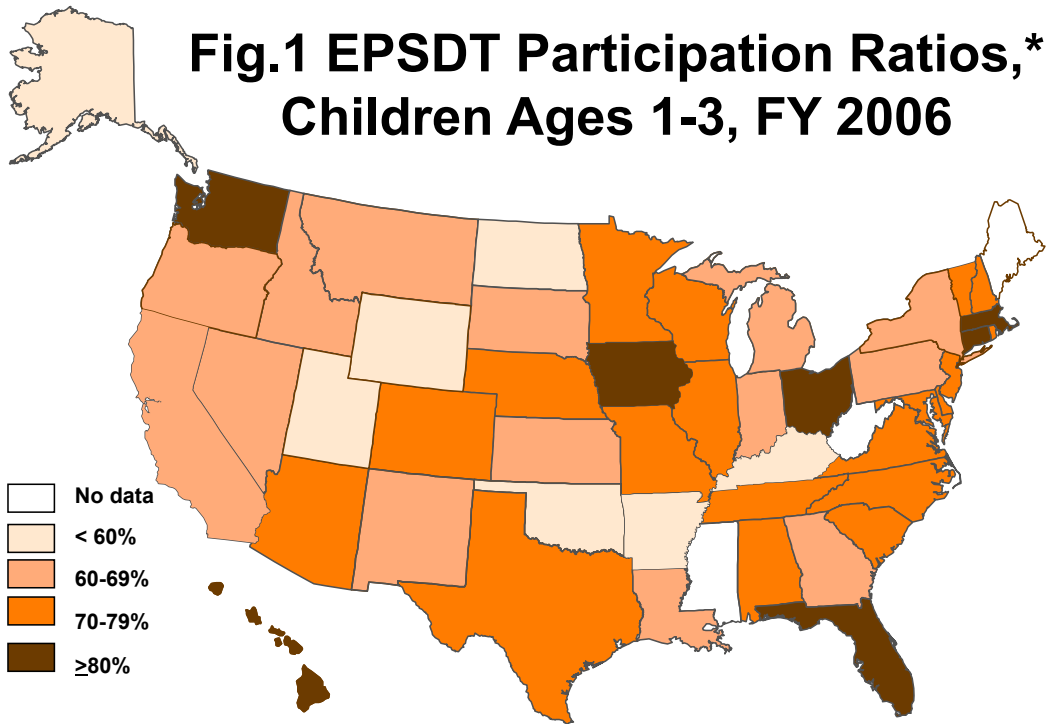
For more than 40 years, the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) component of Medicaid has defined child health benefits, including comprehensive well-child examinations (known as screening visits) and appropriate follow-up for diagnostic services and medically necessary treatment. EPSDT is in essence the child health benefit package of Medicaid. State Medicaid agencies pay for services and also have certain obligations to assure that families use services appropriately. As described by the Centers for Medicare and Medicaid Services (CMS): "*The EPSDT program consists of two mutually supportive, operational components: (1) assuring the availability and accessibility of required health care resources; and (2) helping Medicaid recipients and their parents or guardians effectively use these resources.*"<sup>30</sup> The first component involves coverage of and payment for "medical assistance" services. The second is linked to a series of administrative obligations: informing; supportive services to ensure that care is secured (e.g. transportation); and reporting.

Federal law guarantees children enrolled in Medicaid are covered for a full range of screening, diagnostic, and medically necessary treatment services. In practice, however, even the rates for comprehensive well-child visits (i.e., EPSDT screen) fall short of the 80 percent performance benchmark.<sup>31</sup> In 2006, only six states and the District of Columbia had participation ratios (percent who received at least one well-child EPSDT screening visit during the year) at or above 80 percent for infants and toddlers ages 1-3. While a larger number of states achieved ratios of 70-79 percent for this age group, seven states had ratios for toddlers below 60 percent. (Figure 1)

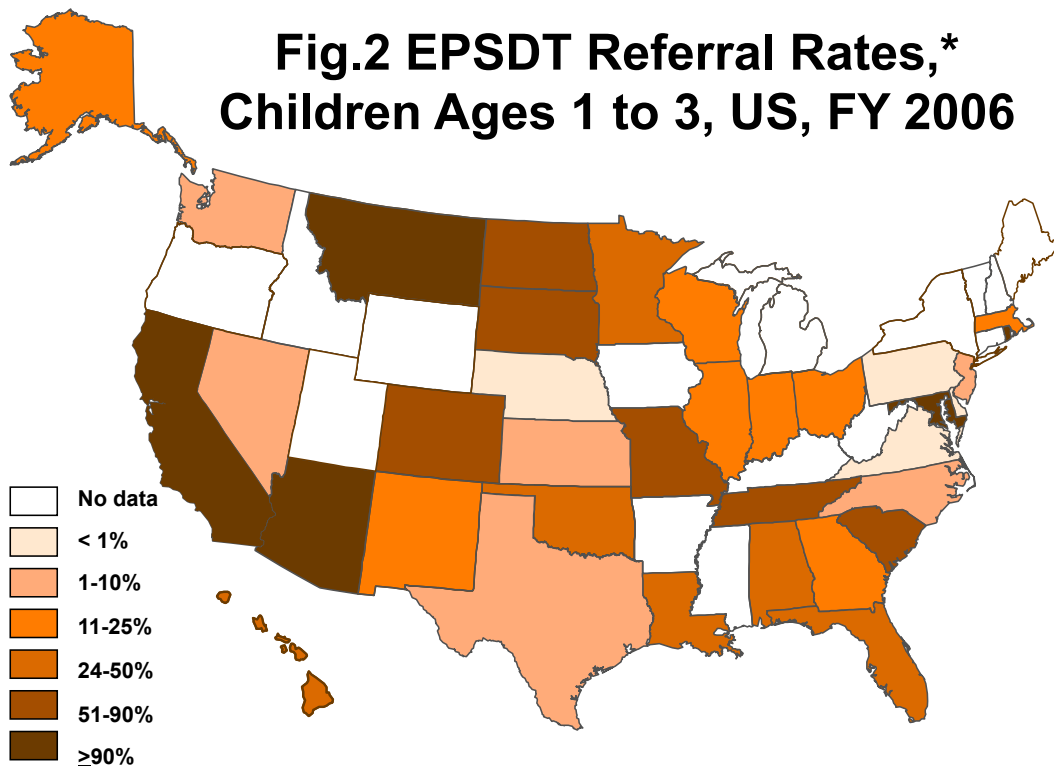
Of even greater concern are the low reported referral rates for these young, low-income children enrolled in EPSDT. Referral rates are the percent of enrolled children who received an EPSDT well-child (screening) visit in which the pediatric primary care provider made a referral or a follow-up appointment to address an identified concern. Ten states had less than 10 percent of children ages 1-3 referred for diagnosis and treatment services, with four states reporting less than 1 percent referrals. Some states have high rates of referral, indicating that many well-child visits identified a concern that called for further assessment, diagnostic testing, or treatment. These state data may not reflect actual referral rates; however, they do indicate the extent that referrals are documented and traceable in health care financing records. State policies affect the both the practice of and reporting in EPSDT. For example, states set the expectations for providers to report referrals (e.g., by noting them in the billing process), and states can conduct training, medical record review studies, and managed care focused quality studies that could improve both reporting rates and actual referrals. (Figure 2)

A majority of states provide Medicaid coverage for children and families through managed care arrangements, and half of the states enroll more than three-quarters of Medicaid beneficiaries under age 21 in





\* Percent of children ages 1-3 who had at least one EPSDT comprehensive well-child visit.  
Source: Data from the State 416 reporting on Federal Fiscal Year 2006  
U.S. Centers for Medicare and Medicaid Services <[www.cms.gov](http://www.cms.gov)>. (Slide by Kay Johnson)



\*Percent of children ages 1-3 who had a referral subsequent to EPSDT well-child visit (screen).  
Source: Data from the Center for Medicare and Medicaid Services [www.cms.gov](http://www.cms.gov). (Slide by Kay Johnson)

managed care. Children enrolled in Medicaid managed care are entitled to the full EPSDT benefit. In some states, managed care plans are responsible for the provision of all EPSDT services, and states structure contractual arrangements with plans. In other states, the Medicaid agency may be responsible for coverage of supplemental services beyond those listed in the managed care agreement (e.g., case management, dental services, specialty care). Certain children, such as those who receive SSI or those in foster care, may be exempt from managed care enrollment requirements and receive all of their coverage on a fee-for-service basis.

