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Issue Brief

Systems of Care Coordination for Children: Lessons Learned Across State Models

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ABSTRACT: There are few organized systems of referral and care coordination for children and families identified with early developmental delays, complex medical conditions, and difficulties negotiating the medical and related support systems, but some promising models are emerging. This report summarizes lessons from programs in five states that refer families to appropriate community or state programs, help coordinate their care, provide support and follow-up to ensure they receive needed services, and provide a feedback loop to primary care providers. Common features of successful programs include: maximizing efficiencies through shared resources, leveraging and partnering with other organizations, in-depth involvement with pediatric practice staff, appropriate training and tools, flexible program design, measurement and evaluation, and a holistic approach to care. The findings point to a need for greater identification and dissemination of best practices and technical assistance, stable funding sources, and integration of care coordination into new models of health care financing and delivery.

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OVERVIEW

Early childhood—the years between birth and age 3—is the time when children begin to develop the foundations of physical, behavioral, and social health that will shape their experiences in school and significantly impact their life. Pediatricians and family practitioners play a vital role in promoting optimal childhood development, as they interact with young children and their families regularly during this period and can monitor children's progress compared with accepted milestones. When a child is suspected of having or being at risk for a developmental delay, guidance and an effective link to appropriate intervention services are critical. Research demonstrates that intervention is of greatest value when it begins early. Delaying services often results in a need for more treatment

and a greater intensity of services, over a longer period of time and with less-effective results.¹

Early identification of potential developmental delays in young children is greatly improved when primary care providers perform structured developmental screenings. The American Academy of Pediatrics acknowledged this in 2006 when it issued a recommendation that children receive standardized screening for developmental delays at 9 months, 18 months, and 24 or 30 months of age.² However, early identification of potential delays is only beneficial to patients when it leads to effective intervention, which requires subsequent action from both providers and families. Providers must be able to refer patients to state Early Intervention programs or link them to other appropriate supplemental services. In addition, families must complete recommended referrals and follow up with service providers in a timely fashion. Both are challenged to accomplish their respective tasks.

Furthermore, families of children and adolescents with an array of medical and nonmedical issues and families in which caregivers are stressed or depressed often have difficulty navigating the health, mental health, education, social welfare, housing, and other support systems that might address their needs. These families are at risk for falling through the cracks, particularly without a qualified person to refer to appropriate community or state programs, help coordinate care, and provide support and follow-up to ensure needed services are received.

Coordinating care is time-consuming for pediatric and family practitioners and often beyond their capacity, particularly for those in small practices. Making appropriate referrals requires an in-depth knowledge of the resources available in the community and state. But this knowledge alone may not lead to an immediate referral. In fact, one study found that even trained care coordinators needed to contact an average of 5.5 service providers to find an appropriate referral.³ Furthermore, it can be difficult, if not impossible, for providers to secure adequate reimbursement for time-consuming care coordination and referral services.

Clearly, having organized systems in place to assist with care coordination for children would be of great benefit to both families and providers—particularly pediatric practices, which serve the majority of families with children. Effective care coordination involves not only assisting families but also informing their primary care providers of the status of the referrals and interventions. This “feedback loop” enables practitioners to better track what needs have and have not been met and better serve their patients.

In this issue brief we sought to identify and study models of care coordination already in place at the state or regional levels. Through interviews with key informants and reviews of program materials and reports, existing models were identified and examined and the following issues considered: program development, scope, financing, challenges, and successes in connecting children and families to the services. This brief synthesizes the findings and presents key themes and lessons that emerged.

It was difficult to identify innovative care coordination programs and even harder to find programs with conclusive, quantitative results on overall costs and utilization of services. There is no national directory nor a simple way to track programs that may be public or private, state or local, well-publicized or barely known. Further, many care coordination programs are relatively new and have not yet undergone objective evaluations.

Nevertheless, through literature reviews, conferences, reports, and discussions with researchers, program directors, and experts in child development, the following programs were identified and selected:

- [1st Five Initiative, Iowa](#)
- [Pediatric Practice Enhancement Project \(PPEP\), Rhode Island](#)
- [Colorado Children’s Healthcare Access Program \(CCHAP\), Colorado](#)

- [Assuring Better Child Health and Development \(ABCD\), North Carolina](#)⁴
 - ◆ Partnership for Health Management
 - ◆ Carolina Collaborative Community Care (4C)
 - ◆ Sandhills Community Care Network
- [Help Me Grow, Connecticut](#)⁵

The programs were selected because of their innovative approaches to care coordination, and indications that they were successfully meeting children's, families', and providers' needs. The diversity found in these programs suggests there is no single way to provide effective care coordination, but that a variety of strategies can be successful and may be needed. Despite this diversity, some cross-cutting themes and lessons emerged, described in more detail below.

KEY FEATURES AND MODELS

Each program is unique, but share many characteristics. Exhibit 1 describes the basic elements of each program. Exhibit 2 illustrates key features common to some of the programs. All of the programs involve active partnerships and liaisons with community resources and flexibility at the community or practice level. Most of the programs include a centralized referral system or referral "utility," provider education and training, up-to-date resource directories, a feedback loop to primary care providers, and a systematic process for identifying service gaps. Some have toll-free telephone help lines or care coordinators on-site in pediatric offices and clinics. Both of these elements were highly valued by families and providers in the programs in which they were featured.

