



**BEYOND REFERRAL:  
PEDIATRIC CARE LINKAGES TO IMPROVE  
DEVELOPMENTAL HEALTH**

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**ABSTRACT:** A growing body of evidence highlights the importance of early development and points to the need for actively promoting healthy development and systematically addressing developmental, behavioral, and psychosocial issues early in life. However, many children with developmental issues or those at risk are not identified early enough and not consistently linked to needed services and supports. Pediatric health care providers have an important role to play in providing developmental care and linking children to services and resources within the broader community. While multiple strategies are being tested by pediatricians and others working in child health, to date no study has primarily focused on how pediatric practices link young children and families to developmental care. This report provides a first step in reviewing the current state of pediatric primary care linkage to developmental services, identifying key strategies, developing a linkage typology, and providing recommendations to improve linkage for developmental care.

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## EXECUTIVE SUMMARY

### Introduction

A growing body of evidence highlights the importance of early development, and points to the need for both actively promoting healthy development and systematically addressing developmental, behavioral, and psychosocial issues early in life. However, many children with or at risk of developmental issues are not being identified early enough, and are not consistently linked to the services and supports they need.

Pediatric health care providers have an important role to play in providing developmental care and linking children to needed services and resources within the broader community. While multiple strategies are being tested by pediatricians and others working in child health, to date there has been no study with a primary focus on how pediatric practices link young children and their families to developmental services and supports. This report provides a first step in reviewing the current state of the art on pediatric linkages for developmental care. More specifically, the report:

- describes the context in which pediatric developmental care and linkage takes place;
- provides working definitions and a typology for describing linkage strategies;
- identifies and discusses key linkage strategies used by exemplary practices; and programs.
- provides recommendations and next steps for improved linkage.

### Defining Linkage: A Closer Look

As used in this report, linkage is defined as: connecting the child to needed services and supports while also staying connected to the child. More specifically, linkage indicates the act of connecting the child and family to needed developmental services and supports, whether within the practice setting or beyond.

### Linkage Typology

A major problem in studying linkages for developmental care is that there is not yet a common language or typology for describing linkage strategies. As a result, it is difficult to systematically identify, assess, and advance these efforts.

This report provides an initial typology of linkage strategies for pediatric developmental care. The typology organizes linkage strategies into three broad categories:

- Level I, or practice-wide systems change strategies;

- Level II, or service provider partnership strategies; and
- Level III, or community-wide systems change strategies.

For each level, key strategies are listed that are common across practices and programs. In total, the typology delineates nine key strategies (Table ES-1).

## **Key Findings**

Key findings from the study review of innovative linkage strategies are as follows:

### ***Level I—Practice-Wide Systems Change Strategies***

- Within the field of pediatrics, efforts to improve developmental care tend to take the form of in-house practice change, which is often implemented as part of a quality-improvement/systems change process.
- Routine surveillance, screening, and anticipatory guidance; and a referral/linkage point person and follow-up system are prerequisite for good linkage to services both within the practice and in the community.
- Adding new, in-house staffing and services eases the transition to new services for children and families, and keeps primary care in the loop. But this approach has limitations: at some point for some children and families, needs will exceed practice capacity (for example, when the intensity of the need requires daily, one-on-one interventions). In addition, an exclusive in-house focus cannot optimize the use of practice or community resources.
- Practice-wide systems change strategies can improve the quality of primary care.

### ***Level II—Service Provider Partnership Strategies***

- The three service provider partnership strategies—co-location, co-management, and networking/information sharing—help use existing resources more effectively and improve the quality of care by: reducing barriers to care; promoting early referral, linkage, and follow-up; promoting cross-discipline problem-solving and family-centered care; and reducing duplication and fragmentation of services.
- Service provider networking and information sharing can help uncover gaps in services and can also set the stage for collaborative efforts to address gaps (e.g., coalitions to change policies and programs).
- Initiating and maintaining regular, multi-sector or multi-agency service provider networking sessions generally exceeds the capacity of individual pediatric practices, requiring commitment and funding from others in the community or beyond.

Table ES-1. Key Strategies to Enhance Pediatric Practice Linkage for Developmental Services and Supports

<b>Key Strategies Identified Across Practice/Program Interviewees</b>		
<b>Practice-Wide Systems Change</b>	<b>Service Provider Partnerships</b>	<b>Community-Wide Systems Change</b>
<p>Strategies that transform the way practices are organized to deliver developmental care</p> <p><b>Routine, Systematic Developmental Surveillance, Screening and Anticipatory Guidance</b></p> <ul style="list-style-type: none"> <li>Practice-wide protocols linking specific developmental surveillance/screening to key well-child visits.</li> <li>Use of validated screening tools.</li> <li>Anticipatory guidance tailored to identified parent concerns.</li> <li>Additional venues for anticipatory guidance (e.g., support and networking meetings; use of practice Web site and other electronic communication).</li> </ul> <p><b>Point Person for Referral/Linkage and Follow-up System</b></p> <ul style="list-style-type: none"> <li>Varied roles and training for point person (e.g., nurse, social worker, developmental specialist, receptionist).</li> <li>Follow-up systems that range from simple to complex (e.g., clinical chart notes, care management notebook, monthly high risk case review, electronic tracking systems, practice registry).</li> </ul> <p><b>Enhanced Staffing</b></p> <ul style="list-style-type: none"> <li>New positions added to existing staffing (e.g., child development specialist, psychologist, social worker, case manager).</li> </ul>	<p>Strategies that strengthen the relationship between pediatric practices and existing community services</p> <p><b>Co-location of Services</b></p> <ul style="list-style-type: none"> <li>Share building with related community services.</li> <li>Community/public sector services place staff in practice (e.g., public health nurse serves as case manager, Early Intervention program eligibility staff screen on-site, Medicaid eligibility staff screen on-site).</li> </ul> <p><b>Co-management</b></p> <ul style="list-style-type: none"> <li>Cross-agency case management/care coordination</li> <li>Cross-discipline case management care coordination</li> </ul> <p><b>Networking and Information Sharing</b></p> <ul style="list-style-type: none"> <li>Networking meetings, mixers, meet-and-greet sessions.</li> <li>Shared resource listings</li> </ul>	<p>Strategies that enhance or transform existing community or state systems of care</p> <p><b>New/Enhanced Community Resources</b></p> <ul style="list-style-type: none"> <li>State/regional referral/linkage centers or networks, including links to services for at-risk, mild, and moderate delays.</li> <li>Mid-level assessment services, with open door policy for referrals.</li> <li>Enrichment and intervention services for at-risk, mild, and moderate delays</li> </ul> <p><b>Systemwide Training and Support</b></p> <ul style="list-style-type: none"> <li>Training, support and resources for primary care practices (e.g., systems change/quality improvement strategies, linkage tools, resource information).</li> <li>Training of pediatric residents and nurse practitioner students on developmental screening, anticipatory guidance, resource mapping, and linkage.</li> <li>Systemwide training and support for child care providers, schools, and parents.</li> </ul> <p><b>Systemwide Policies and Protocols</b></p> <ul style="list-style-type: none"> <li>Cross-agency community protocols for screening, diagnosis, treatment, and cross-sector coordination/management.</li> <li>Medicaid reimbursement policies for screening, coordination/case management, and practice change.</li> <li>Other dedicated funding streams for developmental services and supports.</li> </ul>

### *Level III—Community-Wide Systems Change Strategies*

- New community or statewide programs can improve linkage and fill gaps in needed developmental services. Among the most needed services are: mental health care; centralized referral/linkage resources; mid-level assessment services; and intervention services for children at-risk and with mild-to-moderate delays.
- From a community systems perspective, as more mid-level assessment and intervention services become available, more high-end services can be freed up for children with the greatest needs. Thus, the alignment between needs and services can be improved. In addition, over time, increases in mid-level, secondary prevention services can result in fewer children needing more intensive care.
- Among community-wide programs there is a move to reach out to parents, child care workers, and others who touch children’s lives on a regular basis. These programs help establish a shared understanding of child development and a shared responsibility for both promoting development and identifying and addressing developmental needs.
- Systemwide training programs for pediatric primary care practices improve developmental care and linkage by: 1) providing information to enhance developmental expertise, 2) introducing a practice-wide systems change approach, and 3) stressing the importance of linking to other community services and systems. Similarly, systemwide training programs for medical residents, nurse practitioners, and other trainees prepare the next generation for improved developmental care and linkage.
- Systemwide policy changes can jump-start and/or sustain individual practice change.
- Reimbursement/financing systems for developmental care and linkage are crucial.

### **Recommendations**

The final section of the report incorporates seven broad recommendations for enhancing developmental care linkages in communities, states, and nationwide. Each recommendation is followed by a short set of more detailed “next steps” for implementation. The recommendations are as follows:

1. Use quality improvement (QI) approaches to achieve developmental care systems change at the practice level.
2. Rethink and reorient the well-child component of pediatric primary care so that pediatric practices can substantially contribute to the promotion of healthy development.



3. Engage professional associations and umbrella agencies in identifying and linking developmental resources in their communities.
4. Promote co-location of public sector services in pediatric practices, as well as other innovative and cost-effective ways to deploy existing public sector resources for developmental care.
5. Promote mid-level developmental assessment and referral/linkage capacity at the community or regional level.
6. Support training for pediatricians and other primary care providers to help them implement practice-based systems change focused on developmental care.
7. Identify and promote key policy changes, including policies that improve financing and sustainability of community systems for developmental care.



# **BEYOND REFERRAL: PEDIATRIC CARE LINKAGES TO IMPROVE DEVELOPMENTAL HEALTH**

## **INTRODUCTION**

### **Context for the Report**

Healthy development in childhood is the foundation for healthy functioning throughout life. A growing body of evidence highlights the importance of early development, documents the complex interaction between “experience and biology” in shaping who we are and how we function, and points to the need for both actively promoting healthy development and systematically addressing developmental, behavioral and psychosocial issues early in life.<sup>1</sup>

Despite the explosion of new knowledge on development, many children with or at-risk of developmental issues are not being identified early enough, and are not consistently linked to the services and supports they need.<sup>2,3,4,5</sup>

Pediatric health care providers<sup>6</sup> have an important role to play in providing developmental care and linking children to needed services and resources within the broader community.<sup>7,8</sup> A high percentage of young children have access to a regular source of pediatric care, providing a consistent and non-stigmatizing opportunity for parents to seek and obtain information, support and services that promote healthy child development.<sup>9</sup> Within the pediatric health care community, innovative strategies are being tried that link children and families to needed developmental services and supports. While multiple strategies are being tested by pediatricians and others working in child health, to date there has been no study with a primary focus on how pediatric practices link young children and their families to developmental services and supports.

### **Report Scope and Focus**

This report provides a first step in reviewing the current state of pediatric linkages for developmental care. More specifically, the report:

- describes the context in which pediatric developmental care and linkage takes place;
- provides working definitions and a typology for describing linkage strategies;
- identifies and discusses key linkage strategies used by exemplary practices and programs; and
- provides recommendations and next steps for improved linkage.

The report includes strategies initiated by primary care pediatric practices and by programs that go beyond practice settings. While there are numerous programs nationwide that link children to developmental services via other settings and sectors (child care, schools, libraries and more), this report focuses on program strategies that interface with primary care practices, the health care setting where most children are seen once they leave the hospital as newborns.

The study scope of interest encompasses developmental, behavioral and psychosocial health. For shorthand, the term “developmental” is used to encompass all three.<sup>10</sup> The study definition of developmental services and supports is broad and inclusive, ranging from front-end health promotion and disease prevention approaches (e.g., universal screening, family support groups, and parenting classes) to high-end interventions (e.g., neurodevelopmental assessments, one-on-one behavioral interventions, and intensive therapy and treatment approaches). While developmental care is broadly defined, the literature review and interviews for the study particularly emphasized developmental services provided to all children, at-risk children, and those with mild to moderate delays, since these children are less likely to be identified and receive early care than those with frank developmental delays and/or with complex medical needs.

Because the evidence base on child development clearly points to the importance of working with the youngest age groups, this study focuses on children aged 0–5 years. As noted above, a second reason for focusing on the youngest children is that in the early years almost all children have a regular source of primary health care with more frequent visits than in the later years, giving pediatric health care practices the opportunity to promote healthy development and identify and address developmental issues.<sup>11</sup> While the report focuses on the youngest age group, the linkage typology and key linkage strategies are equally applicable across age groups.