To a great extent state Medicaid agencies also define the structures of how care is provided (e.g., contracting with managed care organizations or financing primary care case management – PCCM – arrangements). Traditionally, Medicaid has financed two types of case management: 1) as an administrative activity with federal contributions set at a fixed 50 percent; and 2) medical assistance (also known as targeted) case management with federal contributions at the state’s medical assistance matching rate. In general, Medicaid’s medical assistance case management is used to provide case management to targeted groups (e.g., pregnant women, CSHCN, a rural county or urban area). Administrative case management is typically used for activities such as informing recipients or utilization review. Both are widely used by states in efforts to provide CC/CM to children. As described above, in some states the term “care coordination” is used interchangeably to describe similar activities; however, most state Medicaid agencies finance only services labeled case management.

The Deficit Reduction Act of 2005 (DRA) included a number of amendments to Medicaid, including changes in the definition of medical assistance case management (found in SSA §1915(g)).<sup>32</sup> Because the DRA amended §1915(g) of Medicaid law, the new definition does not apply to Medicaid administration obligations or administrative case management. The proposed rule on the case management provisions of the DRA issued by the Centers for Medicare and Medicaid Services (CMS) also refers to medical assistance case management.<sup>33</sup> So, for example, case management related to utilization review for care plans or other mechanisms related to efficient administration of benefits remain in effect.

Federal law for EPSDT makes it clear that program administration includes activities that fall within the concept of case management, such as “providing or arranging for the provision of such screening services” and “arranging for corrective treatment.” Depending on the types of barriers a family might face in securing services, various administrative case management services might be needed to assure access to care. EPSDT regulations reiterate and expand on the statute, including specific administrative obligations that families who want care actually can find and get it. For example, states’ obligations to inform families about benefits or provide assistance with transportation and scheduling well-child appointments remain in effect. Moreover, court decisions have served as a reminder to states that there is “a duty under 42 U.S.C. § 1396a(a)(43) to inform Medicaid recipients about the EPSDT services that are available to them and that it [the state] must arrange for the corrective treatment prescribed by physicians,”<sup>34</sup>

### **STATE CHILDREN’S HEALTH INSURANCE PROGRAM (CHIP)**

CHIP is a federal-state program to enable states to expand health coverage to uninsured, low-income children (and their parents). While not an entitlement of coverage like Medicaid, CHIP funds help states provide health insurance coverage to uninsured children up to 200 percent of Federal Poverty Level (and with federal approval above that level). States’ CHIP plans either expand eligibility for children under Medicaid or create a separate children’s health insurance program managed by the state (and typically operated by private insurance companies).

State policies also determine the scope of benefits covered under CHIP. If CHIP is part of Medicaid, benefits must include EPSDT. If the state elects to use a separate CHIP plan, benefits may be more limited and more family cost sharing may be required. The extent to which non-Medicaid CHIP plans cover CC/CM is limited. In a study of six of the 14 such State CHIP programs in operation in 2002, the majority limited (three states) or excluded (two states) CC/CM even for children with serious, complex conditions.<sup>35</sup> States have opportunities for improvement in this area.

## TITLE V PROGRAMS

The Title V Maternal and Child Health Services (MCH) Block Grant program provides grants to states to:

- assist state public health agencies in planning, promoting, coordinating, and evaluating service systems for pregnant women, mothers, infants, and children who do not have access to adequate health care; and
- coordinate or provide health services to children with special health care needs (CSHCN) and their families.

Because the Title V funds are flexible, states can use them to support and fund infrastructure for linkages such as: interagency planning, child health databases, development of common definitions across programs, cross-sector professional training, family support projects, or quality improvement collaboratives.

When EPSDT was enacted in 1967 “to discover, as early as possible, the ills that handicap our children” and to provide “continuing follow up and treatment so that handicaps do not go neglected,” both the Title XIX (Medicaid) and Title V (Maternal and Child Health) portions of the Social Security Act were amended. Thus, Medicaid and Title V both have legal duties to support EPSDT. Since the enactment of EPSDT, state Medicaid agencies—which tend to function as administrative and fiscal managers—have faced challenges in fulfilling their statutory obligations to provide outreach and information, as well as assistance with scheduling and transportation. Over the years, many Medicaid agencies have used state Title V programs to assist in these obligations.<sup>36</sup> One approach is to reimburse local health departments for time spent assisting families in the appropriate use of children’s health services under the EPSDT benefit. Activities might include reminder and recall activities such as telephone calls to reduce missed appointments and reconnect with families with children overdue for an EPSDT screening (well-child) visit. Local EPSDT coordinators (see below) often work out of local health departments. Title V collaborates with Medicaid in some states to finance other types of CC/CM.<sup>37</sup>

In the context of Title V, CSHCN are defined as: “*Children who have, or are at increased risk for, chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.*”<sup>38</sup> Each state defines the categories of special needs children eligible for the programs and services for CSHCN. Typically, these categories include children with chronic illnesses, genetic conditions, and physical disabilities, but usually not those with social, emotional or mental health or developmental conditions. Moreover, the definition of CSHCN may be unique to the Title V program and not used by Medicaid, IDEA, mental health or other programs.

Every state Title V program has both an MCH and a CSHCN unit, which receive both core and special grant initiative funding. A portion of overall funding is “set-aside” at the federal level for special projects and initiatives. The Title V MCH Block Grant funds are then allocated to the states based on a matching formula that requires a \$3.00 state match for every \$4.00 in federal funds. At least 30 percent of each state’s allocation must be spent on activities for CSHCN, and an additional 30 percent on primary health care for children. States vary greatly in the approaches they use in spending these. For Fiscal Year 2007, the reported share of spending ranged from 56/11 percent to 9/46 percent, respectively, with most

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states spending at least 30 percent per group of children. Nationally, for that year, the average was 50 percent for CSHCN and 25 percent for the health of other children aged 1-22 years, with most of the remainder spent on pregnant women and mothers.<sup>39</sup>

### IDEA PROGRAMS FOR YOUNG CHILDREN

Under the Individuals with Disabilities Act (IDEA), Congress authorized two major special education programs for infants, toddlers, and young children with developmental disabilities. One is focused on children birth to age three (Part C) and the other on children ages three to 21 years (Part B).<sup>40</sup> Every state participates in both programs. Both Part C and Part B programs potentially are important for young children, but the eligibility requirements, structures, and services differ.

Part C of IDEA helps pay for states to implement statewide, comprehensive, coordinated, multidisciplinary, interagency systems to provide early intervention services for infants and toddlers (from birth to the third birthday) with disabilities and their families. If a state elects to participate in the program, it must assure early intervention will be available to all eligible children and their families. In other words, states provide an entitlement to services for eligible children. Currently, all states and eligible territories are participating in the Part C program.

Part C requires development of an Individualized Family Service Plan (IFSP) for each eligible child. These plans detail the services needed by the child and family to reduce the impact of risks and conditions that lead to developmental delays. A few states have made efforts to link pediatric primary care providers to the IFSP and Part C; however, progress has been limited to date.