Exhibit 1. Summary Table

Program	Description	Population Served	Scope	Funding	Results
1st Five Initiative	Iowa state public health department administers program that provides mental and developmental health screening and referral forms, training to pediatric practices to conduct the screenings and 1st Five referral, community-based care coordinators that assess and make further care referrals, and feedback loop to primary care physicians.	Serves pediatric practices and their patients, children ages 0 to 5 and their families. Accepts all income and insurance types (majority of referrals are Medicaid enrollees). Focuses particularly on children with early signs of social, emotional, or mental health conditions or parental stress.	39 pediatric clinics serving more than 41,000 children and spanning 21 counties. In 2008, 486 children were referred, resulting in more than 1,500 referrals to services.	State appropriations (Healthy Mental Development Funds, tobacco taxes). EPSDT/ Medicaid and Title V covers care coordination for Medicaid and uninsured, respectively. Additional funding sought to maintain and expand program.	More than 41,000 children are in participating pediatric clinics conducting mental and developmental health and parental stress and depression screening. In one county, 120 clinics and 14 hospitals added social and emotional and family risk questions to electronic medical record assessments. Three to four service needs are identified for each child referred for care coordination.
Pediatric Practice Enhancement Project (PPEP)	Rhode Island department of health administers program, in partnership with Medicaid agency, nonprofit parent organization, and Medicaid health plan. Places trained parents of children with special needs into pediatric practices to provide care coordination to patients and families.	Serves pediatric primary care providers, specialists, and staff, and their patients, children with special needs and their families, regardless of income (majority of children served are Medicaid/CHIP enrollees).	From 2004 through 2008, PPEP served nearly 3,000 children with special health care needs and their families, representing approximately 8% of such children in the state. As of mid-2009, parent consultants were in 24 sites across the state.	Multiple sources including New Freedom Initiative grant, Title V Maternal and Child Health Services federal block grant, and some funding from state's department of human services. Additional funding sources are being sought to maintain and expand program.	PPEP participants have more outpatient encounters but fewer inpatient admissions and less intensive resource use than children with special needs who are not in PPEP practices. Families report greater understanding and satisfaction regarding the health care service system, a sense of empowerment, and enhanced knowledge of available supports.

Program	Description	Population Served	Scope	Funding	Results
Colorado Children's Healthcare Access Program (CCHAP)	Nonprofit organization assists providers and families with care coordination and other support services for Medicaid-eligible children, with feedback loop to pediatrician. Trains clinical practice staff in care coordination functions. Participating practices receive higher medical home reimbursement rate from Medicaid.	Private pediatric and family practices and their Medicaid-eligible child patients and families.	140 pediatric practices (93% of the state's private pediatric practices) with 450 providers serving 1.2 million children across the state, plus 40 family practices participate in CCHAP as of October 2009. CCHAP is active primarily in the state's populous Denver metro area, but is expanding into rural areas.	CCHAP budget funded through multiple foundations; in-kind donations (office space, computers, and IT) provided by the University of Colorado Denver School of Medicine and The Children's Hospital. Financing for the enhanced reimbursement to CCHAP practices provided through the state's existing Medicaid EPSDT program.	High physician and family satisfaction with CCHAP participation; large increase in Medicaid/CHIP children served by private practices; children in CCHAP practices visit the emergency department less often, have more preventive care visits, and are less expensive for the state Medicaid program than children in non-CCHAP-affiliated practices (although the evaluation was not able to determine the extent that CCHAP participation contributed to these outcomes).
Assuring Better Child Health and Development (ABCD)	Community Care of North Carolina (CCNC), a network of 14 community care networks (CCNs) serving Medicaid enrollees throughout the state supported physician practices with training and tools to increase screening, appropriate referral, and follow-up.	Pediatricians and other providers, and their patients, Medicaid-eligible children from birth to age 5 with developmental disabilities and delays, and their families.	14 local CCNs serving low-income individuals enrolled in Medicaid and CHIP across the state.	Three-year Commonwealth Fund grant supported initial ABCD program. CCNs receive \$3 per member per month from the state to provide case management services for a variety of services, including care coordination. Others partner with nonprofits to cover ongoing activities.	Across the state, children from birth to age 3 receiving Early Intervention services increased from 3% in 2003 to 4.3% in 2008. Number of developmental screenings completed at Medicaid EPSDT visits quintupled from 2004 to 2008.
1. Partnership for Health Management (P4HM)	Early intervention specialist hired to work in medical practices. Educated staff, identified resources, coordinated referrals, created referral tracking form, and informed physicians.	(See ABCD)	30 medical practices serving 15,000 Medicaid and CHIP enrollees from birth to age 5 in three counties.	Case management fees cover salary of Early Intervention specialist.	Children from birth to age 3 receiving Early Intervention services increased from 2.6% in 2003 to 4.5% in 2008.
2. Carolina Collaborative Community Care (4C)	A community care network partnered with other nonprofit organizations to inform providers and families about resources and encourage referrals. A local Early Intervention agency ensured follow-up with referring physician.	(See ABCD)	74 medical practices serving 13,000 Medicaid and CHIP enrollees, from birth through age 5 in one county.	Relies on community agencies and organizations with similar goals to pursue some outreach and follow-up functions. Also receives case management fees from CCNC.	Children from birth to age 3 receiving Early Intervention services increased from 3.1% in 2005 (when 4C was created) to 3.8% in 2008.

