

## Improving the Lives of Young Children

### **Opportunities for Care Coordination and Case Management for Children Receiving Services for Developmental Delay**

Carrie Hanlon  
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#### **Executive Summary**

Services that support healthy development in the years before starting school can reduce the incidence of disorders that have high costs and long-term consequences for children's health, education, and well-being. As previous briefs in this series have demonstrated, state policy choices can affect the extent to which Medicaid- and CHIP-eligible children receive developmental screenings and necessary assessment and follow-up treatment. Unfortunately, access to follow-up or referral services continues to be a challenge even with appropriate referral. Often, significant time passes from when a problem is identified to when the child receives appropriate follow-up care, such as Early Intervention services, which are federally defined support, education, and related services to meet the developmental needs of eligible young children (birth to age two) with disabilities and their families.

This brief examines states' Medicaid and State Children's Health Insurance Program (CHIP) policy choices and new opportunities that will soon be available under health reform and other federal legislation to develop a well-coordinated system of care for children receiving early intervention and other ongoing services. It then outlines how early childhood and early intervention providers could potentially support the development of effective care coordination and case management policies. Three other briefs in this series discuss other important components of effective services for children at risk of developmental delays: improving screening, improving referral and follow-up care, and addressing parents' health needs.

Children with developmental delays living in low-income settings or households often interact with multiple programs and sectors, including medical (e.g., Medicaid or CHIP, primary care/pediatrician practices), early intervention, and early childhood programs such as Head Start and child care. This document uses "care coordination/case management"

to refer to activities that help connect children and families to the services they need, improve communication between families and providers, and do so efficiently. These activities are particularly important for young children with or at risk of developmental delays because timely linkages to needed services can mean the difference between healthy development and lifelong health challenges. However, primary care providers do not necessarily have established relationships with service providers or sufficient knowledge of the available resources in the child's community to ensure that these linkages occur.

A person who stays with a family through this process can provide the support families and providers need to make vital connections to community supports more seamlessly and less stressfully. In a well-coordinated system of care for children, primary care providers (PCPs) would receive confirmation that referrals were completed, along with pertinent information such as results of any follow-up tests and lab work and related follow-up services. PCPs would also receive comparable information about patients who receive developmental screening or a referral to early intervention services through other channels (e.g., Head Start). Early childhood providers would know about (or have a resource to find out about) available support services in the community and link families to them. In such a system, children and families would receive timely and appropriate care, including early intervention and support services.

#### **Medicaid and CHIP Rules Provide Platforms for Care Coordination and Case Management**

Medicaid and CHIP together provide health care coverage to half of low-income children and therefore are in a prime position to promote improvement. For children under age 21, federal Early and Periodic Screening, Diagnosis and Treatment (EPSDT) requirements establish a set of covered services and a medical necessity definition that are common for all state Medicaid programs. Medicaid can pay for care

coordination/case management services in several ways:

1. Directly through case management aspects of EPSDT. For example, EPSDT includes services such as informing eligible families about EPSDT, providing or arranging for screening services, and arranging for assessment and follow-up.
2. Directly through targeted case management (TCM). TCM is an optional service that provides assistance to help a specific, defined group of Medicaid beneficiaries access care, most commonly groups of beneficiaries with complex care needs.
3. Through primary care case management (PCCM). PCCM is a type of managed care that states can implement for adults or children. It means that a participating primary care provider (such as a pediatrician's office) agrees to deliver primary care services, manage access to specialty services, and coordinate care. In return, the provider receives a monthly fee beyond the payments for specific services.

States can also support effective care coordination through performance improvement activities (e.g., external quality review) and the use of information systems. States with separate CHIP programs may adopt similar policies if they so choose.

These Medicaid and CHIP rules create platforms for care coordination and case management by giving states the opportunity to

- enhance the ability of primary care practices to coordinate care;
- provide case management staff who are not affiliated with a primary care practice;
- provide tools and resources to support communication among families and medical, early care and education, and early intervention providers;
- assess the effectiveness of care coordination/case management services to identify ways to better target resources and improve systems of care; and
- use health information technology to ensure that primary care providers are aware of all services a child is receiving.

### *Variation in States' Use of Federal Policy Platforms for Care Coordination and Case Management*

Many states are already using the above mechanisms to support care coordination and case management. In Oklahoma, Medicaid and CHIP programs require primary care practices to provide care coordination and case management services in order to be recognized as a medical home in the state; recognition as a medical home in turn allows practices to qualify for incentive payments. In North Carolina, payments are made by Medicaid to community-based networks that support medical home practices with services (such as care coordination) that a single practice could not afford alone. Through contracts between the state and such local entities as county public health agencies, states like Colorado, Iowa, and Arkansas have dedicated staff in communities assisting primary care providers and linking families to the resources they need. In addition, states like Connecticut and Illinois have promoted data sharing across agencies and programs that serve young children, while Oregon is linking these efforts to broader statewide health information technology or exchange activities to promote the use of electronic health records for children and help measure care coordination/case management.

### *Challenges Exist, Yet So Do New Federal Opportunities*

Key challenges that have arisen in implementing care coordination and case management for low-income children with developmental delays include program and system fragmentation, limited provider and service capacity, and inadequate funding. The sectors involved in promoting children's healthy development were developed separately and typically operate autonomously. For this reason, they are often unfamiliar with one another and have different funding streams, data systems, cultures, definitions, and protocols. Additionally, in many places, primary care providers lack sufficient resources to provide care coordination and case management, and the number of providers delivering children's developmental services is limited. Finally, care coordination/case management has historically been underfunded, and states may be hesitant to reimburse these services given that certain case management services have been challenged by the federal government.

Fortunately, recent federal stimulus funding, CHIP reauthorization, and health care reform offer new

opportunities for states to make policy choices that promote care coordination and case management and learn from other states' experiences implementing these policies. As part of the 2009 legislation reauthorizing CHIP, the federal government awarded grants to states to improve child health quality by evaluating care coordination models. The American Recovery and Reinvestment Act of 2009 contains unprecedented funding and capacity-building for health information technology and exchange, and the Patient Protection and Affordable Care Act of 2010 provides several opportunities to support pediatric care coordination and case management, particularly via the medical home.