Finally, a word about the term “linkage:” For purposes of this study, linkage is defined as connecting the child to needed services and supports while also staying connected to the child. More specifically, linkage is defined as the act of connecting the child and family to needed developmental services and supports, whether within the practice setting or beyond.

## **Study Methodology**

The study methodology consisted of three parts:

- *A preliminary literature review*—to gain a better understanding of the context and landscape for pediatric care linkage.

- *Key informant interviews with 29 experts in the fields of pediatric primary care, child development, and developmental services*—to explore key issues and concepts for pediatric care linkages and develop a list of exemplary practices and programs for in-depth interviews.
- *In-depth interviews with principals in 14 practices and programs currently engaged in linking children to needed developmental services and supports*—to identify and understand linkage strategies currently in use.

The study’s key informants were selected to include a broad range of experts and innovators from the fields of pediatrics, public health, and social policy. Most of the key informants have been actively working to expand and improve developmental care provided by pediatric practices. They work at the local, state, and national levels to effect change. Their combined historical, conceptual, and practical knowledge provided an understanding of the landscape for pediatric developmental care and linkages, and guided the identification of innovative practices and programs for in-depth interviews.

In selecting practices and programs for in-depth interviews, consideration was given to setting, type, size, and geographic distribution. The final sample included practices located in rural as well as urban and inner city areas from different parts of the country. One practice is located on a reservation. The sample also included practices that are privately owned, hospital-owned, and/or part of a network, as well as one community health center. Many of the practices serve a large population of children and families who are insured by Medicaid and the State Children’s Health Insurance Program (SCHIP) or uninsured. Several serve a large minority and immigrant, non-English speaking population. A few serve a large number of children with special health care needs. A number of the practices participated in national initiatives such as Healthy Steps, Assuring Better Child Development (ABCD ), the Medical Home Collaborative on Developmental Services, the Rural Medical Home Improvement Project, and National Institute for Child Healthcare Quality (NICHQ) quality improvement collaboratives.<sup>12</sup>

In addition to practices, the sample also incorporates several community or statewide programs that are designed to help pediatric health care and other service providers identify and link children to developmental care. These include a statewide referral, linkage, and mid-level assessment center; state and local training and support programs for providers; and community-wide programs that work across health, education, and social service sectors to connect children to services.

This set of practices and programs provides a broad scan of innovative and promising strategies currently implemented to help pediatric practices link children and families to the developmental care they need. ([See Appendix](#) for a listing of interviewees.)

## LANDSCAPE FOR DEVELOPMENTAL CARE AND LINKAGE

### **Current Trends in Pediatric Developmental Care**

Within pediatrics there is a steadily growing emphasis on incorporating a developmental focus into primary care. Progress has been made over the past decade and particularly in the last five years in developing and validating tools to assess developmental status (e.g., Parents' Evaluation of Developmental Status (PEDS); Ages and Stages Questionnaire (ASQ)), piloting efforts to enhance and improve pediatric health care practices and systems for developmental services (Healthy Steps, NICHQ, Healthy Development Learning Collaborative), measuring the quality of developmental services within provider systems, and working with Medicaid agencies to support quality improvement for developmental services (ABCD). As more pediatric practices and provider systems have begun to enhance and improve developmental services, initial changes have focused on education/anticipatory guidance; effective monitoring of developmental status within the practice setting; and on a more limited basis, enhancing intervention services available within the primary care practice setting. More recently, we have begun to see the development of community-wide programs that focus on enhancing linkage between pediatric practices and other community services and supports (Help Me Grow, North Carolina Community Protocols). This reflects a growing awareness that enhancing provider linkages is the next frontier in advancing developmental care.

### **Evolving Definitions and Roles**

While many changes have taken place in the delivery of developmental care by pediatric practices, the field is still in transition. American Academy of Pediatrics (AAP) policy statements as well as other conceptual frameworks in the literature reflect a gradual broadening of the definitions of developmental care, who should receive it, and the goals and role of primary care pediatrics in providing and linking to developmental services. However, there is variation in interpreting the boundaries and the focus of pediatric developmental care even among experts. Differences of opinion and practice remain regarding what pediatric primary care can and should be doing. Among the key issues still to be resolved, are the following:

- *Scope of care.* What range of developmental issues should primary care pediatric practices address: physical, cognitive, behavioral, emotional, social, and/or environmental? And what scope and intensity of services should practices provide or link to, in order to meet those needs?

- *Target population.* Who needs and should receive developmental care? Is this primarily an issue for children with special needs? Is the focus on children who are at-risk or who have known deficits? Or is it for all children?
- *Goal of pediatric practices.* Is the goal of the primary care pediatric practices to identify children with or at-risk of deficits? Is it primary or secondary prevention? Is it to promote optimal development of all children?

### **Changes in Other Sectors**

Other service sectors are also moving to address developmental needs, transforming their own roles and responsibilities. Child care, in particular, has begun to step up to the plate: new initiatives seek to strengthen the role of child care providers in developmental surveillance and linkage, and in working directly with children and families to address developmental issues. In several ways child care and health care are working on parallel tracks; however, their efforts are not yet well connected.

### **Barriers to Linkage**

While pediatric practices move to more consistently and effectively meet developmental needs, the current landscape for linkage poses significant barriers that must also be addressed. Study interviewees identified barriers at three levels:

- *Practice-based barriers.* These include time constraints, a lack of familiarity with and understanding of non-medical services (and therefore a reluctance to refer), discomfort with a team approach (with parents or other service providers), and organizational constraints (e.g., lack of a systematic or focused approach to addressing the needs of children who are at risk or who have mild to moderate developmental delays).
- *Service provider partnership barriers.* These encompass cultural differences across disciplines (asset-based vs. deficit-based approaches, for example); communication and feed-back issues (e.g., physicians want to hear back from referral services); and infrastructure issues for some community-based organizations (e.g., phone systems don't always work).
- *Community systems barriers.* Adequate and stable funding is a major issue. For pediatric practices as well as other service sectors, reimbursement for cross-sector linkage and coordination is poor to non-existent. In addition, public sector services are frequently under threat of budget cuts. In most communities there are also dramatic gaps the availability of developmental services, particularly mental health, mid-level assessment, and intervention services for children with mild to moderate

delays. This lack of services can make physicians reluctant to screen for developmental risks or delays, since a basic tenet in pediatrics is: don't screen unless you can treat the problem.<sup>13</sup> In addition, even when services exist, there are problems with systems coordination or integration both for children and families and for service providers.

The extent of these and other barriers to good linkage is perhaps best captured in the following observations made by key interviewees:

*Pediatricians are kind of trapped in a box right now: everything we need to do to get out of the box is not reimbursable.*

*The system is so fragmented that the only person who understands it is the educated parent.*

### **Current Status of Linkage Efforts**

Despite considerable barriers, pediatric practices across the country are making headway in linking children and families to developmental care. Study interviewees indicate that a rich array of strategies are currently being used and tested by innovative practices and programs to better link children to developmental services. Most often these strategies are embedded as part of a broader program or initiative to address developmental needs. While linkage may be a key part of a broader program or practice effort, it is not necessarily framed or studied separately. Thus, there is a good deal of practical knowledge about linkage that has remained untapped and unreported.



## WORKING DEFINITIONS AND LINKAGE TYPOLOGY

### Addressing Gaps

In order to move forward in describing the current state of the art for pediatric linkage to developmental care, three things are needed: a working definition of developmental services, a working definition of linkage, and a typology for linkage strategies. Each of these is described below.

### Developmental Services: A Working Definition

Since there is not yet a clear consensus about the parameters of pediatric developmental care, for purposes of this study, we define developmental services using a framework that builds on the Developmental Services Typology developed by Regalado and Halfon. We revisit and to some extent reframe their typology, revising some of the terminology to make it more user-friendly for families and other service providers.<sup>14,15</sup> The framework below takes a family-centered approach, listing first what children and families need, followed by the developmental services to be provided by pediatricians and other service providers. (See Box.)

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#### Developmental Services Framework: Services to Meet the Developmental Needs of Children and Families

1. **Knowledge.** Families need to know what normal development is and how to support it. They also need to know what is abnormal and how to address it. For pediatricians and other service providers, meeting these needs entails offering anticipatory guidance, as well as providing clear information about risks and deficits, if identified.
2. **Monitoring.** Children need a routine, objective assessment of their development. In practice, this takes the form of developmental surveillance, screening, and assessment.
3. **Additional services and supports.** Children and families need services and supports that help them promote development, including adequate resources to meet basic physical, cognitive, and emotional needs. In practice, a designated linkage point person provides a pathway to connect the child and family to additional developmental care, as needed.
4. **Follow-up relationships.** Children and families need a link to one or more sources of caring follow-up and support. This translates in practice to a system and point person for providing supportive follow-up that goes beyond connecting the child to individual services or interventions.

Adapted from: Regalado and Halfon.<sup>16</sup>

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## **Defining Linkage: A Closer Look**

As noted earlier, in this study, “linkage” is defined as connecting the child to needed services and supports while also staying connected to the child. More specifically, linkage is the act of connecting the child and family to needed developmental services and supports, whether within the practice setting or beyond.

This broad definition of linkage derives from the study’s key informant interviews. When practices and programs were queried about their linkage strategies (that is, what makes them exemplary), they responded not by simply describing how they connect children to other services in the community, but rather by describing how they connect children to needed developmental services, including services provided within the practice setting. In addition, some pediatric primary care practices have begun to push the boundaries of traditional pediatric primary care by incorporating into their practice settings, services and providers generally found in other, community-based settings (e.g., developmental specialists; eligibility workers from the Early Intervention (EI) program). Therefore, focusing on linkage to services outside the practice setting is both too limiting and too varied to be a useful way of describing linkage efforts.

## **Linkage Typology**

With linkage likely to be the next frontier in advancing pediatric developmental care, there is a need for a systematic review of innovative and promising strategies currently in the field. However, a major problem in studying linkages for developmental care is that there is not yet a common language or typology for describing linkage strategies. As a result, it is difficult to systematically identify, assess and advance these efforts.

Based on the study review of linkage strategies used by innovative and exemplary practices and programs, we developed an initial linkage typology for pediatric developmental care (Table 1). The typology organizes linkage strategies into three broad categories or levels: Level I—practice-wide systems change strategies; Level II—service provider partnership strategies; and Level III—community-wide systems change strategies. Within each level of the typology, key strategies are identified, reflecting prominent and consistent linkage patterns across practices and programs. In total, the typology delineates nine key strategies across the three linkage levels (Table 1):

- *Level I—Practice-Wide Systems Change* strategies include: 1) routine, systematic developmental surveillance, screening, and anticipatory guidance; 2) a point person for referral and linkage and a follow-up system; and 3) new or enhanced staffing.

Table 1. Key Strategies to Enhance Pediatric Practice Linkage for Developmental Services and Supports

<b>Key Strategies Identified Across Practice/Program Interviewees</b>		
<b>Practice-Wide Systems Change</b>	<b>Service Provider Partnerships</b>	<b>Community-Wide Systems Change</b>
<p>Strategies that transform the way practices are organized to deliver developmental care</p> <p><b>Routine, Systematic Developmental Surveillance, Screening and Anticipatory Guidance</b></p> <ul style="list-style-type: none"> <li>Practice-wide protocols linking specific developmental surveillance/screening to key well-child visits.</li> <li>Use of validated screening tools.</li> <li>Anticipatory guidance tailored to identified parent concerns.</li> <li>Additional venues for anticipatory guidance (e.g., support and networking meetings; use of practice Web site and other electronic communication).</li> </ul> <p><b>Point Person for Referral/Linkage and Follow-up System</b></p> <ul style="list-style-type: none"> <li>Varied roles and training for point person (e.g., nurse, social worker, developmental specialist, receptionist).</li> <li>Follow-up systems that range from simple to complex (e.g., clinical chart notes, care management notebook, monthly high risk case review, electronic tracking systems, practice registry).</li> </ul> <p><b>Enhanced Staffing</b></p> <ul style="list-style-type: none"> <li>New positions added to existing staffing (e.g., child development specialist, psychologist, social worker, case manager).</li> </ul>	<p>Strategies that strengthen the relationship between pediatric practices and existing community services</p> <p><b>Co-location of Services</b></p> <ul style="list-style-type: none"> <li>Share building with related community services.</li> <li>Community/public sector services place staff in practice (e.g., public health nurse serves as case manager, Early Intervention program eligibility staff screen on-site, Medicaid eligibility staff screen on-site).</li> </ul> <p><b>Co-management</b></p> <ul style="list-style-type: none"> <li>Cross-agency case management/care coordination</li> <li>Cross-discipline case management care coordination</li> </ul> <p><b>Networking and Information Sharing</b></p> <ul style="list-style-type: none"> <li>Networking meetings, mixers, meet-and-greet sessions.</li> <li>Shared resource listings</li> </ul>	<p>Strategies that enhance or transform existing community or state systems of care</p> <p><b>New/Enhanced Community Resources</b></p> <ul style="list-style-type: none"> <li>State/regional referral/linkage centers or networks, including links to services for at-risk, mild, and moderate delays.</li> <li>Mid-level assessment services, with open door policy for referrals.</li> <li>Enrichment and intervention services for at-risk, mild, and moderate delays</li> </ul> <p><b>Systemwide Training and Support</b></p> <ul style="list-style-type: none"> <li>Training, support and resources for primary care practices (e.g., systems change/quality improvement strategies, linkage tools, resource information).</li> <li>Training of pediatric residents and nurse practitioner students on developmental screening, anticipatory guidance, resource mapping, and linkage.</li> <li>Systemwide training and support for child care providers, schools, and parents.</li> </ul> <p><b>Systemwide Policies and Protocols</b></p> <ul style="list-style-type: none"> <li>Cross-agency community protocols for screening, diagnosis, treatment, and cross-sector coordination/management.</li> <li>Medicaid reimbursement policies for screening, coordination/case management, and practice change.</li> <li>Other dedicated funding streams for developmental services and supports.</li> </ul>

- *Level II—Service Provider Partnership Strategies* include: 4) co-location of services; 5) co-management; and 6) networking and information sharing.
- *Level III—Community-Wide Systems Change Strategies* include: 7) new or enhanced community programs; 8) systemwide training and support; and 9) community or state policies and programs.

