

# BUILDING A BRIDGE FROM BIRTH TO SCHOOL: IMPROVING DEVELOPMENTAL AND BEHAVIORAL HEALTH SERVICES FOR YOUNG CHILDREN

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#### **EXECUTIVE SUMMARY**

Most American infants and young children receive adequate, often excellent, wellchild care, but they may not receive needed help if developmental problems arise. Although pediatric practices and health plans are ideally positioned to address developmental problems and promote optimal development, many barriers to doing so exist. Doctors may be unequipped to offer families the comprehensive health promotion and developmental health services they need, and health plans and other payers may not adequately reimburse such services. Without appropriate health services, many cognitive, speech, language, and other developmental problems may not be identified. If parents do not receive information and counseling to help them stimulate their children's learning capacities, school readiness and academic potential can be jeopardized.

This report examines primary health care services that promote infant and young child development in the United States and suggests ways to improve those services. It documents what we know about the provision of primary health care services that promote the development of infants and young children in this country. It then addresses opportunities to improve the content and quality of developmental health services as part of routine primary child health care.

## Current Recommendations for Developmental Services in Primary Care

A review of existing guidelines for developmental health supervision of young children shows that recommendations fall into four general categories:

- 1. *Assessment* services, including input from parents, screening tests when indicated, and observation.
- 2. *Education* services, including guidance on the parent-child relationship, behavior, and typical developmental questions such as sleep habits and discipline.
- 3. *Intervention* services such as counseling during doctor's office visits, telephone information lines, and home visits.
- 4. *Care coordination* between the pediatrician's office and community resources to manage such needs as referrals and diagnosis.

## Effectiveness of Developmental Services

There is a growing body of evidence to support the clinical effectiveness of developmental health services in primary care settings during a child's first three years of life. Major findings indicate:

- 1. Structured assessments can help to pinpoint parents' concerns, gauge a child's psychosocial environment, and monitor developmental progress.
- 2. Clinically based health and development education should emphasize social interaction between a parent and child and take into account a child's temperament when suggesting child-rearing approaches.
- 3. Counseling parents in a pediatrician's office about common behavioral concerns is helpful.
- 4. It may be useful to promote mechanisms that link primary care services to services available in the community, but this aspect of care still needs more research and evidence-based clinical evaluation.

## Survey Results

Several studies report significant gaps between the current guidelines for child health care, the care that parents report their children are receiving, and the services pediatric practices currently offer. In the 1996 Commonwealth Fund Survey of Parents with Young Children, parents reported that pediatric health care providers were meeting their children's physical needs but largely ignoring non-medical concerns (Young et al., 1998; Schuster et al., 2000). Parents want more information and guidance on topics such as sleep habits, discipline, learning, and toilet training. The 2000 National Survey of Early Childhood Health (NSECH) confirmed that there is room for improvement in preventive and developmental services for young children (Halfon, 2002a).

Most pediatricians in a 2000 American Academy of Pediatrics (AAP) survey agreed that they should inquire about a child's developmental status (94%) and felt confident in their ability to advise parents (80%) (AAP, 2000a). But two-thirds of these physicians felt that they were not adequately trained to conduct developmental assessments. Most pediatricians spend time discussing traditional topics such as immunizations and nutrition (93%), sleeping positions (82%), and sleep problems (52%). They are less likely to spend time on developmental issues such as reading (47%), how a child communicates (41%), parental substance abuse (29%), and emotional support for parents (29%) (Halfon et al., 2001).

## The Quality of Developmental Services

Not only is routine monitoring of the quality of developmental health services inadequate, but the monitoring does not guarantee either performance or accountability. Common measures of the quality of pediatric health supervision such as the widely used Health Employer Data Information System (HEDIS) focus on the number of well-child care visits and immunizations. Such systems do not explicitly measure the content or quality of care. The Promoting Healthy Development (PHD) survey provides the first comprehensive examination of the quality of developmental services in well-child care visits (Bethell et al., 2001b). When the PHD survey was tested in several managed care organizations in different states, and with a large population of Medicaid-enrolled children, the results indicated poor quality of developmental services in these settings. Half of the parents surveyed reported having one or more concerns about their child's behavior or development that were insufficiently addressed by their child's health provider. Parents with such concerns routinely rated the quality of the anticipatory guidance they received lower than did parents who expressed no concerns about their children's behavior or development. On the other hand, when parents received information and guidance from their health care providers, they also reported increased confidence in their parenting skills.

## **Barriers to Services**

Barriers to developmental services may be either internal or external to a doctor's office. Internal barriers are specific to the pediatric health care setting, such as overly short office visits, insufficient physician training, and ineffective administrative and clinical practices. External barriers are those conditions that extend beyond a specific office that make it difficult to draw upon community services, such as difficulties in determining eligibility for early intervention programs, or conditions that emanate from health care systems that provide inadequate reimbursement and insufficient administrative support. The value of developmental services is generally not recognized or appreciated by payers and health care delivery organizations. Current accountability systems consequently do not measure the content and quality of developmental health services.

#### **Innovative Service Models**

There are several innovative models of integrated developmental services for young children. Practices can adopt a team approach to service delivery such as the Healthy Steps for Young Children program. Practices can also opt for the approach championed by the National Initiative of Child Health Quality collaborative change process, in which practices identify an area in need of change and work together in a stepwise fashion to implement change. Both approaches provide tools to help practices reorganize and improve how they provide developmental services. For example, in two cities, the innovative models are linking community and practice-based developmental services to create a more seamless developmental health services pathway. In Denver, Colorado, a developmental surveillance and community referral system has been instituted in the city's network of public pediatric clinics. In Hartford, Connecticut, ChildServ offers a

centralized case management and coordination program that links parents, pediatric practices, and community services.

# **Research Findings**

Recent pediatric research demonstrates the efficacy of specific activities directed at promoting child development in a particular clinical setting. However, there is less evidence for the effectiveness of these and other activities as primary care services and interventions that can be more generally implemented. The following conclusions can be derived from the findings in this report:

- Developmental services in the pediatric health care setting do not meet the needs of most families.
- The research literature, though limited, suggests that specific developmental services are potentially effective when delivered in primary care settings.
- In terms of accuracy in identifying children with significant developmental problems, validated assessment tools exist to aid the health practitioner in developmental surveillance.
- Pediatric medical education should train pediatricians to improve the parent-child relationship by emphasizing social interactions. Pediatricians need to be able to counsel parents on the best child-rearing approaches for an individual child.
- Counseling for behavioral concerns such as sleep habits and infant fussiness appears to be effective in a primary care setting.
- Care coordination strategies have not received adequate attention. Because effective developmental services require a successful link between the health care office and services in the community, care coordination is critical.
- Barriers to effective delivery of developmental services include time limitations, inadequate financial support and reimbursement, inadequate training of physicians, and insufficient connections between the health office and other community providers.

# Recommendations

The success of any strategy to improve developmental services depends on changes at the provider, practice, community, and policy levels. We recommend:

• Working together, providers, community leaders, and policymakers should institute a community-wide vision and plan for a system of developmental health services.

- Pediatricians should overhaul their practices to offer better content and quality in their developmental health services.
- Providers and community leaders should coordinate and integrate practice-based and community-based developmental services.
- Training programs should improve the training of physicians and ancillary personnel in developmental health services.
- Government agencies and medical schools should support basic and applied research to broaden, test, and improve the evidence base on developmental services.
- Payers and health care delivery organizations should improve coverage and reimbursement policies to minimize financial barriers to developmental care.
- Providers and payers should improve quality measurement and accountability mechanisms to enhance incentives for good performance.
- Providers and payers should monitor, track, and report on the developmental functioning of children and the content and quality of developmental health services that they receive.

The child health care system could be a gateway for the promotion of the best possible development for each child. However, at present, the system does not function effectively: too many developmental problems go unnoticed and untreated. We need to give greater attention to improving developmental services for children.

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### INTRODUCTION

We now know without a doubt how important the first few years of life are for a child's development. This scientifically based understanding has begun to alter how we use our national resources to support the healthy development of children (Halfon and McLearn, 2002). Primary health care services, in particular, hold great promise as a setting in which we can address developmental problems, prevent disabilities, and promote optimal health development.