### *Early Care and Education Providers Can Play Key Roles*

Within the aforementioned platforms in Medicaid and CHIP as well as new federal opportunities, early care and education providers can promote greater care coordination and case management. State experience (and research) working through these providers is limited, but early care and education providers are important partners for states to consider, given their frequent interactions with and knowledge of low-income children receiving early intervention and other developmental services. Potential roles for early care and education providers include serving as Medicaid or CHIP-funded care coordinators, interacting with existing care coordinators, informing or advising Medicaid/CHIP-funded care coordination/case management activities, and engaging families.

While ensuring that children with developmental delays complete referrals and access appropriate and timely follow-up services continues to be a challenge, current and future opportunities in Medicaid and CHIP can support greater care coordination and case management. In addition, states can potentially implement these opportunities in ways that bring together early childhood and health providers to take advantage of each partner's unique strengths. States have already begun to implement these opportunities for care coordination and case management, yet further refinement and testing of alternative service delivery and payment methods at the state level is critical. Such experimentation will enhance researchers' knowledge of appropriate care coordination/case management measures and generate data on the effectiveness of these strategies.

## Introduction

Services that support healthy development in the years before starting school can reduce the incidence of disorders that have high costs and long-term consequences for children's health, education, and well-being (Shonkoff and Phillips 2000). As previous briefs have demonstrated, states can choose policies that help ensure that Medicaid- and CHIP-enrolled children receive developmental screenings (Kenney and Pelletier 2010) and that children with or at risk of developmental delay receive necessary assessment and follow-up treatment (Pelletier and Kenney 2010). With standardized screening tools, primary care medical providers can identify children at risk of developmental delay or disability and then refer them for diagnostic assessments to determine what treatment (if any) they may need and be eligible to receive. Unfortunately, access to follow-up or referral services continues to be a challenge even with appropriate referral; often, significant time passes between when a problem is detected and when follow-up and early intervention services are received (Hebbeler et al. 2007).

Experience from the Assuring Better Child Health and Development (ABCD) program, which is funded by the Commonwealth Fund and administered by the National Academy for State Health Policy, indicates that the providers involved in meeting children's health and developmental needs should improve their coordination and communication. Care coordination is particularly important for young children with or at risk of developmental delays for a number of reasons. Timely linkages to needed services can mean the difference between healthy development and lifelong health challenges. Unfortunately, primary care providers do not necessarily have established relationships with the service (family support, early education, Early Intervention, etc.) providers or specialists a child needs or sufficient knowledge of the available resources in a child's community. This means a pediatrician may be unsure of a service provider's area of expertise, quality of care, or the criteria a child must meet to be seen; additionally, the pediatrician may be unable to communicate with that provider in a timely manner on behalf of the child and family. With limited specialists to treat children, parents and primary care practices may experience frustration with and difficulty managing waiting lists and the

numerous attempts to locate available providers and schedule appointments. A person who stays with a family through this process can provide support that both families and providers need to in order to make vital connections to community supports more seamlessly and efficiently.

This brief examines Medicaid/State Children’s Health Insurance Program (CHIP) policy choices that states have made and others newly available under health reform and other federal legislation to develop a well-coordinated system of care for children with developmental delays.

### *Defining Care Coordination and Case Management*

Children with developmental delay living in low-income settings or households often interact with multiple programs and service sectors, including medical (e.g., Medicaid or CHIP, primary care/pediatric practices), Early Intervention, and early childhood (e.g., Head Start, child care). Different sectors use different terms. For example, Medicaid references and reimburses “case management services” or “services which will assist individuals eligible under the [state Medicaid] plan in gaining access to needed medical, social, educational, and other services.”<sup>1</sup> Early Intervention uses “service coordination” to refer to “the activities carried out by a service coordinator to assist and enable a child eligible under this part and the child’s family to receive the rights, procedural safeguards, and services that are authorized to be provided under the State’s Early Intervention program.”<sup>2</sup> A review of literature by medical experts and researchers resulted in defining “pediatric care coordination” as a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families (Antonelli, McAllister, and Popp 2009).

Although programs and sectors have their own terminology, they share a commitment to helping children and families access needed services, and doing so by working across sectors. This brief uses “care coordination/case management” to refer to activities conducted by staff (primary care providers, public health nurses, or others) from medical, early care and education, and Early Intervention sectors that help connect children and families to the services they need, improve communication between families and providers, and do so efficiently (Johnson and

Rosenthal 2009). Specific examples of care coordination/case management activities include establishing relationships with children and families by setting care coordination expectations; promoting ongoing communication with families and among providers; completing child or family assessments; developing care plans with families that reflect mutual goals; setting up, coordinating, and tracking referrals; tracking test results; providing condition-specific information about medical, educational, and social supportive resources; coaching families to help them build caregiver skills; making sure the child’s health care team integrates multiple sources of health information; facilitating all care transitions from practices and providers; coordinating health care team meetings; and monitoring care coordination and the effectiveness of service delivery via health information technology (Antonelli et al. 2009, 10–11).

The following sections outline Medicaid and CHIP policy options available to states to help them move closer to achieving a coordinated system of care for children and their families. Although little information is available about effectiveness, states are developing and testing strategies to promote care coordination and case management. Others can learn from these experiences as states assess impacts on the lives of young children. Following the discussion of Medicaid/CHIP policy options and state innovations, the brief addresses remaining challenges faced by these care coordination initiatives, new and future federal opportunities that could help address these challenges, and specific potential roles of early care and education providers in case management and care coordination.

### **Medicaid and CHIP Rules: Platforms for Care Coordination and Case Management**

Mechanisms within Medicaid and CHIP support care coordination and case management for eligible children with developmental delays. These programs collectively provide health care coverage to half of low-income children and therefore are in a prime position to promote improvement (Pelletier and Kenney 2010). Medicaid and CHIP are federal programs administered by states that provide health benefits to individuals who meet program and service eligibility requirements (Kenney and Pelletier 2010; Pelletier and Kenney 2010). For children under age

21, federal Early and Periodic, Screening, Diagnostic and Treatment (EPSDT) requirements establish a set of covered services and a medical necessity definition that are common for all state Medicaid programs. EPSDT includes requirements to bring families into care, periodically screen children to identify needs, treat identified needs, and provide services that help eligible children and their families access care.