Each state establishes its own eligibility criteria for what constitutes developmental delay. States must define and serve infants and toddlers with developmental delays or disabilities, or a high probability of developmental disabilities or delays, who meet the state's eligibility criteria. All states have the authority to adopt the "at risk" definition if they choose, but in doing so, they must use the very specific definition of "at risk" as established in Part C regulations: "an individual under three years of age who would be at risk of experiencing a substantial developmental delay if early intervention services were not provided to the individual."<sup>41</sup> A small number of states have adopted the more generous criteria, choosing to serve children who are at risk of developmental delay if early intervention services are not provided. As of 2008, only six states were serving at risk infants and toddlers under Part C of IDEA (California, Hawaii, Massachusetts, New Hampshire, New Mexico, and West Virginia). As a result of the variability in eligibility criteria, the proportion of children served differs substantially from state to state. In 2006, 2.5 percent of children were served by Part C, with ranges among states from a low of 1 percent to a high of 7 percent.<sup>42</sup>

A substantial proportion of young children—an estimated one in seven—have measurable developmental delays. Analysis of the National Health Interview Survey (NHIS) indicates that as many as 17 percent of U.S. children 0-17 years may have had a developmental disability. The prevalence of specific categories of disabilities ranged from 0.2 percent for cerebral palsy to 6.5 percent for learning disabilities.<sup>43</sup> These data are based, however, on parent reports and not direct assessment. The Early Childhood Longitudinal Study, Birth Cohort (ECLS-BC), which completed assessments on children at ages 9 months and 24 months, provides a more specific and reliable measure of developmental delay in early childhood. Almost 30,000 children were assessed through ECLS-BC 2001-02 and 2003-04. The results indicate that approximately 13 percent of children in the sample had developmental delays sufficient to make them eligible for Part C early intervention in most states.<sup>44</sup>

An additional group of at risk children must be taken into account when estimating Part C eligibility. In 2003, the Child Abuse and Prevention Treatment Act (CAPTA) and Part C of IDEA were amended to

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require that infants and toddlers who have experienced substantiated child maltreatment be referred to Part C. Due to slow implementation, the full impact of these provisions has yet to be realized. However, using data from the National Survey of Child and Adolescent Well-Being, a recent study estimated that while 55 percent of infants and toddlers with substantiated cases of maltreatment are subject to at least five risk factors associated with adverse developmental outcomes, only 3 percent were reported to have a diagnosed medical condition (an established risk condition) that would make them automatically eligible for Part C services.<sup>45</sup>

The IDEA Part B Preschool Special Education program provides grants to states to make special education and related services available for children aged three through five with disabilities. Unlike the Part C program, the preschool program uses definitions comparable to those used for older children and youth through age 21. As a result, eligibility and family support services (often including CC/CM) are more limited.

States also have the option to combine Part C and Part B preschool programs to create a continuum of services and early interventions to all children ages birth to 5. In theory, this would allow for an improved continuum of family-centered services. In practice though, no state has combined these programs, frequently citing concerns about levels of funding.

While states choosing to participate in the Part C program agree to assure an entitlement for eligible infants and toddlers, the federal funding is not an open-ended entitlement but rather a set allocation. Allocations of grant funding to each state are based on census figures of the number of children, birth through 2, in the general population. As with Part B programs, state and local health and education agencies provide a majority of program funding. In addition, some states bill or require that families and private health plans contribute to Part C financing.<sup>46</sup>

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## STRATEGIES THAT PROMOTE EFFECTIVE LINKAGES BETWEEN PEDIATRIC PRIMARY CARE AND OTHER SERVICES

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States have used a variety of programs, both within and outside of the health sector, to promote coordination between medical providers and community referral and resource agencies. Linkage and CC/CM strategies can address the barriers mentioned previously. These strategies can be grouped similarly to those outlined in a linkage typology that delineates how pediatric primary health care practices link young children and families to developmental care:

- primary care practice-based strategies, which transform the way pediatric primary care practices are organized to deliver care;
- service provider linkage strategies, which strengthen relationships between pediatric primary care and other providers; and
- systems change and cross-system strategies, which enhance or transform operations between health and other service systems at the state level.<sup>47</sup>

The strategies can also be categorized according to whether they:

- maximize use of personnel in assuring effective linkages and CC/CM
- assure and monitor quality of referrals, linkages, and CC/CM,
- support data, information, and technology that facilitates linkages and communication among families and providers, or
- support individualized care plans and cross systems planning.

Table 3 (next page) illustrates these frameworks for categorizing strategies and their intersection.

This report categorizes strategies using this second framework to focus on the various roles that states can play to facilitate and support CC/CM and linkages. The following section describes each of these four categories and includes strategies that create improvements at the primary care practice, service provider linkage, and cross-system level. Although not all strategies described focus on creating change within primary care practice (i.e. family-to-family health information and education centers), regardless of the strategy type, the primary goals are to make services more family centered, efficient, and effective. Moreover, no single strategy can overcome the weaknesses of the current U.S. child-serving systems; a multi-strategy approach is needed.

### MAXIMIZING THE USE OF PERSONNEL IN LINKAGES AND CC/CM

The strategies outlined below can expand primary care provider capacity to refer to and link with other community resources and address insufficient payment and financing for pediatric providers' time spent in referral and coordination efforts.

### Medical Home and Primary Care Case Management Initiatives

Studies indicate that having a routine source of primary care is associated with better individual and population health, lower costs, and reduced health disparities between socially disadvantaged subpopulations and more socially advantaged populations.<sup>48</sup> The American Academy of Pediatrics and other medical societies stress the importance of having a routine source of primary care and, particularly for children, having a primary care provider who accepts responsibility for coordination and overall management of health services. These characteristics are linked to the concept of a "medical home."

The term medical home has many meanings in today's health system. Some believe that having a primary care provider is the same as having a medical home. Others set specific qualifications for a medical

**TABLE 3: LINKAGE AND CC/CM STRATEGIES TO PROMOTE COORDINATION BETWEEN MEDICAL PROVIDERS AND COMMUNITY REFERRAL AND RESOURCE AGENCIES**

	<b>Primary care practice-based strategies</b>	<b>Service provider linkage strategies</b>	<b>Systems change and cross-system strategies</b>
<b>Role of State Fiscal and Administrative Support</b>	<i>Strategies that transform the way pediatric primary care practices are organized to deliver care</i>	<i>Strategies that strengthen relationships between pediatric primary care and other providers</i>	<i>Strategies that enhance or transform operations between health and other service systems at state level</i>
<b>Support for strategies that maximize use of personnel in linkages and CC/CM</b>	<ul style="list-style-type: none"> <li>• Medical homes that use care planning and care coordination approaches.</li> <li>• Staff assigned to assure referrals and linkages, including onsite care coordinators.</li> </ul>	<ul style="list-style-type: none"> <li>• Community-based staff that assist providers and families in completing referrals and linkages.</li> <li>• Co-location of primary health care and other service providers (e.g., child development, social work, mental health).</li> <li>• Resource and referral strategies to help medical providers and families learn about/link to resources, including parent-to-parent approaches.</li> </ul>	<ul style="list-style-type: none"> <li>• Care coordination utilities that operate across a state (e.g., EPSDT coordinators statewide, coordination networks).</li> <li>• New structures to organize CC/CM personnel and programs (e.g., public health nurses, community social workers, MCO staff, CSHCN coordinators).</li> <li>• Health and mental health consultants in early care and education programs who provide referral and linkages to other providers.</li> </ul>
<b>Support for quality improvement initiatives and other mechanisms for assuring and monitoring quality</b>	<ul style="list-style-type: none"> <li>• Quality improvement efforts within clinical practice settings which can address gaps in knowledge and behavior (e.g., introduce new tools, quality measurement).</li> </ul>	<ul style="list-style-type: none"> <li>• Quality improvement initiatives that engage networks of providers in measuring and changing performance.</li> <li>• Monitor and provide incentives for quality of care coordination, including completion of referrals, care plans, etc.</li> </ul>	<ul style="list-style-type: none"> <li>• Shared or common standards, definitions, and protocols across systems (e.g., common referral forms, shared definitions of special needs or special risks).</li> <li>• Public-private payer quality initiatives.</li> <li>• Cross-system professional training.</li> </ul>
<b>Support for data, information, and technology that facilitates linkages and communication among families and providers</b>	<ul style="list-style-type: none"> <li>• Adoption of technology such as electronic medical records that facilitate linkages and CC/CM</li> <li>• Practice-based follow-up systems (e.g., practice registries, tracking systems).</li> </ul>	<ul style="list-style-type: none"> <li>• Data, information, and technology strategies that support linkages (e.g., common referral forms, telephone consultation, telemedicine).</li> <li>• Electronic medical/health records that support patient-centered care.</li> </ul>	<ul style="list-style-type: none"> <li>• Macro data and information strategies (e.g., surveys, early childhood information systems, shared resource data bases) that guide planning for early childhood health and related services.</li> <li>• Strategies to reduce administrative barriers for sharing information.</li> </ul>
<b>Support for individualized care plans and cross-systems planning</b>	<ul style="list-style-type: none"> <li>• Individualized care plans used by primary care providers/medical homes.</li> </ul>	<ul style="list-style-type: none"> <li>• Care plans that incorporate multiple provider perspectives and recommendations.</li> <li>• Part C Individualized Family Service Plans (IFSP) that link to pediatric primary care providers.</li> </ul>	<ul style="list-style-type: none"> <li>• Planning for improved integration of early childhood services and systems with support for local implementation (e.g., early childhood comprehensive systems initiatives).</li> </ul>