This linkage typology with related key strategies should be considered primarily as a starting point for describing and understanding the current state of pediatric practice linkage to developmental care. Like other aspects of pediatric developmental care, linkage efforts are a work in progress. Thus, it is anticipated that the typology and some of the key strategies will be refined or replaced by new and different approaches over time.

## CONTEXT FOR THE STRATEGIES

### **Practice and Program Roots**

The key strategies identified in this report are all derived from a review of 14 innovative practices and programs and their work to link children to developmental care. The interviews did not start with questions about the specific strategies, but rather with questions about how practices and programs approach linkage. Looking across the practice and program efforts, clear themes emerge: first, strategies focus on change at three different levels (i.e., practice-based, service provider partnerships and/or community systems); and second, within these levels similar approaches are being used in different settings across the country.

While the review that follows describes and discusses each strategy separately, in practice these are not stand-alone approaches. Most of the innovative programs and primary care practices interviewed combine several strategies, across levels.

Often the strategies are part of an integrated effort to address developmental needs within one or more communities. As a result, in practice there is not necessarily a clean line separating one strategy from another, either within or between linkage levels. For example, routine screening and anticipatory guidance may be implemented via enhanced staffing; changes in primary care practice systems such as identifying a referral/linkage point person or setting up a follow-up system may result from participation in a systemwide training program; and community networking meetings may help identify community gaps in services and lead to the development of new, community-wide resources.

Many of the pediatric practices in the study sample have also been engaged in community or national initiatives, so that their strategies are not isolated endeavors, but are part of broader efforts to improve developmental care.

### **Underlying Tenets**

Across practices and programs in the study sample, several consistent underlying tenets or guiding principles stand out as shaping the strategies used to improve developmental care and linkage. These include:

- **Parents as partners.** A central tenet for practices that have embraced the medical home model, this is also a key component of the chronic care model. Including

parents as equal partners in a team approach facilitates linkage and has benefits for the practice as well as the families. As one interviewee put it:

*I wish other people could see how great this is: working with parents. The new morbidities require parent input, changing from a paternalistic role to listening to what parents want. Motivational interviewing, communication shift: that is where the future lies.*

- **No wrong doors.** Several programs take a “no wrong doors” approach to identifying children who may need additional developmental assessment or services. These programs accept referrals based on assessments from pediatric practices, parents, child care workers, teachers, and others who care for the child. The goal is to connect children to services regardless of the source of referral.
- **Go where the children are.** The idea behind “go where the children are” and a related tenet of “web and funnel” is to bring developmental assessment and other services to places where children are likely to be: child care settings are a prime example, as are pediatric primary care practices. The goal is to develop a network of providers and caregivers who can help identify children with or at-risk of developmental delays and connect them to needed services. Some programs also work directly with child care workers or parents to help them promote healthy development and address problem behaviors and other developmental issues in their day-to-day interactions with children.
- **Referral as a first resort.** Also expressed as “when in doubt, refer,” this idea focuses on promoting early identification and intervention for children and their families, with a secondary goal of decreasing the number of children who will eventually need intensive intervention and thus, more effectively utilizing available high-end resources. This shift to more children being referred earlier and fewer children needing intensive, high-end services is also referred to as a curve shifting strategy.

### **Quality Improvement/Systems Change**

Finally, several of the practices and programs in the study sample have used a quality improvement/systems change approach to design and test strategies for improved developmental care. Among the initiatives providing training and tools for this purpose were: the National Initiative for Children’s Healthcare Quality (NICHQ), the Center for Medical Home Improvement, the North Carolina–Child Health Improvement project, and the Rural Medical Home Improvement project. All of these initiatives share a common approach that includes: engaging both pediatricians and other office staff, viewing the practice as a system of care, using data to assess needs of the population served by the practice, systematically reviewing office practices and systems, testing incremental

changes, and then applying the changes practice-wide. In addition, the training frequently involves “learning collaboratives,” in which several practices come together to learn and share experiences. In short, the quality improvement/systems change model can have a profound effect on how practices function, well beyond the provision of developmental care. As one interviewee noted:

*We’ve learned the value of the quality improvement model of plan, do, study, act: making a few changes at a time and then measuring improvement and success. Also, it’s important to talk to patients about what should change. The NICHQ model changes the whole practice.*

## STRATEGY REVIEW

### LEVEL I—PRACTICE-WIDE SYSTEMS CHANGE STRATEGIES

The first level of linkage strategies involves changes made internally that allow the pediatric practice to better link children to developmental care. Three key strategies were identified at this level: 1) routine, systematic developmental surveillance, screening, and anticipatory guidance; 2) a referral/linkage point person and a follow-up system; and 3) enhanced staffing.

#### **Strategy 1. Routine, Systematic Developmental Surveillance, Screening, and Anticipatory Guidance**

##### *Definition and Examples*

Routine, practice-wide implementation is essential in this strategy. In the study sample, implementation involved one or more of the following: practice-wide protocols linking selected developmental surveillance or screening to specific well-child visits; use of validated screening tools; anticipatory guidance tailored to parent concerns; and additional venues for anticipatory guidance (such as parent support groups and networking meetings, use of a pediatric practice Web site, or email communication with the primary care provider).

All the practices in the study sample have incorporated some form of developmental surveillance or screening into well-child visits. While some use validated screening tools, others use tools or questions developed by the practice. Some practices offer an electronic route to parent education and screening, providing information and screening tools online through their Web sites. Others provide informational, support, and networking meetings for parents. Finally, several practices noted that they integrate developmental screening and anticipatory guidance by first identifying parental concerns through parent responses on screening tools, and then tailoring guidance to address information parents most want and need. Examples include:

- In South Carolina, Beaufort Pediatrics routinely provides comprehensive psychosocial, socioeconomic, and developmental screening and has shifted its anticipatory guidance to “pre-school development support.” Among the screening tools it uses are: a modified Orr Prenatal Socio-Environmental Inventory, PEDS, Pediatric Symptom Checklist, and Joint Attention Questions from the Modified Checklist for Autism in Toddlers (M-CHAT), Vanderbilt and Connected Kids Questionnaire.



- Guilford Child Health in North Carolina provides routine developmental and behavioral screening for all children in the practice at well-child visits from birth through 18 years. In addition, Guilford Child Health screens for maternal depression at the 2- and 4-month well-child visits; and for new patients, the practice's registration questionnaire includes questions related to risks such as chronic medical or mental health conditions, as well as housing and transportation issues. For developmental screening Guilford Child Health uses the Edinburgh Postnatal Depression Scale, ASQ, ASQ-Social Emotional, Pediatric Symptom Checklist, Children's Depression Inventory, and Guidelines for Adolescent Preventive Services.
- In Boston, MGH Revere HealthCare Center offers monthly, evening parenting groups for families of children up to 4 years old. In addition to information provided by the Healthy Steps Specialist, the groups provide an opportunity for parents to develop friendships and share information on other community resources.
- Kaiser of Northern California conducts developmental screens at every well-child visit, with the screening tools appearing as part of the child's electronic medical record. At 18 and 24 month visits, Chat Screen or M-CHAT screening is conducted. Some of the Kaiser facilities conduct parent groups, including structured anticipatory guidance sessions facilitated by a nurse practitioner, as well as support group sessions conducted by a health educator. All of the groups are open to all parents in the plan with infants up to a year old. Kaiser uses its Web site in innovative ways: prior to each well-child visit, parents can fill out developmental questionnaires online and return them electronically to the child's pediatrician. The Web site also includes parent education information on healthy development.

### *Advantages*

Among the benefits of routine, systematic surveillance, screening, and anticipatory guidance are the following:

- Routine, practice-wide surveillance and screening promotes earlier and more complete detection of developmental risks and deficits within the practice population, leading to increased referral and linkage to additional developmental care, as needed.
- Screening tools that start with a parent's assessment of developmental status and concerns—such as the ASQ and the PEDS—help pediatricians combine screening and guidance with a patient-centered approach that has some additional benefits, such as reducing the need for “hand on the doorknob questions:” the significant

questions that come at the very end of the visit, as the pediatrician is heading out the door. The use of family-centered, routine surveillance, screening and anticipatory guidance can improve the quality of care, enhancing both patient and physician satisfaction with the visit.<sup>17</sup> As one interviewee noted:

*The PEDS is important because it reorients the tenor of the visit: In our practice, we are not aware that we are picking up new kids through the PEDS, but we are aware that it changes the tenor and kind of anticipatory guidance we provide. We know from the start of the visit what is most on the parent's mind, and what issues to address. We use different screens at different visits. This gets us past the hand on the doorknob issue.*

- Perhaps the greatest advantage of incorporating routine developmental surveillance, screening and anticipatory guidance into a practice setting is that together, these changes are an essential starting point for developmental care and linkage. By committing to these components, practices start down the route of shifting to a developmental focus in well-child care and beyond.
- Finally, from a cost perspective, routine developmental surveillance, screening and anticipatory guidance does not require extensive start-up funds or a substantial new funding stream for ongoing implementation. Costs associated with use or purchase of screening tools and parent education materials can be kept low. In addition, training programs or collaboratives are available in many parts of the country, to help practices get started.

### ***Limitations***

- Instituting any practice-wide systems change requires an upfront investment in time and commitment: Interviewees noted that it is best to have at least one physician champion and one support staff champion to launch practice-level systems change. In addition, the practice will need to train and to get buy-in across both clinical and support staff.
- If practices try to add routine screening and anticipatory guidance without taking a quality improvement/systems change approach, clinical and support staff are more likely to feel the additions are burdensome (sometimes described as “yet another add-on to the laundry list” of screening and anticipatory guidance requirements). The result: effectiveness and sustainability may be reduced.

## **Strategy 2. A Referral and Linkage Point Person and a Follow-up System**

### *Definition and Examples*

This strategy involves designating one individual within the practice as the primary contact for developmental referral and linkage, and establishing a system for follow-up care. The training and background of the designated point person can vary and may include, among others: nursing, social work, and child development. In some smaller practices front office staff might serve this function. Generally, the pediatrician is not the designated office point person for linkage. Follow-up systems vary as well: from a simple listing of all individuals referred, which is reviewed regularly by the linkage point person, to a sophisticated electronic record and recall system with a task list that can be accessed both by the point person and the clinician. Often the follow-up is relationship-intensive. In some practices the primary focus is on assuring the child and family are connected to services outside the practice. In others, the referral and linkage coordinator takes a more comprehensive role.

The practices interviewed all have a designated point person for referral and linkage to additional developmental care, and a system for follow-up with identified patients. In some practices, the role of the developmental linkage point person and the scope of follow-up care have expanded over time.