Medicaid and CHIP can pay for care coordination and case management services directly through case management aspects of EPSDT, targeted case management, or primary care case management; and through activities that enable care coordination and case management, specifically quality assurance (external quality review, performance improvement) and/or the use of data (i.e., information systems).

### *EPSDT Case Management*

Under Medicaid, states can implement case management aspects of EPSDT (and separate CHIP programs may adopt similar policies if they so choose). EPSDT requires state Medicaid agencies to ensure children receive the care they need; doing so may require providing some or all of the following covered administrative case management services: informing eligible families about EPSDT; providing or arranging for screening services; arranging for assessment and follow-up (either directly or through referral); and arranging for transportation to services at clinics, schools, or other community settings.

Federal guidelines also encourage care coordination and case management across sectors and agencies in several ways. Medicaid agencies must use state Title V and health agencies to link and arrange care and follow-up, then pay these agencies for both administration and medical assistance activities (Rosenthal, Hanlon, and Hess 2008). Federal rules also direct state Medicaid agencies to help families access public health, mental health, and educational programs (Rosenbaum 2008). Federal EPSDT guidance to states notes the importance of strong relationships between Medicaid and early care and education agencies such as Head Start, which “shares the same child health and development goals as EPSDT.”<sup>3</sup> Additionally, federal Medicaid funding (50–75 percent of the total state cost) is available for staff who administer the program.

States can opt to have staff coordinate care for Medicaid beneficiaries by providing the aforementioned covered case management services; if they do so by setting up an EPSDT administrative case management program, the federal government matches 50 percent of covered service costs. States are required to provide EPSDT services to eligible children, but have a number of options for how to do so. Implementing case management aspects of EPSDT (e.g., through an administrative case management program) is one such option.

### *Targeted Case Management*

States also have the option to implement targeted case management (TCM), which is assistance to help a specific, defined group of Medicaid beneficiaries access care (Kaye, May, and Snyder 2008). (Again, separate CHIP programs may adopt similar policies if they so choose.) States can define the TCM beneficiary group by age, a particular medical condition (e.g., children with severe mental health problems), or geographic location (Binder 2008). TCM is most commonly used to support groups of beneficiaries with complex care needs, such as severe mental illness. TCM services include such activities as outreach, identification and coordination of needed services, and case planning and monitoring. The federal government reimburses states a portion of TCM service costs; the rate varies by state but is always at least 50 percent of the total cost and at the same rate as other services, such as physician services.

States may be leery of taking advantage of TCM because it is complex and has been subject to federal challenge. For example, in 2009 the Centers for Medicare and Medicaid Services rescinded federal TCM regulations issued under the previous administration; if left in place, the regulations would have ended states’ ability to bill for case management services that are essential to administer nonmedical programs (e.g., child welfare, special education) and disallowed schools from administering Medicaid.<sup>4</sup> The changes would have affected health care and rehabilitation services for children with special health care needs as well as public health nursing services in various community settings. In 2007, 48 states covered TCM; as of 2005, at least 14 states appeared to cover TCM specifically for children in Early Intervention.<sup>5</sup>

States set TCM provider qualifications in their state plan amendments. Case management services may be provided by state Medicaid agencies, other state agencies such as the Department of Health or Title V, and/or other entities with which state Medicaid has interagency agreements.<sup>6</sup> States rather than the federal government establish minimum qualifications for case management service providers. Depending on a state's standards, service providers such as nurses, social workers, home visitors, and Head Start, child care, and or local education agency providers may qualify to deliver case management services.

### *Primary Care Case Management*

As an earlier brief in this series noted, states can implement a type of managed care known as primary care case management (PCCM) in their programs (Pelletier and Kenney 2010). In PCCM, a participating primary care provider agrees to deliver primary care services, manage access to specialty services, and coordinate care. In exchange, the PCCM provider receives fee-for-service payment for the services he or she delivers and a small monthly fee for every enrolled (Medicaid or CHIP, depending on the program) beneficiary. Although the individual monthly payments are small (often \$2–3), they can become substantial when aggregated by the number of beneficiaries enrolled with the provider (sometimes over 1,000).

In this type of system, Medicaid and CHIP agencies will not pay for services provided by a provider other than the PCCM provider without the PCCM provider's authorization. The Medicaid agency establishes requirements that providers have to meet in order to become PCCM providers. These vary among states and may be minimal.

As of June 2009, 17 states were using (or planning to use) PCCM in conjunction with medical home initiatives to create a broad structure for care coordination and case management.<sup>7</sup> States implement PCCM programs through state plan amendments or waivers.

### *External Quality Review and Performance Improvement*

Additionally, state Medicaid and CHIP programs can use quality improvement requirements under

managed care to facilitate care coordination and case management. Some states require Medicaid beneficiaries to enroll in managed care organizations (MCOs), a delivery system in which the state contracts with an organization to deliver a set of services to a defined group of beneficiaries for a set amount per member each month. According to federal law, these states must carry out a number of activities to assess the quality of care that beneficiaries receive: hire an external quality review organization (EQRO) for certain activities, and have the MCOs conduct performance improvement projects (PIPs) to measure and implement strategies to improve performance. States can initiate PIPs and have EQROs conduct activities that monitor or assess the extent of care coordination/case management and develop targeted interventions for improvement.

States use various managed care arrangements in Medicaid (Kaiser Commission on Medicaid and the Uninsured 2010). As of June 2009, Medicaid beneficiaries in 37 states received care through comprehensive MCOs.<sup>8</sup> States with MCOs can implement EPSDT case management and TCM as described above.