Health plans and pediatric practices are uniquely positioned to offer high-quality, comprehensive health promotion and developmental health services that allow families to nurture healthy children who are ready to learn. Virtually all families with young children visit pediatric practices on multiple occasions during a child's first three years of life. Nationally, more than 95 percent of all children from birth to three years of age have a regular source of health care, with rates as high as 85 percent even for uninsured children in this age range (Newacheck et al., 2002). Pediatric health care providers are thus ideally situated to provide developmental health services in the context of an ongoing, supportive primary health care relationship. Moreover, parents respect the authority of the pediatric clinician. Recent national surveys of parents with young children indicate that they turn to their pediatrician, in addition to other parents or their own parents, when they want information on parenting and child development. Parents say that if pediatricians or nurses discuss certain topics with them, they are more likely to adopt health-promoting behaviors. For example, mothers will breastfeed longer and parents will read to their children more frequently (Young et al., 1998; Halfon et al., 2002b).

While health care coverage and access to health care services are critical to any effort to improve child health, they are not sufficient to ensure that children receive the preventive and developmental services they need. In fact, many cognitive, speech, language, and other developmental problems and issues go unidentified by providers. Parents report that they are not receiving the counseling they need to help stimulate their children's learning capacities. Therefore, the content and quality of developmental health services that specifically address behavior and development must improve in order for the health care system to work effectively. Comprehensive reform will require the awareness, motivation, and commitment of child health care providers, health delivery organizations, non-medical community service providers, payers, and policymakers. This report explores issues that each of these key constituencies must resolve if the quality of developmental health services is to improve.

Our focus is therefore twofold. First, we document what we know about the provision of primary health care services that promote the development of infants and young children in this country. Second, we address opportunities to improve the content and quality of developmental health services as part of routine primary child health care. For this discussion, developmental, behavioral, and psychosocial services are described collectively as developmental health services.

# BACKGROUND

Early childhood experiences have an enormous impact on later development. Research on neural plasticity tells us that a child's development depends on a continuous interaction between biology and experience, and on nurturing and dependable relationships that form the basis for all cognitive, language, social, emotional, and physical development (Shonkoff and Phillips, 2000). Just as poor nutrition, environmental toxins, drug exposure, and chronic stress can harm a child's developing brain, so too can problems such as maternal depression, substance abuse, and family violence place heavy developmental burdens on young children (Nelson, 2001; Shonkoff and Phillips, 2000).

During a child's first five years, there are many opportunities to intervene to optimize development. These strategies include:

- promoting developmental capacity through positive experiences and environments;
- identifying and eliminating threats to optimal development;
- modifying deviations in normal development through early interventions; and
- assessing and treating disabilities through targeted intervention.

Evidence suggests that services promoting the healthy development of children can be highly effective in changing long-term developmental trajectories (Shonkoff and Phillips, 2000). Primary care health providers for children are strategically positioned to provide these services (Shonkoff and Green, 1998; Zuckerman and Parker, 2002). However, many opportunities to provide developmental health services to children are being missed.

Ensuring good health for a child's parents is one of the best ways to influence a child's early experiences. Identifying and addressing parental health needs may in turn

most easily be accomplished in conjunction with routine child care, but the relationship between parental and child health has received inadequate attention in the past (Zuckerman and Parker, 1995). Several studies, nevertheless, have highlighted the connection between parental mental health and adverse child development (Repetti et al., 2002). New research shows a clear link between a mother's use of health services for herself and her use of services for her child (Newacheck and Halfon, 1986; Zuckerman and Parker, 2002). These findings suggest the benefits of a two-generation approach to pediatric care, in which parental health and psychosocial problems can be addressed along with the child's needs. Parental problems such as depression, domestic violence, and smoking and other addictions that are known to adversely affect child health and wellbeing may require attention through child health services. Mental health problems, especially depression among mothers, are common; for example, one study found that between 12 to 47 percent of mothers experienced depression (Olson et al., 2002). Such problems can lead to behavior problems, poor growth, accidents, and affective disorders in children (Lyons-Ruth et al., 2002). But, as structured today, most child health care practices have little expertise in these parental problems, and most health care delivery organizations have not yet made the required systematic changes to meet this growing service need.

# CURRENT SUPERVISION GUIDELINES AND THE DEVELOPMENT CONCEPT

Child health supervision has traditionally revolved around the concept of health "maintenance," which includes the management of acute conditions and chronic diseases as well as a limited set of disease prevention and health promotion practices. However, children's health is characterized by a dynamic process of developmental change that influences their health and, later, their social function and productivity (Halfon and Hochstein, 2002). Therefore, health service delivery for children requires a new delivery system model that emphasizes developmental change and trajectories (Halfon et al., 2000a).

Over the past several decades, a broad array of developmental services has been put into practice to address a broad array of risk and protective factors. Pediatric primary care has continued to adapt its practices in order to address the "new morbidities" as key health supervision priorities (Palfrey, 1994). "New morbidities" refer to the increasing prevalence over the past 30 years of developmental, behavioral, and learning problems faced by children and families (Haggerty, 1975). According to recent estimates, 12 to 15 percent of American children have developmental or behavioral disorders (Boyle, Decouflé, and Yeargin-Allsopp, 1994). Thirty to 40 percent of parents with young children worry that their child has learning, behavioral, or developmental problems (Halfon et al., 2002a). It is essential to recognize these problems in their early stages in order to intervene effectively. Primary health care practices are one of the few places where parents can have their children routinely assessed, and are therefore an ideal setting for behavioral and developmental screening and surveillance.

Health supervision guidelines from both the American Academy of Pediatrics and the Maternal and Child Health Bureau (MCHB) Bright Futures Initiative call for a greater focus on the relationships among health, education, and social issues; partnerships between families, health professionals, and the community; and improved diagnostic approaches for health supervision (AAP, 1997; Green and Palfrey, 2000). In response to the new morbidities, these guidelines include a growing list of developmental health services as part of routine care. These services include surveillance and screening to elicit parental concerns about child development and behavior, anticipatory guidance through parent and child education and counseling, determination of family psychosocial health risks, and interventions beyond the standard developmental screening exam.

#### DEVELOPMENTAL SERVICES IN PEDIATRIC PRIMARY CARE

Health care experts are challenging traditional approaches to primary health care delivery in light of new knowledge about early childhood development. For example, although past and present guidelines recommend that all children receive a developmental assessment at each visit, questions remain about the effectiveness of this approach. Addressing the limitations of developmental screening approaches, Paul Dworkin suggests a more comprehensive model for monitoring the development of children, which he calls "developmental surveillance." Developmental surveillance refers to a "flexible, longitudinal, continuous process of eliciting and attending to parents' concerns, obtaining a relevant developmental history, making accurate and informative observations of children, and sharing opinions and concerns with other relevant professionals, such as child care providers, visiting nurses, and preschool teachers" (Dworkin, 1989). Rather than viewing development in isolation during a screening session, the doctor would monitor development within the context of the child's overall well-being (Dworkin, 1992). In 2001, the American Academy of Pediatrics' Committee on Children with Disabilities published a policy statement recognizing developmental surveillance as an important strategy for health supervision (AAP, 2001). Developmental surveillance during preventive health care visits also encourages a pediatrician to offer anticipatory guidance about supporting a child's development (Appendix Table A1).

Health supervision guidelines, published by the American Academy of Pediatrics and the Maternal and Child Health Bright Futures Initiative, make detailed recommendations for developmental surveillance, assessment, and intervention activities for each health visit (Green and Palfrey, 2000). Michael Regalado and Neal Halfon have suggested viewing these activities as an integrated set of developmental services with four major categories (Regalado and Halfon, 2001) (Table 1).

# Table 1. Typology for Developmental Services

- Assessment services include evaluation of information from parents, developmental monitoring (including screening for developmental problems when indicated), psychosocial assessment, parent-child observation, and assessments of child behavior.
- Education services include anticipatory guidance about the parent–infant relationship, child behavior, and various developmental issues (e.g., promoting healthy sleep habits and discipline practices) as well as parenting education in different formats, such as classes, support groups, and instruction by a physician or nurse.
- Intervention services include counseling in the office setting, telephone information lines, and home visitation.
- Care coordination refers to the management of service needs such as referrals for diagnostic assessments or specialists.

