

## Improving the Lives of Young Children

### ***Increasing Referrals and Follow-Up Treatment in Medicaid and CHIP***

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#### **Executive Summary**

Many young children have developmental or behavioral problems that could be addressed with appropriate services but are not identified or treated before entering kindergarten, compromising a child's ability to perform up to his or her potential in school and leading to more costly special education and health care interventions later. The patchwork of public programs that finances services for these children creates barriers in access to follow-up services for children identified by diagnostic assessments as having developmental delays or behavioral problems that would benefit from intervention. For other young children, their healthy development is jeopardized and they and their families lack access to guidance, support, and community services that could improve their opportunities for healthy development. This brief discusses referrals to services to address developmental delays and behavioral and physical health problems. Other resource briefs in this series address screening for developmental delay, case management/care coordination, and two-generational services that affect the health and development of young children.

Despite the fact that Medicaid mandates that enrolled children have access to all necessary treatments and therapies, gaps in service receipt exist for children enrolled in Medicaid. Together, Medicaid and the Children's Health Insurance Program (CHIP) cover half of low-income children and two-thirds of low-income young children. Increasing referral rates and increasing the number of Medicaid- and CHIP-covered at-risk children who receive treatment and intervention services could therefore have a large impact on treatment rates among low-income young children.

This brief discusses the following barriers that limit referral and treatment for children in Medicaid and CHIP:

- uninsured children identified as needing these services may be eligible for Medicaid and CHIP but not enrolled;
- reimbursement rates and complex billing rules may make it difficult for providers to serve Medicaid enrollees;
- primary care providers may not have the capacity to meet the treatment needs of young children within the context of their primary care practice;
- the lack of medical specialists and community-based treatment providers to provide needed services to children in Medicaid; and
- the system is fragmented between primary care providers and treatment providers.

These problems undercut the intent of the law that all children should receive medically necessary treatment services.

States can take steps within the existing Medicaid/CHIP policy environment to address gaps. Further, to track gaps and progress in this area, states will need to invest in data systems that allow them to evaluate Medicaid/CHIP participation, screening, assessment, referral, and treatment rates are changing.

#### ***Establish Clear Connections between Medicaid/CHIP and Part C Early Intervention***

Because the basic purpose of and eligibility criteria for Medicaid and Part C programs differ, some children who would benefit are not enrolled in both programs. For children who meet the eligibility criteria for both programs, better coordination between Medicaid and Part C could improve access to care. Ensuring that all Medicaid-eligible children already enrolled or newly enrolling in the Individuals with Disabilities Education Act Part C Early Intervention program are also enrolled in Medicaid could increase the likelihood that they receive recommended care. Conducting Medicaid outreach to parents of children enrolled in Part C and placing Medicaid application assistants at early intervention sites could facilitate Medicaid enrollment for these children, while simplifying and coordinating billing systems between Medicaid and

Part C could increase the share of Part C services that Medicaid reimburses.

### *Increase Supply of Specialty and Community Providers Accessible to Medicaid Children*

For severe behavioral, developmental, and mental health problems that require referral to a specialist for treatment, primary care physicians may face a limited number of specialty providers, who are often not located in high-poverty areas where the need for services may be greatest. In addition, low reimbursement rates, payment delays, and complicated billing rules may deter providers who would be otherwise willing to serve Medicaid-enrolled children. Increasing reimbursement rates for specialty care and treatment services, modifying rules that prevent billing for physical and mental health visits on the same day, addressing delays in reimbursement from Medicaid/CHIP, allowing the use of diagnostic codes more appropriate for young children, and expanding the types of providers and settings eligible for Medicaid reimbursement are strategies states can use to better align billing and reimbursement rules with the needs of young children. In addition, funding interpretation, transportation, case management, and home visiting services could reduce barriers related to language, transportation, stressful family environments, and parental depression that impede access to needed treatment services .

### *Enhance Capacity of Primary Care Providers*

A lack of capacity, appropriate training, and confidence among primary care providers in their ability to manage young children's mild developmental, behavioral, or mental health problems may preclude interventions that could be provided in a pediatric or other primary care practice. Some strategies states have used to address this problem include provider training on primary care interventions and screenings for family or neighborhood situations that could negatively affect a child's health, and ensuring that these providers can receive appropriate reimbursement for services they provide.

### *Connect Primary Care Providers to Specialists and Intervention Programs*

Increasing referral rates and receipt of treatment services depends on establishing links between the

primary care system, which screens children, and the network of medical and behavioral specialists, therapists, and community-based intervention programs that conduct assessments and provide treatment. Some states addressed this issue by reducing and streamlining required paperwork and creating online service networks and referral systems or by contracting with managed care plans that are explicitly designed to serve children with complex needs.