### *Information Systems*

Federal Medicaid funding is available to states for administrative activities to support their Medicaid Management Information Systems (MMIS). Medicaid agencies originally used MMIS for automated claims processing but now also use the systems for managed care, clinical support, prior authorization, data analysis, and fraud prevention (Centers for Medicare and Medicaid Services n.d.). Federal dollars are available to cover 50–90 percent of states' MMIS costs associated with such services as ongoing claims processing or system enhancements.<sup>9</sup> Federal matching is also available through the Centers for Medicare and Medicaid Services' (CMS) Medicaid Information Technology Architecture (MITA) initiative. MITA helps Medicaid agencies update their information systems to promote standardization across states, support interoperability with other agencies involved in health care in a state, integrate public health data, and become more patient-centered, among other things (CMS n.d.).

## State Uses of Federal Platforms to Promote Care Coordination and Case Management

Many states are already using some of the above platforms to support care coordination and case management. For ten years, ABCD states have participated in learning collaboratives to develop and test models for improving the delivery of early childhood development services to low-income children and families. In 2009, five ABCD states began work to develop and test models for improving care coordination and linkages between pediatric primary care providers and other child and family service providers.<sup>10</sup> While more needs to be done to take these efforts systemwide, experience from the pilots demonstrates how states can take advantage of opportunities in Medicaid and CHIP to promote care coordination/case management for children with or at risk of developmental delay. For example, through ABCD III, Minnesota and Oregon are exploring ways to establish Medicaid billing policies for care coordination reimbursement codes for children receiving early intervention services.

Many policy options are available to states to use federal platforms to promote care coordination case management (Johnson and Rosenthal 2009). This section focuses on three examples: medical homes, dedicated care coordination/case management staff, and data sharing or linking.

### *PCCM/Medical Home*

States such as North Carolina and Oklahoma use the medical home model to support care coordination and case management. Medical home initiatives facilitate coordination by requiring and financially supporting it.<sup>11</sup> A pediatric medical home offers a child a regular primary care provider who takes responsibility for ensuring that child's health services are well managed by, for example, coordinating with necessary nonmedical providers serving the child in the community. Care in a pediatric medical home is defined as “accessible, continuous, comprehensive, family-centered, coordinated, and compassionate” (Johnson and Rosenthal 2009, 11). The American Academy of Pediatrics (2007) has a policy statement underscoring the importance of the medical home (and pediatricians) in helping to meet the needs of children receiving early intervention services.

Through medical homes, states can enhance the ability of primary care practices to coordinate care in several ways. States can require that primary care providers (PCPs) be recognized as a medical home in order to treat Medicaid or CHIP beneficiaries (or a subset of them, such as children). States can then establish standards for medical home recognition and pay practices based on how well they function as medical homes—through different tiers of medical home standards and/or pay for performance, both of which can include care coordination and case management.

Oklahoma established three tiers in its SoonerCare (Medicaid) Choice Medical Home program; each tier requires a minimum set of care coordination services (e.g., coordinate with mental health professionals, track tests and referrals) and some optional care coordination services that result in additional payment. Higher-tiered medical homes have more requirements and are eligible for higher payments.<sup>12</sup> SoonerCare Choice is linked to SoonerExcel, a quarterly incentive program that rewards practices for meeting certain performance levels; one measure is for EPSDT initial and periodic screening services.<sup>13</sup> As part of its ABCD III initiative, Oklahoma will explore ways to potentially strengthen the recognition process for developmental screening and referral system practices to support improved care coordination and case management.

In addition to paying PCPs for care coordination/case management or administrative activities, states can provide a separate payment to a community-based network to which each medical home practice belongs. The latter enables networks to offset the cost of care coordination and case management by providing network practices with resources that the practices might not be able to afford on their own. For example, in North Carolina's PCCM medical home program (Community Care of North Carolina), nonprofit community care networks receive \$3 per member a month to support primary care practices with care coordination. Networks use this funding to meet with practices, help fund staff oversee network quality or operations, and hire care managers to help practices.<sup>14</sup>

This public-private partnership in North Carolina has led some practices to take more advantage of personnel (early intervention specialists) who provide a more seamless system because they are placed in the

practices to, among other things, oversee the referral process, follow up with families, and respond to program and provider questions on children or referral outcomes (Klein and McCarthy 2009). A medical home is not required for other care coordination/case management policy options, but it provides a structure upon which states can continue to build.

### *Dedicated Care Coordination/Case Management Staff*

As demonstrated by Colorado, Iowa, and Arkansas, states can use EPSDT case management and TCM to dedicate staff in local communities to assist primary care providers and link families to the resources they need. Colorado redesigned its EPSDT administrative case management program and placed “medical home navigators” throughout the state to support families and providers. Through contracts between the state and local organizations/agencies, these staff provide care coordination/case management services, such as educating children and families about EPSDT benefits and linking them to available providers; they also support primary care provider practices by, for example, following up on referrals to other providers. Early findings from Colorado show an increase in referrals for corrective treatment (Kaye and May 2010).

In Iowa, the Medicaid agency contracts with the Title V agency to provide technical assistance and training for EPSDT, including outreach, informing, care coordination, and/or screening services for Medicaid-eligible children. Each day, the Title V agency receives from the state Medicaid agency a list of Medicaid clients eligible for EPSDT informing and care coordination services. The local contract agencies then explain the benefits of preventive health care and other services available to Medicaid families. Title V providers notify newly eligible Medicaid recipients of covered services, help them access needed services such as screenings, and link them to needed follow-up services. Expenditures for services included in the contract are eligible for federal Medicaid matching funds. The contract between Medicaid and Title V also makes Title V providers eligible to be reimbursed for wraparound services provided to Medicaid beneficiaries, such as transportation.

Finally, as part of its ABCD III project, Arkansas will help provide individuals unaffiliated with a

primary care practice coordinate care. Specifically, Arkansas will shape the role of “early intervention liaisons” within the Department of Human Services’ Division of Developmental Disabilities (which houses Part C Early Intervention and the Children with Special Health Care Needs Program). These positions will have responsibility for promoting coordination between developmental service providers and primary care providers, and providing any needed technical assistance.