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home provider. The consensus among leaders in child health (including the American Academy of Pediatrics and MCHB-HRSA) is that a pediatric medical home includes a way to provide continuous and comprehensive primary pediatric care that is accessible, continuous, comprehensive, family-centered, coordinated, and compassionate. The medical home approach to health care aims to assure that all providers of a child's care operate as a team; that families are critical members of that team; and that all team members understand the importance of quality, coordinated medical, mental and oral health care. Thus, the pediatric primary care medical home coordinates services beyond those provided at a medical practice to include systemic services such as patient registries, planned co-management with specialists, patient advocacy, and patient education.<sup>49</sup>

Financing the medical home approach has been a challenge in today's health care system that typically reimburses providers for visits and procedures. States' strategies to structure payments to support the medical home concept are evolving. In some states, these activities are fulfilled by managed care organizations with Medicaid contracts, while in others the relationship is defined by an agreement between the state and the provider practice or clinic.

In primary care case management (PCCM) a provider assumes some responsibility for coordination and management of health services and is paid a small fee for administrative time/services. This can be used to support medical home activities beyond direct care.<sup>50</sup> An increasing number of state Medicaid agencies reimburse for primary care case management (PCCM) on a monthly or fee-for-service basis. PCCM providers augment their primary care services with CC/CM. Families participating in PCCM programs choose a primary care provider (PCP) who is responsible for managing their child's care and, in some states, acting as a gatekeeper to specialty services. Typically, PCCM providers are required to provide routine preventive care, 24-hour access to information, emergency contact, and appropriate referrals. PCPs may include primary care physicians, clinics, group practices and nurse practitioners, among others. Some studies have found that a PCCM model reduces costs and improves access. Several states are using PCCM to improve the coordination and continuity of pediatric care (e.g., Connecticut, Illinois, North Carolina, and Texas).<sup>51</sup>

The ABCD Project in **North Carolina** began in August 2000, piloting formal developmental screening and surveillance for children receiving EPSDT well-child (screening) visits in pediatric and family practices. The project was designed to:

- assist primary care practices in implementing an efficient and practical process for developmental screening;
- promote early identification and referral; and
- facilitate practices' ability to link to early intervention and other community services.

The goal of the project was to pilot approaches that would lead to a sustainable system for the entire state. The pilot in one county was replicated in nine additional counties, and then adopted as statewide Medicaid policy in 2004. The model builds on the state's enhanced primary care case management program which uses Community Care of North Carolina—networks of health care providers—to promote medical homes and care coordination. Primary care providers who are network members receive per member per month (PMPM) payments to link patients to a medical home, coordinate referrals to specialists and provide 24-hour coverage, and hire case managers, conduct case management, disease management, and quality improvement activities. Successful collaboration started with medical and non-medical providers, in conjunction with families, who developed cross-sector relationships focused on understanding their roles in caring for and treating children. The state's chapter of the American Academy of Pediatrics (AAP), American Academy of Family Physicians (AAFP), Part C, Medicaid, Health Check (EPSDT), Medicaid's managed care contractors, and Smart Start (state early childhood readiness program) have all promoted and supported the North Carolina ABCD model.<sup>52</sup>



**Illinois** has taken the medical home and PCCM approaches to a different level in a program called “Health Connect.”<sup>53</sup> Illinois is enrolling all children with publicly-subsidized health coverage (including Medicaid, SCHIP, and others in the state’s All Kids plan) into the PCCM program – this includes 1.5 million children plus 300,000 adults, with a few special populations exempted. More than 5,000 PCCM medical homes—with a capacity to serve over 5 million adults and children—have been enrolled. Providers receive \$2 per child per month as a PCCM fee, over and above payments for medical care services. Each medical home provider must agree to provide prompt medically necessary care with a focus on the provision of quality primary and preventive health care services that support continuity of care initiatives and avoid unnecessary emergency room visits and hospitalizations. The supportive CC/CM services include: making medically necessary referrals, scheduling diagnostic consultation and specialty visits, communicating with other case managers, and providing families direct access 24 hours a day through an answering service/paging mechanism or other approved arrangement for coverage 24 hours, seven days a week. Illinois’ ABCD II efforts are being continued through the Enhancing Developmentally Oriented Primary Care (EDOPC) project.<sup>54</sup>

Contract provisions between Medicaid agencies and primary care providers have been used in other states to define the role of the medical home. For example:

- In **North Carolina**, the PCPs’ role is described as: *“The ongoing responsibility for directly providing medical care (including diagnosis and/or treatment) to an enrollee regardless of the presence or absence of disease. It includes health promotion, identification of individuals at special risk, early detection of serious disease, management of acute emergencies, rendering continuous care to chronically ill patients, and referring the enrollee to another provider when necessary.”*<sup>55</sup>
- In **Alabama** PCCM providers are responsible for *“provision of integrated, accessible health care services by clinicians who are accountable for addressing a large majority of personal health care needs, developing a sustained partnership with patients, and practicing in the context of family and community.”*<sup>56</sup>

### **Child health and EPSDT care coordination staff**

Some states have hired local EPSDT coordinators, who have the time, capacity, and capability to assist providers in making referrals to community services. Typically EPSDT coordinators are public health nurses or social workers employed by a local health department or another local agency. States extensively using this approach include Colorado, Iowa, Minnesota, and Maine. In North Carolina, child service coordinators play a similar role.

In **Iowa**, the EPSDT program is known as *Care for Kids*, and at least one EPSDT Care Coordinator is available in every county. The Department of Human Services (DHS) is the administrative agency for the EPSDT *Care for Kids* program. Through a formal written agreement, DHS engages the Iowa Department of Public Health to provide EPSDT eligible children with information and care coordination services. This agreement supports information exchange and financing arrangements. The State public health/Title V agency, in turn, fulfills the responsibilities of this agreement by contracting with local Title V agencies to work with families in their respective service areas. EPSDT care coordinators inform families about the importance of EPSDT services and preventive care, remind families when EPSDT periodic visits are due, assist health care providers in making referrals for additional developmental screening or other intervention services, help connect families to providers when a referral is made, link families to community resources (including translators and child care), arrange transportation to medical and dental visits, and assist families in overcoming barriers as they negotiate the health care system. Care coordinators are registered nurses, registered dental hygienists, and/or other professionals with a Bachelor’s degree in health education, social work, counseling, psychology, and so forth.<sup>57</sup> The state has used its ABCD project to further enhance the role of these care coordinators.