### *Use Data to Monitor, Develop, and Fine-Tune Policy Changes*

To track progress in this area, states will need to invest in data systems that allow them to evaluate how rates of screenings, assessments, referrals, and treatment services are changing. Accurate data are needed on the number of children receiving these services and the number of children who should be receiving these services. However, determining which children should have received a referral or treatment services is not feasible from existing administrative data. The adoption of electronic health records (EHRs) may increase states' ability to track treatment for children with and at risk for developmental delays. In some instances, EHRs can be financed with Medicaid administrative funds and economic stimulus funds made available in 2009.

### *Take Advantage of New Opportunities in CHIPRA and Health Reform*

The Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009 and the Patient Protection and Affordable Care Act (PPACA) of 2010 both contain provisions that could improve access to treatment for children at risk for or in need of services under Medicaid and CHIP. CHIPRA funds demonstration projects focused on child health quality improvements (including delivery system changes, implementation of electronic health records, quality measurement, and childhood obesity reduction) that may draw more attention to the inadequacies of the current system and lead to corrections.

PPACA contains provisions that change the playing field for children's health. First, federal health care reform will likely increase the number of children and parents covered under Medicaid due to new investments in outreach, enrollment simplifications,

and eligibility expansions to adults. Second, the new law contains provisions aimed at increasing provider access in Medicaid, which could increase receipt of treatment services by young children covered under the program. However, it is unclear whether the scheduled increase in reimbursement rates will be sustained beyond 2014 or whether the higher rates will ultimately be available to non-physician providers of primary care, such as registered nurses. Moreover, there is no scope in current legislation for federal funding that specifically increases Medicaid rates for specialty care. Third, the law also includes funding for the promotion of a medical home model, a demonstration project for the creation of pediatric accountable care organizations, and expanded home visiting services for children, which could increase children's access to needed services. Home visiting can be used for delivering treatment services when families need them and for coordinating and case managing services.

While promising policy developments could increase the extent to which young children are referred to and receive needed assessments and treatment services, this is only one of the many issues that affect children's health and development. Concerns persist about the underidentification of children at risk for or with developmental problems, the effectiveness of care coordination and case management systems for children identified as needing services, and the availability of services to treat parents' mental and physical health problems. These issues and available policy choices to address them are discussed in other briefs in this series.

## Introduction

Many young children have developmental or behavioral problems that could be addressed with appropriate services but are not identified or treated before entering kindergarten, compromising a child's ability to perform up to his or her potential in school and leading to more costly special education or health care interventions later. Child health encompasses not only physical health, but mental and social-emotional health, and well-being and development (Bruner 2010b; Institute of Medicine 2004). Approximately 14 percent of all children, and 18 percent of poor children, have an established risk condition for developmental delay (such as low birth weight) or an observable cognitive or motor delay by age 24 months (Rosenberg, Zhang, and Robinson 2008).<sup>1</sup> In addition, young children may have behavioral health problems that interfere with their social-emotional development and functioning or speech or hearing problems that interfere with their ability to communicate (Blanchard, Gurka, and Blackburn 2006).

Other young children are in situations where their healthy development is jeopardized but they and their families lack access to guidance, support, and community services that could improve their opportunities for healthy development. For instance, young children in poor households are at higher risk of health problems that interfere with normal development and functioning because they experience less verbal communication with parents; have less access to toys; have higher family stress and more environmental hazards, such as exposure to lead paint; and because they are more likely to live in violent or distressed neighborhoods where they cannot safely play (Moore and Vandivere 2000; Zero to Three and Ounce of Prevention Fund 2010). In addition, their parents may be experiencing depression and stress that make it difficult for them to ensure the healthy development of their child.

Estimates vary on how many children with identified needs do not receive treatment services (Rosenberg et al. 2008; Simpson, Colpe, and Greenspan 2003). One study estimates that only 26 percent of children in Medicaid with a chronic condition or disability saw a specialist during the year (Kuhlthau et al. 2004), while another finds that only 10 percent of children with cognitive delays are

receiving services to meet their needs (Rosenberg et al. 2008). There are also gaps in the extent to which children with less severe problems receive needed treatment services outside the context of Part C, such as behavioral, mental, or nutritional health services and counseling and devices such as eyeglasses and hearing aids (Johnson 2010). However, it is difficult to define what the appropriate rates of referrals and specialty care receipt should be because of difficulties accurately defining children in need from the available Medicaid claims data and tracking these children to verify receipt of treatment.

The current patchwork of public programs and agencies that finance services for these children, including Medicaid/CHIP, Part C, Title V Maternal and Child Health block grant, and state and local mental health agencies, creates barriers to follow-up services for children identified as having developmental delays or behavioral problems that would benefit from intervention. Many children identified in screenings as needing further assessment do not receive a standardized assessment because of limited capacity of the primary care provider or inadequate resources to refer these children to providers or programs with the capacity to conduct assessments (Halfon et al. 2003; Sand et al. 2005). Further, many children referred to specialists or other programs for assessment or treatment do not receive that care because of barriers related to provider availability and the family's ability to access that care (Reuland and Bethell 2005; Richardson et al. 1995). These barriers are likely interrelated in that lack of referral and treatment resources may deter primary care providers from screening children out of a fear of not being able to meet a child's needs once they are identified.