# EFFECTIVENESS OF DEVELOPMENTAL SERVICES

We used the typology above to guide a systematic literature review of the clinical effectiveness of primary care activities directed toward child development during the first three years. The review yielded a limited but useful evidence base. The major findings are summarized below, along with additional evidence for the preschool period (up to age 5), although the literature from this developmental period was not systematically reviewed.

# Assessment

Assessment provides an important database for clinical care. In the past, assessment has focused on screening to determine the risk of developmental disability. This is partly in response to parents' expectations that the health visit should inform them about their child's developmental progress. More recently, assessment has also been a response to the expanded Individuals with Disabilities Education Act (IDEA), which mandates early intervention services to children at risk for developmental disabilities. Other types of assessment tools for the office setting recognize the complexity of the developmental process and strive to understand the child's behavior and psychosocial environment. These tools include assessments of parents' concerns, parent–child interaction, quality of the home environment, and psychosocial risk factors for parenting. Most child health

providers, however, routinely use informal methods of assessing developmental needs rather than the more elaborate tools available (Halfon et al., 2000b).

When doctors inquire regularly about parental concerns, parents are not only encouraged to discuss their concerns, but children with developmental problems are more likely to be diagnosed. The nature and number of parents' concerns correlate with different probabilities of children having diagnosable developmental problems (Glascoe, 1999). A relatively new, validated tool, the Parents' Evaluation of Developmental Status (PEDS), compares favorably with longer, more costly developmental screening assessments (Glascoe, 1997). This innovative and easy-to-use clinical approach, which is based on asking parents a series of questions about their concerns in different domains of their child's development, is currently being incorporated into primary care procedures in many sites throughout the United States, Australia, and the United Kingdom.

Another approach for identifying developmental problems is the Simultaneous Technique for Acuity and Readiness Testing (START) procedure. Developed by pediatricians at Johns Hopkins University, this procedure observes preschool children in the office to screen for both developmental and visual acuity problems (Sturner, 1991). It has proven both efficient and accurate in identifying children at risk for developmental problems.

Other assessment tools identify problems in the psychosocial environment. Maternal depression, exposure to domestic violence, substance abuse, housing instability, and histories of child abuse are associated with adverse child development. Given the sensitive nature of these problems, identifying them can be difficult in the office setting. Questionnaires filled out by parents that elicit psychosocial risk factors appear more effective than physicians' clinical appraisals (Kemper and Babonis, 1992; Wissow et al., 1992). Other tools to assess the psychosocial context have addressed the quality of the home environment and the quality of social interaction between parent and child (Frankenburg and Coons, 1986; Casey et al., 1988; Casey et al., 1993).

Tools to assess children's social, emotional, and behavioral development include the Ages and Stages Social Emotional Scales (Bricker and Squires, 1994), the Infant-Toddler Social Emotional Assessment (ITSEA), the Brigance Screens (Glascoe, 2002), and the Temperament and Behavior Scales (TABS). These are all validated assessments of children's social and emotional development during the first three years of life. The Child Behavior Checklist (Achenbach, 1992) examines behavior problems in children from one to five years of age and the Eyberg Scales (Eyberg and Ross, 1978) apply to children from two to 11 years, but these tools have not been evaluated for effectiveness in the pediatric office context. On the other hand, the Pediatric Symptom Checklist (Jellinek et al., 1999) has been extended for office use with preschool children and provides a useful tool to stimulate discussion between health providers and parents about a child's behavioral and social and emotional development. Other assessments of behavior that seek to characterize temperament have been evaluated in the context of anticipatory guidance, as discussed below.

In spite of the availability of various types of structured assessment tools, doctors prefer to use informal assessment techniques during routine visits (AAP, 2000). Because informal approaches may be inaccurate or biased, this area of clinical care could be improved if validated assessments were folded into a routine surveillance strategy. Given that pediatric clinicians are trained to assess children as they pass through the health system and recommend necessary treatments, there are inherent but unrealized opportunities for them to intervene for positive outcomes.

#### Education

The health visit provides an important opportunity to advise parents on such key childrearing topics as their interaction with infants, their child's temperament, sleep habits, promotion of learning, and discipline. For example, child health providers who implement programs like Reach Out and Read, demonstrate how to read to a young child, or provide books to their patients have seen the time and frequency parents devote to reading to their children increase (High et al., 1998). Book distribution programs also increase parent–child book–sharing activities and promote learning.

Effective teaching by a physician can help parents express warmth in their social interactions and help parents understand their child's individual behavioral style (Chamberlin et al., 1979). Pediatricians can counsel parents about infant sleep behavior to reduce night waking problems and give written anticipatory guidance to parents on "time-outs" for behavior problems (Adair et al., 1991).

As with developmental assessments, however, doctors do not routinely use structured teaching approaches in clinical practice (Chamberlin et al., 1979). Instead of tailoring discussions to the particular needs of a family, providers tend to discuss general development, a technique that has been shown to be less effective than responsive and personalized discussions (Dworkin et al., 1987).

### Intervention

Physicians who make themselves available to address parents' concerns are routinely asked for their recommendations on common developmental problems. Counseling can offer strategies to calm fussy babies or manage night waking and bedtime settling difficulties. It can improve child and family relationships, building parents' confidence in their childrearing skills. Though pediatricians encounter many other behavior concerns (e.g., biting, temper tantrums, toilet training refusal, and hyperactive behavior), the current literature on the effectiveness of pediatric recommendations or management in these areas is surprisingly limited.

#### **Care Coordination**

A fourth category of developmental activities addresses the need to coordinate and monitor the ongoing care of children and connect children with appropriate services in their community. Hampering these activities are the many conflicts that arise over service obligations (e.g., who should perform diagnostic developmental testing), time and labor costs, and boundary issues with other behavioral subspecialties (e.g., among general pediatrics, social services, developmental-behavioral pediatrics, psychology, and psychiatry). Numerous and significant access barriers may arise when referrals are made to intervention programs, diagnostic services, or specialists. Fragmentation, duplication, and poor integration of services compound the problems.

Families and health care providers need more accessible pathways to facilitate referrals within the community and promote the evaluation and management of developmental problems. Delivery pathways for other health conditions have proven effective, and several communities have formed new pathways and procedures to improve access, coordination, and integration of health and developmental services for young children. Quality improvement efforts also need to address methods of linking a child's health care home to other developmental services in the community.

#### SURVEY RESULTS

The American Academy of Pediatrics and the Maternal and Child Health Bureau have always incorporated developmental components in their health supervision guidelines, and the strategic role of pediatric care in promoting early childhood development has received new policy and practice attention over the past 10 years, as the importance of brain development during early childhood has been understood (Halfon et al., 2002b). But significant gaps exist among guideline recommendations, what parents report they are receiving, and what pediatric practices offer in terms of developmental services. These gaps may reflect:

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- practices' orientation toward treating childhood illnesses and providing only basic preventive care, such as immunizations, rather than more comprehensive child and family health services;
- clinicians' lack of knowledge of and skills for addressing behavioral and developmental issues, including not knowing when and how to formally assess child development;
- clinicians' lack of familiarity with community resources that are available to families;
- insufficient time and staff to deliver developmental services; and
- inadequate reimbursement.

# National Surveys of Parents on the Provision of Developmental Services

With a decline in morbidity and mortality from childhood infectious diseases and a shift in focus on what have been termed the new morbidities, pediatricians are increasingly asked to address child behavior and parenting concerns within the pediatric practice. Yet, reports from individual pediatricians show that too often they do not address the growing need among parents for information and services to address child behavior and parenting issues. Two recent surveys of parents provide the first national data on content of primary health care and its ability to provide developmental services to young children and their families.