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In **Colorado**, the Medicaid program has long used EPSDT outreach and case management staff to assist families and providers. The Department of Health Care Policy and Financing, where the Medicaid program resides, contracts directly with local agencies, such as visiting nurse associations, hospitals, and local health departments, to provide EPSDT outreach and coordination. Staff is available in every area of the state, with rural counties being clustered into regions. These EPSDT Outreach Coordinators act as first-level client advocates, who may explain benefits, encourage receipt of preventive health services, identify available Medicaid providers, and encourage families to seek preventive and appropriate health care. EPSDT Outreach Workers also connect families to available low or no-cost services and referrals to places in the community such as food banks, housing agencies, Head Start and WIC. For providers, the coordinators follow-up on referrals, as well as excessive missed appointments. They support linkages with other community services and programs. Reflecting changes in the health care system, these coordinators will be given a new title next year and will be known as “medical home navigators.”

### Resource and referral centers

Whether staffed by professionals or led by parents, resource and referral centers can provide a central location where families and providers can find support. Since patient and family education to build self-management skills is considered a critical characteristic of high performance pediatric care coordination,<sup>58</sup> two types of approaches are highlighted here. First, Family-to-Family Health Information and Education Centers are being developed in every state. Second, we describe a unique approach to providing a coordinating center for families with children who have risks that do not qualify for Part C entitlement services.

Family-to-Family Health Information and Education Centers are family-led organizations to assure families—particularly families of CSHCN—have access to adequate information about health care and community resources so they may make informed decisions about their children’s health care. The U.S. Department of Health and Human Services, through MCHB-HRSA and CMS), awarded grants for Family-to-Family Health Information and Education Centers in 37 states prior to passage of the DRA, which called for centers in every state. In 2007, HRSA awarded 30 additional grants for such centers. As part of their overall mission, these centers assist families, conduct outreach, promote family-professional collaboration, and provide parent and professional training. These centers offer resource and referral and peer-to-peer support, with some also providing enhanced support for service linkages, particularly helping families identify an appropriate medical home for children with complex medical conditions.<sup>59</sup> Family Voices—a national grassroots organization of parent leaders—developed the early centers and continues in a key role through training and technical assistance to Family-to-Family Health Information Centers.<sup>60</sup>

In recent years, Parent-to-Parent of **Vermont**, a Family-to-Family Center which merged in 2008 with the Vermont Parent Information Center into the Vermont Family Network, has partnered with local community-based organizations to establish local satellite offices aimed at improving information outreach. Vermont leaders took a deliberate approach to expanding its network and partners by identifying family support organizations that have offices in each county, and asking families in these communities to identify provider organizations that are the most family-friendly. Local communities for satellite offices were selected on the basis of unmet needs. To stretch resources, staff in the satellite offices is employed part time by *Parent-to-Parent of Vermont* and part time by the host organization. This joint employment allows both organizations access to a dedicated employee and provides opportunities for cross programming, as one person provides information and support available from multiple programs. Community partners include a local early intervention program, a pediatrician’s office based at a medical center, and a multi-service child development center. From these satellite offices, staff conducts outreach to local physicians and service agencies, receive local calls for information and assistance, and provide training for nearby parents who

want to become volunteer mentors or support group leaders. The investment in this partnership is paying off; in each community where *Parent to Parent Vermont* has placed local staff, the number of calls for information and assistance increased by 28 percent or more.<sup>61</sup>

In **Rhode Island**, four CEDARR Family Centers (Comprehensive, Evaluation, Diagnosis, Assessment, Referral and Re-evaluation) serve as a gateway to health, educational and social services for families of children with special health care needs. The CEDARR network was designed to advance a more positive, family-centered system of care, to encourage clinical excellence, to improve health outcomes and to promote overall cost-effectiveness for Medicaid-eligible children who have special medical, behavioral or developmental health care needs. Services rendered by the CEDARR Family Centers are deemed as medically necessary under EPSDT, with state dollars spent for this initiative eligible for Federal Medicaid matching dollars. The Rhode Island Department of Human Services Medicaid program administers the initiative, but the development and implementation of the CEDARR Family Centers has been an on-going interagency collaboration. CEDARR, through direct services, care coordination and resource and referral supports, can help children with special health care needs and their families get information, assessment, specialty evaluation, care planning, coordination of services and referral assistance. CEDARR Enhanced Services also provides families with speedier access to licensed clinicians, therapeutic groups and group health education sessions. The staff and providers are supported through payments from Medicaid and other sources. While these centers serve families with children of all ages, they have been a valuable resource for children age birth-to-3 who do not qualify for Part C, as well as children age 3-to-5.<sup>62</sup>

Rhode Island's Pediatric Practice Enhancement Project (PPEP), which partners with CEDARR, fosters partnerships among families, pediatric primary care practices and community resources to help pediatric primary care practices provide care to children with special healthcare needs and their families within a medical home. PPEP places and supports trained parent consultants in clinical settings to link families with community resources, help providers and families get specialty services and identify systems barriers to coordinated care. The Rhode Island Department of Health, the Rhode Island Department of Human Services, Neighborhood Health Plan of RI and the Rhode Island Parent Information Network (including Family Voices) oversee and monitor PPEP.<sup>63</sup>

### **Co-location of other service providers with pediatric primary health care providers**

Co-location of various provider types within pediatric primary health care practices can support coordination and linkages among providers. The Healthy Steps demonstration projects found, for example, that co-location of child development staff with pediatric primary care providers benefited families and had utility in office practice.<sup>64</sup>

During the ABCD II initiative, **Minnesota** tested the co-location of medical and mental health providers. Child and adolescent psychiatrists were available four hours a week to primary care providers for ongoing education and case consultation. Several models for the co-location and coordination of existing medical and mental health services were being used to identify the best practices and lessons learned for dissemination and replication in other regions of the state.

### **Health and mental health consultants for early care and education**

Child care health consultants provide health information and guidance to early care and education programs, as well as linking health, education, and social services providers.<sup>65</sup> Early childhood mental health consultants also suggest ways to promote healthy mental development in early care and education settings and to link children to community resources.<sup>66</sup> In a NASHP survey of states, which looked at resources available to assist primary care providers who identify a child in need of further assessment or referrals to

promote healthy mental development, nearly half of the states mentioned mental health consultation.<sup>67</sup> Child care health and mental health consultants include nurses, physicians, social workers and other professionals. Consultants frequently provide: referrals to primary care providers or other community services; encouragement to use a medical home; consultation and education to child care staff about child development, health and safety issues and accommodating children with special health care needs; and linkages between child care, health and other community providers.

States use a variety of methods to support and deploy these consultants.<sup>68</sup> Consultants may work through local health departments or private agencies. For example, in **Kentucky**, a statewide network of child care health consultants, coordinated through the state health department, are linked and provide consultation on mental health concerns. In the less populated **North Dakota**, regional child care consultants provide coverage for the state. In **Illinois**, each of the 25 community-based intake centers for Early Intervention has a contracted social/emotional consultant. These professionals provide early childhood mental health services and consult with other service providers on how to increase capacity.

#### QUALITY IMPROVEMENT INITIATIVES AND OTHER MECHANISMS FOR ASSURING AND MONITORING QUALITY

Some initiatives have focused on quality improvement and changes inside clinical practice settings.<sup>69</sup> Quality improvement projects across the country are testing strategies for improved developmental care, including linkages and CC/CM. These projects share a quality improvement philosophy and approach that includes bringing practices together for shared learning, engaging providers and other office staff, viewing the practice as a system of care and working through a cycle of change and assessment (e.g., plan, do, study, act, or PDSA).<sup>70</sup>

The National Quality Forum (NQF) has developed a framework that can support quality improvement efforts that focus on CC/CM. The NQF defines care coordination as a “function that helps ensure that the patient’s needs and preferences for health services and information sharing across people, functions, and sites are met over time.”<sup>71</sup> The framework specifically describes five key dimensions:

- Healthcare (medical) home;
- Proactive plan of care and follow-up;
- Communication;
- Information systems; and
- Transitions or hand-offs.