Together, Medicaid and CHIP cover half of low-income children and two-thirds of low-income young children.<sup>2</sup> Increasing the number of Medicaid/CHIP-covered at-risk children who receive treatment and intervention services would therefore positively affect treatment rates in this population. Increasing treatment requires several steps: improved treatment within primary care; increased referral to assessment, follow-up, and treatment services; and appropriate ongoing, coordinated intervention services once referred. This brief focuses on what policies could facilitate needed referrals indicated by the screening outcome (either further assessment or treatment

services) and what policies could ensure a successful outcome of the referral (children receive recommended visits with specialists or treatment providers). An earlier brief explored the factors that prevent Medicaid- and CHIP-eligible children from being screened for developmental and behavioral health problems (Kenney and Pelletier 2010). Subsequent briefs will address care coordination and case management and gaps in two-generational services that may adversely affect children.

## Medicaid and CHIP Policy: The Overall Framework

Medicaid provides a comprehensive benefit package to children that includes Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) services, which under federal law covers any service deemed medically necessary to promote a child's healthy physical, behavioral, and emotional development. EPSDT mandates that all children in Medicaid receive screenings in accordance with state-established periodicity schedules, additional screenings when a problem is suspected, and any follow-up services that are medically necessary to "correct or ameliorate defects and physical and mental illnesses and conditions discovered by the screening services" and can be covered according to federal Medicaid law (box 1).<sup>3</sup> Treatment services are required for all types of conditions—medical, mental health, developmental, acute, and chronic—and must be provided not only to treat existing conditions but also to prevent conditions from developing or worsening (Johnson 2010). While coverage of well-child visits is required in all CHIP plans, children in CHIP are not guaranteed the full range of EPSDT services.<sup>4</sup> While no published estimates exist on the share of CHIP enrollees with EPSDT benefits, considering both children in Medicaid expansion programs funded by CHIP and those in separate CHIP programs that offer Medicaid-level benefits, at least 35 percent of CHIP enrollees are estimated to have EPSDT benefit coverage (Rosenbaum and Wise 2007; Wyses, Pernice, and Riley 2003).<sup>5</sup> Children in CHIP who do not have the full EPSDT benefit but have high health needs may face limits on specialty services, such as physical, occupational, and speech therapies, mental health services, and home-based care (VanLandeghem et al. 2006). In addition, states can require children in CHIP to share in the cost of coverage through

premiums, copayments, and coinsurance as long as the total amount that a family pays out of pocket per year is not more than 5 percent of the family's income, though cost-sharing levels have historically been much lower than allowed under the statute (Selden et al. 2009). We focus on policy opportunities within the context of EPSDT and Medicaid because most young children served by these two programs are covered under Medicaid.

**Box 1. Diagnostic and Treatment Services Covered by Medicaid Early and Periodic Screening and Diagnostic Treatment Benefit**

- Inpatient hospital services
- Outpatient hospital services
- Rural health clinic services
- Federally qualified health center services
- Laboratory and X-ray services
- Physician services
- Pediatric nurse practitioner or family nurse practitioner services
- Home health services for persons eligible to receive nursing facility services
- Case management services
- Dental services, including orthodontia and dentures
- Prescribed drugs
- Physical therapy and related services
- Eyeglasses
- Home health care services (includes nursing services, home health aides, medical supplies and equipment, physical therapy, occupation therapy, speech pathology, audiology services)
- Private duty nursing services
- Clinic services
- Prosthetic devices
- Other diagnostic, screening, preventive, and rehabilitative services, including any medical or remedial services recommended for the maximum reduction of physical or mental disability and restoration of an individual to the best possible functional level
- Intermediate care facility for the mentally retarded services
- Inpatient psychiatric hospital services
- Hospice care
- TB-related services
- Respiratory care services
- Personal care services
- Primary care case management services
- Any other medical care, and any other type of remedial care recognized under state law, specified by the Secretary of the Department of Health and Human Services

Source: 42 U.S.C. §§ 1396d(r)(5), 1396d(a) as found in Johnson (2010).

In practice, however, not all children in Medicaid receive comprehensive EPSDT services. Barriers to treatment services are likely even higher than the barriers that limit the receipt of well-child visits for children in Medicaid due to the gaps in the number of and accessibility to specialists and intervention providers and the fragmentation between primary and specialty care that can cause difficulties for families trying to navigate between them (Johnson 2010). In addition, children from racial and ethnic minority groups are less likely to receive specialty care, even when taking income into account (Kuhlthau et al. 2004).