Program	Description	Population Served	Scope	Funding	Results
3. Sandhills Community Care Network	A project coordinator created a referral and resource guide, educational brochures for parents, and forms and instructions for providers in making referrals. The coordinator spent time in practices regularly to educate, track referrals, and conduct follow-up. Also encouraged agencies to provide feedback (e.g., send providers copies of child evaluations).	(See ABCD)	85 medical practices serving 11,300 Medicaid and CHIP enrollees from birth to age 5 in seven rural underserved counties.	A nonprofit organization (funded by state and private donors) funded a project coordinator for two years. New funding source being sought.	Children from birth to age 3 receiving Early Intervention services increased from 4.4% in 2003 to 4.7% in 2008.
Help Me Grow (HMG)	The Connecticut Children's Trust Fund administers a program that provides families referrals and care coordination through a toll-free phone line, with feedback loop to providers. Provides follow-up for families screened for birth-to-age-3 services, on-site training for providers and parents in screening and early detection of developmental and behavioral concerns. Liaisons with community services and agencies. The 2008 pilot connected hard-to-reach families referred by other agencies with services.	Serves pediatricians and other providers and their patients, children up to age 8 who are at risk for developmental or behavioral problems and their families, regardless of income or insurance coverage.	Available statewide. In the 2008–2009 program year, HMG care coordinators made over 4,000 referrals on behalf of children and families.	HMG supported by state-funded Children's Trust Fund and contracts with United Way, with early support from The Commonwealth Fund	In 2008–09, 88% of service needs were addressed, an increase from 80% reported in the previous year.

Exhibit 2. Key Features of Programs

Key Features	1st Five	PPEP	CCHAP	P4HM	4C	Sandhills	HMG
Centralized referral system, or care coordination utility: Community-based or centrally located staff assist providers and families in care coordination and medical home training	✓		✓	✓	✓	✓	✓
Toll-free help line: Phone line available to families and providers for information, referrals, care coordination, follow-up			✓				✓
On-site care coordinators: Trained parents, Early Intervention specialists, or others are placed in clinical practice setting to fill care coordination gaps in knowledge and staff		✓		✓	✓	✓	
Provider education/training: On-site training of pediatric providers and staff in child development screening, early signs of disorders	✓		✓	✓	✓	✓	✓
Resource directories: Develop and maintain resource lists for providers, continually revise and update	✓	✓	✓	✓	✓	✓	✓
Partnerships and liaisons with community resources: Work closely with community service providers and agencies to facilitate links to providers and families, fill gaps	✓	✓	✓	✓	✓	✓	✓
Feedback loop: Inform pediatric providers of patient status regarding services referred and obtained, evaluation results, etc.	✓	✓	✓	✓	✓	✓	✓
Flexibility at community or practice level: Allows individual communities or practices to provide input, design or modify methods to best meet needs	✓	✓	✓	✓	✓	✓	✓
Identification of service gaps: Systematic process for tracking barriers and service gaps, and sharing with stakeholders to address them	✓	✓	✓	✓	✓	✓	✓

CROSS-CUTTING THEMES

Maximizing Efficiencies Through Shared Resources

One key feature of the programs examined is the use of a shared community resource or care coordination and referral utility. This refers to one community-based or statewide entity providing centralized services or support, such as assistance with referrals and linkages, for multiple medical practices and families in a community. Colorado's CCHAP and Connecticut's Help Me Grow, for example, provide centralized telephone help lines that family members, physicians, and practice staff can call to learn about community resources and to get referrals to other programs and services. The help lines also provide care coordination to families when needed. Similarly, Rhode Island's PPEP model involves one outside organization, the Rhode Island Parent Information Network, which hires, trains, and manages coordinators who are placed in numerous medical practices.

The model of shared resources brings obvious efficiencies: it eliminates the need for each medical practice to hire, train, supervise, and compensate care and resource coordinators. The task of developing and maintaining a resource database alone is a tremendous undertaking and is one that can be most efficiently conducted on a community-wide basis rather than duplicated in each medical practice. The shared resource model also allows each entity—such as a medical practice, family-to-family organization, or group of specially trained public health nurses, for example—to focus primarily on what it does best (e.g., primary care, peer support, care coordination).

Leveraging Existing Systems and Creating Partnerships with Other Organizations

Regardless of whether publicly or privately administered, the care coordination programs examined build on some type of existing infrastructure at the state level and involve partnerships with state and community agencies. Iowa's 1st Five Initiative, for instance, uses the public health system to build programs at the

community level—using visiting nurse agencies and county health departments to provide care coordination services. Help Me Grow in Connecticut has its own toll-free number but shares information with the state's 211 telephone line, which provides free information and referral for community-based social and health services.