*Commonwealth Fund Survey of Parents with Young Children.* This 1996 survey of more than 2,000 mothers and fathers of children from birth to age 3 indicated that pediatric health care providers are meeting children's physical needs, but are failing to meet their non-medical needs (Young et al., 1998; Halfon et al., 2002b). Specifically, parents wanted more information and guidance on psychosocial topics such as sleep habits, discipline, learning, and toileting problems. When choosing from a list of different child-rearing topics, fewer than 50 percent of parents surveyed said they received information from their pediatrician about each of the topics. Although developmental services such as home visits, assessments, telephone information services, and records to chronicle a child's health and developmental progress were valued by parents, the majority were not receiving these services. Parents who did receive these services reported higher levels of satisfaction with their child's physician than parents who did not receive these services. Nearly three-quarters of parents who received three or more of these developmental services rated their child's physician as excellent in providing good health care and guidance in helping them understand their child's growth and development.

National Survey of Early Childhood Health. This 2000 telephone survey of more than 2,000 parents, designed by the AAP and the UCLA Center for Healthier Children, Families & Communities and conducted by the National Center for Health Statistics, also found that there is room for improvement in developmental care (Halfon et al., 2002a). While most parents said that well-child checkups were very important to them, only about half of parents reported that health care providers had ever said they were doing a developmental assessment or recalled a developmental assessment ever taking place. More than 80 percent of parents wanted physicians to ask about psychosocial and family issues that could affect a child's development. But fewer than half of all parents were asked about such issues as substance abuse, violence in their communities, or emotional support in their lives. Topics that parents did not discuss with their child's pediatrician, but would have liked to discuss, included toilet training, guidance and discipline, child care, and reading (Inkelas et al., 2002a). Parents whose child had a regular physician for well-child care were more likely to discuss key topics with the physician than parents whose child did not have a regular provider, even when taking into account the location of care (e.g., community clinic versus private group practice) (Inkelas et al., 2002b).

#### Surveys of Pediatric Clinicians

Despite the availability of professional guidelines, evidence suggests that many pediatric practices are having difficulty providing developmental services in an effective and efficient manner. As managed care transforms service provision, pediatricians often find themselves with less time than ever before to provide more complex services to their patients (Hirsh, 1995; Thompson et al., 1999). A recent national survey of pediatricians provides a current picture of how extensively developmental services are practiced and identify the challenges pediatricians face in providing them. Conducted in 2000, a random, national sample of 794 American Academy of Pediatrics members who provide primary care to children from birth to age 3 confirmed that there are significant variations in the content of developmental services and major barriers to the provision of these services (AAP, 2000). Overall, most members agreed that pediatricians should inquire about a child's developmental status (94%) and felt confident in their ability to advise parents (80%). However, two-thirds of these physicians felt that they were not adequately trained to conduct developmental assessments. Apart from poor training, the primary barriers they reported were lack of time (80%), inadequate reimbursement (55%), and lack of nonphysician staff to do developmental assessments (51%). Pediatricians report that, during the 18 minutes of an average well-child visit, they discuss traditional topics such as immunizations and nutrition (93%), sleeping positions (82%), and sleep problems (52%). Pediatricians were less likely to spend time on developmental and psychosocial issues such as reading (47%), how a child communicates (41%), parental substance abuse (29%), and

emotional support for parents (29%). More than three-fourths of the pediatricians agreed that it was important to discuss family psychosocial issues during well-child supervision, but less than half felt confident in their ability to advise parents on such issues. Only a third felt that they were adequately trained and only 16 percent felt that they had enough time. Other barriers included inadequate reimbursement and billing (59%), lack of familiarity with instruments (54%), and lack of referral options for treatment (48%).

Judging from these survey findings, many important developmental topics are typically not addressed in clinical practices. Even though practices use a range of approaches to provide developmental services, this diversity was not necessarily associated with recommended guidelines, training, or evidence-based practice.

#### MEASURING QUALITY IN DEVELOPMENTAL SERVICES

Quality measurement, including health plan score cards on the quality of services, has become a familiar component of the public and private health care marketplace. Although developmental services are an important component of preventive care, few quality measures assess how well the health care system provides these services. Common measures of the quality of pediatric health supervision, such as the Health Employer Data Information System (HEDIS), focus on the number of well-child care visits and immunizations. They do not explicitly measure the content of care or the quality of developmental services.

Until recently, there were few tools to measure quality and guide quality improvement for terms of developmental services, but that changed when Christina Bethell and her colleagues published an extensive description of one methodology using the Promoting Healthy Development (PHD) survey (Bethell et al., 2001b). Created by the Foundation for Accountability, a national organization that assesses consumers' experiences with health care, this 36-item survey of parents asks whether health care providers discuss recommended topics, provide follow-up for children who may be at risk for developmental problems, and address psychosocial well-being and safety within the family. This new tool provides the first comprehensive examination of the quality of developmental services in well-child care visits. Extensive testing of the PHD survey in several managed care organizations in different states, and with a large population of Medicaid-enrolled children, indicates a poor quality of developmental services in these settings (Bethell et al., 2001b). Half of the parents surveyed reported having one or more concerns about their child's development that were addressed insufficiently by their child's health provider. Parents with concerns routinely rated the anticipatory guidance that they received lower than did parents who expressed no concerns about their children's behavior

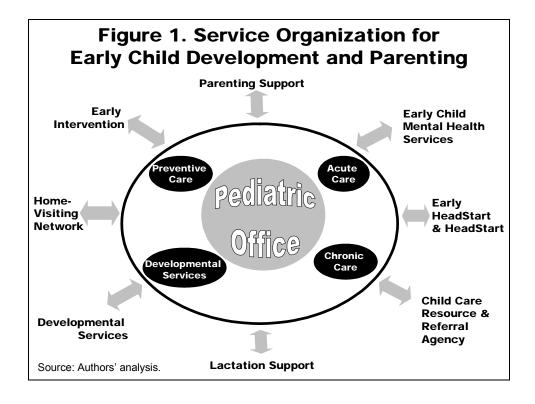
or development. On the other hand, when parents received information and guidance from their health care providers, they felt increased confidence in their parenting skills.

The PHD survey is gaining recognition for its usefulness in quality measurement, accountability, and quality improvement. The states of Washington, Maine, North Carolina, and Vermont have all recently used the PHD survey as part of their efforts to improve the quality of developmental services provided by their state-funded Medicaid programs. The PHD survey and other quality measurement tools represent an opportunity to introduce greater accountability, support changes in practice and physician behavior, and create incentives for change.

### **BARRIERS TO SERVICES**

Too many barriers clog the pathway to developmental services at present. Barriers can be classified as either internal or external to the practice. Since the scope and depth of developmental services in any one pediatric practice are of necessity limited, it is especially important for practitioners to draw on diagnostic, educational, intervention, and other supportive services in the community.

Figure 1 illustrates the strategic importance of connecting pediatric health providers to community-based developmental services. The figure represents the four key components of pediatric primary care: acute care, chronic illness care, preventive care, and developmental health services. Separating developmental health services from other preventive and health-promoting services highlights the need to consider developmental services as a distinct set of services that differ from acute and prevention services and have unique delivery requirements within the content of office-based pediatric primary care. Not only do developmental services constitute a unique package of pediatric services, but they also require specific linkages to community-based developmental health services.



The scope of developmental health services that any single child health practice can offer is partially determined by the availability of certain services in the community and the links between the pediatric office and those community resources. If a community does not have services for depressed mothers, then pediatric providers are unlikely to screen for this condition because they have no place to refer for treatment. If community programs routinely provide developmental screening for high-risk infants, then pediatricians may provide referrals to such programs. Or, if no program exists to treat behavior problems in preschool children, then pediatric offices may choose to offer this service with appropriately trained personnel (e.g., licensed clinical social workers, marriage, family, and child counselors, or psychologists) or not to screen for these problems at all. In each community, the opportunities to overcome barriers and improve the linkages between practices and community services are different. In some cases, pediatric practices are limited by reimbursement authorization. For example, some states mandate that certain services be reimbursed only when delivered by a designated center.