Most children in Medicaid are covered by managed care plans.<sup>6</sup> The evidence is mixed on whether managed care increases or decreases children's access to and use of a range of different services (Curtis, Kaye, and Riley 1999; Hill, Westphal Lutzky, and Schwalberg 2001; Huffman et al. 2010; Newacheck et al. 1996; Szilagyi 1998). Some states have used mental and behavioral health "carve outs" that cover services provided by mental health specialists that are separate from their primary care providers. Other states have designed integrated managed care programs specifically for children with special health care needs that combine coverage for all primary and specialty services with reimbursement rates that reflect the higher cost of insuring these children. According to one study, the plans that carve out certain services reduce children's access to specialty care, while small (but statistically insignificant) improvements are seen for children in the integrated plans (Davidoff et al. 2007; Tang et al. 2008).

While Medicaid's EPSDT benefit covers services based on medical necessity, Part C covers services targeted at families to promote healthy relationships and provide supports for children who qualify.<sup>7</sup> These services may include family service coordination or case management, parent training, counseling, support groups, and transportation to nonmedical services (Berson et al. 2004). Therefore, children enrolled in Part C generally have access to a wider range of services than those covered in Medicaid alone, though states can choose to include these services in their Medicaid benefit packages (Johnson and Kaye 2003; Kaye, May, and Abram 2006).

While Medicaid is a medical insurance program, Part C is a state system of intervention services and supports, not all of which may be considered medically necessary by Medicaid. An important difference between Part C and Medicaid eligibility is that there is no income limit for eligibility in Part C. Another important difference in eligibility is that states can set their own definitions for the severity of risk that makes a child eligible under Part C, whereas all needs identified through EPSDT screening are eligible for services under Medicaid. This is especially important in practice because the federal government provides only a limited amount of Part C grant funds to each state based on the number of children from birth through age 2 recorded by the Census. As a result, while states are required by the Individuals with Disabilities Education Act (IDEA) to identify all children eligible for Part C and to provide access to all services included in a child's Individualized Family Service Plan, states often adopt strict eligibility definitions for Part C that limit the number of children the state is required to serve (Shackelford 2006). Because Part C is the payer of last resort, many Part C services are paid for with non-Part C funds. State and local health and education agencies (including Medicaid, Title V Maternal and Child Health programs, state mental health programs, and schools), a child's private insurance, and a child's family may be required to help finance Part C services (Apling and Herz 2003; Johnson and Rosenthal 2009; Shackelford 2006). States vary widely in the proportion of children age 0 through 2 who are enrolled in Part C, from 1 percent of all children to nearly 7 percent of all children. Nationally, 2.5 percent of all infants and toddlers receive Part C services.<sup>8</sup>

Given these different legislative mandates, the overlap between Medicaid and Part C is complex. One study in Florida found that over half of children under age 3 receiving behavioral health services in Medicaid were also enrolled in Part C, and about a third of young children enrolled in Part C were also receiving behavioral health services through Medicaid. As expected, children receiving services through both programs had more need (as evidenced by the higher number of service claims) than children enrolled only in Medicaid (Berson et al. 2004).

## State Medicaid/CHIP Policy Choices That Promote Referral and Treatment Services for Children

Despite the importance of timely receipt of treatment services for young children and the fact that such treatment is mandatory for children enrolled in Medicaid, many children do not receive recommended referrals and treatment (Johnson 2010). Major barriers limiting referral and treatment for children in Medicaid and CHIP include

- some uninsured children needing these services may be eligible for Medicaid and CHIP but not enrolled;
- low reimbursement rates, payment delays, and complicated billing rules may deter providers who would be otherwise willing to serve Medicaid-enrolled children;
- primary care providers may be unable to treat children within the context of primary care;
- the lack of medical specialists and community-based treatment providers to provide needed services to children in Medicaid; and
- fragmentation or lack of communication between primary care providers and treatment providers can inhibit referrals and impede children's access to treatment.

Together, these problems undercut the intent of the law that all children should receive medically necessary treatment services. States can take a number of steps within the existing Medicaid/CHIP policy environment to address gaps. To track both gaps and progress in this area, states will need to invest in data systems that allow them to evaluate how Medicaid/CHIP participation, screening, assessment, referral, and treatment rates are changing.

### *Establish Clear Connections between Medicaid/CHIP and Part C*

Because the basic purpose of and eligibility criteria for Medicaid and Part C programs differ, some children who would benefit from enrollment in both programs are not enrolled in both programs. Some children in Medicaid who are at risk for developmental problems do not meet their state's eligibility criteria for enrollment in Part C. While children in Medicaid are entitled to all medically necessary services allowed

under federal Medicaid law through Medicaid's EPSDT benefit, children enrolled in both programs benefit from access to additional family-level support services and case management services available through Part C (Berson et al. 2004).