Because children enrolled in Medicaid often have complex needs involving social and medical factors, having a formal or informal partnership between a care coordination program and Medicaid is particularly important. Colorado's CCHAP is addressing systemic barriers to the provision of medical home services to Medicaid patients, including care coordination. CCHAP has partnered with the state's Medicaid agency to ensure higher payments for some Medicaid services. Colorado's Medicaid program was able to provide this enhanced reimbursement to medical practices through federally approved Early Periodic Screening, Diagnosis, and Treatment (EPSDT) incentive payments without requiring a waiver, as long as the practices meet the state's medical home mandate.

In addition to Medicaid, care coordination programs partner with state agencies and programs in which responsibility or funding may overlap and to whom patients are most often referred, such as Early Intervention and Title V services. For example, to provide care coordination through 1st Five, Iowa's department of public health contracts with visiting nurse agencies and county health departments that are already designated as Title V Maternal and Child Health organizations. The program uses care coordinators at these agencies who generally work with children covered under Medicaid or the Children's Health Insurance Program (CHIP) to arrange Early Periodic Screening, Diagnosis, and Treatment (EPSDT) and other services.⁶ Becoming a 1st Five Child Health Center expands the care coordinators' roles to integrate the principles of children's healthy mental development into their work.⁷ It also expands their client base to include all children referred by participating medical practices, including those with commercial insurance. 1st Five care coordination for Medicaid

beneficiaries—the majority of referrals—are reimbursed as a covered EPSDT service. Because private commercial insurance does not reimburse for care coordination, 1st Five covers these costs. For uninsured children, Title V funds help to cover these services.

In addition to partnering with public agencies, some of the care coordination programs found private partners for supplying or augmenting resources. Help Me Grow in Connecticut collaborates with the United Way, for instance, and Colorado’s CCHAP program receives in-kind support (as well as funding) from philanthropic organizations. Advocacy groups can also play an important role in developing, implementing, sustaining, and publicly promoting programs. This is true in Rhode Island, where private nonprofit Family Voices is responsible for hiring, training, and supervising PPEP’s parent consultants. In addition to Family Voices, PPEP partners with an array of public and private organizations (Exhibit 3).

Programs have learned that engaging stakeholder groups from the outset and continuing to solicit their input and support throughout the implementation process is critical to success. Collaboration at both the state and local level is important. Locally, programs must engage both medical practices and community

agencies to ensure open communication and to reduce duplication of efforts. In fact, care coordination often already exists for certain populations, but families and providers do not know what is available and how to access it. At the state level, collaboration among stakeholders increases efficiency by reducing duplication of efforts and breaks down barriers that tend to exist across disciplines. It also creates a unified message to policymakers about the goals and value of a program, which can lead to sustained financial and policy support.

Making Funding and Sustainability a Priority

Even if programs leverage and partner with existing programs and systems, they must have an initial capital investment for pilot projects and keep an eye toward securing sustainable funding. The programs in this report use different strategies, but most find that funding and sustaining care coordination programs are ongoing challenges, especially given economic conditions that have fueled state cutbacks in pilot programs and Medicaid, among other initiatives. Given this environment, a combination of private and public (federal and state) funding is beneficial, at least until services

Exhibit 3. Rhode Island’s Pediatric Practice Enhancement Project (PPEP) Partners

Rhode Island Department of Health (www.doh.ri.gov): Administers PPEP, supports and maintains statewide PPEP data system.

Rhode Island Department of Human Services (www.dhs.ri.gov): Administers Medicaid, CHIP, and Comprehensive Evaluation, Diagnosis, Assessment, Referral and Re-Evaluation (CEDARR) program, the state’s care coordination system for children with special needs and their families.

Rhode Island Parent Information Network(RIPIN)/Family Voices: The state’s contracting agency for hiring, training, and supervising parent consultants. RIPIN is designated as Rhode Island’s Family-to-Family Health Information Center, Parent Training and Information Center, and Parent Information Resource Center.⁸

Neighborhood Health Plan of Rhode Island: The state’s Medicaid/CHIP managed care plan that serves the largest number of children with special health care needs.

Rhode Island Chapter, American Academy of Pediatrics: The state chapter of the national physician organization promotes medical home practices through recruitment, training, and identifying key practice concepts.

Pediatric Practice Enhancement Project sites: Pediatric primary and specialty care practices including private practices, community health centers, hospitals, and three nonhealth sites.

Hasbro Children’s Hospital: Rhode Island’s only children’s hospital and the hub of services for many of the state’s children with special needs and their families.

and programs are embedded in comprehensive, integrated, statewide systems of care.

In Colorado, private sources such as foundations, corporate entities, medical schools, and health care institutions have provided start-up funding and in-kind support for CCHAP pilot testing and ongoing work. CCHAP trains and provides practical support for medical practices, which over time learn to take on many of the support functions so that the trainers “work themselves out of a job.” And as noted previously, EPSDT covers enhanced payments for CCHAP participating medical practices. Similarly, 1st Five care coordination for Medicaid beneficiaries—which represents the majority of its referrals—are reimbursed as a covered EPSDT service.

In Colorado, it took an external third party to provide the impetus and initial funding to provide or extend care coordination and other medical home services into pediatric offices. With support from local philanthropies, a pediatric leader from a children’s hospital and medical school spearheaded the CCHAP program. In a county in Michigan that implemented a similar program, initial funding came from a coalition of stakeholders. An outside neutral force was instrumental in pushing payers (Medicaid, health plans) and practitioners (medical offices, clinics) to change the status quo and provide care coordination services.