## **Internal Barriers**

Internal barriers are specific to the pediatric health care setting. These include inadequate time during the office visit, inadequate training of physicians, and ineffective administrative and clinical practices. With the average office visit lasting about 18 minutes, practitioners have little time to address developmental concerns (Halfon, 2002a). Compounding this problem is the inadequate training of physicians. Most physicians

receive four to eight weeks of training devoted to child development during their residency training, which is probably inadequate to acquire basic knowledge and clinical skills. Moreover, physician training focuses on developing and perfecting diagnostic and treatment skills based upon a medical disease model, which is not the most appropriate model for addressing developmental concerns. Developmental problems lack a validated classification system and exhibit a wide range of normative variation. Thus, strategies to promote healthy development may be at odds with the disease and disability approach. Moreover, physicians receive little clinical training in effective communication techniques, although such techniques are crucial in helping parents cope with developmental issues.

The lack of an efficient and effective office practice strategy to implement surveillance procedures is also a barrier. For example, until recently, a mass population approach that used screening tests to detect problems was the recommended norm for developmental assessment. This approach has been criticized for its narrow focus, which neglects parents' concerns and the psychosocial context, and inefficiency (e.g., low accuracy rates of most screening tests and time costs) (Dworkin, 1987; Dworkin, 1989; AAP, 2001). Many pediatricians continue to practice this approach, and many training programs continue to teach it, even though other clinical tools (such as the PEDS and Ages and Stages instruments) have been proven to be more effective. Developmental surveillance ultimately requires clinical expertise in child development and a system of clinical routines that facilitate delivery of these services.

In summary, the prevalent model of pediatric training, which is heavily loaded with care of hospitalized patients, does not prepare clinicians to deliver child health care with the knowledge and skills that they need. Moreover, routine practice patterns for addressing the developmental needs of children and their families in community systems need to be overhauled.

## **External Barriers**

External barriers are imposed from outside a pediatric practice. For example, certain conditions may make it difficult for practices to connect with community services. Other external barriers include inadequate reimbursement and insufficient administrative support for developmental services.

Connections between pediatric practices and community services have not been streamlined because practices are usually established as a self-contained unit to diagnose and treat medical conditions. Pediatricians are ill equipped to address some of the new morbidities that affect a child's development and behavior, such as maternal depression, family violence, or parental drug abuse. Even if they are skilled in assessing these problems, doctors must have the resources to make referrals by connecting to an appropriate community-based service provider. Moreover, for a range of developmental and behavioral problems in children, diagnostic and treatment services are given by different providers and even by different systems, which may be administered and funded separately through schools and public mental health systems. For example, school districts in most communities, as part of their IDEA-mandated services, provide diagnostic services for developmental disabilities in school-age children. In spite of such barriers, communities throughout the country have made connections between providers and community resources by developing case management and coordination systems, described below.

Developmental services are often undervalued by accountability systems. Accountability systems that use quality measurement tools, such as the Consumer Assessment of Health Plans Survey (CAHPS) and the HEDIS measurement system, do not measure the content and quality of developmental services or whether a developmental assessment was even given. Incorporating measures of developmental services into existing instrument sets could redress this problem.

Finally, there are coverage, reimbursement, and billing issues that also form barriers to developmental care. These include the lack of adequate reimbursement under existing managed care and capitation contracts for developmental health services and the assumption by most payers that developmental health services are simply part of preventive well-child care. Resolving this issue requires reviewing managed care contracts and making appropriate adjustments (George Washington University Medical Center, 2000).

A provider's lack of familiarity with appropriate billing codes may also constitute a barrier (Rushton et al., 2002). Several states, however, have implemented more appropriate reimbursement mechanisms and many individual practices and groups have educated providers about billing codes to optimize reimbursement. A systematic approach for instituting payment is necessary to ensure widespread and long-term solutions to billing problems.

## SUMMARY OF RESEARCH FINDINGS

The literature review for this report revealed that recent research demonstrates the potential efficacy of developmental activities in the research setting. There is less evidence for the effectiveness of many of these same activities when they are taken out of the research setting and put into regular use in a community setting. Our findings indicate:

- The provision of developmental services in the pediatric health care setting is inadequate to meet the needs of most families.
- The research literature is limited but compelling in suggesting that a specific array of developmental services is potentially effective when appropriately delivered in health care settings.
- The health practitioner has an array of validated assessment tools for developmental surveillance.
- Physicians require better training to promote healthy parent-child social relationships. Doctors need to encourage stimulating social interactions and foster parents' understanding of the child's unique needs to ensure a "good fit" between the child's needs and the type of child-rearing approaches that are adopted.
- Counseling parents about common behavioral concerns seems to be effective in the office setting.
- Care coordination strategies have not received adequate attention. Because effective developmental services require a successful link between the health care office and the community, care coordination is a critical component of a systemic strategy for providing better care.
- Barriers to effective delivery of developmental services include time limitations, inadequate financial support and reimbursement, inadequate physician training, and poor linkages between the health office and other community resources.
- A number of new quality measurement and assessment tools, clinical strategies, and office management procedures could be helpful in improving the content and quality of developmental services.

# RECOMMENDATIONS

Improving the delivery of developmental health services in primary health care settings will require a comprehensive strategy to address the strengths and weaknesses of the current system. Our strategy for improvement includes the eight recommendations outlined below.

# 1. Institute a Community-Wide Strategy for Developmental Health Services

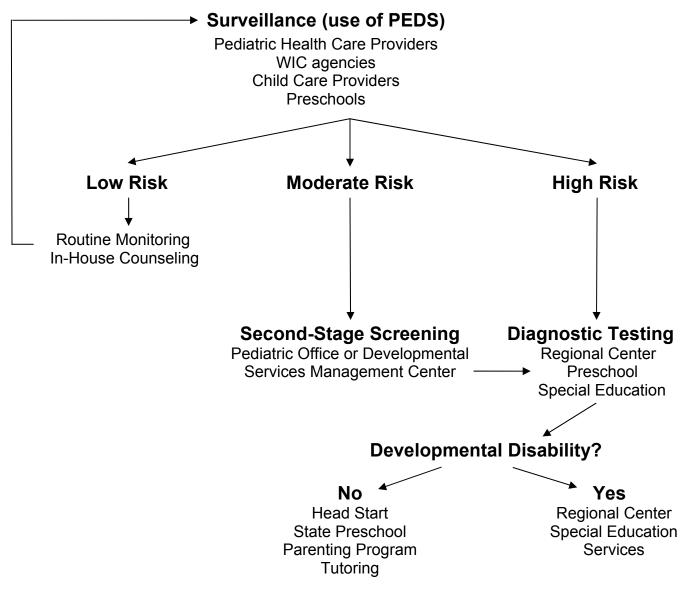
Pediatric health care must be fully integrated into a community-wide system of developmental care. This is important not only because of the strategic role of primary pediatric care, but also because of the inherent limitations, barriers, and constraints that child health providers confront when they are not connected to community services.

Child health providers can play a pivotal role in articulating a vision for an integrated developmental health services system by specifying objectives and approaches to guide the implementation of a community-wide system. Goals might include early identification of problems and interventions to promote healthy development. The roles, responsibilities, linkages, and boundaries for each aspect of developmental care should be specifically defined. For example, the role of the health care provider and the roles of other providers (e.g., the Women, Infants, and Children program, child care providers, or family resource centers) in identifying developmental problems need to be explicit. Together, this group of providers must elicit and assess parental concerns, identify criteria for performing screening tests, and refer children for diagnostic testing. The assumption on the part of pediatric leadership and health policymakers that the health care provider is willing and able to deliver comprehensive developmental care may be unfounded. The evidence suggests that health care providers are limited in their roles as counselors and gateways to services. In many communities, physicians are poorly trained to fulfill those roles and service system redesign must take that into account. Developmental health services must also have a coordination component, with tracking and monitoring procedures, and must lay out delivery pathways for children with special needs.

Communities might consider the benefits of extending developmental surveillance to the Women, Infants, and Children program, preschools, and child care programs to take advantage of their early contact with children and families. Developmental surveillance information collected at these sites could be transmitted to child health providers or used in making direct referrals to diagnostic, preventive, and treatment services.