Among the examples from the study sample:

- At Phoenix Children’s Hospital Clinic, the Healthy Steps Specialist is the designated point person for referral and follow-up. The Healthy Steps Specialist uses an online system to refer and track appointments with the Early Intervention (EI) program, checking with the family 45 days out to make sure EI intake has been completed. The Healthy Steps Specialist also provides “bridging” intervention services for children to age 3, who are waiting to be accepted for EI services.
- At MGH Revere HealthCare Center, the physicians make most of the referrals (for billing reasons). The Healthy Steps Specialist does follow-up on referred families: for example, calling the speech pathologist to make the referral more seamless, and checking with families to find out what they think of services they receive. The center uses an electronic medical record, so the Healthy Steps Specialist can see what other providers within the Center have done for the child and family. They also have a separate database to keep track of their interactions with the family.
- Exeter Pediatrics in New Hampshire develops a registry of all children in the practice with “complex needs”; that is, issues lasting more than a year. The registry

allows the practice to: 1) identify the most complex patients and distribute them equally across providers in the practice; 2) identify the families who are most in need of a care plan for their children; 3) identify families and invite them to attend focus groups for parents of children with special needs; 4) identify and appropriately schedule patients who require extra time for appointments; and 5) gather information that potentially can be used to negotiate with payers for optimal coverage of complex patients.

- Inscription House Health Center, an Indian Health Service (IHS) clinic has a Memorandum of Agreement with the Navajo Nation that spells out joint responsibility of IHS and Navajo Nation for identification, referral, and follow-up care. Their system is relatively simple: following identification of children with or at-risk for developmental disabilities by IHS clinical staff, the Community Health Nurse, or others, referral is made to the Growing In Beauty Program Coordinator (referral/linkage point person), who is responsible for follow-up assessment and linkage. Follow-up care is also coordinated across agencies in monthly high-risk clinics, which are co-management sessions for children and families with complex or chronic issues or conditions. ([See Strategy 5](#) for description and discussion of co-management.)
- Kennebec Pediatrics in Maine has a nurse on staff who serves as the linkage point person and developmental care coordinator/case manager. She uses an electronic medical record with a task list reminder system to keep track of referrals and follow-up. Originally, the developmental care coordinator/case manager served as a medications manager. Her role was expanded to help coordinate care and services for patients with school performance, behavioral issues, and other medical problems “with the goal of decreasing crises and improving the child’s success at home, school and with peers.”<sup>18</sup> The practice also provides a care management notebook for parents to keep track of referrals and care plans from multiple community providers. Parents take the notebook with them to various clinical and service appointments, giving providers a chance to review what others have done and add their own information, as well.
- Tufts-New England Medical Center has a social worker as the referral and linkage point person. She sees the family at the same visit at which the risk or need is identified, sorts out various needs, helps the family with problem solving, refers and/or links the child and family to resources, notes in the clinical chart her activities along with needed follow-up, and is available to “pop in” at the next visit to check on the child and family.

### *Advantages*

- Designating a point person for referral and linkage and for follow-up care promotes effective and efficient utilization of human resources. One “go to” person means that not everyone in practice needs to expend time and effort on learning about community resources and building relationships with community-based service providers.
- Designating a linkage point person and developing a follow-up system are important steps in orienting a practice to the developmental services children and families need, and can lead to further expansion of the practice’s role in developmental care.
- This strategy does not require outside support or an additional funding stream, at least at the initial stages. However, most of the practices interviewed have moved to a full-time referral/linkage position through enhanced staffing. (See Strategy 3.)

### *Limitations*

- Linkages to community resources are limited by the knowledge and time of the designated linkage point person.
- Some practices are unwilling to invest in linkage and follow-up activities unless or until they feel confident there are adequate developmental services available in the community. This is especially true for mental health care and for services addressing mild to moderate deficits.
- From the community perspective, there is no economy of scale across pediatric practices for resource mapping or connections to resources. Each practice builds its own knowledge base and relationships.
- Again from the community perspective, this approach does not by itself address coordination across the sectors (e.g., with public health, child care, education, family support). There is no strategic pooling of resources/assets or coordination of responsibilities to achieve shared goals of early identification of developmental problems and linkage to needed services.

## **Strategy 3. Enhanced Staffing**

### *Definition and Examples*

A third key strategy, enhanced staffing, involves adding one or more new positions to traditional pediatric primary care staff in order to enhance developmental care: for example, a care coordinator, social worker, child development specialist, psychologist, developmental pediatrician, or psychiatrist. The purpose of enhanced staffing varies. In

some cases the new staff primarily assesses non-medical needs and serves as a connector and follow-up point person, linking children and families to additional services outside of the practice. In other cases, the new staff provides intervention or treatment services that otherwise would have required referral to services outside the practice. Most frequently, enhanced staff positions focus on children who have identified risks or deficits. However, in some cases—the Healthy Steps Specialists being the most notable example—the staff person works with all children in the practice to promote healthy development and to identify developmental problems.

Examples of practices incorporating more than one new/enhanced position include the following:

- Guilford Child Health staffing includes a developmental pediatrician, a psychologist, social workers, and community liaisons.
- Beaufort Pediatrics employs both a mental health worker and a social worker, and utilizes other enhanced staffing provided by public sector partners. ([See Strategy 4.](#))
- Large HMOs such as Kaiser have access to medical specialists—developmental pediatricians, psychiatrists, neurologists, and more—as part of their broader care system.

Examples of variations in job descriptions include:

- Exeter Pediatrics Associates describes its social worker/care coordinator position as follows: “Care coordination supports parents and guardians in their efforts to: 1) obtain information, education and counseling related to family needs; 2) communicate with physicians, schools and other agencies; 3) advocate for their child’s well-being; 4) obtain assistance during stressful times or crises; and 5) locate and access supportive community and state resources.”<sup>19</sup>
- The Healthy Steps practice coordinator at Phoenix Children’s Hospital provides parent education/modeling services, including Reach Out and Read; bridging services (before EI services are available); linkage assistance; follow-up for children through age 3; and staffing for a child information line. And the Healthy Steps Specialist at MGH Revere HealthCare Center combines a similarly diverse set of functions.
- The social worker at Tufts-New England Pediatric Clinic focuses primarily on further identifying and sorting out needs, and connecting children and families to developmental and family support services in the community, such as housing

assistance, parent support groups, and the Special Supplemental Nutrition Program for Women, Infants and Children (WIC).

### *Advantages*

The pediatricians interviewed in the study were highly enthusiastic about enhanced staffing, citing multiple ways it had changed their practices for the better, including the following:

- Expansion of developmental services within a practice reduces or eliminates access barriers for families (for example, transportation, availability, insurance coverage, familiarity, and trust). It also reduces the stigma associated with being referred to a mental health provider or other outside specialist. Since this is a crucial barrier for many families, providing services on-site goes a long way toward providing what families need to connect with developmental care.

*We got tired of not being able to get children in for mental health services, so we hired our own.*

*For linking kids to the services they need, having the services on-site works best because it de-stigmatizes and provides one-stop shopping.*

- Having on-site services encourages referrals as a “first resort,” facilitating early identification and intervention. If a pediatrician suspects issues, she or he can send the child and parent—and in some cases walk them down the hall—to on-site staff for further assessment, referral and/or interventions.

*The behavioral health specialist can pop into the room and provide short-term intervention.*

- Having a care coordinator who facilitates linkage and follow-up with community resources improves the quality of care and helps pediatric practices function as a medical home. In addition, social workers, child development specialists, and other non-medical staff complement the knowledge and skills of pediatricians, and free up the pediatrician for other clinical work.

*Working with a care coordinator has re-energized my commitment to pediatric practice; it has also enhanced the quality of care that we can offer. Care coordination is important in providing a community-based medical home.<sup>20</sup>*

*This is not a time issue: the social worker does what I do not really know how to do, even if I had more time.*

### *Limitations*

- First, it requires additional financial resources. A very strong theme running throughout the interviews was the need to find a regular source of funding for enhanced staffing, particularly for care coordination and linkage functions and for developmental health promotion services. Some practices fund enhanced positions through grants, which are time-limited, and require proposal writing and other skills to maintain or renew. Others—primarily practices that are part of large, hospital-based care systems—are able to cover the cost of the enhanced care coordination not through direct reimbursement, but by taking it out of the practice revenues. Paying for a care coordinator is most difficult for small, solo practices. In some states, reimbursement rates can cover care coordination for practices with a large enough patient population, but most of the study interviewees are still grappling with ways to obtain and sustain funding for referral, linkage, and coordination functions.
- In addition, working out roles and relationships can be a challenge:  
*There is a mentality among some physicians of “this is my job and this is yours” versus co-managing a family. Having them view developmental specialists as professionals is a big leap for some. But once they do see your value, then they can’t live without you.*
- And finally, enhanced staffing reduces but does not eliminate the need for linkage to community-based resources. No matter how expansive additional services are, they cannot cover all of the developmental and family support services that children and families might need. Practices still need to network and build relationships with other community-based resources. For example, housing assistance, legal services, and employment services for parents are beyond the scope of most health care practices. Similarly, relationship-based interventions that require a “daily dose,” such as one-on-one behavioral interventions, are best provided in a child care setting or in school-based special education programs.

### **Key Findings from Level I Strategies**

- Within the field of pediatrics, efforts to improve developmental care tend to take the form of in-house practice change, which is often implemented as part of a quality-improvement/systems change process.
- Routine surveillance, screening, and anticipatory guidance; and a referral/linkage point person and follow-up system are prerequisite for good linkage to services both within the practice and in the community.



- Adding new, in-house staffing and services eases the transition to new services for children and families, and keeps primary care in the loop. But this approach has limitations: at some point, for some children and families, needs will exceed practice capacity (for example, when the dosage and intensity of need requires daily, one-on-one interventions). In addition, an exclusive in-house focus cannot optimize the use of practice or community resources.
- Practice-wide systems change strategies can improve the quality of pediatric primary care.

## **LEVEL II—SERVICE PROVIDER PARTNERSHIP STRATEGIES**

Level II strategies strengthen the relationship between pediatric practices and existing community services. While practice-wide systems change strategies largely focus on building capacity within the practice, partnership strategies primarily focus on active linkage between the practice and specific community services. Among practices in the sample, three types of provider partnership strategies were identified: co-location of services, co-management of children, and networking and information sharing.

### **Strategy 4. Co-location of Services**

#### *Definition and Examples*

Co-location involves a physical link between the pediatric practice and one or more other community services. In some ways akin to enhanced staffing, co-location provides a streamlined route for practices to connect children to additional developmental care. While some practices co-locate by sharing a building or office space with related community services, others house and integrate community services staff (frequently from the public sector) within the pediatric health care practice setting. Among the examples of co-location:

- Kennebec pediatrics is located in Augusta’s historic Vickery Building, whose tenants includes, among others: EI services, WIC, Families First, child abuse and neglect services, Pediatric Rapid Evaluation Program (a foster care evaluation program), a children’s museum, an adult literacy program, and the Children’s Health Collaborative, which identifies and addresses gaps in health care services.<sup>21</sup>
- MGH Revere HealthCare Center, a community health center, shares a building with speech and language specialists, mental health services, Project Bread (a program that identifies hunger and refers to WIC and food pantries), domestic

violence and substance abuse services, and social workers. In addition, the Revere Healthy Steps Specialists conduct eligibility screens for the EI program. (This relationship with EI is not technically co-location, but it provides a bridging function between the practice and a needed community service.)

- Beaufort Pediatrics has incorporated multiple public sector staff within the office practice, including a public health social worker who serves as a case manager for children with special health needs, a public health nurse who provides on-site family support services, and a public health nutritionist.
- Guilford Child Health places four Department of Social Services Eligibility Specialists on-site to screen children for Medicaid and SCHIP eligibility.