Rhode Island’s PPEP has been supported largely by a New Freedom Initiative federal grant, with some state funding. But with the grant ending, the state has been exploring whether it could build ongoing funding for the program into the Medicaid reimbursement system. PPEP leaders were also having discussions with the major health plans about ways to support PPEP services.

The Title V Maternal and Child Health Services federal block grant supports some of the PPEP database, networking, supervision, and program coordination on an ongoing basis in Rhode Island. Title V also covers some care coordination for uninsured families in Iowa’s 1st Five program. In addition, 1st Five’s implementation and ongoing administration has been supported with state appropriations, supplemented by

a state health care trust fund financed by a tobacco tax. The program suffered hiring freezes, however, when the state faced economic hardship.

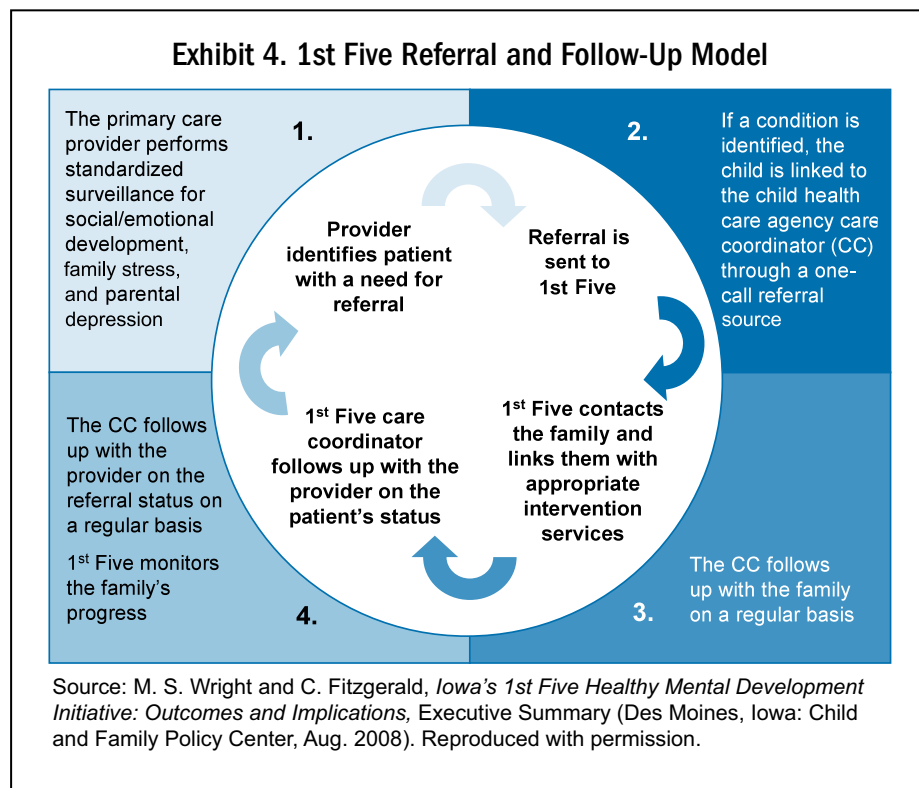
There is a need for payers, including Medicaid and private insurers, to permanently reimburse for care coordination and other medical home services, once it is determined that these services are cost-effective. Preliminary studies of programs in Rhode Island, Connecticut, and Michigan suggest these care coordination investments pay off in reduced inpatient utilization and other costly services for a child population.⁹ Further evaluation is needed to provide additional evidence to convince states, health plans, and practitioners that the investment pays off.

Engaging Pediatric Practices Through Education, Feedback, and Ongoing Support

Ongoing, in-depth involvement with individual medical practices is essential, and engaging with medical practice staff is the first step. Care coordination program planners and administrators stress that getting practices on board requires engaging not only pediatricians, but often more importantly, office managers and nurses who put new policies (e.g., referral forms, phone calls to community-based care coordinators) into practice.

It is important to identify individuals who are the decision-makers at physicians’ offices or clinics and who can implement change and become “champions” for the new program. This is generally accomplished through early meetings with practice staff. It may be a pediatrician who can help bring other physicians in the practice on board with a new screening and referral protocol. More often, it is an office manager or nurse who integrates a new process into daily routine. A relationship with this change agent can be developed, nurtured, and maintained through face-to-face meetings, supportive phone calls, and technical assistance.

In addition, it is often necessary to educate medical practice professionals and staff to broaden their view of health. Screening for and addressing developmental, behavioral, and social delays can be unfamiliar



and even uncomfortable for practitioners accustomed to a more traditional medical model. In Iowa, for instance, 1st Five staff needed to educate nurses in pediatric practices about the potential consequences of parental stress and depression on children's health and safety.

Two programs, 1st Five and CCHAP, understood the importance of using a physician to bring other physicians on board. CCHAP is led by a pediatrician who is a faculty member of the state university's medical school and of a major children's hospital. His reputation and personal connections with most pediatricians in the state are very effective tools in recruiting practices to participate. 1st Five uses a physician consultant to help community-based physicians review their current well-child assessments and plan strategies for practice changes. The program also provides direct technical assistance and links practices with medical education resources.