Communities should also consider lowering the threshold for children to receive services that promote healthy development. They need to address the needs of children who would benefit from developmental services but who do not meet criteria that would make them eligible for IDEA Part C services or other programs. Children who fail developmental screening tests but do not qualify as disabled, based on a battery of diagnostic tests, may still need parenting programs, social services, and supplemental educational assistance. Frances Glascoe has shown that children who fail screening tests but who pass diagnostic tests continue to perform lower as a group on intelligence and achievement tests than do children who pass screening assessments (Glascoe, 2001). These "sub-threshold" children also tend to have more psychosocial problems and could benefit from additional services such as enhanced learning experiences at home or in preschool (e.g., Head Start, Title I programs, or tutoring). Many children would benefit from other family services that promote healthy development. One solution to this gap in the service system is the creation of community-based developmental assessment and management centers. Such centers could serve as regional hubs for pediatric practices and child care providers and could be linked directly into an IDEA and regional center system. Figure 2 outlines a delivery pathway in a model community system of comprehensive developmental care. A similar model has already been created in Denver (Appendix B).





Source: Authors' analysis.

#### 2. Overhaul Pediatric Practices to Improve Developmental Health Services

Child health practices must improve their capacity to provide developmental health services and dismantle the barriers that impede delivery. This can be done in at least two ways: by individual practices deciding to adopt tools, techniques, or new approaches for service delivery (such as the Healthy Steps for Young Children program) or by communities taking the initiative to engage multiple practices in a more systematic reengineering of practices to improve developmental health care. Both approaches have merit and in fact can be complementary. For example, the National Initiative for Children's Healthcare Quality (NICHQ) has created a set of tools and procedures to help practices reorganize developmental health services (Appendix B). The NICHQ approach suggests, for instance, how to use structured, validated assessment tools to:

- identify parental concerns;
- evaluate risk for developmental problems;
- define the strengths and needs of the psychosocial environment;
- identify priority areas for anticipatory guidance and education;
- manage problems; and
- coordinate care.

The NICHQ also supports a collaborative practice improvement process called a "Breakthrough Series" (Appendix B).

Practices should also consider adopting team approaches to pediatric developmental health care. Several recent reports, including the Institute of Medicine's *Crossing the Quality Chasm: A New Health System for the 21st Century*, have highlighted the value of physicians working in teams with non-physician professionals to deliver care more effectively (IOM, 2001). One of the best models for this approach is the Healthy Steps Program, which leverages the skills of a child development specialist with the medical skills of the physician (McLearn et al., 1998). Healthy Steps team approaches demonstrate the value of a nurse or social worker in the office who can navigate the various community systems, perform developmental assessments, address the needs of both parents and their children, make community referrals, and provide education, anticipatory guidance, and counseling (Appendix B). The American Academy of Pediatrics *Future of Pediatric Education II* report confirms that pediatricians need to work in teams in order to improve quality of care (AAP, 2000). Enhancing the functioning of pediatric offices could also help to strengthen the connections between the health and child care systems.

# 3. Coordinate and Integrate Practice and Community-Based Developmental Health Services

The entire spectrum of community-based early childhood providers should collaborate with the health care provider's office—a child's medical home. The medical home model championed by the American Academy of Pediatrics identifies a doctor's office as a regular place for health care, where a child has an ongoing relationship with a primary provider, all of his or her health and developmental needs can be assessed, and referrals can be made (AAP, 2002). Figure 1 suggests how the medical home model can also serve as a hub to connect the child and family to other community services.

To connect the medical home with the full range of developmental services, a community would need to plan and implement a set of appropriate policies and procedures that effectively link a child's medical home with other community-based resources, such as the local Women, Infants, and Children program providers, the child's care provider, and other services.

Medical homes can extend their reach by partnering with schools through local education agencies (LEAs). All LEAs that receive federal funds under the Elementary and Secondary Education Act are required to have local improvement plans. These planning documents are developed in partnership with schools, parents, families, and communities to administer federal, state, and local programs to improve children's academic achievement and well-being. The plans could foster a closer collaboration among schools, health care providers, regional centers for developmental disabilities, and early intervention programs.

Denver, Colorado, and Hartford, Connecticut, have initiated innovative models for linking community and practice-based developmental health services. In Denver, the city's network of public pediatric clinics implemented a developmental surveillance system in the mid-1990s. When this system identifies a child with developmental health needs, the child is referred to a special unit that performs a developmental assessment, links families to appropriate services, and serves as the front door to IDEA systems. In Hartford, the ChildServ System, implemented in 1997, provides centralized case management and coordinates services for community pediatric providers, thus providing linkages between providers, parents, and community resources. When child health providers identify a potential problem, they can enlist ChildServ as a partner to coordinate that child's care (Appendix B).

# 4. Support Basic and Applied Research to Enhance the Evidence Base and Improve Developmental Health Services

While a great deal can be done with existing assessment tools and best practice models of developmental health services delivery, there is also a need to advance research. Although our literature review found that many developmental health services can be effective, there are still gaps in available evidence. We need to make sure that what works in a controlled experimental environment also works when more broadly applied.

The National Initiative for Children's Healthcare Quality, which champions comprehensive approaches for improvement, is introducing a range of practice and system-based methodologies to take advantage of innovations and promote a collaborative learning model. The NICHQ's partnership with Vermont and the majority of the state's child health practices to improve preventive health services is an innovative way to give new tools to practicing providers.

As Michael Regalado and Neal Halfon note, most of the research literature on developmental services focuses on efficacy in research settings (Regalado and Halfon, 2001). The leap from the laboratory to the community is long and frequently unsuccessful. Additional investments are necessary to document the effectiveness of developmental services in clinical settings and make changes based on lessons learned.

There is no validated strategy to help pediatricians tailor care to meet the specific needs of individual families. Some parents need only new information about child rearing, while others may need more individualized help to address a developmental challenge. Still others may need referrals to parenting programs or mental health specialists. Developing a strategy to identify and prioritize the individual needs of parents is critical to the success of any developmental services program. Universally applied prescriptions for parenting or developmental advice are likely to be ineffective when transmitted as didactic lessons to uninterested or unreceptive parents (Regalado and Halfon, 2001). Physicians' reliance on the disease model and the lack of a conceptual framework for a clinical understanding of the parent–infant relationship form major barriers to progress. As noted above, approaches that address parent–child relationship issues show the most promise for effectiveness.

By monitoring changes in the delivery of developmental services and expanding the scientific evidence for what works, quality improvement and innovation can be stimulated. One of the best and most efficient ways to encourage innovation at the practice level is to support practice-based research and quality improvement networks.

#### 5. Improve Training of Physicians and Non-Physician Health Professionals

A significant gap exists between what professional practice guidelines such as Bright Futures and Health Supervision Guidelines recommend and what pediatric practices offer in terms of developmental information, assessment, and referral (Green and Palfrey, 2000; AAP, 1997). This reflects the orientation on the part of practices toward treating illness and providing only basic preventive care. It also reflects clinicians' lack of knowledge and skills for assessing and addressing behavioral and developmental issues, their lack of familiarity with community resources, and the lack of physician time and clinical staff to deliver developmental services. The Future of Pediatric Education II project states that providing optimal health care in the 21st century requires changes in pediatric residency education to develop competencies in developmental and behavioral pediatrics (Task Force of the Future of Pediatric Education, 2000).

Recognizing the relationship between early childhood development and health, the Future of Pediatric Education II states that training efforts must include prevention and guidance to alter parent and child behaviors when necessary to improve outcomes. It also suggests that non-pediatrician child health professionals play a greater role in direct patient contact. The pediatric Residency Review Committee (RRC) has recently issued a requirement for one month of training in child development and behavioral pediatrics. The RRC report also recommends working in a team approach with non-physician personnel as part of training.

The Future of Pediatric Education II recommendations and pediatric RRC requirements address major needs in pediatric graduate education and physician training. Residency program directors need curricula and clinical experiences for their residents, but no standard developmental health services curriculum exists at this time. Both pediatric and family practice residency training programs should focus more on child development training, using models that simulate general practice and impart knowledge and skill. Clinical teaching modules, innovative training programs at academic medical centers such as Healthy Steps, and other training programs would help transform the provider pipeline. In addition, the use of quality measurement tools as part of physician training, such as the FACCT Promoting Healthy Development Survey, could help providers adjust their practice behaviors in response to parents' feedback.