Recent estimates suggest that 75 percent of uninsured young children are eligible for Medicaid/CHIP but not yet enrolled.<sup>9</sup> Ensuring that all children already enrolled or newly enrolling in Part C who are eligible for Medicaid/CHIP are enrolled in these programs could increase the likelihood that they receive recommended medical care available through Medicaid. In addition, enrolling these children in Medicaid/CHIP would free up scarce Part C resources, enabling states to better serve children enrolled in Part C, expand eligibility for children with delays or disabilities, or expand eligibility to include at-risk children (Johnson and Kaye 2003). Conducting Medicaid outreach to parents of children enrolled in Part C and placing Medicaid application assistors at early intervention sites could facilitate Medicaid enrollment for these children.

Complicated billing rules and unclear coordination between Medicaid and Part C can deter providers from seeking Medicaid reimbursement for the Part C services they deliver, which increases financial pressure on the Part C program and may reduce children's access to care. An example of a state that has attempted to simplify the billing process is Indiana, which has created an electronic system that bills the various funding streams (including Medicaid, state and federal early intervention/Part C allocations, Title V Maternal and Child Health Services block grant, Social Services block grant, and TANF) that pay for Part C services delivered to a child according to an established hierarchy. The state has reported an increase in financial resources following this billing change (Johnson and Kaye 2003).

### *Increase Supply of Specialty and Community Providers Serving Medicaid Children*

For problems that require referral to a specialist for the treatment of more severe behavioral, developmental, and mental health problems, primary care physicians are faced with a limited number of providers in these specialties, and they are often not located in high-poverty areas where need for these services may be greatest (Rubin Stiffman et al. 2010). Such issues combined with complicated billing rules

and payment delays may deter providers who are willing to serve Medicaid-enrolled children from billing Medicaid for these services. States have attempted to address these problems through multiple strategies (Bruner 2010b; Johnson and Kaye 2003; Kaye et al. 2006).

Medicaid and CHIP often reimburse providers at rates that are below commercial insurance (Kautz, Mauch, and Smith 2008; McManus 2006), and there is some evidence that increasing reimbursement makes providers more willing to accept Medicaid- and CHIP-covered children in their practices (Berman et al. 2002; Zuckerman et al. 2004). However, increasing reimbursement rates for services provided under Medicaid alone is unlikely to be sufficient to address provider supply issues. Addressing those issues may require that states address other reimbursement issues, such as rules that prevent billing for physical and mental health visits on the same day (Kautz et al. 2008) and delays in reimbursement from Medicaid/CHIP, which appears to reduce provider willingness to participate in the programs (Cunningham and O'Malley 2009).

One major challenge that states have tried to address in their billing systems is that the codes providers use to bill Medicaid are often built from the health needs of adults, not young children. For example, some behavioral and developmental problems young children face do not fit into established diagnostic categories, which have been designed for adults. While a diagnosis code is typically required for billing in Medicaid, some states have tried to increase the ability of providers to bill Medicaid for these services by using codes explicitly set up to address the behavioral and developmental needs of young children. Iowa, Montana, and Utah use the DC: 0-3R for billing (Kaye et al. 2006). The DC: 0-3R is a diagnostic classification system designed specifically for children from birth to age 3 (Johnson and Kaye 2003; Lyman, Holt, and Dougherty 2010). Another approach states have taken is to use V-codes when treating certain mental health conditions in children (Johnson and Kaye 2003). V-codes are used when a problem has been identified but a specific diagnosis has not been made.<sup>10</sup> These codes allow providers to bill Medicaid for serving at-risk children without a diagnosis code and to avoid mislabeling a child. Again, while these strategies are

promising, there is no published evidence on their impact on receipt of these services.

Some states have attempted to increase access to these services by expanding the types of providers that can bill Medicaid for specific services, including independent certified nurse practitioners (Illinois), clinical nurse specialists (Illinois), licensed independent social workers (Iowa), mental health providers who enroll as providers (North Carolina), and family support workers who provide home visiting care (Vermont) (Kaye, May, and Abrams 2006). In addition, some states have expanded the locations where those services can be provided. For example, while some states restrict Medicaid reimbursement for services provided by child psychologists to only services provided in a mental health center or pediatric office, other states allow early childhood mental health consultations delivered in child care centers to be billed to Medicaid (Johnson and Kaye 2003). While it is reasonable to assume that allowing more provider types and service locations to bill Medicaid would expand access to services, to date there has been no published evaluation of the effects that such policy changes have on access to care for children in these states.

In addition, to increase provider supply, states may need to address other factors, such as billing, reimbursement, perceived gaps in cultural competence, and negativism about the Medicaid program and the population served by Medicaid. Many providers believe they lack appropriate training to serve a low-income, racially and ethnically diverse patient population and to deal with the challenges this population faces that affect patients' relationship with the health care system. Connecting providers to practices in their area that successfully serve Medicaid and CHIP populations and providing cultural and financial training on how to understand the needs of this population, Medicaid billing, and how to integrate them into the practices could help bridge these gaps (Edelstein 2009).