It is important to develop programs that do not merely add new responsibilities to a physician's practice, but that truly alleviate their burden in the long run. Those who recruit medical practices must effectively communicate that despite an up-front investment in

time and a change from status quo, the new care coordination program will better serve patients and ultimately make practitioners' work easier by more effectively addressing the needs of children and families.

Another important feature that the programs provide is the feedback loop. Participating practices hand off families to care coordinators and referral specialists who can better address the families' needs, saving staff time and promising better outcomes in the process. Then, practices are informed of the status of the referrals so they can more knowledgeably serve the family on their next visit (Exhibit 4). This feedback loop keeps the practices updated and involved in the child's care. In the case of CCHAP, it also provides an indirect training approach: by informing the practices how CCHAP was able to resolve the issue, the practices learn how to resolve similar issues in the future.

Finally, education, training, and support are not one-time activities but ongoing ones. Program staff must return to the medical practices, check in with nurse and office managers, monitor which physicians and practices are not fully participating to find out why, and address problems. Iowa's 1st Five project coordinator, for example, contacts participating practices on

a regular basis—ranging from three times per week to every two weeks, attends nurses’ meetings, and frequently talks with front-line office staff. CCHAP conducts practice manager meetings every other month to update office staff on programmatic changes, community resources, and budget issues affecting support services. Other ongoing activities include updating of resource lists, manuals, and tools.

Providing Training and Tools for Care Coordination Staff

There is no one-size-fits-all approach to hiring and training care coordinators. The experiences of the programs included in this report suggest that the qualifications, background, and training of care coordination and other personnel should be based on the target population and the goals of the program. All programs struggle with cost pressures and are looking to find the right balance of lower-cost and higher-cost personnel. PPEP’s approach involves hiring “peer-to-peer” parent consultants—that is, family members of children with special needs who act as counselors and advisors to other families. These parent consultants are relatively low cost, but have real life experience and can directly address family concerns with true empathy as well as skills for negotiating complex medical and nonmedical systems. Supplemental training in public programs and eligibility guidelines, care coordination, community services, identifying gaps in services, and administrative functions (e.g., intake forms), along with supervision and a monthly professional development day help ensure that the parent consultants are equipped to do their jobs.

In other cases, nurses with clinical experience may be more appropriate for care coordination initiatives. Care coordinators who take calls and inquiries from physicians and medical practice nurses, in addition to fielding questions and requests from families, benefit from being able to talk the same language as their clinical counterparts. Alternatively, social workers may be most appropriate to coordinate services for families with multiple social and economic needs. Regardless of the credentials and background, care coordinators must have good training and tools to

document and track client information and to identify resources for the child and family. Similarly, resource coordinators (i.e., those responsible for making referrals) must have the tools to track and update lists of community resources and state programs, eligibility criteria, and capacity of programs. Such tasks are infinitely easier, and the subsequent product more useful, when systems are computerized. Therefore, states may need to make investments in equipment and training to increase effectiveness of care coordination.

Given the emotional nature of trying to address the needs of families with multiple and complex needs, regular meetings, phone calls, and conferences among care coordinators and other project staff are common. Such interactions allow care coordinators to share experiences and give each other emotional support, practical information about services and programs, and ways to better serve both families and practitioners.

Incorporating Flexible Program Design

Allowing for flexibility of program design at the community or practice level is critical to implementing and sustaining initiatives across locations. Communities implementing a care coordination model vary widely in terms of gaps in services, demographics, geography, and provider capacity. Further, individual practices within a community range in terms of size, patient mix, and level of information technology. Successful programs allow each community or practice the ability to adapt a model to best meet the needs of its providers and patients.

For instance, Community Care of North Carolina (CCNC) relies on local networks to determine the types of community partnerships and staffing models that will best serve its individual communities. Each network delivers screening, referral, and care coordination services that are most appropriate to its population, geography, and provider capacity. Iowa’s 1st Five program takes a similar approach, bringing together coalitions of public and private community stakeholders to determine how best to adapt the general 1st Five model to their particular circumstances.

Similarly, flexibility at the practice level is necessary to accommodate implementation by a diverse range of practice types. In the PPEP program, each participating practice decides how best to use 25 percent of parent consultants' time; in doing so, practices are able to tailor the program to their specific needs. Some have parent consultants follow up on referrals, while others assist with patients' Medicaid enrollment.

While allowing individual practices or communities the opportunity to adapt a program to specific needs is necessary, it can also contribute to variability in performance. This is evident in North Carolina, where three different communities took somewhat different approaches to providing care coordination to pediatric patients, with varying results. For instance, networks operating in rural areas, with more dispersed populations and smaller medical practices, faced more challenges in linking services. Even so, gains have been made across sites, indicating that locally appropriate versions of the model are succeeding in increasing the overall program goals.

Building Measurement, Evaluation, and Follow-Up

Regular evaluation is essential to alter processes that are not working properly and to assess and document the value of the program. Care coordination programs can help identify gaps in patient and family services. For instance, higher rates of developmental screening of young children lead to the identification of more children in need of services. Understanding the demand and the adequacy of supply are critical for any program.