Residency training should emphasize doctor-patient communication, along with counseling skills and knowledge of basic child development. Training should engender in physicians a proactive attitude toward child development concerns, communication with parents, and effective surveillance skills. One of the major barriers to improvement is providing a realistic learning environment for resident trainees. The current requirement of one month is insufficient to impart the requisite knowledge and skills to the physician and may have the effect of implying that this aspect of care is not important to primary care. New training models should reinforce the role of the primary care provider in promoting developmental health throughout the three years of residency.

Academic medical centers with clinical training programs should become "centers of excellence" for training in developmental health services, linking community-based providers with specialized developmental services and promoting innovations in developmental care. The academic medical center is an existing resource that has leveraged its expertise and knowledge in other domains (e.g., cancer care, children with special health care needs) to provide special training, services, and connections to community-based providers. A marginal investment in infrastructure development could allow academic medical centers to play long-term roles in workforce development and quality improvement in developmental health services.

Practicing child health providers should have education requirements linked to quality improvement strategies. This would go beyond routine continuing medical education and incorporate practice reengineering techniques that are effective in other clinical areas, such as the approach that the National Initiative for Children's Healthcare Quality is spearheading. These collaborative practice efforts could also be linked to academic training programs.

States and large cities should also consider how they can serve as regional resources for developmental health services to communities, child health providers, and other parties. This could range from information about new assessment tools and parent education materials to access to best practice models. State and local Maternal and Child Health programs might also take on the role of regional resources as they continue their involvement in building comprehensive early childhood systems.

#### 6. Improve Statewide Coverage and Reimbursement Policies

Including language in state Medicaid and state Children's Health Insurance Program (CHIP) managed care contracts to cover developmental services for children from birth to age 5 would be a major step forward. If medical plans (e.g., Medicaid, CHIP, and private insurance plans) are to provide developmental health services to children, managed care organizations must include appropriate language in their contracts that specify that these services are expected to be routinely provided. According to a recent report from the George Washington University Center for Health Services Research and Policy, the

contract package should include services in four areas: screening and assessment, developmental health promotion, general developmental interventions, and care coordination, including referrals to child service agencies. The George Washington Center has created model contract language to facilitate the adoption of such provisions.

Medicaid-eligible children under 5 are entitled to Early Periodic Diagnostic Screening and Treatment Program (EPDST) services. If a developmental service falls into a statutory or regulatory Medicaid benefit category (such as EPSDT services or physician services), and even if this service category is not covered under a state's Medicaid Plan, federal matching funds are available for those services in that state. Thus, if framed correctly, matching funds can be obtained for some developmental services.

In many states that have implemented CHIP, large amounts of unused money are being sent back to the federal government. States should use this excess money instead to reimburse health care providers for developmental health services either by increasing capitation rates for these services or by directly reimbursing the practitioner.

# 7. Improve Quality Measurement and Accountability to Enhance Incentives for Optimal Performance

Quality measurement tools that many state health departments routinely use, such as HEDIS, should be modified to measure developmental health services. This type of administrative change would create a powerful incentive for change within managed care organizations and physician practices because of the accountability demanded by state-funded programs.

In addition, state Medicaid and CHIP programs should consider launching practice improvement initiatives focused on developmental health services; Maine, Washington, Vermont, North Carolina, and several other states have already done so. In these states, the Foundation for Accountability Promoting Healthy Development consumer survey is being used to assess quality of services and improvement efforts.

# 8. Monitor, Track, and Report the Developmental Functioning of All Children and the Developmental Health Services They Receive

At a city, state, and national level, there is an obvious need for better data about the developmental functioning and needs of young children. From a population health perspective, there is also an urgent need to assess and track the content and quality of developmental health services and to monitor progress in early childhood systems. New quality assessment tools such as the PHD and the National Survey of Early Childhood

Health (NSECH) measure both population and practice-based experience and help to formulate integrated data collection strategies (Bethell et al., 2001a; Halfon et al., 2002a).

Just as states now administer the Youth Risk Behavior Surveys on the changing profile of youth risks and the impact of preventive services, states could consider modifying the NSECH to develop a state-level profile of the developmental health needs, risks, and service use of children from birth to age 5. Linking such statewide populationbased surveillance with the content and quality of developmental health services would allow states to assess the impact of policy, program, and practice-based changes.

The federal Maternal and Child Health Bureau announced, in August 2002, a national initiative to improve the development of comprehensive early childhood systems, with a major focus on improving access to and quality of developmental health services. This initiative could help states begin to develop the kind of strategic vision needed within states and at the national level. This also has the potential to encourage a collaborative process, with public and private partners working to improve the quality of developmental health services.

# APPENDIX A. TABLES AND FIGURES

# Table A-1. Recommendations for Developmental Surveillanceand Screening of Infants and Young Children

- Maintain and update knowledge about developmental issues, risk factors, screening techniques, and community resources, such as early intervention, school, Title V, and other community-based programs, for consultation, referral, and intervention.
- Acquire skills in the administration and interpretation of reliable and valid developmental screening techniques appropriate for the population.
- Develop a strategy to provide periodic screening in the context of office-based primary care, including the following:
  - Recognizing abnormal appearance and function during health care maintenance examinations
  - Recognizing medical, genetic, and environmental risk factors while taking routine medical, family, and social histories
  - Listening carefully to parental concerns and observations about the child's development during all encounters
  - Recognizing troubled parent-child interaction by reviewing history or by observation
  - Performing periodic screenings of all infants and young children during preventive care visits
  - Recognizing that test procedures and processes should be culturally sensitive and appropriate to the population.
- Present the results of the screening to the family using a culturally sensitive, family-centered approach.
- With parental agreement, refer children with developmental delays in a timely fashion to the appropriate early intervention and early childhood education programs and other community-based programs serving infants and young children.
- Determine the cause of delays or refer to appropriate consultant for determination. Screen hearing and vision to rule out sensory impairments.
- Maintain links with community-based resources, such as early intervention, school, and other community-based programs, and coordinate care with them.
- Increase parents' awareness of developmental disabilities and resources for intervention by such methods as display and distribution of educational materials in the office.
- Be available to families to interpret consultants' findings.

Source: AAP Committee on Children with Disabilities, 2001.

# Table A-2. National Initiative for Children's Healthcare QualityDevelopmental Services "Change Concepts"

- Seek patient/family input
- Agree on guidelines
- Stratify care (by risk)
- Use structured assessment tools
- Use prompting systems for staff and patients
- Distribute work and train staff for new roles
- Simplify referral process
- Optimize billing
- Link with community resources

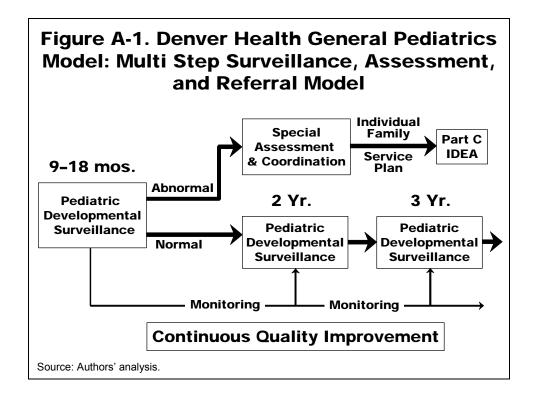
Source: Authors' analysis.

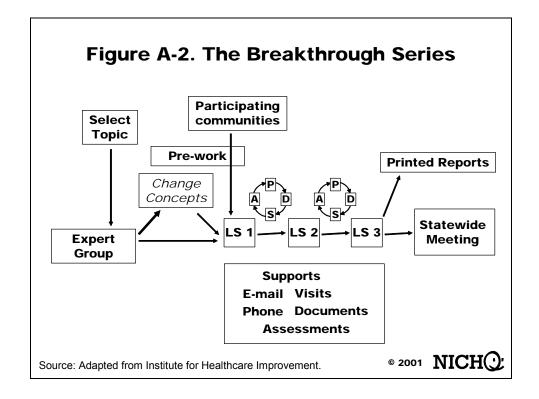
Table A-3. National Initiative for Children's Healthcare Quality	1
Office Processes and Support Tools	

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Process	Tools
Identifying service needs	PEDS survey
Prompting provider	Structured record
Educating patients	Patient activation
Documenting services	Flow sheet
Following up	Tracking system
Monitoring effectiveness	Periodic chart reviews

Source: Authors' analysis.