### *Data Sharing and Linking*

Since primary care and early intervention providers operate with separate data systems, they have different information about available community resources for families and different clinical information about the same children. Therefore, another policy choice for states is to promote data sharing, particularly within statewide health information technology (HIT) or health information exchange (HIE) activities to help ensure that providers know about all the services a child receives from medical, Early Intervention, and other sectors. As experiences from Connecticut, Oregon, and Illinois demonstrate, these activities can help providers and families identify necessary or available follow-up resources, facilitate overall communication and coordination of services, and track and measure performance and care coordination/case management.

Connecticut has established a single resource called the Child Development Infoline that parents and pediatric providers can use to access information and make referrals for several programs serving children, including Part C (Pelletier and Kenney 2010). At its core, the Infoline facilitates communication among providers and with families. It is staffed by care coordinators who make assessments, link children and families to needed services, and follow up to ensure families successfully access those services. Help Me Grow is one program linked to the Infoline; it supports children birth through age eight who are at risk for developmental or behavioral problems by linking families to community resources and providing feedback about referrals to providers. The Child Development Infoline collects data from the various programs it includes that show where gaps in service utilization exist and how well children are connecting to providers.

As part of its ABCD III initiative, Illinois established a subcommittee focusing explicitly on service data integration. The subcommittee is exploring ways to expand and enrich the data shared with primary care providers about their patients through the state's PCCM medical home program (Illinois Health Connect, or IHC). IHC providers receive a monthly patient panel roster with information about every patient assigned to their practice. The panel roster includes information about demographics, clinical indicators, and developmental screening. Through ABCD III, Illinois is surveying medical providers to determine how they use the panel roster and what other data might be helpful to include in it. Illinois is also focusing on opportunities to integrate other types of data (e.g., EI service claims data) into the panel roster so PCPs can see whether a child has received an EI assessment or currently receives EI services. Insight from the initiative is intended to promote care coordination/case management between EI and primary care by helping primary care providers use patient panel rosters more effectively and by informing policy change recommendations (e.g., clarifying or updating provider handbook information) to support data sharing.

The subcommittee is also piloting ways to increase provider access to the Internet application of Cornerstone (eCornerstone), a statewide data management information system that facilitates the integration of community maternal and child health services provided by the Department of Human Services to effectively measure health outcomes. Cornerstone provides a single point of enrollment for multiple state programs and builds a file for each individual that includes a comprehensive needs assessment and care plan.<sup>15</sup> Regional Child and Family Connections offices (the system point of entry for EI services) receive referrals from providers and use Cornerstone to coordinate EI assessment and to track whether families complete referrals. To pilot access to these data, the subcommittee is, for example, working on data-sharing agreements.

In Oregon, several federal funding opportunities and state initiatives have come together to support and inform statewide adoption and promotion of HIT/HIE. In concert with statewide HIT planning, Oregon will help develop and explore the effects of expanded use of electronic health records for

children, pediatric medical homes, care coordination/case management measures, and methods of tracking child health outcomes to help assess how HIE/HIT may help drive quality improvement, especially for children in CHIP and Medicaid.<sup>16</sup> These efforts will inform the state's ABCD III initiative, through which Oregon (building on previous ABCD experience) is implementing an EQRO-led PIP that will test practice and system-level measures for quality well-child visits and care coordination between early intervention and primary care. Development of measures will enable the state to identify system improvement needs and target resources accordingly.

The statewide HIT Plan and ABCD III efforts will draw from and incorporate existing state resources for data sharing, such as FamilyNet. In an effort to overcome program database silos and allow providers to follow a child across systems, FamilyNet links all public health databases including Women, Infants and Children; lead, hearing, and oral screening; immunization; and home visiting programs. The state is piloting the next phase of FamilyNet, which is a child health record that providers will use to access information from the linked databases. Longer-term goals include incorporating the Medicaid enrollment program into FamilyNet.

### *Summarizing State Uses*

As demonstrated above, Medicaid and CHIP rules create platforms for care coordination and case management by giving states the opportunity to

- enhance the ability of primary care practices to coordinate care;
- provide case management staff who are not affiliated with a primary care practice;
- provide tools and resources to support communication with families and among medical, early care and education, and early intervention providers;
- assess the effectiveness of care coordination/case management services to identify ways to better target resources and improve systems of care; and
- use health information technology to ensure that primary care providers are aware of all services a child is receiving.

## Challenges to Care Coordination and Case Management

Despite the accomplishments of these innovative state pilots, which in many cases have produced statewide policy change,<sup>17</sup> translating pilot projects into statewide practice is a long-term effort. Given tight state budgets, cuts to community resources, and the ongoing challenges of trying to transform long-standing program processes and provider behaviors, systemic change is not easy or quick. Key challenges that have arisen in implementing care coordination and case management for low-income children with developmental delays include program and system fragmentation, limited provider and service capacity, and inadequate funding (Johnson and Rosenthal 2009; Pelletier and Kenney 2010).

First, the sectors involved in promoting children's healthy development (e.g., health, early intervention, early care and education) have overlapping missions and serve overlapping populations, yet they were developed separately and typically operate autonomously (Rosenthal et al. 2008). For this reason, the sectors have different funding streams, data systems, definitions (including of care coordination/case management), and protocols for such programs as Early Intervention and Medicaid; further, these programs usually are unfamiliar with each other.<sup>18</sup> Primary care providers may not know when to refer a child to early intervention and/or confuse it with other programs. In one national survey, over two-thirds of responding Early Intervention (EI) programs cited primary care practices' lack of knowledge about EI as a challenge (Allen 2010). Although there is no data to support the claim, this is likely true with other programs. This fragmentation becomes a greater challenge for low-income children whose Medicaid eligibility may change over the course of time when they need care coordination and case management.

Since programs and systems serving young children operate independently, they also have cultural differences that can impede care coordination and case management. Early Intervention providers work in teams, have a long-term focus, and approach their work through assessment and intervention, whereas primary medical providers work much more independently, focus more on acute needs, and use identification, diagnosis, and referral to help children

and families (Allen 2010; Johnson and Rosenthal 2009). Early care and education providers (in child care, Head Start and home visiting programs) often have different education levels (and, therefore, perhaps perceived status) than primary care medical providers; they may experience initial difficulty engaging medical providers.