States have also implemented policies to address language and transportation barriers that reduce receipt of needed services (Cohen and Christakis 2006; Fairbrother et al. 2005; Kelly et al. 2005; Perry 2008). New funding for interpretation and translation services in the CHIP reauthorization could help states expand access to these services (Georgetown Center for Children and Families 2009; Jacobs et al. 2004).

Targeted case management, which is covered by Medicaid, can assist families in overcoming barriers that make navigating the health system difficult. State Medicaid programs can provide funding for these activities at the practice level through capitated payments in managed care contracts or primary care case management programs, as is being done in North Carolina and Illinois (Johnson and Rosenthal 2009). A later brief in this series describes these programs in more detail (Kaye and Hanlon 2010). It may be useful to states to address ways that families can better use the transportation benefit available under EPSDT to help families reach providers (Arcury et al. 2005; Grant et al. 2010; Yang et al. 2006).

### *Enhance Capacity of Primary Care Providers*

Lack of capacity and appropriate training as well as a lack of confidence among primary care providers in their ability to successfully manage young children's mild developmental, behavioral, or mental health problems may reduce how often interventions are provided in the context of pediatric or other primary care practices and may limit the provision of screenings (Halfon et al. 2003). Provider confidence and skill in interventions in primary care settings may be increased through training, such as nutritional counseling for an overweight child or teaching eye exercises for a child with vision problems that can be easily delivered during a well-child visit and can prevent problems from worsening without the need for a referral (Bruner 2010b). In addition, as addressed in other briefs in this series, it will be important to increase screenings for parental depression and family or neighborhood environments that could be negatively affecting a child's development as part of regularly conducted developmental surveillance and to refer families to community programs that can address underlying determinants of health, such as poverty, homelessness, domestic violence, and/or food insecurity (Bruner 2010a).

Staffing and time limitations may also pose barriers to delivering treatment services. Ensuring the practices can bill for treatments they provide (e.g., through alternative diagnostic codes) and case management services provided by office staff could help address these capacity issues.



## Connect Primary Care Providers to Specialists and Intervention Programs

Increasing referral rates and receipt of treatment services depends on establishing links between the primary care system that screens children and the medical and behavioral specialists, therapists, and community-based intervention programs that conduct assessments and provide treatment. Because primary care providers are often unaware of the community programs available to serve children in need of treatment, training and education on how these systems interact could improve referrals rates and outcomes. A later brief in this series addresses states' opportunities for connecting providers from these different sectors, including supporting the development of medical homes to facilitate communication among primary care providers, specialists, and community-based programs; dedicating staff to care coordination services; and using health information technology for data sharing on children to monitor and better coordinate care (Kaye and Hanlon 2010). We limit our discussion in this brief to ways states can connect these systems to improve referral rates and rates of successful referrals (i.e., those that result in a visit with the referred provider).

While states must have a process in place for referring children who need follow-up visits after an EPSDT screening visit, as indicated above, the process does not always work smoothly. Some states have attempted to promote higher successful referral rates by reducing the number of forms required (Vermont) (Kaye et al. 2006), creating a universal referral and fax-back form for statewide use (Maryland), creating referral forms specifically to connect children to non-physician providers, and establishing online service networks to connect children to specialists, services, and programs (Johnson and Rosenthal 2009). Web-based referral systems can reduce paperwork and improve opportunities for tracking the number and outcome of referrals. In Connecticut, the *Help Me Grow* program connects parents and primary care providers to specialists. Further, the Child Development Infoline, which houses *Help Me Grow*, also coordinates referrals to Part C services, Title V Children with Special Health Care Needs program, and Preschool Special Education; and it collects data on how long it takes to connect children to services, how many

families have and have not been served, and the types of services received. States can use these data to identify gaps in service utilization and to track progress connecting children to providers (Rosenthal, Hanlon, and Hess 2008). Importantly, *Help Me Grow* also identifies other factors that affect children's healthy development, including parental stress, knowledge and ability to respond to child behaviors and discipline, and other family and community factors.

Some states that provide mental health services through a managed care health plan that is separate from physical health services (known as a carve-out) have improved coordination between these plans by clearly enumerating in the managed care contracts what responsibility each plan has for delivering services to children and for coordinating with the other plan to ensure children receive needed services (Johnson and Kaye 2003). For example, Iowa clarified that services for a diagnosis not specifically covered under its behavioral health plan could be billed to the fee-for-service Medicaid plan (Kaye et al. 2006). Progress could be achieved by clarifying the list of services included in both the physical health and mental health plans (Johnson and Kaye 2003).