Evaluation can document the value of a program and can justify to funders or state officials its continuation or expansion. Objective evaluation should assess whether and to what extent a care coordination program affects: patient and provider satisfaction, appropriate and completed referrals, utilization of different types of services (e.g., preventive care visits, inpatient care, mental health counseling), total cost of care, and the child and family's functioning.

All of the programs examined track and assess some of these indicators, but measuring impact can be complex. The programs reported an increase in the number of children and families identified with unmet needs and referred to appropriate services, as well as higher patient and provider satisfaction. There are even more promising preliminary findings from some programs, indicating substantial cost savings from a reduced use of expensive services such as inpatient care. Demonstrating that higher-quality, more efficient care can reduce costs is an effective argument for maintaining or replicating successful programs. Evidence of CCHAP's early success, for instance, helped spark a similar initiative in a county in another state.

Successful models can also be replicated for other populations. A Rhode Island pilot project is taking the PPEP "co-location" approach (placing a peer consultant in pediatric offices) and piloting it with disabled adults, another vulnerable population in particular need of care coordination.

Care coordination programs can recognize service gaps that might otherwise go undetected. For instance, the 1st Five program found that treatment for parental depression was universally lacking. In addition, PPEP discovered a number of common barriers to service delivery, including availability and accessibility of child care, dental care, therapeutic recreation, translation, and other services. Programs in Colorado, North Carolina, and Iowa found that rural or remote communities face different challenges and often much more severe service gaps, which can require creative solutions. Most have a systematic way of identifying and tracking these gaps and can then inform advocates, policymakers, funders, and relevant stakeholders to begin to address the issues.

Taking a Holistic Approach to Care Coordination

The nature of child development demands a focus on the entire family, including the relationships and well-being of caregivers and siblings. 1st Five screening includes an assessment of caregiver depression, based on an understanding that caregiver stress puts children

at risk of neglect and abuse. CCHAP care coordinators contact the family within 24 hours of a referral from a pediatric office, not only to discuss the reason for the referral but to also more generally assess how the family is functioning and if additional support services would help. Rhode Island's parent consultants are trained to provide practical guidance as well as empathy to caregivers. The parent-to-parent model addresses the difficulties and frustrations of navigating medical and nonmedical systems to access services for children with special needs.

The programs studied in this brief acknowledge that child development goes beyond the traditional medical model. Child development affects and is affected by education, nutrition, and housing, among other factors. 1st Five personnel teach medical practice staff about mental health development. Further, referrals to a care coordinator for one problem frequently result in multiple additional referrals, as care coordinators discover additional unmet needs reflecting the integrated nature of developmental and other issues, especially among vulnerable populations.

There is a need, therefore, to educate the family about the interconnected nature of issues and the importance of adhering to suggested referrals and care plans. In some programs, multiple no-shows for appointments trigger a phone call to discover the underlying problems—transportation, child care, a need for additional information about the medical issue, or even a simple need for reminders—and how to address them.

Three of the programs examined—PPEP, CCHAP, and CCNC—and others around the country are integrating care coordination into medical home initiatives. In Colorado for example, CCHAP provides 14 support services to pediatric practices, which qualify for medical home enhanced payments from Medicaid. Support services include assisting in Medicaid enrollment and claims submissions, helping families obtain transportation, training in cross-cultural communication, obtaining child development screening tools, and assisting with quality improvement projects. In North Carolina, CCNC physicians are paid a \$2.50

per-member-per-month supplement to provide a medical home and play a more active role in the health needs of their patient population. The 14 networks in CCNC also receive funding to provide case management services to the same population.

POLICY IMPLICATIONS/LOOKING FORWARD

Need for Greater Identification and Dissemination of Best Practices and Technical Assistance

Researchers and analysts who study child development, assessment, and care coordination, as well as those who provide technical assistance to program administrators, acknowledge that there seem to be few broad, systematic, sustainable care coordination programs for children and practitioners with evidence of positive outcomes. However, we did uncover a few innovative programs with promising results. And while there is a dearth of statewide care coordination programs that are directly linked to medical practices, there are “homegrown” programs that are not yet broadly known outside their community or state.

The Commonwealth Fund's Assuring Better Child Health and Development (ABCD) program, launched in 2000 in collaboration with the National Academy for State Health Policy (NASHP), is designed to work with states to support the healthy development of young children. Early phases of the program focused on improving structured developmental screening in states through practice improvement and state policy, reaching a total of 27 states and territories. It was this work, in part, that highlighted the great need for referral, linkages, and coordination of care for children and families. The current ABCD III initiative, which began in October 2009, has engaged five states in developing and testing practice and policy improvements that will build and sustain care coordination services between primary care and other service providers.

Funding and Sustainability Must Be Addressed

Funding and sustainability challenges exist across all programs. Many states are looking to address difficult fiscal situations through Medicaid cuts. This underscores the need for further evaluation of promising care coordination models and more definitive evidence that they can deliver better outcomes and value. It also points to the need to leverage multiple funding sources, including private local philanthropies, hospitals and medical schools (for in-kind support such as physical space and leadership), Medicaid, health plans, federal grants, and incentive programs. The pilot CCHAP replication project in Michigan also involves local businesses, which have a significant stake in reducing the growth of health care costs.