### *Advantages*

Co-location has benefits for children and families, pediatric practices, and other public and private service providers:

- For families, co-location reduces both internal and external barriers to seeking additional care (e.g., transportation, availability, lack of familiarity or trust, and potential stigma associated with being referred to mental health or other outside specialists). The result for the child and family: timely linkage, better continuity of care, and greater patient satisfaction. Co-location is more than a matter of convenience: it contributes to the quality of care.
- From the perspective of the pediatric practice, co-location makes it easier to refer and link children to needed services, making referral a “first resort,” which can lead to earlier identification and intervention. Co-location also provides opportunities for practices to build relationships with other, complementary, community services.
- For public sector and other community programs, co-location can help use limited resources in a more targeted and effective way by “going where the children are.” By placing eligibility workers in practices serving large numbers of potentially eligible children and families, Medicaid, SCHIP (the State Child Health Insurance Program), and EI programs provide a smoother route for families to obtain health coverage and other services. Similarly, by placing nurses, nutritionists or social workers in practices with a high proportion of eligible children, public health programs such as State Title V (Maternal and Child Health/Children with Special Health Care Needs) programs or WIC can directly reach children in a setting where they are already receiving services, and where public program

representatives can more easily coordinate with the primary health care provider. Interviewee “testimonials” for co-location include the following:

*Having the State Early Intervention program in the same building makes it much easier to refer children to the program.*

*By referring to the developmental evaluation clinic located in our building, we are able to get kids behavioral health evaluation services and not lose them to the practice.*

*Our EI linkage developed as part of a relationship with a new person at EI. This part of the care is now seamless: we’re able to introduce the family to EI services, provide continuity of care. Families are happier and learn to trust us when we say we need to refer them.*

### **Limitations**

- In instances where co-location involves sharing a building or office space, there generally is no additional financial obligation for the pediatric practice or the co-located services. However, pediatric practices that co-locate by incorporating public sector program staff into their offices sometimes find that public programs are subject to funding cuts or other variability beyond the control of individual pediatric practice. In these cases, sustaining service requires flexibility and creativity, and in some cases, the practices absorb additional costs. Interviewees reported a range of opportunities and issues related to funding/sustainability of public sector co-location:

*Conducting EI eligibility screening is also a funding opportunity: we bill for the screen. We get reimbursed for all of the screening, even if they are not eligible.*

*Initially, there was a financial/billing benefit from having mental health services in-house. As an FQHC [Federally Qualified Health Center], we were able to bill at a higher rate and get services delivered in our practice. Now, we don’t have FQHC status so we are keeping the mental health services by absorbing the billing costs and giving the social worker 100 percent of the reimbursement we receive.*

*We still have a public health nurse who provides family support services, but the Health Department has had to back off on the level of services they give us. There is more fluidity on the public side; that is, the public sector is more subject to budget cuts or changes in policy directions. The private side is much more flexible.*

*The Title V social worker/case manager for the Children with Special Health Care Needs program is out in the community and goes to meetings to find out about services. But more recent changes at the State Public Health Department have resulted in her pay also being based on productivity, so she is less likely to attend networking and other meetings.*

## **Strategy 5. Co-management**

### *Definition and Examples*

Within the context of community linkage, co-management is defined as collaborative case management between the pediatric practice and one or more other service provider, focused on an individual child. In some practices, co-management comes on a case-by-case basis. In others, there is a regular meeting time established for case reviews, collaborative assessment, and problem solving. Case management meetings can be conducted in-person or by phone. The study sample includes varied case management arrangements:

- On an as-needed basis, Kennebec Pediatrics co-manages patients with other services located in its building and with a child psychiatrist in the community. The practice also provides support to schools, helping them co-manage the individual child's developmental needs. Families are an important partner in this process, as well.
- Inscription House holds a monthly high-risk pediatrics clinic, which is a case-management meeting involving a variety of service providers within the Navajo Nation. Meeting members include the pediatrician from the IHS–Inscription House pediatrics clinic; other IHS–Inscription House medical, nursing, and counseling staff; the Growing in Beauty Program Coordinator; school personnel; the Department of Social Services; Community Health Nursing, the Arizona School for the Deaf and Blind, and occasionally, the Developmental Disabilities Division of the Arizona Department of Health, and Children's Rehabilitation Services. Originally focused on child abuse, the high-risk clinic was expanded to include children with varying complex and/or chronic issues, such as diabetes, malignancies, prematurity, and children with or at-risk of emotional and/or behavioral issues.
- Beaufort Pediatrics holds quarterly meetings with occupational therapy, physical therapy, and speech therapy services in the community, to review and consult on individual children.
- MGH Revere HealthCare has developed a seamless system of care with EI services: The health center conducts EI eligibility screens; introduces qualifying families to EI program contacts; provides regular follow-up assessments and care; stays in touch with the program regarding referred children, and occasionally joins the EI program staff for home visits.

### *Advantages*

Co-management provides a way for pediatric practices to work directly with other service providers to assure that children are getting the developmental services they need. It is a personalized way of assuring individual children get integrated services.

- Under the best circumstances, co-management helps multiple providers get a more holistic understanding of the child and the environment in which she or he is developing, and it promotes joint problem solving to meet the child's needs:

*The primary purpose of the high risk clinic is to link back information on what is going on with the child and family: domestic violence and other issues are identified here.*

*There is a very good feedback loop. Also, we use the clinic for problem solving across agencies; and the clinic gives us an opportunity to find out about other services that are available in the community.*

- From a family perspective, co-management that includes family members empowers the family to take a guiding role in the coordination of their child's care.
- For the pediatric practice, co-management provides a means for pediatric primary care to implement a fundamental component of the medical home: care coordination.
- From a system-of-care perspective, co-management promotes coordinated care, reduces fragmentation and duplication of services, and increases understanding of other service sector programs and perspectives.

### *Limitations*

As with other strategies, the availability of reimbursement affects co-management activities and options. Often, payment is not available; however, this is not always the case.

- Beaufort Pediatrics reports that Medicaid will pay \$10 for every child discussed in its quarterly case management meetings, and the Indian Health Service provides release time for the Inscription House pediatrician to hold and participate in monthly, multi-service, high risk clinic meetings. While payment may be quite minimal, it can make a significant difference by acknowledging and legitimizing the importance of co-management:

*The most supportive circumstance at IHS is having the half day per month at the high risk clinic officially recognized as part of the job.*

There are potential downsides to co-management, as well:

- It requires additional time beyond the regular clinic schedule, which is not necessarily reimbursed.
- In addition, co-management may present confidentiality challenges that need to be addressed to honor the family's wishes regarding sharing information about their child and their family.

## **Strategy 6. Networking and Information Sharing**

### *Definition and Examples*

A final set of service provider partnership activities cited by interviewees can be categorized as networking and information sharing. It includes activities such as networking meetings or mixers, meet-and-greet sessions, academic detailing sessions, shared resource listings, and other, less structured outreach efforts from practices to programs or vice versa. A primary focus of these activities is to build and sustain relationships—a factor considered by many interviewees to be the very foundation of linkage. As described by interviewees, networking and information sharing can be used either to jump-start a referral and linkage process or to sustain and maintain the process. And, as with other strategies, activities vary in the extent to which they are systematic or formal.

For most practices and programs in the study sample, regularly staying in touch, building personal relationships with community service providers, and other (not necessarily structured) networking activities are the bread and butter of staying on top of resources and maintaining good linkage with community-based services. For practices with a designated care coordinator or community liaison, finding and building relationships is a major part of the job.

*Our referral coordinator builds and maintains relationships with developmental, behavioral, and mental health services across the community.*

*Our practice reaches out to Healthy Families America, the Early Intervention Program, the health department, and the school system.*

*The community liaisons often meet with representatives from other social service providers. They know about family support networks.*

Several programs in our sample provided examples of networking and information sharing meetings designed to introduce practices to community services, thereby jump-starting linkage from the practice to the service. A common thread across networking and

information sessions cited by interviewees is that they are not initiated by the pediatric practices, but rather by special programs targeted to improving linkage for developmental care. While the special programs themselves are examples of the third level of linkage—community-wide systems change—the networking and information sessions are included here because these efforts provide an important avenue for helping pediatric practices begin to link children to existing services in their communities.

- In its role as ABCD trainer, Guilford Child Health gives pediatric practices a preliminary list of local community services (referral resources), and organizes networking meetings or “mixers,” which bring practices together with community service programs.
- In Connecticut, the Help Me Grow program reaches out to primary care practices using a brief lunchtime “academic detailing” session to both promote developmental surveillance and to tell the practice about developmental assessment and referral services provided by Help Me Grow. These in-person sessions—based on the model used by pharmaceutical companies to sell new products—provide information and put a face on the Help Me Grow services.
- In Seattle–King County, the Children’s Preventive Healthcare Collaborative (part of the King County Health Action Plan, designed to spread the best practices of the Kids Get Care Program) organizes a meet-and-greet session that introduces participating pediatric practices to community services in the area. Like the Help Me Grow academic detailing meetings, these sessions “put a face” on the services as a means of promoting better linkage.
- In Illinois, the Enhancing Developmentally Oriented Primary Care Project (EDOPC) includes meet-and-greet sessions in training programs for practices, and also provides an initial set of resource listings for participating practices (with updates via a Website).

Networking and information sharing meetings are also used to sustain good relationships and linkages:

- Guilford Child Health holds a monthly “wrap-around meeting” that includes a psychiatric nurse from the local community health center, school nurses, social workers, community liaisons, providers, and nurses. The meeting is used “to discuss system-to-system and sector-to-sector collaboration and relationships.” Guilford Child Health also occasionally brings together care coordinators from

both pediatric practices and community services, to promote coordination across practices and programs.

- In a process that is one step removed—the focus is not on pediatric practices—the Help Me Grow program in Connecticut holds bi-monthly networking breakfasts that bring together family support and other community service providers to share information on community resources and gaps, and to problem solve around particular resource needs.

One final form of information sharing mentioned by interviewees is shared resource lists. For example:

- In Beaufort, S.C., the local school system’s Early Childhood Services compiles a resource list and shares it with pediatric practices.

### *Advantages*

Networking and information sharing are important strategies both for starting and maintaining links to other developmental services in the community.

- Introductory networking activities help to jump-start the referral process by “putting a face” on community-based services.

*Practices need to know their community resources before they are willing to screen. Many do not and really appreciate assistance in becoming more familiar.*

- By starting with “gatekeeper” or “nodal” community contacts (i.e., contacts with multiple connections to other community services), formal networking activities can simplify the referral process, making it easier to get started and continue linkage.

*We usually invite Child Family Connections because they are the gatekeepers. Their job is to know about services in the community. They find the community services for the providers [pediatric practices and others]. Most of the time they can find occupational therapy, physical therapy, speech, and nursing services.*

- Regular networking meetings play an important role in helping service providers meet the needs of the families they serve, and also provide an opportunity to identify and address community-wide needs.

*Of all the things we’ve done, the community networking breakfasts have been amazing. It’s the simplest thing we provide but they have given us a way of understanding gaps and barriers in communities.*



- And most important to many interviewees, ongoing networking activities help to build and maintain relationships.

*We are part of a community. It works. It is all about the relationships. We trust and respect each other.*

*We have a close working relationship with the developmental center and with the specialists. We know the people providing the services. That's the luxury of living in small communities.*

*My advice: Develop community networks and become an integral part of the network in your community.*

### **Limitations**

- Several interviewees noted that resource listings have a very limited shelf life and need to be coupled with solid community knowledge and relationships:

*Of course, any list is incomplete the day you put it together and is out of date the next day. Part of what we know has to do with being in the community for the past 24 years.*

- Time constraints make it difficult for pediatricians to be the primary networking or resource contact.
- While networking is essential, it is generally not directly reimbursed; and when funding gets tight, meetings in the community may be the first to go.
- In general, organizing and sustaining multi-sector or multi-agency networking meetings seems to be beyond the capacity of individual pediatric practices. Initiating and maintaining regular networking sessions may require commitment and funding by others in the community.

### **Key Findings from Level II Strategies**

- The three service provider partnership strategies—co-location, co-management and networking/information sharing—help use existing resources more effectively and improve the quality of care by: reducing barriers to care; promoting early referral, linkage, and follow-up; promoting cross-discipline problem-solving and family-centered care; and reducing duplication and fragmentation of services.
- Service provider networking and information sharing can help uncover gaps in services and can also set the stage for collaborative efforts to address gaps (e.g., coalitions to change policies and programs).

- Initiating and maintaining regular, multi-sector or multi-agency service provider networking sessions generally exceeds the capacity of individual pediatric practices, requiring commitment and funding from others in the community or beyond.

### **LEVEL III—COMMUNITY-WIDE SYSTEMS CHANGE**

While Level II strategies focus on linking pediatric practices to existing community services, and thereby improving linkage for children, Level III strategies take a more expansive view of the linkage landscape and focus on systemwide change. Three sets of broad community-wide systems change strategies were identified in the study sample: new or enhanced community resources; systemwide training and support (for practice or program-level change); and systemwide policies and protocols. Like practice-level systems change (found in Level I strategies), community systems change starts with an assessment of what is working, what is missing, and what is needed to better link children to developmental care. However, the unit of analysis for Level III change is broader: a geographic area (e.g., a community or state); a targeted population (e.g., children in foster care; the 0–5 age group); pediatric health care providers (including those in residency programs and continuing medical education training); or the policy environment (e.g., reimbursement policies; school system protocols).