There are also differences among early care and education providers, but the differences point to some potential opportunities for supporting care coordination and case management. For example, Head Start and Early Head Start staff may have particularly strong relationships with primary care medical providers because their programs include health services requirements for all enrolled children and pregnant women. Unlike primary care medical providers and EI, Head Start/Early Head Start and child care providers also interact daily with children and families. These early care and education providers—along with home visitors, who experience a child's living environment first hand—likely have keen insight into the barriers (e.g. abuse, unsafe neighborhood, lack of transportation) a family may face that affect access to care or support service needs. Unfortunately, the separate cultures, structures, and organization lead to fragmentation, gaps, and missed opportunities, which result in miscommunication and possible redundancy, as well as confusion and delay for children and families.

Provider and service capacity limits are another challenge. Primary care providers may lack sufficient staff or time to provide care coordination and case management, especially if it requires familiarity with community resources. Even if pediatricians have resources to support care coordination/case management, they often express concern about their ability to manage children's developmental problems (Johnson and Rosenthal 2009). Early intervention staff report being understaffed, and they therefore manage high caseloads (Allen 2010). Compounding this challenge is that state budget deficits are leading to hiring freezes in state agencies and cuts to funding for support services in communities. As a result, service providers may be consolidated into fewer geographic areas. These changes in community resources affect primary care providers and care coordinators/case managers' ability to refer and link children to the resources they need.

Finally, care coordination and case management is expensive and underfunded (Johnson and Rosenthal 2009). A 2004 study placed the annual cost of care coordination at about \$23,000–\$33,000 for a medical practice with four full-time-equivalent (FTE) physicians and one FTE nurse practitioner (Antonelli and Antonelli 2004 as cited by Antonelli et al. 2009). Health plans do not typically fund staff that focus exclusively on care coordination and case management services, and while primary care practices can provide these services, cuts to early intervention and state and local health department budgets, mean fewer staff and resources are available in communities for children and families.

## New and Future Opportunities

Fortunately, recent federal stimulus funding, the legislation reauthorizing CHIP, and health care reform offer new opportunities for states to address these barriers, helping states make policy choices that promote care coordination/case management, contribute to new evidence, and learn from other states' experiences implementing these policies. In February 2010, the federal government awarded 10 demonstration grants as part of the Children's Health Insurance Program Reauthorization Act of 2009 (P.L. 111-3). These grants will support efforts in 18 states to improve child health quality by enhancing medical home initiatives, implementing or strengthening health information technology, measuring provider performance, and evaluating models of care coordination. Lessons from these states will be an invaluable resource for others.<sup>19</sup>

Additionally, the American Recovery and Reinvestment Act of 2009 (ARRA, P.L. 111-5) contains unprecedented funding and capacity-building for health information technology and exchange, which may help facilitate pediatric care coordination and case management.

- The Health Information Technology for Economic and Clinical Health (HITECH) Act of ARRA contains a Meaningful Use Incentives Program administered by state Medicaid agencies. This program provides incentive payments to providers who can demonstrate the “meaningful use” of certified electronic health record (EHR) technology. Funding has been awarded for the first of several stages of meaningful use criteria

rollout, and one early and critical expectation is that providers be able to use EHR technology for care coordination. State Medicaid agencies are able to receive a 90 percent match from the federal government for administrative costs associated with implementing the EHR incentive program.

- HITECH also includes the State Health Information Exchange Cooperative Agreement Program, which will allow states (or a state-designated entity) to plan and implement the statewide infrastructure for health information exchange. Recently released program guidance directs states to create a plan to support the sharing of patient care summaries across unaffiliated organizations, which is an opportunity to facilitate care coordination and case management.<sup>20</sup>

Finally, the Patient Protection and Affordable Care Act of 2010 (ACA, P.L. 111-148) provides several opportunities to support pediatric care coordination and case management, particularly via the medical home:<sup>21</sup>

- Beginning January 1, 2011, ACA gives states an option to implement “health homes” for Medicaid beneficiaries with chronic conditions via a state plan amendment. Children are not explicitly referenced or excluded, but there seems to be an opportunity for states to implement health homes for children with two chronic conditions, one serious and persistent mental health condition, or one chronic condition and risk factors for a second condition. ACA will provide 90 percent federal matching for medical home provider reimbursement for the first two years it is in effect.
- ACA establishes a pediatric accountable care organization demonstration project to run from 2012 to 2016. Participating states will be authorized to allow pediatric medical providers that meet certain requirements to be recognized as an accountable care organization (ACO) and receive incentive payments. An ACO is “a local entity and a related set of providers, including at least primary care physicians, specialists, and hospitals, that can be held accountable for the cost and quality of care delivered to...defined populations” (Devers and Berenson 2009, 1).

- ACA also includes funding to promote the use of a medical home model via the establishment of a new Center for Medicare and Medicaid innovation to test different health care delivery and financing models. It, for example, establishes a grant program for states to create “community health teams” to support the medical home. These teams will be made up of an array of health care providers (that may include specialists, social workers, and behavioral/mental health professionals) to help primary care practices effectively provide care planning and case management, collect data, share information, collaborate with community-based resources, and create a coordinated system of early identification and referral for children at risk of developmental or behavioral problems.
- Beginning in fiscal year 2011, ACA authorizes funding for five years for a second grant program to support “community-based collaborative care networks,” which are consortiums of health care providers (including federally qualified health centers and disproportionate share hospitals) that provide coordinated and integrated services for low-income populations. Team responsibilities will include case management and helping individuals access a medical home.

Together, these federal opportunities could help states change the way early childhood providers from various sectors communicate health care information across systems and with families.

## Potential Roles for Early Care and Education Providers

Within the platforms in Medicaid and CHIP as well as new federal opportunities, early care and education providers can play important roles to promote greater care coordination/case management. State experience (and research) working through these providers is limited; however, given their frequent interactions with and knowledge of low-income children receiving early intervention and other developmental services, early care and education providers are important partners for states to consider. Early care and education providers could potentially serve as Medicaid or CHIP-funded care coordinators, interact with existing care coordinators, inform or advise Medicaid/CHIP-funded care coordination/case

management activities, and engage families. Each one of these is discussed in turn.