### **APPENDIX B: BEST PRACTICE MODELS**

### DENVER SYSTEM FOR ASSESSMENT AND REFERRAL

The Denver General Hospital and Clinics system for assessing and referring children with developmental disabilities for treatment has three tiers. Primary care pediatric clinics are linked to a second tier, which has more centralized developmental assessment and coordination. This center is in turn linked to the Individuals with Disabilities Education Act (IDEA) system for treatment of children with developmental disabilities (Figure A-1). In the Denver model, children are routinely screened using the PEDS Developmental Surveillance Instrument at nine and 18 months. Children with problems are referred to a central assessment team that conducts additional assessments and refers children to diagnostic and treatment providers in other community locations. This unit also coordinates care and serves as the entry point to the IDEA system. Funding for the initial screenings comes from Medicaid-related health service delivery dollars. Funding for the assessment and coordination into the IDEA system comes from IDEA funds and Title V funds, in addition to Medicaid funds.

This model results in developmental surveillance for all children, and uses a multitier process to assess those children identified as most at risk. Innovation also occurs along a pathway that links the primary care, developmental screening, and developmental treatment systems to facilitate movement of children and families to the appropriate level of care.

# NATIONAL INITIATIVE FOR CHILDREN'S HEALTHCARE QUALITY: BREAKTHROUGH SERIES REENGINEERING MODEL

The National Initiative for Children's Healthcare Quality process identifies delivery problems within the current system and uses a collaborative approach to develop solutions. Called the "Breakthrough Series," this process discusses change concepts and ideas on how to improve developmental care using specific tools (for example, assessment tools) to make change (Tables A-2 and A-3).

The NICHQ process also provides a model for improvement of health care systems. It identifies goals, actions needed to reach the goals, and evaluation of outcomes. A four-step method includes formation of a plan, implementation of the plan, analysis of what has been done, and revision based upon data received in the analysis. This cycle of ideas/hunches/theories for change is repeated until changes that result in improvement occur (Figure A-2).

# HEALTHY STEPS: A PRACTICE-BASED MODEL

In December 1994, the Commonwealth Fund launched the Healthy Steps for Young Children Program. With a panel of experts and multidisciplinary teams, the program formed partnerships with nearly 70 funding sources and 24 pediatric and family practice sites across the country to reorganize pediatric primary care. The goal was to promote the physical, emotional, and intellectual development of young children by enhancing the knowledge, skills, and confidence of parents in their child-rearing abilities. The program included:

- A team approach to care, including pediatric clinicians and Healthy Steps specialists.
- Enhanced well-child visits by teams and a sequence of home visits by Healthy Steps specialists.
- Written materials for parents emphasizing health promotion and healthy development.
- Periodic child development screening and family health assessment.
- A child development telephone information line.
- Parent groups and linkages to community resources.

The program accomplishes its objectives through a training institute and curriculum to enhance the knowledge and skills of pediatric clinicians participating in the Healthy Steps program. Early findings suggest that the Healthy Steps model provides better care for behavioral and developmental services. The model also better meets the needs of parents and improves parental safety practices.<sup>1</sup>

# CHILDSERV: CITYWIDE COORDINATION AND ENHANCED CONNECTIVITY

The ChildServ program was developed in Hartford, Connecticut, in response to the need for a coordinated, citywide system of developmental surveillance to serve the large number of Hartford children with developmental and behavioral problems. ChildServ has been collecting data on an ongoing basis to evaluate the program's effectiveness. The program has already made improvements in meeting the developmental and behavioral needs of Hartford's children and families. The program emphasizes, moreover, that its

<sup>&</sup>lt;sup>1</sup> C. Minkovitz et al. and the Healthy Steps evaluation team, "The Early Effects of the Healthy Steps for Young Children Program," *Archives of Pediatric and Adolescent Medicine* 155 (2001): 470–79.

success is largely due to the collaborative relationships formed among the program's providers and community agencies. Major components of the program include:

- Training local child health care providers in effective developmental surveillance and monitoring.
- A computerized inventory of regional services for developmental needs.
- A triage, referral, and case management system that helps children and families access services.
- Gathering systematic data on the developmental status and needs of local children in local communities.
- Educational programs for parent groups and child care providers that offer information about early detection of developmental concerns and promote increased communication with child health care providers.

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*Estimating the Cost of Developmental and Behavioral Screening of Preschool Children in General Pediatric Practice* (October 2001). Deborah Dobrez et al. *Pediatrics,* vol. 108, no. 4. Copies are available from American Academy of Pediatrics, 141 Northwest Point Blvd., Elk Grove Village, IL 60007–1098, Tel: 888–227–1773, Fax: 847–434–8000, E-mail: journals@aap.org.

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Growth, Development, and Behavior in Early Childhood Following Prenatal Cocaine Exposure: A Systematic Review (March 28, 2001). Deborah A. Frank et al. Journal of the American Medical Association, vol. 285, no. 12. Copies are available from Deborah A. Frank, Boston Medical Center, Growth and Development Programs, 820 Harrison Avenue, FGH Bldg, 3rd Fl., Boston, MA 02118-2393, E-mail: dafrank@bu.edu. **#448** Child Development and Medicaid: Attitudes of Mothers with Young Children Enrolled in Medicaid (March 2001). Susan Kannel and Michael J. Perry, Lake Snell Perry & Associates. This report on mothers with young children enrolled in Medicaid finds that while generally pleased with the overall care their sons and daughters receive, many mothers feel that the program—as well as pediatricians—could do a better job of providing guidance on early development.

Healthy Steps: Delivering Developmental Services for Young Children Through Pediatric Primary Care (2001). Margot Kaplan-Sanoff. Infants and Young Children: An Interdisciplinary Journal of Special Care Practices, vol. 13., no. 3. Copies are available from Aspen Publishers, 200 Orchard Ridge Drive, Gaithersburg, MD 20878, Phone: (301) 417-7591, E-mail: LMcKenna@aspenpubl.com.

Primary Care Pediatricians' Roles and Perceived Responsibilities in the Identification and Management of Depression in Children and Adolescents (2001). Ardis L. Olson et al. Ambulatory Pediatrics, vol. 1, no. 2. Copies are available from Ardis L. Olson, MD, Department of Pediatrics, Dartmouth Hitchcock Medical Center, 1 Medical Center Drive, Lebanon, NH 03756-0001, E-mail: Ardis.Olson@Hitchcock.org.

*New Roles for Developmental Specialists in Pediatric Primary Care* (October/November 2000). Margot Kaplan-Sanoff, Claire Lerner, and Andrea Bernard. *Zero To Three*, vol. 21, no. 2. Copies are available from Zero To Three: National Center for Infants, Toddlers and Families, 2000 M Street, NW, Suite 200, Washington, DC 20036, Tel: 800-899-4301. Available online at http://www.zerotothree.org/vol21-2sb.pdf.

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*Child Development Services in Medicaid Managed Care Organizations: What Does It Take?* (July 2000). Carolyn Berry, Pamela Butler, Linda Perloff, and Peter Budetti. *Pediatrics*, vol. 106, no. 7. Copies are available from American Academy of Pediatrics, 141 Northwest Point Blvd., Elk Grove Village, IL 60007-1098, Phone: 888-227-1773, Fax: 847-434-8000, E-mail: journals@aap.org.

Assessing the Impact of Pediatric-Based Developmental Services on Infants, Families, and Clinicians: Challenges to Evaluating the Healthy Steps Program (March 2000). Bernard Guyer et al. and the Healthy Steps Evaluation Team. Pediatrics, vol. 105, no. 3. Available online at www.pediatrics.org/cgi/content/full/105/3/e33.

**#367** Assuring the Healthy Development of Young Children: Opportunities for States (February 2000). Peter Budetti, Carolyn Berry, Pamela Butler, Karen Scott Collins, and Melinda Abrams. This issue brief examines opportunities for states to enhance the provision of health-related developmental services to children in low-income families, particularly by emphasizing the importance of preventive developmental services in primary, pediatric practices.

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