#### **Strategy 7. New or Enhanced Community Resources**

##### *Definition and Examples*

Among the most innovative and ambitious approaches to improving pediatric care linkages, this strategy involves assessing the system of developmental care within a given community, identifying gaps, and then developing new or enhanced community-based resources to fill the gaps.

In the study sample, this kind of population-based approach was either initiated by the public sector or included a public sector partner. While each of the programs in the sample developed its own model, there are some consistent themes across communities with regard to the newly developed resources. In general, they include one or more of the following: 1) centralized referral/linkage resources; 2) secondary or mid-level assessment services (i.e., assessment that goes beyond initial surveillance or screening, but is less than a full neurodevelopmental work-up); 3) enhancement and intervention services for at-risk children and those with mild to moderate delays; and/or 4) promotion and prevention resources for normally developing children and their families. Gaps in these four types of resources were consistently cited by interviewees as barriers to pediatric care linkage.

Examples of new or enhanced community resources include:

- In Connecticut, the Help Me Grow (HMG) program contracts with the state's 211 information and referral system to provide a referral/linkage call-in center for children with or at-risk of developmental, behavioral, and mental health issues. Via the Child Development Infoline, HMG provides: outreach; care coordination services; background information on the various service delivery systems; referrals to programs and supports for children; advocacy, when necessary; and follow-up contact with families to determine if their needs have been met. Child Development Infoline maintains a client tracking/data collection system that provides a range of information on callers.
- HMG staff includes regionally focused Child Development Community Liaisons, who continually map and network with developmental services/resources in the state to keep call center information up-to-date and to identify emerging needs within the state. Originally a call center for physicians, HMG now has an open-door policy for referrals.
- The Growing in Beauty (GIB) program improves linkage by serving as the point source for all developmental referrals for 0-3 year olds in the Navajo Nation. The program includes one GIB coordinator in each of eight regions. The coordinators conduct home visits; use the ASQ to screen at in-take; refer children and families to additional services, including comprehensive evaluation; provide case management; and check to make sure appointments are kept. While the program only goes through age 3, the GIB Coordinator helps families with the transition to new services after age 3.
- In North Carolina, the state Medicaid program has established 15 regional Community Care Networks, each with a Network Care Manager who helps pediatric practices link children to needed developmental and mental health services in the community, including: Children's Developmental Services Agency, Early Intervention, Head Start, preschool programs, and independently enrolled mental health providers. Thus, the Care Networks function as referral and linkage centers for further assessment and intervention. The Networks also include a Web-based component for tracking services provided.
- In San Diego, Calif., the Children's Care Connection (C3) program improves linkage to developmental care by providing interdisciplinary, community-based services to young children with mild to moderate developmental delays or behavioral problems. Services include: screening and secondary evaluation, enrichment services, one-on-one developmental and behavioral treatment, and

referrals to additional services, as needed. The program also provides educational classes for parents of children with mild to moderate developmental delays or behavioral problems, as well as for parents of typically developing children.

In addition to new community resources serving a broad cross-section of the population, some programs provide new, systemwide resources to serve a specific, high-risk population: children in foster care.

- In San Diego, the Developmental Screening Enhancement Program (DSEP) was established to provide universal developmental screening and linkage for foster care children. Services provided under DSEP include: initial screening within one week of entry into the foster care system; a secondary assessment for positive screens; referral/linkage for additional services, as needed; care coordination, and transfer of discharge information to a public health nurse or to a community-based case manager.
- Similarly, the Pediatric Rapid Evaluation Program in Augusta, Me., was established to expedite and consolidate physical and mental health assessments for foster care children into a single report that is provided to the child's new primary care physician. In this case, the new program works to assure linkage back to the medical home for further monitoring and care.

### *Advantages*

New community-wide programs such as the ones described above enhance pediatric primary care linkage to developmental services in several ways.

- Some of the new resources fill community service gaps that in themselves are barriers to linking children to needed developmental care: this is especially true for mid-level assessment and intervention services. Having these services in place can encourage referral as a first resort, making it more likely that children with mild to moderate delays receive timely and appropriate care.
- New, centralized community assessment, linkage, and intervention services can provide a welcome adjunct to in-house services. Particularly for small practices and those without enhanced staffing, centralized referral and linkage services provide a means for practices to effectively link children to developmental care without incurring additional costs.

- An added advantage of community programs that accept self-referral from parents is that the programs can pick up and address issues needing immediate attention, and then connect the child and family to a medical home if needed.
- From a community systems perspective, as more mid-level assessment and intervention services become available, more high-end services can be freed up for children with the greatest needs. Thus, the alignment between needs and services can be improved. In addition, over time, increases in mid-level, secondary prevention services can result in fewer children who end up needing more intensive care.
- Also from a community systems perspective, having regional or community resources for referral, linkage, secondary assessment and interventions can be less costly and much more comprehensive than having each independent pediatric practice map resources, build and maintain relationships with a broad array of services, and develop mid-level assessment and intervention skills.

### *Limitations*

- Some child health care providers feel that control of the referral process is central to implementation of the medical home, and therefore may be reluctant to “outsource” or share this responsibility. Others feel that some of the families in their practice cannot handle a referral to another resource. Flexibility seems to be the key to addressing these concerns. For instance, the HMG program offers the option of providing referral resource information directly to the pediatric practice, which can then provide it to the family.
- Some families feel there is a stigma attached to seeking and receiving any kind of additional services, even “mid-level” services, either because of family or community cultural norms or because of the entrenched notion of a medical “deficit model” (i.e., since medical interventions tend to focus on what is wrong, families tend to view referrals as negative). As a result, parents may not seek these services or, if they do obtain services, others in the community may view the child as a problem.
- Finally, creating new community or statewide developmental services requires a substantial ongoing commitment of resources; interdisciplinary and cross-sector expertise and collaboration; political will; leadership; vision; and a time frame measured in years, if not decades.

## **Strategy 8. Systemwide Training and Support Programs**

### *Definition and Examples*

This strategy applies training systemwide to improve developmental care and linkage. In the study sample the “system” of interest varies: it can be focused exclusively on pediatric practices, or on multiple sectors (e.g., child care providers and primary care practices). Some of the training efforts focus on changing established pediatric health care clinics or offices. Others enhance skills upfront through pediatric residency training. Most of the training programs are focused geographically on a community or state. What all have in common is an effort to change the orientation, skills, and practices of pediatric primary care to better address the developmental needs of children. All embed in their training information on linking children to additional services, as needed. Examples include:

- In North Carolina, the ABCD project provides training and tools to help pediatric practices improve developmental care and linkage to community services. Among the resources they provide to practices are: “Getting Started” worksheets for identifying office roles and responsibilities and for mapping community resources; parent education materials; and a physician curriculum, including a training video and companion workbook.<sup>22</sup>
- In San Diego, the C3 program offers a range of training tools for pediatric primary care providers: a behavioral health manual for primary care practices; parent handouts regarding behavior and development; as well as information and handouts on linkages to C3 programs and services. C3 also offers training and referral resources to child care providers and teachers in the community so that they might accurately address the developmental needs of the children and families they serve. Through its training efforts, C3 has been building a community-wide system of developmental care that includes support and promotion of healthy development, as well as establishing linkages to additional resources to help children with or at risk for delays. (Similarly, DSEP—a sister program in San Diego—provides training, resources and support for foster care parents to manage emotional and behavioral health issues in children.).
- In Seattle–King county, Kids Get Care and the Children’s Preventive Healthcare Collaborative—two programs that are part of the King County Health Action Plan—provide integrated, multi-pronged training and support programs to improve developmental and other services for children in the community. The Children’s Preventive Healthcare Collaborative uses a quality improvement model to help pediatric primary care practices transform care. The program trains community health centers and other primary care practices, focusing on

developmental and dental health. Training sessions include: use of the ASQ, meet-and-greet sessions to introduce practices to other community resources, and a resource book on the NICHQ quality improvement model. The Kids Get Care program (like C3) offers training and support for child care providers, community-based organizations, parents, and others working directly with children to enhance developmental surveillance and linkage. For these sectors, KGC uses a “Red Flags” basic surveillance tool for developmental delay and oral health needs. One of the Kids Get Care basic tenets is “web and funnel,” which the program describes as follows: “Kids Get Care casts a web of community connections around participating clinic sites and funnels identified children to services. Community staff in the area are trained about appropriate developmental milestones and oral health promotion so they can support parents in securing services for their children. If staff find that the family is in need of services they can refer them to a KGC case manager to establish a health home.”<sup>23</sup>

- In Arizona, the Healthy Steps program at Phoenix Children’s Hospital provides training for pediatric residents on developmental screening, anticipatory guidance, resource mapping, and linkage. The program also brings representatives from community services to the training sessions. Currently, the program has seed money to train EI service providers on topics similar to those covered in the residents’ training.
- And, in Illinois, the Enhancing Developmentally Oriented Primary Care Project (EDOPC) provides multidisciplinary developmental primary care training and technical assistance to: pediatric and family practice residency programs, nurse practitioner and physician assistant training programs, public health departments, family case managers from the Department of Human Services, the Child and Family Connections program, and other strategically targeted practices and programs that serve large numbers of children. EDOPC training covers: screening and referral for social and emotional health, maternal depression, and developmental issues; office systems change; billing practices; resource mapping; and meet-and-greet sessions with community services representatives. For sites receiving more intensive training and technical assistance, the program provides additional tools, including developmental screening tools (ASQ and ASQ-SE), a template for resource mapping, video clips, case discussions, and a sample 2-way release form for referral information.

### *Advantages*

These programs improve developmental care and linkage by pediatric primary care practices in several ways:

- Training at the front end of the health professions pipeline—e.g., for pediatric residents and nurse practitioner students—provides an effective mechanism for changing the practice of the next generation of pediatric health care providers.
- Centralized development of training materials and outreach is an efficient and cost-effective strategy. Collaboratives and other training programs for those already in practice provide tested approaches and support for change: individual practices do not have to reinvent the wheel or go it alone to improve developmental care.
- Programs that provide training and tools for more than one sector help to build a shared knowledge base and approach to developmental care, increase opportunities for cross-sector linkage, and also promote new and enhanced developmental services. By integrating a developmental focus into multiple systems of care, community-wide training programs can go a long way both in promoting optimal development and building a developmental care safety net that identifies and addresses needs early on.

### *Limitations*

- Retraining and reorienting pediatric practices can be labor-intensive and costly.
- Influencing medical schools, pediatric residency programs, and other health professions training programs to focus more on developmental care can be extremely difficult, requiring buy-in from professional associations and accrediting organizations as well as the training institutions.
- Systemwide training involving multiple sectors, requires a system-level commitment of resources, expertise, and leadership, as well as an appreciation of the importance of cultural competence and outreach.

## **Strategy 9. Systemwide Policies and Protocols**

### *Definition and Examples*

One last strategy identified in the study sample is the development or use of systemwide policies and protocols to promote or sustain linkage for developmental care. These include cross-agency protocols, reimbursement policies, and other dedicated funding streams for developmental services and supports.

Community protocols in the sample ranged from relatively simple to highly complex:

- On the streamlined end, the Navajo Nation and the Indian Health Service have developed and implemented a Memorandum of Agreement to jointly accomplish:



identification of young children with or at-risk for developmental disabilities; initial screening of these children; referral to comprehensive evaluation and direct services; and follow-up of referrals to facilitate timely completion of evaluations.<sup>24</sup>

- In San Diego County, DSEP (the Developmental Screening and Enhancement Program) works with community agencies to create cross-agency standardized referral processes and procedures for children in foster care.
- In North Carolina, two counties—Guilford and Forsyth—initiated community consensus projects aimed at improving collaboration between schools and pediatric health care providers on identification and management of Attention Deficit Hyperactivity Disorder (ADHD). The result: cross-sector ADHD protocols were developed and implemented in both counties. Among other key provisions, the new protocols clarified and better aligned roles and responsibilities for schools and for pediatric practices; spelled out expectations regarding the scope of assessments (to include potential co-morbidities); articulated information and paperwork requirements; and spelled out procedures and expectations for communication and follow-up care. The plan also includes provisions for educating and orienting school and health staff to the new processes.<sup>25</sup>

Medicaid and other financing policies play a crucial role in both jump-starting and sustaining changes in practice. In some cases, the programs in the sample were instrumental in changing financing policies:

- In North Carolina, a pediatrician with Guildford Child Health worked with the state chapter of the American Academy of Pediatrics to improve Medicaid reimbursement to pediatric practices providing behavioral and developmental care. To work on the issue, the chapter formed a Task Force on Mental Health Care Access and Reimbursement, which included other mental health care providers and mental health advocates. The results: an impressive expansion of state Medicaid rules. Among the changes were provisions allowing: 1) primary care provider referral for up to 26 mental health visits annually for children under 21; 2) billing by physicians for on-site, supervised mental health services provided by employees who are either clinical social workers or clinical nurse specialists with psychiatric training; and 3) direct billing to Medicaid by independent licensed clinical social workers, licensed psychologists, and advanced-practice nurses.<sup>26</sup> While there is still a long way to go, these and other changes in reimbursement policies enable primary care pediatric practices in the state to step up to the plate and improve care and linkage for children with developmental or behavioral health problems.