Meanwhile, program leaders note that there is some existing funding for care coordination, through EPSDT reimbursement to providers for care coordination services and Title V funds to support data systems and state-level supervision. As noted previously, Colorado's Medicaid program can guarantee enhanced reimbursement to medical practices through federally approved incentive payments without requiring a waiver, as long as the practices meet the state's medical home mandate. States participating in the ABCD III initiative will continue to explore and leverage such financing sources and serve as examples for others.

Integrating Care Coordination into New Health Care Delivery Models

The models examined in this report are being replicated and expanded. As noted previously, the PPEP model was adapted for a program that places trained peer navigators in internal medicine practices and health centers to assist adult and adolescent patients with disabilities. The Help Me Grow model is now being replicated in other states and regions and a manual for building this type of shared provider resource is [available online](#). The Colorado CCHAP model is moving into rural areas of the state and is also expanding from pediatric practices to family practices. In

addition, the model is being adapted in Kent County, Michigan. There is potential to adapt these models to other vulnerable populations that require significant care coordination services, such as adults with disabilities or the frail elderly.

Care coordination systems also could be adapted to serve geographically defined populations rather than specific subpopulations. The care coordinators would be a shared resource for a variety of health and human services providers.

Just as Colorado has built care coordination for children into its medical home enhanced payments, there are opportunities to build care coordination methods into broader state and federal reforms and demonstration projects. It is essential to build reimbursement for effective care coordination into medical home initiatives, global payments, accountable care organizations, and other emerging financing and delivery models.

In building new systems, a key lesson gleaned from these programs is to engage both public and private sector stakeholders—including physicians, medical practice staff, Medicaid, private health plans, and families—from the beginning and include their input into the design of the program.

Measure, Monitor, and Improve

As programs expand to new populations and are adapted into new models, there is a need for careful measurement, monitoring, and improvement.

First, it is important to collect data on the need for and prevalence of care coordination. Such data could help build support for public and private investment in care coordination programs.

In addition, there is a need to develop standards for care coordination, including defining the key components and designating benchmarks to use in assessing care coordination services. This also involves developing measures of the quality of care coordination services, which may include both process and outcome measures. Process measures may include time

from physician referral until care coordinator contacts family and existence of feedback loop to primary care physician, among others. Outcome measures may include number and proportion of completed referrals, use of preventive services, emergency room or inpatient utilization, physician and family satisfaction, overall cost of care, and return on investment in the short and long term.

Evidence of the effectiveness and impact of care coordination will help to shape and improve these crucial services into the future.

NOTES

- ¹ L. Sices, *Developmental Screening in Primary Care: The Effectiveness of Current Practice and Recommendations for Improvement* (New York: The Commonwealth Fund, Dec. 2007).
- ² Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee, Medical Home Initiatives for Children with Special Needs Project Advisory Committee, “Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening,” *Pediatrics*, July 2006 118(1):405–20.
- ³ Communication with Karen Foley-Schain, division director for the Children’s Trust Fund.
- ⁴ This is a statewide model that varies by locality; three versions in three different communities are highlighted here.
- ⁵ The Commonwealth Fund supported case study reports of the Iowa, Rhode Island, Colorado, and North Carolina programs during 2008–2010. It supported and published a manual on implementing and evaluating a statewide system for linking families with community resources, based on Connecticut’s Help Me Grow program in 2006. See <http://www.commonwealthfund.org/Content/Publications/Fund-Manuals/2006/Jul/How-to-Develop-a-Statewide-System-to-Link-Families-with-Community-Resources--A-Manual-Based-on-Conne.aspx>.
- ⁶ Through a partnership between the Iowa Department of Public Health and Medicaid, about 22 agencies serving Iowa’s 99 counties are selected as Title V child health screening centers through a competitive bid process every five years. With state, local, and federal funding from a Maternal and Child Health Block Grant, as well as Medicaid reimbursement for covered services, these agencies coordinate screening and referrals for Early Periodic Screening, Diagnosis, and Treatment (EPSDT) services (including periodic screening, vision, dental, and hearing services) and conduct public health training, nutrition, and other preventive health services and referrals.

- ⁷ While such screening and referral has long been an EPSDT requirement, this requirement is often not closely adhered to.
- ⁸ Family-to-family health information centers are nonprofit organizations that assist families of children and youth with special health care needs and the professionals who serve them. Led by parents of children with special needs, family-to-family health information centers typically offer information, resources, referrals, training, support, and referral services. Under the Family Opportunity Act, part of the 2006 Deficit Reduction Act, the Health Resources and Services Administration, Maternal and Child Health Bureau, provides primary funding to all states for family-to-family health information centers.
- ⁹ A. Tinajero and D. Garneau, “Evaluation of the Pediatric Practice Enhancement Project,” *Health by Numbers*, Rhode Island Department of Health July 2009 92(7):253–55, <http://rimed.org/med-healthri/2009-07/2009-07-253.pdf>.; Program Report Care: Help Me Grow, June 2010; E. H. Morrato, R. Allen, and A. Kempe, Colorado Children’s Healthcare Access Program: 12-Month Evaluation of the Program, July 1, 2007–June 30, 2008 (Denver, Colo.: Children’s Outcomes Research Program, Mar. 19, 2009).

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