This definition of care coordination helps ensure that patients’ needs and preferences for health services and information sharing are met. It also fits well with state and local efforts to improve linkages and CC/CM between pediatric primary care providers and other services for young children.

A recent project (using a series of strategies that included literature review, key informant interviews and a multilateral stakeholder expert panel) developed a proposed multidisciplinary framework for care coordination in a high performing pediatric healthcare system.<sup>72</sup> The characteristics of high performing pediatric care coordination were defined through this process (see box). The proposed framework uses a family-centered approach and a health systems view and pays special attention to key interdisciplinary and environmental structures, processes and outcomes. The framework also builds upon the six elements of the care model developed by Wagner and colleagues.<sup>73</sup>

The National Initiative for Children’s Healthcare Quality, Inc. (NICHQ), with support from the US Maternal and Child Health Bureau, convened two National Medical Home Learning Collaboratives. These 15-month programs helped improve care for the growing population of CSHCN both by disseminating the medical home

## Critical Characteristics of High Performing Pediatric Care Coordination

The foundational characteristics and attributes of excellent pediatric care coordination include the following:

### 1. Patient and Family-centered

- Links patients and families to an accessible, community-based primary care Medical Home

### 2 Pro-active, Planned, and Comprehensive

- Supports anticipatory, proactive, continuous and longitudinal care
- Builds upon family strengths and is guided by a comprehensive, standardized assessment of needs
- Supports and relies upon team care
- Facilitates the care planning process including consultation, referral, testing, goals (jointly developed and shared), monitoring and follow-up
- Plans for the transition of youth from pediatric to adult systems of care

### 3. Promotes Self Care Skills and Independence

- Care coordination ensures the provision of patient/family education to build self-management skills
- Care coordination seeks to equip families with the necessary skills to navigate a complex health care system

### 4. Emphasizes Cross Organizational Relationships

- Care coordination builds strategic relationships across a community which support integration of care and patient/youth/family self-management skills
- Care coordination assures effective communication and collaboration back and forth along the continuum of care

Antonelli RC, McAllister JW, and Popp J. *Developing Care Coordination as a Critical Component of a High Performance Pediatric Health Care System: Forging a Multidisciplinary Framework for Pediatric Care Coordination*. (In press) The Commonwealth Fund, forthcoming 2009.

concept in 10 states (three practices per state) and by building capacity for state Title V programs, which promote, sustain and spread improvements after the project period is completed. Because the medical home model dealt with care coordination and linkages between services and supports, these programs demonstrate how to use existing agencies and infrastructure to disseminate the medical home model and support linkages. One national study assessed the feasibility of implementing a bundle of Bright Futures<sup>74</sup> recommendations and evaluated a modified learning collaborative's effectiveness in improving preventive and developmental care. The results demonstrated significant changes across a learning collaborative.<sup>75</sup>

Several states provide outstanding examples of state-level child health quality improvement. Vermont and Utah are among those with focused efforts.

The **Vermont** Child Health Improvement Program (VCHIP)—a program of the University of Vermont Department of Pediatrics, in collaboration with the Vermont Department of Health and the Vermont chapter of the American Academy of Pediatrics—has demonstrated the broad effectiveness of a statewide quality improvement outreach project. VCHIP engaged most pediatric providers in the state. The program's mission is to optimize the health of Vermont's children by initiating and supporting measurement-based efforts to enhance private and public child health practice.<sup>76</sup> One VCHIP project demonstrates how an effective statewide pediatric quality improvement outreach program can improve preventive services for children 5 years old.<sup>77</sup> VCHIP has designed and shared a model for "improvement partnerships" that consist of public and private collaboratives that use measurement-based efforts and a systems approach to improve the quality of children's health care. Improvement partnerships can ad-

vance quality improvement efforts within a state or region because they provide an institutional home, staff and resources dedicated to facilitating quality improvement processes in clinical settings. Improvement partnerships are often housed within a state entity (e.g., a public health agency) or another organization that has broad reach throughout the region (e.g., the AAP chapter).<sup>78</sup> Improvement partnerships in more than 10 other states seek to engage pediatricians, family physicians and other primary care providers in quality improvement efforts.

**Utah** Medicaid is using its managed care quality improvement requirements to improve the delivery of follow-up services available to children identified with potential delays in mental development. This effort grew from the ABCD project in the state. In Utah, physical health services are delivered by health plans that offer a comprehensive set of benefits, while mental health services are delivered by health plans that deliver only mental health services. The state directed the Medicaid-contracted External Quality Review Organization to conduct a medical chart review and determine whether the two types of plans were coordinating the care of enrollees served by both systems. Based on the findings, the Medicaid program required both plan types to conduct a performance improvement project to improve coordination between the two systems.<sup>79</sup> Utah also has a larger child health quality initiative that has increased the delivery of preventive services through learning collaboratives.<sup>80</sup>

#### **DATA, INFORMATION, AND TECHNOLOGY THAT FACILITATE LINKAGES AND COMMUNICATION BETWEEN FAMILIES AND MULTIPLE PROVIDERS**

Shared information and resource databases can help ensure that children get coordinated services by: identifying families most in need of a care plans for their children; finding appropriate follow-up resources; helping families connect with programs and services; and enabling case managers to communicate and coordinate services. States can design and implement programs that help medical providers and families get the information they need and learn about and link to resources (for example, encouraging communities to map resources to populate a centralized resource database upon which all types of child and family services providers might draw). States can also foster two-way communication between families and multiple providers to ensure children receive needed services.

The Connecticut Help Me Grow 211 information model (also known as a “warmline”) is a prime example. A number of states have developed so called “integrated child health databases” that combine information from a variety of programs (e.g., Missouri, North Carolina, Oregon, Rhode Island and Utah), and some are using this information to improve provider and family linkages. Other centralized referral systems, relying on internet and other technology, are emerging. Development of child health information systems is accelerating with newer technologies.<sup>81</sup>

#### **Internet and telephone technology**

Since 2002, **Connecticut** has tried to reach children up to age 8 who have, or who are at risk for, developmental problems, using a systematic, multi-faceted program. *Help Me Grow* is a model program that helps families and providers identify developmental concerns and find appropriate follow-up resources, and helps families connect with programs and services. Program components developed through this collaboration include a statewide toll-free telephone number that providers and families can use to access care, partnerships with community-based agencies and child development community liaisons who serve as conduits between the community-based services and the telephone access point.<sup>82</sup> *Help Me Grow* trains and supports pediatric practitioners on how to screen and assess potentially at-risk children, and to elicit parents’ opinions and concerns. The program then helps match children and their parents with needed services, using a centralized referral and case management system. *Help Me Grow* is supported and run by the Connecticut Children’s Trust Fund, in collaboration with an array of agencies.<sup>83</sup> The collaboration includes The United Way of Connecticut/Infoline (the state’s telephone information and referral service), the Connecticut Birth to Three (Part C) program (through the Department of



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Mental Retardation), the state's Department of Education Preschool Special Education Program, and pediatric primary care providers. The Commonwealth Fund supports replicating *Help Me Grow* in additional states and has a guidebook for states.<sup>84</sup>

### Datasets and registries

In **New Hampshire**, one large pediatric practice maintains a database of all children in the practice with complex/special needs (i.e., likely to last more than a year). This registry approach allows the practice to:

- identify the most complex patients and distribute them equally across providers;
- identify the families that most need a care plan for their children;
- invite families to attend focus groups for parents of children with special needs;
- appropriately schedule patients who require extra time for appointments; and
- gather information that can be used to negotiate with payers for optimal coverage of complex patients.<sup>85</sup>

Over the past decade, **Rhode Island** has refined a child health information system, KIDSNET, which is designed to support families and providers with health and related services. While other states have linked child health data, few states use this data to promote service linkages. KIDSNET links health data from pediatric providers and 10 public health programs including newborn screening, immunization services, Part C Early Intervention, the Supplemental Nutrition Program for Women, Infants, and Children (WIC), home visiting and birth defect surveillance. It provides access to linked health information to families, doctors, school nurses, health plans and early care and education providers. To facilitate care coordination, Rhode Island law permits qualified health care professionals to share health data without patient consent.<sup>86</sup> With reliable, real-time data, providers and families can help ensure timely provision of preventive care and follow-up services. The universal approach and engagement of a wide array of stakeholders, as well as privacy protections, have sustained this effort since 1997.