In other cases, interviewees pointed out the importance of state reimbursement policies to their own work:

- In San Diego, targeted case management funds from Medicaid (Medi-Cal) are used to support the Developmental Screening and Enhancement Program for children in foster care.
- In Massachusetts, Child Find laws allow reimbursement for EI screening on all children, regardless of findings. Massachusetts also allows at-risk children to receive EI services for 6 months and then evaluates the impact: if the child has improved, she or he can continue on EI.
- And again in North Carolina, the Medicaid program supports 15 Community Care Networks throughout the state, which include—along with other components—a per capita payment of \$2.50 per individual per month for in-office care management, and \$2.50 per member, per month to the network for care management activities. Other quality projects of the networks include asthma, diabetes, and mental health integration protocols.

Several of the community/state systems change initiatives in the study sample receive substantial support from other dedicated funding streams:

- In California, Proposition 10 earmarked tobacco settlement funds for the First 5 Initiative, a statewide initiative that supports early childhood development in every county in the state. In San Diego, First 5 dollars are used to fund the C3 program.
- In Connecticut, the state legislature dedicates child abuse and neglect prevention funds to the Help Me Grow program.

### *Advantages*

It is difficult to overstate the importance of supportive systemwide policies and protocols in helping pediatric practices link children to developmental care.

- Financing policies rank very high in their potential to improve linkage to developmental care: Virtually every practice interviewed raised the issue of inadequate reimbursement for developmental services—an issue linked to nearly all of the key strategies in this report. In some cases, even when the total payment is minimal, reimbursement can have the important impact of legitimizing the role of primary care pediatrics in developmental care. In addition, state Medicaid policies allowing direct billing by social workers, licensed psychologists, and other mental

health professionals increase the pool of accessible providers available for referral and linkage.

- Cross-sector protocols spelling out roles and responsibilities and formalizing expectations around linkage also provide multiple advantages, including the potential to improve practice efficiency and standards of care, and enhance identification of children needing additional developmental assessment or intervention.<sup>27</sup> In short, systemwide protocols provide support and infrastructure for pediatric practices to optimize the impact of their own care, while also coordinating with care across sectors. In addition, from a community or population-based perspective, collaboration of public health, education, and other community systems promotes strategic pooling of resources to achieve shared goals of healthy children, engaged and learning.

### *Limitations*

- This is not a strategy that can be promoted by a single champion over a short period of time. In many cases, developing and implementing systemwide policies and protocols requires extraordinary leadership, collaboration, time, persistence and political skills to craft and maintain.
- In most cases, full-time clinicians do not have the time required to direct or coordinate the development of systemwide changes. Instead, pediatricians and other clinical personnel leading these efforts have developed additional means of financial support (e.g., as academics, researchers, or directors of demonstration projects), freeing them to devote time to community or state policy efforts.

### **Key Findings from Level III Strategies**

- New community or statewide programs can improve linkage and fill gaps in needed developmental services. Among the most needed services are: mental health care; centralized referral /linkage resources; mid-level assessment services; and intervention services for children at-risk and with mild-to-moderate delays.
- From a community systems perspective, as more mid-level assessment and intervention services become available, more high-end services can be freed up for children with the greatest needs. Thus, the alignment between needs and services can be improved. In addition, over time, increases in mid-level, secondary prevention services can result in fewer children needing more intensive care.
- Among community-wide programs there is a move to reach out to parents, child care workers, and others who touch children's lives on a regular basis. These

programs help establish a shared understanding of child development and a shared responsibility for both promoting development and identifying and addressing developmental needs.

- Systemwide training programs for pediatric primary care practices improve developmental care and linkage by: 1) providing information to enhance developmental expertise, 2) introducing a practice-wide systems change approach, and 3) stressing the importance of linking to other community services and systems. Similarly, systemwide training programs for medical residents, nurse practitioners, and other trainees prepare the next generation for improved developmental care and linkage.
- Systemwide policy changes can jump-start and/or sustain individual practice change.
- Reimbursement/financing systems for developmental care and linkage are crucial.

## SUMMARY FINDINGS

Key findings for each of the three strategy levels are recapped below, along with cross-level findings.

### **Key Findings from Level I—Practice-Wide Systems Change Strategies**

- Within the field of pediatrics, efforts to improve developmental care tend to take the form of in-house practice change, which is often implemented as part of a quality-improvement/systems change process.
- Routine surveillance, screening, and anticipatory guidance; and a referral and linkage point person and follow-up system are prerequisite for good linkage to services both within the practice and in the community.
- Adding new, in-house staffing and services eases the transition to new services for children and families, and keeps primary care in the loop. But this approach has limitations: at some point, for some children and families, needs will exceed practice capacity (for example, when the intensity of the need requires daily, one-on-one interventions). In addition, an exclusive in-house focus cannot optimize the use of practice or community resources.
- Practice-wide systems change can improve the quality of pediatric primary care.

### **Key Findings from Level II—Service Provider Partnership Strategies**

- The three service provider partnership strategies—co-location, co-management and networking/information sharing—help use existing resources more effectively and improve the quality of care by: reducing barriers to care; promoting early referral, linkage and follow-up; promoting cross-discipline problem-solving and family-centered care; and reducing duplication and fragmentation of services.
- Service provider networking and information sharing can help uncover gaps in services and can also set the stage for collaborative efforts to address gaps (e.g., coalitions to change policies and programs).
- Initiating and maintaining regular, multi-sector or multi-agency service provider networking sessions generally exceeds the capacity of individual pediatric practices, requiring commitment and funding from others in the community or beyond.

### **Key Findings from Level III—Community-Wide Systems Change Strategies**

- New community or statewide programs can improve linkage and fill gaps in needed developmental services. Among the most needed services are: mental

- health care; centralized referral /linkage resources; mid-level assessment services; and intervention services for children at-risk and with mild-to-moderate delays.
- From a community systems perspective, as more mid-level assessment and intervention services become available, more high-end services can be freed up for children with the greatest needs. Thus, the alignment between needs and services can be improved. In addition, over time, increases in mid-level, secondary prevention services can result in fewer children needing more intensive care.
  - Among community-wide programs, there is a move to reach out to parents, child care workers, and others who touch children's lives on a regular basis. These programs help establish a shared understanding of child development and a shared responsibility for both promoting development and identifying and addressing developmental needs.
  - Systemwide training programs for pediatric primary care practices improve developmental care and linkage by: (1) providing information to enhance developmental expertise, (2) introducing a practice-wide systems change approach, and (3) stressing the importance of linking to other community services and systems. Similarly, systemwide training programs for medical residents, nurse practitioners and other trainees prepare the next generation for improved developmental care and linkage.
  - Systemwide policy changes can jump-start and/or sustain individual practice change.
  - Reimbursement/financing systems for developmental care and linkage are crucial.

### **Cross-Level Findings**

Looking across the strategies and linkage levels, several findings emerge that contribute to understanding how the strategies fit together to enhance developmental care.

- These are not stand-alone strategies. Most of the innovative programs and practices in the study sample combined several strategies, and often at different levels: practice-based, service provider partnerships and/or community systems levels.
- To optimize impact and resources, practice-based strategies need to integrate with strategies for community programs and policies (and vice-versa).
- There is no "one size fits all": The ways in which individual practices, programs, and communities combine these and other strategies (still to emerge), will vary depending on the size, setting, type and location of the practice or program, as well as other contextual or environmental factors. Future evaluations of the strategies should also take these factors into account.

## **MOVING FORWARD: GUIDING PRINCIPLES AND RECOMMENDATIONS**

This final section of the report incorporates lessons learned into a set of guiding principles for practices and programs interested in enhancing linkage for developmental care and a broader set of recommendations for enhancing developmental care linkages in communities, states, and nationwide.

### **Guiding Principles**

For practices and programs that want to improve developmental care and linkage, several guiding principles emerge from this review:

- **Work in partnership with families.** The exemplary practices and programs in the study sample pointed to the transformative impact of parents as partners in developmental care. In the final analysis, it is parents who are responsible on a day-to-day basis for the healthy development of their children. Pediatric primary care providers, along with other service providers, need to address parents' concerns and questions, support and strengthen parenting skills, and contribute to a broader community environment that assists parents in promoting optimal child development.
- **Build relationships.** Interviewees repeatedly noted the importance of building key relationships—with families, with other providers, and with community services and supports—in order to effectively link children and families to the developmental services they need. A corollary to this principle is that pediatricians and pediatric primary care practices cannot address developmental issues alone; instead, they need to work in partnership with families and with other service providers.
- **Collaborate, integrate, and reinforce across services and supports.** These activities transform relationships into effective and efficient programs at the community level. In a time of limited resources for developmental care, it is particularly important to reduce duplication and to coordinate across practices, agencies and sectors.
- **Use a systems-focused, quality improvement approach.** A systems focus provides the broad analysis and framework needed to guide change. The quality improvement approach makes implementation manageable. The systems and quality improvement combination is equally useful at the practice, program, and community/state/national levels, and can be integrated across all levels.

- **Shift the balance of resources from high end to front end.** Both from a child development and from a community resources perspective, a key to success is to shift the use of resources from predominantly high-end interventions (i.e., waiting until there are severe deficits to intervene) to predominantly front-end interventions (i.e., early identification and intervention for those at-risk and with mild to moderate delays, enhancing parenting skills, and building a culture and environment that supports healthy development). To achieve these results, practices and programs are encouraged to use a “no wrong doors” approach for referrals into the practice or program (accepting self-referral, referral from child care, etc.) and in referring out, to shift to “referral as a first resort.” At the same time, at the community level, other sectors need to enhance knowledge and regularly monitor developmental status, and community resources need to be developed or enhanced to better address mild to moderate delays.
- **For “daily dose” interventions, go where the children are.** It is important to recognize that interventions requiring daily or more frequent interaction with a child need to be available where the child spends his or her time. These types of interventions (particularly for behavioral issues) require training and support for child care workers, teachers, parents, and others who are part of the child’s everyday life, and need to be coordinated with other essential, but less frequent care, such as that provided by pediatric primary care practices.
- **And finally, use a “no wrong doors” approach to getting started: start at whatever level, with whatever strategies are available to the practice or program.** Start where you can, and apply the other guiding principles as you move forward.

## **Recommendations**

The following are recommendations and next steps for implementation to enhance developmental care linkages in communities, states and nationwide:

### *Recommendations for Practice Level Change:*

1. **Use quality improvement (QI) approaches to achieve developmental care systems change at the practice level.**

Next Steps:

- AAP, public health agencies, and Medicaid should jointly or individually promote systemwide implementation of QI/practice change initiatives focused on helping pediatric practices implement developmental care systems that include: routine



- surveillance, screening, and anticipatory guidance; a linkage point person; and a system for follow-up care. ([See Recommendation 6](#) for next steps on training.)
- Private foundations and public sector research entities should support evaluation research both on the costs and outcomes related to practice-based systems change for developmental care. Outcomes of particular interest include: detection, referral, and linkage rates; age at which risks or deficits are identified; parent satisfaction; and improved coordination and collaboration with other community services and resources. From a population perspective, additional outcomes of interest might include: expulsion rates from day care and school readiness measures.
  - Private foundations and public sector research entities should support cost and outcome evaluation of varying roles, responsibilities and training for the position of practice-based linkage point person, with the goal of identifying the most effective and feasible options for practices of differing sizes and settings.
  - State and local AAP Chapters, public health agencies, parent groups and other children’s advocates should work collaboratively to promote Medicaid and private sector reimbursement policies that encourage and sustain practice-level changes, including care coordination and co-management. [Note: because of the crucial role financing plays in practice change, this recommendation is listed here as well as in the section on community systems change ([See Recommendation 7.](#)).]