### *Serve as Medicaid/CHIP-Funded Care Coordinators*

Early childhood sectors can work with the state Medicaid agency to explore having early care and education providers receive Medicaid reimbursement for providing care coordination/case management services. Both case management services covered under EPSDT and TCM can be delivered to eligible children by an array of early childhood providers. States must offer any service provider or entity that meets the qualifications and would like to participate in Medicaid as a case management service provider with the chance to do so.<sup>22</sup> There is limited information and research to date on states using Medicaid or CHIP funding to employ early childhood providers as care coordinators or case managers. However, Rhode Island has a TCM program for children enrolled in Head Start who are eligible for EPSDT. For this program, eligible TCM providers include Head Start Agency professionals who complete a training and meet all Head Start Program requirements.<sup>23</sup> Additionally, in some states Head Start staff help link Medicaid-eligible or enrolled children to needed oral health care services (American Dental Association 2004). These experiences may inform state efforts to coordinate care for children receiving services for developmental delays.

### *Interact with Medicaid/CHIP-Funded Care Coordinators*

Early care and education providers can also interact with care coordinators in the medical sector (primary care practices) to better understand or help improve the medical aspects of a child or family’s needs. Making that local connection can help strengthen lines of communication between the two sectors so each benefits from the other’s expertise to improve the lives of children and their families. For example, a local primary care practice may participate in a medical home initiative that funds a care coordinator/case manager; this individual may be a resource early care and education staff can turn to for assistance with family medical needs. To facilitate this type of cross-sector interaction, medical and early care and education providers will need to explore and address privacy considerations.

### *Inform Care Coordination/Case Management Activities*

Early care and education providers can add their expertise and experience to inform Medicaid/CHIP care coordination and case management activities. These providers can strengthen new or existing medical home, quality improvement, health information technology, or data-sharing activities by ensuring they include early childhood data and resources for families and incorporate a family or caregiver perspective. This can be achieved by, for example, participating in state or local workgroups that guide medical home or other initiatives or by attending public meetings about these initiatives to provide feedback.

### *Engage Families in Care Coordination/Case Management*

Finally, early care and education providers are uniquely positioned to engage families in care coordination and case management. Families and caregivers may need education about the importance of care coordination/case management and the role they can play in sharing information with medical, early intervention, and early care and education providers. Families also may need encouragement to feel empowered to expect and participate in care coordination/case management for children with developmental delays. Home visitors, Head Start/Early Head Start, and child care providers can share information about new or existing initiatives such as medical homes or dedicated care coordination/case management staff in the community. They also can encourage families to participate in planning or advisory workgroups or public meetings for these initiatives. Although all sectors share responsibility for engaging families, early care and education have insight about and relationships with families that other sectors lack.

As outlined by Johnson and Rosenthal (2009), there are several initial steps to understanding which care coordination and case management roles may be most feasible in a state. All involve exploring current Medicaid- and CHIP-funded care coordination/case management policies within the state, including whether the state does any of the following:

- provides Medicaid/CHIP financing to support care coordination/case management by a child's medical home
- funds county- or community-level care coordination/case management staff
- has Medicaid or managed care policies (e.g., primary care provider guidelines, billing codes) that support care coordination/case management
- defines the role of the pediatric primary care provider in early intervention referrals, assessment and treatment
- evaluates the availability and quality of care coordination/case management services

### **Conclusion**

Ensuring that children with or at risk of developmental delays complete referrals and gain access to appropriate and timely follow-up services continues to be a challenge within Medicaid and CHIP. However, there are policy options in both programs to support care coordination/case management that can promote more appropriate and timely follow-up for children needing such care. States continue to use these mechanisms to develop and test improvement models; refining and testing alternative service delivery and payment methods for care coordination and case management at the state level are critical, given the need for more research on appropriate care coordination/case management measures and the effectiveness of these strategies.

Although state budget cuts may reduce the availability of local child and family supports, federal health reform provides opportunities for states to develop the infrastructure they need to ensure families receive timely and appropriate early intervention and other follow-up services. Early care and education providers could inform and strengthen care coordination and case management activities. Successfully identifying children with or at risk of developmental delays, improving referral and follow-up treatment, and meeting the mental and physical health needs of parents are all important components of a well-coordinated system of care. Other briefs in this series address these related topics in depth.

## About the Author

Carrie Hanlon is a policy specialist at the National Academy for State Health Policy, where she analyzes best practices in health system performance, such as state policies to improve quality of care, health equity, care coordination, and patient safety.

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## About the Project

The four briefs in this series provide a common core of knowledge about how state Medicaid/CHIP policy choices affect young children's development, knowledge that can be shared among state Medicaid/CHIP policymakers and state early childhood policymakers and advocates. State Medicaid and CHIP decisions have a large impact on young children's healthy development, both because those programs serve so many young children and because the policy framework for Medicaid and CHIP offers the potential to address children's physical, social, emotional, and developmental health. Above all, the briefs intend to inform early childhood leaders and advocates so they can be at the table for these high-stakes policy decisions.

Young children's healthy development depends on far more than medical treatments for physical conditions, illnesses, and injuries. Health and early childhood fields understand that healthy development requires early identification of a variety of developmental issues, effective referrals to professional treatment services, ongoing involvement in navigating different services and supports, and responses to parents' health and behavioral health challenges and family stress. Each brief concentrates on one of these four areas: screening, professional referrals, care coordination, and two-generation approaches.<sup>1</sup>

In each area, the federal-state policy framework for Medicaid and CHIP offers major opportunities to support effective child health systems that in turn can help communities, child health practitioners, and early childhood providers promote young children's healthy development. In these briefs, the Urban Institute seeks to identify the major opportunities and barriers, provide a summary of available research about promising approaches, and set the stage for more detailed state-by-state discussions.