Increasingly, the concept of a patient-centered medical home that provides both continuity of service to patients and connections to both treatment services and community support systems is being promoted within state statutes and as part of state quality improvement activities. Colorado and Iowa have developed definitions of a "medical home" that includes comprehensive approaches to child health and development (Lyman et al. 2010).<sup>11</sup>

## Use Data to Monitor, Develop, and Fine-Tune Policy Changes

To increase referral rates and receipt of needed treatment services, states need to address shortages of specialists in Medicaid and fragmentation between primary care and specialty care. An important first step would be to evaluate whether promising models in such states as Connecticut and North Carolina can be implemented elsewhere and achieve similar results. California and Iowa have implemented the *Help Me Grow* model, and South Carolina, Oregon, New York, Kentucky, and Massachusetts are receiving technical assistance to develop *Help Me Grow*, which will provide valuable information on the portability of

these models (Dworkin 2009).<sup>12</sup> In addition, states currently can raise reimbursement rates and simplify billing procedures that may be deterring providers from serving children in Medicaid/CHIP. While several promising policy options are available to states, more systematic analysis of how state policy choices influence referral and treatment rates could help guide state action.

To track progress in this area, states will need to invest in data systems that allow them to evaluate how rates of screenings, assessments, referrals, and treatment services are changing (Reuland and Bethell 2005). Accurate data are needed on the number of children receiving these services (the numerator) and the number of children who *should* be receiving these services (the denominator). Calculating the correct denominator therefore depends on collecting detailed information on the outcome of screens and assessments, which is currently only done for children whose assessment reveals a diagnosable problem. Children whose screening or assessment result indicates that they are at risk for developmental delay but do not have a diagnosed problem should ideally be included in the denominator, but current data systems are limited in their ability to track these children. In addition, because receipt of treatment services may be tracked separately from primary care services (as in the case of behavioral or mental health carve-outs in Medicaid), numerators and denominators may come from different sources and therefore require a larger investment in data analysis. The adoption of electronic health records, which, in some instances, can be financed with economic stimulus funds made available in 2009 (through the American Recovery and Reinvestment Act) and Medicaid administrative funds, can improve data collection and analysis (Johnson and Rosenthal 2009). States can begin by piloting electronic health records and appropriate data collection in a few practices to test possible best practices before expanding statewide.

### *Take Advantage of New Opportunities in CHIPRA and Health Reform*

The Children's Health Insurance Program Reauthorization Act (CHIPRA) of 2009 (PL 111-3) and the Patient Protection and Affordable Care Act (PPACA) of 2010 (PL 111-148) both contain provisions that could lead to greater receipt of referrals and treatment services among children at risk

for or in need of services under Medicaid and CHIP. In particular, CHIPRA funds a number of demonstration projects focused on child health quality improvements (including delivery system changes, electronic health records, quality measurement, and childhood obesity reduction) that may identify solutions to inadequacies in the current system and lead to improvements (Georgetown Center 2010b). Moreover, development and use of the proposed quality measures could increase the extent to which children receive needed care under Medicaid.

The PPACA contains provisions that change the playing field for children's health. First, federal health care reform will likely increase the number of children covered under Medicaid due to new investments in outreach and enrollment simplifications (Georgetown Center 2010a). Further, more parents will qualify for Medicaid coverage, which has the potential to increase children's health care access and improve health and well-being (Davidoff et al. 2003; Dubay and Kenney 2003).

Second, the new law contains provisions aimed at increasing provider access in Medicaid, which could increase receipt of treatment services by young children covered by the program. While many provisions target primary care, the Medicaid and CHIP Payment and Access Commission (MACPAC), funded by the PPACA, is charged with assessing the adequacy of provider payment and access under Medicaid and CHIP and may stimulate more policy changes aimed at improving access to both primary and specialty care. The law uses federal funding to increase reimbursement rates for primary care physicians providing certain primary care services up to the rates paid by Medicare in 2013 and 2014 (Zuckerman, Williams, and Stockley 2009), which could increase provider access in Medicaid and the provision of services. Whether the scheduled increase in reimbursement rates will be sustained beyond 2014 or the higher rates will ultimately be available to non-physician providers of primary care, such as registered nurses, is unclear. Moreover, there is no scope in current legislation for federal funding that specifically increases Medicaid rates for specialty care. At the same time, the increased enrollment in Medicaid could lead to more provider shortages if the number of providers serving the Medicaid population does not increase to keep up with demand. The extent to

which specialty services are accessible through community health centers and other places children access care should also be considered.

Third, the law includes funding for the promotion of a medical home model and a demonstration project for the creation of pediatric accountable care organizations (ACOs). While originally designed specifically for the Medicare population, the Medicaid population was added, and therefore there is the potential to focus some attention on medical homes for children with chronic conditions. The emphasis on medical homes and ACOs could help link primary care providers to specialists and intervention programs and could result in more referrals, and more successful referrals, as multiple providers work together to meet a child's service needs. Further research is needed to assess how integrated managed care plans designed for children with special health care needs can best function within a medical home model.

In addition, a new program to promote home visiting has the potential to reach more families that would benefit from additional guidance and support. Home visiting, which as noted earlier can be supported by Medicaid, can also be used for delivering treatment services when families need them (for example, the home visitor works closely with a behavioral health clinician, introducing her to the family so she can provide services to the child and family in the home) and for coordinating and case managing services.