**2. Rethink and reorient the well-child component of pediatric primary care so that pediatric practices can substantially contribute to the promotion of healthy development.**

Next Steps:

- Private sector foundations—in collaboration with AAP and the federal Maternal and Child Health Bureau—should jointly engage a small group of “early adopter” practices in devising and testing strategies that reorient well-child visits to promote healthy development. Particular attention should be paid to: 1) what parents want and need; and 2) the interface between pediatric primary care and other community services and resources.
- Private foundations and public sector research entities should evaluate early adopter outcomes, including: parent satisfaction, changes in type and frequency of developmental issues raised and addressed, changes in referral patterns, and changes in linkage with other community resources.

- AAP should develop a “Task Force on Rethinking Well-Child Care” to propose new guidelines reorienting well-child care to focus on promoting healthy development.<sup>28</sup>

*Recommendations for Service Provider Partnerships:*

**3. Engage professional associations and umbrella agencies in identifying and linking developmental resources in their communities.**

Next steps:

- State and local public health agencies, EI programs, school districts, AAP Chapters, and other umbrella organizations should jointly develop and frequently update a short list of “nodal” or “gatekeeper” resources for developmental care at the local and/or regional level within each state. This could serve as a starter list of referral resources across sectors.
- State and local AAP Chapters, public health agencies, EI programs, schools and/or other community service providers should regularly host community-based meet-and-greet sessions or mixers to introduce new providers to community resources that support healthy development. To the extent possible, these should be jointly hosted or at least coordinated across sectors.
- Community liaisons, care coordinators, and linkage point persons within and across service sectors should regularly meet and network, to build relationships, share resources, and jointly problem solve. These meetings could be sponsored by one or more sector.

**4. Promote co-location of public sector services in pediatric practices, as well as other innovative and cost-effective ways to deploy existing public sector resources for developmental care.**

Next steps:

- State and local public health agencies, Medicaid, EI programs, and other public sector services should explore placement of eligibility workers, care liaisons, and/or direct service providers (e.g., developmental specialists, mental health professionals) within high volume pediatric practices, particularly in underserved areas.
- Private foundations and public sector research entities should support cost-effectiveness evaluations of public sector co-location, with particular focus on costs and benefits across varying sectors, settings, and locales.

*Recommendations for Community Systems Change:*

**5. Promote mid-level developmental assessment and referral/linkage capacity at the community or regional level.**

Next steps:

- State and local public health agencies, Medicaid, EI programs, and other public sector services should continue to identify, implement, and evaluate innovative uses of existing resources to provide community-wide, mid-level assessment and referral/linkage services.
- Private and public sector funders and agencies should collaborate to further review community-wide referral/linkage and assessment models to delineate core components, costs, impacts, and lessons learned across models. Particular attention should be paid to innovative and effective use of existing community resources.
- Private and public sector funders and agencies should collaborate to support implementation and diffusion of effective community-wide referral/linkage and assessment models, and related components.

**6. Support training for pediatricians and other primary care providers to help them implement practice-based systems change focused on developmental care.**

Next steps:

- AAP, public health agencies, and Medicaid should jointly or individually promote systemwide implementation of QI/practice change training focused on helping practices implement developmental care systems that include: surveillance, screening, anticipatory guidance, a linkage point person, and follow-up care.
- AAP and other providers of continuing medical education should offer CME credit as an added incentive for participation in QI/practice change training focused on developmental care.
- AAP and the Accreditation Council of Graduate Medical Education (ACGME) should promote pediatric residency training components focused on developmental care and linkage, and on quality improvement/practice-based systems change.
- AAP, public health agencies, private foundations, and other service sectors should explore and support multi-discipline and multi-sector training on developmental care in order to encourage integrated, community-wide surveillance and linkage efforts.

**7. Identify and promote key policy changes, including policies that improve financing and sustainability of community systems for developmental care.**

Next steps:

- State and local AAP Chapters, public health agencies, parent groups, and other children’s advocates should work collaboratively to promote Medicaid and private sector reimbursement policies that encourage and sustain practice-level changes, including funding for care coordination and co-management.
- State and local AAP Chapters, public health agencies, parent groups, and other children’s advocates should work collaboratively to promote state and community policies that promote and sustain new and enhanced community resources for developmental care.
- Credentialing and certifying organizations should require practice-based, quality improvement activities focused on developmental care, as a basis for maintenance of specialty certification.
- Local and regional pediatric health care providers should work collaboratively with schools, EI programs, child care, and other sectors to develop clear and feasible community protocols for delivering developmental care to children and their families.

## NOTES

<sup>1</sup> J. P. Shonkoff and D. A. Phillips (eds.), *From Neurons to Neighborhoods: The Science of Early Childhood Development* (Washington, D.C.: National Academy Press, 2000).

<sup>2</sup> American Academy of Pediatrics, Division of Health Policy Research. Identification of children less than 36 months at risk for developmental problems and referral to early identification programs: Executive summary, Periodic Survey of Fellows, number 53 (Elk Grove Village, Ill.: American Academy of Pediatrics, 2003).

<sup>3</sup> N. Halfon and L. M. Olson, "Introduction: Results from a New National Survey of Children's Health," *Pediatrics*, June 2004 113(6):1895–98.

<sup>4</sup> D. B. Bailey, K. Hebbeler, A. Scarborough et al., "First Experiences with Early Intervention: A National Perspective," *Pediatrics*, Apr. 2004 113(4):887–96.

<sup>5</sup> D. R. Halloran, T. C. Wall, H. Evans et al., "Hearing Screening at Well-Child Visits," *Archives of Pediatrics and Adolescent Medicine*, Oct. 2005 159(10):949–55.

<sup>6</sup> In this study, the definition of "pediatric health care providers" includes: pediatricians, family practice physicians, pediatric nurse practitioners, physicians assistants, and others in practices who provide health care services to children.

<sup>7</sup> American Academy of Pediatrics, Committee on Children with Disabilities, "Developmental Surveillance and Screening of Infants and Young Children," *Pediatrics*, July 2001 108(1):192–96.

<sup>8</sup> American Academy of Pediatrics, Committee on Children with Disabilities, "Role of the Pediatrician in Family-Centered Early Intervention Services," *Pediatrics*, May 2001 107(5):1155–57.

<sup>9</sup> P. Newacheck, Y. Hung, M. Hochstein et al., "Access to Health Care for Disadvantaged Young Children," *Journal of Early Intervention*, Winter/Spring 2002 25(1):1–11.

<sup>10</sup> This is the same definition used in N. Halfon, M. Regalado, and K. T. McLearn, *Building a Bridge from Birth to School: Improving Developmental and Behavioral Health Services for Young Children* (New York, N.Y.: The Commonwealth Fund, 2003).

<sup>11</sup> The Bright Futures periodicity schedule calls for eight visits during the first year of life (including a prenatal visit) and six visits during early childhood (ages 1–4). See M. Green, J. S. Palfrey, E. M. Clark et al. (eds.), *Bright Futures: Guidelines for Health Supervision of Infants, Children and Adolescents (2nd ed., rev.) Pocket Guide* (Arlington, Va.: National Center for Education in Maternal and Child Health, 2002).

<sup>12</sup> For further information on national initiatives, see the following Web sites: Healthy Steps (<http://www.healthysteps.org>), ABCD (<http://www.nashp.org>), Medical Home Improvement (<http://www.cmhi.org>), and NICHQ learning collaboratives and related activities (<http://www.nichq.org>).

<sup>13</sup> E. C. Perrin, "Ethical Questions About Screening (Commentary)," *Journal of Developmental and Behavioral Pediatrics*, Oct. 1998 19(5):350–52.

<sup>14</sup> M. Regalado and N. Halfon, "[Primary Care Services Promoting Optimal Child Development from Birth to Age 3 Years: A Review of the Literature](#)," *Archives of Pediatrics and Adolescent Medicine*, Dec. 2001 155(12):1311–22.

<sup>15</sup> Ibid.

<sup>16</sup> Ibid.

<sup>17</sup> K. T. Young, K. Davis, C. Schoen et al., "Listening to Parents: A National Survey of Parents with Young Children," *Archives of Pediatrics and Adolescent Medicine*, Mar. 1998 152(3):255–62.

<sup>18</sup> Kennebec Pediatrics KP Cares Program, “Why Care Coordination?” (Augusta, Maine: Kennebec Pediatrics). Accessed 4/17/2006 from [http://www.kennebecpediatrics.com/kp\\_cares/](http://www.kennebecpediatrics.com/kp_cares/).

<sup>19</sup> Exeter Pediatrics Core Health Services, “Care Coordination at Exeter Pediatrics: Putting the Pieces Together” (Exeter, N.H.: Exeter Pediatrics, Core Health Services, undated brochure).

<sup>20</sup> Ibid.

<sup>21</sup> Communities Can, “Communities of Excellence,” (Washington, D.C.: Georgetown University Center for Child and Human Development, 1999). Available at [http://gucchd.georgetown.edu/files/products\\_publications/ccexcellence2000.pdf](http://gucchd.georgetown.edu/files/products_publications/ccexcellence2000.pdf).

<sup>22</sup> For more information on North Carolina’s ABCD Project (as well as ABCD projects in other states), see the Web sites for The Commonwealth Fund (<http://www.cmwf.org/tools/>) and the National Academy for State Health Policy (<http://www.nashp.org/>).

<sup>23</sup> Public Health, Seattle and King County [Washington], Kids Get Care Program. <http://www.metrokc.gov/HEALTH/kgc/about.htm>. Accessed 4/17/2006.

<sup>24</sup> *Intergovernmental Agreement Between the Navajo Nation and Navajo Area Indian Health Services Concerning Children with Disabilities Ages 0–5 and Their Families* (Unpublished Memorandum of Agreement, 2003).

<sup>25</sup> J. M. Foy and M. F. Earls, “A Process for Developing Community Consensus Regarding the Diagnosis and Management of Attention-Deficit/Hyperactivity Disorder,” *Pediatrics*, Jan. 2005 115(1):e97–e104.

<sup>26</sup> J. M. Foy, M. F. Earls, and D. Horowitz, “Working to Improve Mental Health Services: The North Carolina Advocacy Effort,” *Pediatrics*, Dec. 2002 110(6):1232–37.

<sup>27</sup> Foy and Earls, “Process for Developing,” 2005.

<sup>28</sup> E. L. Schor, “Rethinking Well-Child Care,” *Pediatrics*, July 2004 114(1):210–16.

## APPENDIX

### Practices and Programs

Beaufort Pediatrics—Beaufort, S.C.

Interviewee: Francis E. Rushton, M.D., F.A.A.P.

Children's Care Connection

Children's Hospital, San Diego—San Diego, Calif.

Interviewees: Laurel K. Leslie, M.D., M.P.H., F.A.A.P.; Nancy Cohen, M.A.

Developmental Services Enhancement Program

Children's Hospital, San Diego—San Diego, Calif.

Interviewees: Laurel K. Leslie, M.D., M.P.H., F.A.A.P.; Jeanne Gordon, M.A.

Enhancing Developmentally Oriented Primary Care Project

Healthy Steps for Young Children Program

Advocate Health Care—Park Ridge, Ill.

Interviewee: Anita Berry, M.S.N., C.N.P./A.P.N.

Exeter Pediatric Associates—Exeter, N.H.

Interviewee: Gregory Prazar, M.D.

Guilford Child Health, Inc.—Greensboro, N.C.

Interviewee: Marian F. Earls, M.D.

Help Me Grow

Children's Trust Fund—Hartford, Conn.

Interviewees: Joanna Bogin, M.S.; Paul H. Dworkin, M.D.

Inscription House Health Center—Shonto, Ariz.

Interviewee: William Flood, M.D.

Kaiser Permanente Northern California—Oakland, Calif.

Interviewee: Scott Gee, M.D.

Kennebec Pediatrics—Augusta, Maine

Interviewees: Paula Marshall, R.N.; Joan Marson, B.S., R.N.; Stephen J. Meister, M.D.;

Sydney R. Sewall, M.D., M.P.H.

Kids Get Care

King County Health Action Plan

Public Health—Seattle—King County—Seattle, Wash.

Interviewee: Lisa Podell, M.H.A.

MGH Revere HealthCare Center

Healthy Steps for Young Children Program—Revere, Mass.

Interviewee: Susan Curley, M.S.Ed.

Phoenix Children's Hospital

Healthy Steps Program—Phoenix, Ariz.

Interviewee: DeAnn Davies, B.A.

Tufts–New England Medical Center—Boston, Mass.  
Interviewee: Robert D. Sege, M.D., Ph.D.

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