### Electronic Health Records

An ideal child health system would routinely use electronic health records (EHR), personal health records (PHR) and integrated child health databases based on standards.<sup>87</sup> New consensus standards have been developed for pediatric EHR, through the efforts of the Alliance for Pediatric Quality.<sup>88</sup>

Public agency support is essential to the success of child health information technology. Public agencies, particularly public health and Medicaid, play an important role developing data standards, pediatric functions in health information systems, privacy policies, research and implementation funding and incentives for technology adoption.<sup>89</sup> Opportunities exist for states to move beyond surveillance systems and integrated databases into more effective use of information to inform families and providers and improve linkages in the child health system.<sup>90</sup>

Medicaid can be used to support expanded use of health information technology, particularly through administrative financing for upgraded information systems. Medicaid can also support effective information exchanges between providers and patients, the alignment of incentives for quality based on information and the application of new technology and standards. The Center for Medicare and Medicaid Services-sponsored Medicaid Information Technology Architecture Initiative, which is aligned with the goals of the Nationwide Health Information Infrastructure and the Strategic Framework, would enable a physician's EHR system to connect to the Medicaid agency to validate eligibility, review utilization data, authorize payments and complete other tasks.<sup>91</sup>

### Referral Forms and Processes

Many state and local child health leaders have noted that most pediatric primary care practices only have referral forms designed to link patients to other physicians. Forms are needed that facilitate referrals to a wider array of

providers. Two-way communication is essential to support families and ensure children receive needed services. Some providers are turning to web-based referrals processes to improve tracking and coordination. Web-based systems can improve efficiency by standardizing procedures and reducing failure in linking children and families to appropriate services. When health providers refer to a public program such as Part C Early Intervention, policies can require and support reporting back to the medical home. While follow-up tracking can help ensure that children get services, according to a survey of state Medicaid, mental health and maternal and child health agencies, fewer than 20 percent of state respondents indicated that they track referrals.<sup>92</sup>

During **Maryland's** ABCD initiative, the Referral and Follow-up Subcommittee, which includes representatives from Maryland Infants and Toddlers Program (ITP), developed and approved a standard, universal referral and fax back form for statewide use. ABCD pilot practices are testing the form. After any needed refinements are made, the form will be disseminated to primary care providers and local ITP.

In **Maine**, when an EPSDT well-child “screening” visit results in a referral, a public health nurse receives a copy. This provides an opportunity for follow up—typically on an as-needed basis and graduated from telephone to face-to-face support—to ensure the family has support to complete the referral and that the health care provider gets information back.

#### INDIVIDUALIZED CARE PLANS AND CROSS-SYSTEMS PLANNING

Improving linkages and CC/CM requires, in particular, that the administrative mechanisms and processes be “retooled” within and across systems of care. Fostering a common knowledge base and shared definitions also can strengthen cross-system linkages. For example, some states have built cross-system databases, used common indicators to measure performance or adopted a common interagency definition of children with special health care needs and of young children at risk. Using a common front-line screening tool or having common referral protocols can support linkages. New and standardized referral forms and related policies are needed.

#### Strengthening linkages between primary care providers and IDEA Part C/Part B systems

For children referred to Part C Early Intervention and Part B Preschool Special Education—both of which require the development of an Individualized Education Program (IEP) or an Individualized Family Service Plan (IFSP)—the pediatric primary care provider’s central role is to contribute information for the multi-disciplinary assessment. Ideally, the pediatric primary care provider will collaborate with community resources in treatment planning and in promoting early intervention programs that work. For example, the pediatric primary care provider’s role might be approving or signing off on care plans or participating in the development of IEPs and IFSPs. (In most instances, pediatric primary care providers will not be available to attend IFSP team meetings, so it is critical that their role is clarified.) When medical services are part of the IEP or IFSP, the pediatric primary health care provider or another appropriate pediatric specialist may provide them.

For the **Navajo Nation**, the Growing in Beauty (GIB) program is a gateway for all developmental referrals for birth to age 3. Eight GIB coordinators (one for each region) conduct home visits, provide screening with the Ages and Stages Questionnaire (ASQ), refer to additional services, including comprehensive evaluation, provide case management and ensure appointments are kept. Follow-up care is also coordinated across agencies in monthly high-risk clinics that are co-management sessions for children and families with complex or chronic issues or conditions. GIB Coordinators also help families transition to new services after age 3. Building on the strengths of the GIB program, the Inscription House Health Center (an Indian Health Service clinic) has a memorandum of agreement with the Navajo Nation that spells out joint responsibility for identification, referral and follow-up care for children with or at-risk of developmental disabilities. Following identification of a child who needs services, a referral is made to the GIB coordinator. Inscription House also holds a monthly high-risk



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pediatrics clinic, which is a case management meeting involving a variety of service providers within the Navajo Nation. Originally focused on child abuse, the clinic was expanded to include children with varying complex and/or chronic issues, such as diabetes, high risk newborns and children with or at-risk of emotional and/or behavioral issues.<sup>93</sup>

### **Early Childhood Comprehensive Systems (ECCS)**

Since 2002, Title V federal set-aside funds have been used to support the Early Childhood Comprehensive Systems (ECCS) initiative to help states develop more comprehensive approaches to early childhood service delivery. Nearly every state has developed a plan for improved integration of early childhood services and systems. The five core components are:

- access to health care and medical home;
- mental health;
- early care and education;
- family support; and
- parent education.

In some states, local entities support early childhood system integration. States provide money to communities to support their systems efforts, promulgate rules or guidance; or provide staff or written technical support for local systems development. Most states combine funding with guidance or technical assistance for community leaders.<sup>94</sup>

The Great Start System Blueprint in **Michigan** (an ECCS plan) was approved by Governor Granholm and the Children's Cabinet with two main priorities: 1) creating a public-private entity to oversee implementation of the state's early childhood system plan (Early Childhood Investment Corporation), and 2) developing local early childhood systems. Implementation efforts are led by 14 local Great Start Collaboratives (GSC), which have funding and staff and are managed through Intermediate School Districts.<sup>95</sup> Each local collaborative uses a results-based accountability framework, conducts a local systems review and produces a community report card on the outcomes for young children and their families. Each GSC is required to include parents in the community-level leadership and planning efforts. Web-based resources and communications help link parents and service providers, including primary care providers.<sup>96</sup>

**Vermont's** Building Bright Futures (BBF), which was created in 2006 by executive order, supports the creation of a unified, sustainable system of early care, health and education for young children and their families. ECCS and BBF's work at the state level has led to the establishment of 12 BBF Regional Councils for community-level systems building. The existing local Early Childhood Councils in each of Vermont's 14 counties were used as the base for creating new BBF Regional Councils, which will have staff and more responsibility for local decision making. State funding supports staff in each region. The regional BBF councils bring together parents, providers, employers and others at the community level to support creation of an integrated early childhood system, develop a regional plan, advise the state BBF Governing Council and monitor child and family outcomes. Regional planning efforts are guided by data and indicators in a results-based accountability framework. Current year plans include an array of efforts to better link health, Part C, home visiting, early childhood mental health, early care and education and other community resources.