The briefs are particularly timely because federal actions have provided new opportunities to states. The recent CHIP reauthorization legislation and the

new health reform legislation include important provisions that will affect children's health care access as well as the quality and coordination of health care. States' responsibilities to implement these laws also mean that many states are engaged in a range of major health policy decisions that could affect children and their families. For all these reasons, this is an important time for early childhood experts, policymakers, and advocates to engage in these discussions.

These briefs are one component of a project aimed at engaging early childhood leaders in state health policy decisionmaking. Because the health policy and financing issues that affect young children are so complex, data are so scarce, and states are so diverse, no series of short briefs can convey the full range of information. In addition, the Medicaid/CHIP and early childhood policy worlds have different frames of reference that are hard to bring together: different federal statutes and funding streams, professional backgrounds, even sometimes different languages. Therefore, the project includes three other components to enhance the potential partnerships and improve decisions:

- a federal memo, intended to identify for federal officials who oversee Medicaid and the HHS early childhood programs some of the issues and opportunities to promote more effective connections;
- webinars convened by the BUILD initiative to discuss the briefs with early childhood leaders; and
- targeted state discussions, led by the BUILD initiative, to bring state early childhood and Medicaid/CHIP leaders together in a small number of states.

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<sup>1</sup> The National Academy of State Health Policy (NASHP) is the author of the care coordination brief, and experts from NASHP, the BUILD Initiative, and other experts in the field represented on the Institute's advisory board have provided invaluable comments on all the briefs.

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## Notes

<sup>1</sup> SSA §1915(g).

<sup>2</sup> 34 C.F.R. § 303.23(a)(1). Early intervention was originally established in 1986 and reauthorized by Part C of the Individuals with Disabilities Education Act of 2004. (For more about Part C, see Johnson and Rosenthal 2009.) Early Intervention programs provide support, education, and related services to young children (birth to age two) with disabilities and their families.

<sup>3</sup> See the state Medicaid manual part 5, section 5320.2(B).

<sup>4</sup> See P.L. 110-252, Supplemental Appropriations Act of 2008, §7001.

<sup>5</sup> This information was derived from Health Resources and Services Administration, “Medicaid Case Management Services by State,” <ftp://ftp.hrsa.gov/TPR/webcast-Sept1-2004-Medicaid-Case-Management-Services-by-State040825.pdf> (accessed November 4, 2010) and a November 2010 search for the word “targeted” in Medicaid State Plan Amendments posted online by the Centers for Medicare and Medicaid Services.

<sup>6</sup> See the state Medicaid manual part 4, section 4302.2. (Each chapter of the manual can be accessed at <http://www.cms.gov/manuals/pbm/itemdetail.asp?itemid=CM5021927>.)

<sup>7</sup> Twelve states were advancing medical homes through PCCM; five additional states were doing so through multiple delivery systems including PCCM. See Kaye and Takach (2009).

<sup>8</sup> Centers for Medicare and Medicaid Services, 2009 Medicaid Managed Care Enrollment Report, “Number of Managed Care Entity Enrollees by State as of June 30, 2009,” [https://www.cms.gov/MedicaidDataSourcesGenInfo/04\\_MdManCrEnrllRep.asp](https://www.cms.gov/MedicaidDataSourcesGenInfo/04_MdManCrEnrllRep.asp).

<sup>9</sup> Centers for Medicare and Medicaid Services, “Medicaid Management Information Systems Overview,” <https://www.cms.gov/MMIS/> (accessed November 4, 2010).

<sup>10</sup> The five ABCD III states are Arkansas, Illinois, Minnesota, Oklahoma, and Oregon. To learn more about ABCD, visit the ABCD resource center at <http://nashp.org/abcd-welcome>.

<sup>11</sup> For a more thorough discussion, see Kaye and Takach (2009).

<sup>12</sup> See Oklahoma Health Care Authority physician addendums, [http://www.okhca.org/pdf/Physician\\_Addendum.pdf](http://www.okhca.org/pdf/Physician_Addendum.pdf).

<sup>13</sup> Oklahoma Health Care Authority, “SoonerExcel: Methodology Effective January 1, 2009,” [http://www.okhca.org/pdf/SoonerExcel\\_Methodology.pdf](http://www.okhca.org/pdf/SoonerExcel_Methodology.pdf).

<sup>14</sup> Community Care of North Carolina, “Community Care of North Carolina,” <http://www.communitycarenc.com/> (accessed August 13, 2010).

<sup>15</sup> Illinois Department of Human Services, “Cornerstone,” <http://www.dhs.state.il.us/page.aspx?item=32215> (accessed November 4, 2010).

<sup>16</sup> See Oregon Health Information Technology Oversight Panel (2010).

<sup>17</sup> See, for example, Kaye and May (2009) and Kaye and Rosenthal (2008).

<sup>18</sup> For more discussion, see Pelletier and Kenney (2010).

<sup>19</sup> Insure Kids Now, “CHIPRA Quality Demonstration Grants—Summary,” [http://www.insurekidsnow.gov/professionals/CHIPRA/grants\\_summary.html](http://www.insurekidsnow.gov/professionals/CHIPRA/grants_summary.html) (accessed November 4, 2010).

<sup>20</sup> David Blumenthal, “Requirements and Recommendations for the State Health Information Exchange Cooperative Agreement,” [http://statehieresources.org/wp-content/uploads/2010/07/Program-Information-Notice-to-States-for-HTML\\_7-6\\_1028AM.htm](http://statehieresources.org/wp-content/uploads/2010/07/Program-Information-Notice-to-States-for-HTML_7-6_1028AM.htm) (accessed November 4, 2010).

<sup>21</sup> For additional information, see Cover Missouri (2010).

<sup>22</sup> State Medicaid manual part 4, section 4302.2.

<sup>23</sup> See “Head Start Program” at Rhode Island Department of Human Services, “Targeted Case Management,” <http://www.dhs.ri.gov/ForProvidersVendors/ServicesforProviders/ProviderManuals/Rehab/TargetCaseManagement/tabid/701/Default.aspx> (accessed November 4, 2010).