## Conclusion

While a number of promising policy developments could increase the extent to which young children are referred to and receive needed assessments and treatment services, to date, major policy changes in this area have been limited to a few states. While lack of data on appropriate measures has limited the ability of some states to demonstrate results, others have shown increases in referral rates and access to treatment services following the introduction of policy changes.<sup>13</sup> More evidence on the effectiveness of alternative policy approaches is needed to encourage their adoption so policies found to be successful at increasing referrals and receipt of treatment services become routine practice in Medicaid and CHIP programs around the country.

However, this is only one of many issues that affect children's health and development. Concerns persist about the underidentification of children at risk for or with developmental problems; the effectiveness of care coordination and case management systems for children identified as needing services; and the availability of services to treat parents' mental and physical health problems that negatively affect parents and children. These issues and the policy choices to address them are discussed in the other briefs in this series.

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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, different 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> Although eligibility criteria for Part C varies by state, the study used a definition that that was validated with eligibility criteria from 44 states and the District of Columbia and found to have excellent specificity and good sensitivity in classifying children.

<sup>2</sup> Tabulations from the 2008 Urban Institute Health Policy Center Eligibility Simulation Model, based on data for children age 0–5 from the 2009 ASEC to the Current Population Survey.

<sup>3</sup> U.S. Department of Health and Human Services, Health Resources and Services Administration, "EPSDT Overview," <http://www.hrsa.gov/epsdt/overview.htm>.

<sup>4</sup> Children who qualify for Medicaid through the Medically Needy eligibility criteria are not guaranteed EPSDT benefits. However, few children in Medicaid qualify through this category (Crowley 2003).

<sup>5</sup> See also Centers for Medicare and Medicaid Services, "FY 2008 Number of Children Ever Enrolled Year-SCHIP by Program Type,"

<http://www.cms.hhs.gov/NationalCHIPPolicy/downloads/FY2008StateTotalTable012309FINAL.pdf>.

<sup>6</sup> See Kaiser State Health Facts, "Enrollees in Comprehensive Medicaid Managed Care Plans as a Percent of State Medicaid Enrollees, as of June 30, 2008," <http://www.statehealthfacts.org>.

<sup>7</sup> Public Law 99-457, signed in 1986 and reauthorized as the Individuals with Disabilities Education Act in 1991, created a new Early Intervention state grant program specifically for infants and toddlers from birth to their third birthday known as Part C (Committee on Children with Disabilities 1994; Arc of the United States 1990). All states have a Part C program and are required to provide all necessary early intervention services to all children who qualify under the state's eligibility rules (Johnson and Rosenthal 2009). IDEA requires that all children who have developmental delays or diagnosed mental or physical conditions that have a high probability of resulting in a developmental delay be eligible for Part C; however, states have flexibility to define what constitutes developmental delay. This is commonly defined by deficits in functioning of 1–2 standard deviations below the mean in one or more developmental areas (cognitive, physical, communication, social/emotional, and adaptive), differences between chronological age and developmental age, and/or clinical judgment (Shackelford 2006). Additionally, states have the option to extend eligibility to children at risk of experiencing developmental delays, but few choose to do so due to the limited amount of Part C funds and the fact that all children who qualify are entitled to Part C services. In 2008, six states were covering children with biological or environmental risk factors (Johnson and Rosenthal 2009; Shackelford 2006). This flexibility in defining the population of eligible children has resulted in wide variation across states in the number and share of children served by Part C. Each child enrolled in Part C receives an Individualized Family Service Plan, which lists the services and supports the child needs given the individual's developmental needs and family context.

<sup>8</sup> Data Accountability Center, Individuals with Disabilities Education Act Data, State Rank-Ordered Tables, "Table 8-1. Infants and Toddlers Ages Birth through 2 Receiving Early Intervention Services under IDEA, Part C, by Age and State (in Descending Order of Percent of Population): 2007,"

<https://www.ideadata.org/StateRankOrderedTables.asp#partc>. Based on data from U.S. Department of Education, Office of Special Education Programs and the U.S. Census.

<sup>9</sup> Tabulations from the 2008 Urban Institute Health Policy Center Eligibility Simulation Model, based on data for children age 0–5 from the 2009 ASEC to the Current Population Survey.

<sup>10</sup> Tulane University, "Guidelines for Using V-Codes (Status Codes)," <http://tulane.edu/counsel/upco/upload/ICD-9-codes-Part-2-V-codes.pdf>.

<sup>11</sup> See also National Academy for State Health Policy, "Eight State Teams Selected to Form New NASHP Consortium to Advance Medical Homes," press release, September 1, 2009, [http://www.nashp.org/sites/default/files/Med\\_Home\\_Consortium\\_Announcement.pdf](http://www.nashp.org/sites/default/files/Med_Home_Consortium_Announcement.pdf).

<sup>12</sup> See also "Help Me Grow Orange County," <http://www.helpmegrowoc.org/>.