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## CONCLUSIONS

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**A**lthough barriers exist to effective CC/CM and linkages for early childhood services, this paper has identified opportunities for states to develop policies and programs that can improve cross-service and cross-system linkages. States have used a variety of programs and strategies to promote coordination between medical providers and other community service providers and resource agencies. Strategies related to linkages and care coordination/case management can be grouped as follows:

1. *Support for strategies that maximize use of personnel in assuring effective linkages and CC/CM.* For example:
  - Financial incentives and support for medical home providers that use care planning and care coordination approaches (e.g., enhanced reimbursement for certified primary care providers).
  - Financing for care coordinators and other co-located professionals in primary care settings (e.g., direct or indirect reimbursement for primary care settings that add capacity through co-location).
  - Financing for care coordination utilities, such as EPSDT coordinators in every county.
  - Support for state or regional information or service centers designed to improve linkages and CC/CM.
2. *Support for quality improvement initiatives and other mechanisms for ensuring and monitoring quality related to referrals, linkages and CC/CM.* For example:
  - Incentives for quality improvement within clinical practice and networks of providers.
  - Structures for monitoring quality of referrals and CC/CM.
  - Interagency agreements that support common standards, definitions and protocols across programs and providers.
3. *Support for data, information, and technology that facilitates linkages and communication among families and providers.* For example:
  - Financing and other incentives for electronic health records for children.
  - Structured referral processes, forms and accountability.
  - Integrated child information and data systems that provide information helpful to families and providers.
  - Interagency agreements designed to improve sharing of information between providers and systems.
4. *Support for individualized care plans and cross systems planning.* For example:
  - Incentives and supports for use of individualized, patient-centered care plans in primary care and medical homes.
  - Review and reorganize existing CC/CM programs, using a tiered approach to maximize available staff capacity (e.g., from community health workers to advanced practice nurses).
  - Structures that maximize the impact of Individualized Family Service Plans through systematic involvement of pediatric primary care providers, specialty care providers, child welfare programs and other services.
  - Early Childhood Comprehensive System plans that include explicit strategies to link health and other services and supports.

## RECOMMENDATIONS TO IMPROVE CARE COORDINATION AND LINKAGES AMONG SERVICES THAT PROMOTE HEALTHY CHILD DEVELOPMENT

To a great extent, state Medicaid, SCHIP, Title V, Part C, home visiting and other health-related program policies define the context in which CC/CM take place. Perhaps the most important step any state can take is to review existing policies of key programs to identify opportunities for improvement. In particular, it is critical to review case management and care coordination rules and payments under the programs identified here (see box for sample review questions).

### Top Ten Questions for States Reviewing Policies that Support Cross-system Linkages and Care Coordination/Case Management

#### Does your state:

1. Provide Medicaid and CHIP financing to support the care coordination/case management activities of children's medical home providers?
2. Fund county or community-level care coordination staff (e.g., EPSDT county staff)?
3. Have Medicaid and Medicaid managed care policies that support care coordination and case management, including provider guidance, billing codes and graduated/tiered fee schedules?
4. Have mechanisms to track referrals from EPSDT well-child screening visits? To track referrals to Part C/Part B? To track results of referrals?
5. Use Title V funding to support linkages and care coordination/case management for children both with and without special health care needs?
6. Identify children with special health care needs using a common and comprehensive definition regardless of health program?
7. Define the role of the pediatric primary care provider in Part C and Part B referrals, assessment and treatment?
8. Use blended funds to finance cross-system training, including Title V, Child Care and Development Fund, Part C, TANF and Social Services Block Grant?
9. Finance or provide technical assistance to family support, parenting education or similar programs that provide services to families at higher risk?
10. Evaluate the availability and quality of care coordination services?

Perhaps most important are the policy barriers to financing CC/CM and other approaches that facilitate cross-system linkages. For example, financing from Medicaid, CHIP and private health plans for the care coordination activities of a medical home provider is critical to the ability of providers to fully adopt and adapt to new ways of practice. Likewise, making Title V funds available to provide CC/CM for a wide array of CSHCN and others who face barriers to access, can help to fill gaps left by entitlement programs such as Medicaid or Part C. Notably, only a few states have committed funding to local staff that has responsibility for CC/CM.

## EXAMPLES OF FINANCING STRATEGIES TO DRIVE CHANGE

- Advance Medicaid and private sector reimbursement policies that provide enhanced reimbursement for medical home providers (e.g., through primary care case management or other fee structures).
- Advance Medicaid and private sector reimbursement policies that support care coordination and case management, including provider guidance, billing codes and graduated fee schedules. In Medicaid, it is critical to define appropriate uses of case management (administrative) and medical assistance (targeted) case management.
- Develop mechanisms (e.g., referral forms and codes) to report and track referrals made subsequent to an EPSDT well-child comprehensive screening exam. With such mechanisms in place, states could pay bonuses to providers with high rates of completed referrals.
- Provide pediatric primary care providers with incentives to deliver comprehensive assessments of family needs to guide care coordination service delivery.
- Review and reorganize CC/CM personnel and programs (e.g, public health nurses, community social workers, EPSDT staff, MCO staff and CSHCN program staff). Tiered reimbursement can be used after roles and responsibilities are clarified.
- Coordinate state and private resources to develop a multi-site quality improvement initiative for pediatric primary care providers in private practice, as well as for FQHC and other publicly subsidized clinics. Such initiatives can help pediatric primary care providers implement developmental care models that include surveillance, screening, anticipatory guidance, a linkage point person, referrals to other providers and programs and integration of planning and services.
- Increase accountability for a cross-system, linked approach to Part C services. For example, Medicaid can require that pediatric primary care providers (medical home) approve an IFSP as a “prior authorization” to payment for services in the Part C plan. Another approach would be to make financing for Part C evaluations dependent upon all parties participating in a multi-disciplinary team that includes health and mental health.
- Promote policies and financing to create and sustain community resources to provide access to varying levels of intervention for developmental needs. For example, state reimbursement policies can promote enhanced capacity for early childhood mental health services at federally qualified health centers or early intervention service programs.
- Make Medicaid financing part of a braided funding stream to finance child health and mental health consultants for early care and education programs (e.g., Medicaid can finance the mental health intervention services provided to a child if the child, provider and service is eligible, even if provided in child care center).
- Develop and fund explicit service networks to serve young children who have identified developmental risks but do not qualify for early intervention services through Part C or who age out of Part C but do not meet Part B eligibility criteria. This would include protocols for managing referrals of children with substantiated cases of abuse and neglect to Part C for assessment (i.e., evaluation) and follow up services.

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## NEXT STEPS

States have made great progress in screening for developmental delays. The experience of the ABCD states reveals four factors associated with successful policy and practice improvements. They are:

1. A strategic plan with clarity about goals, objectives and policy priorities;
2. Broad stakeholder participation and an active public-private partnership that ensures leadership from all potentially affected agencies and organizations are actively engaged from the beginning, and that children's primary health care provider leadership are explicitly involved;
3. Grounding proposed policy improvements in experience by pilot testing new ideas with local physician practices and communities and collecting data to show progress over time; and
4. Creating opportunities built on complementary state and local initiatives.<sup>97</sup>

Having focused primarily on screening up to this point, the ABCD initiative now intends to provide focused attention on improving CC/CM and linkages that can improve child development as the result of those screenings.

States need good models, tools, strategies and policies for facilitating referrals and referral relationships. With this report, NASHP provides a foundation for a third ABCD Consortium in 2009 that will focus on developing bridges between primary pediatric health care providers and community resources. The collaborative will help state agencies, especially Medicaid agencies, develop more effective referral pathways and linkages between pediatric practices and community intervention agencies, to support the healthy development of young children.

APPENDIX

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APPENDIX A  
ABCD III Planning Committee

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