

State Early Childhood Policy Technical Assistance Network

**Health Care and School Readiness:
The Health Community's Role in Supporting Child
Development -- New Approaches and Model Legislation**

October 2003

Network Resource

About the Brief

This Brief contains excerpts from several reports.

Chapter One is a reprint of the full report (less the executive summary), *Reasons and Strategies for Stengthening Childhood Development Services in the Healthcare System*, produced by the National Academy for State Health Policy with support from The Commonwealth Fund (http://www.cmwf.org/programs/child/vanlandeghem_nashp_O03.pdf).

Chapter Two is the executive summary from *Partnering with Parents to Promote the Health Development of Young Children Enrolled in Medicaid: Results from a Survey Assessing the Quality of Preventive and Developmental Services for Young Children Enrolled in Medicaid in Three States*, published by The Commonwealth Fund (http://www.cmwf.org/programs/child/bethell_partnering_570.pdf).

Chapter Three is the executive summary from *Building a Bridge from Birth to School: Improving Developmental and Behavioral Health Services for Young Children*, published by The Commonwealth Fund (http://www.cmwf.org/programs/child/halfon_bridge_564.pdf).

Complete versions of all three publications are available through The Commonwealth Fund or online (see paths shown above).

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Introduction

What can I do to get my child to go to sleep at night?

My toddler doesn't want to share his toys. Is that normal?

I don't know what to do about my three-year-old's temper tantrums.

I don't know if I can go on another day. He's a handful and I am tired all the time. What should I do?

My daughter has problems with her "s's." Will she grow out of it?

These are questions or concerns that parents may raise when taking their child to a doctor or other health practitioner, for routine check-ups or for medical emergencies. In fact, pediatricians and other health care providers are often the first, and sometimes the only, professionals with the opportunity to identify and make the first response to young children's developmental concerns.

At the same time, the structure for check-ups, or well child visits, often does not enable health practitioners to most effectively respond to such questions when they are raised, let alone probe for them when they are not directly asked. Pediatricians and other health practitioners may have limited knowledge of child development issues that extend beyond traditional medical concerns, and they may lack knowledge of other systems that can be drawn upon outside the medical community to address developmental issues. They may be unfamiliar to the type of referral protocols to special education than they have with other medical specialists.

As a result, an opportunity to address developmental issues, often essential to child health and well-being, is often lost, even though there often is funding available both for more detailed diagnoses and for follow-up services, both under special education and through health insurance coverage. Medicaid, in particular, provides very extensive coverage, under its early and periodic screening, diagnosis, and treatment (EPSDT) program, for a broad range of diagnostic and treatment services to address developmental issues, even when these extend beyond what otherwise would be covered as traditional medical services.

There are at least two compelling reasons for school readiness advocates to look to the health care community for support and action in addressing children's developmental needs.

First and as noted above, health care practitioners are frequently the first responders to children and their families and who are in the best position to identify potential developmental issues and concerns. They can provide some of this developmental support in their own offices, in a variety of ways. They can also serve as referral sources to other systems to address the child's developmental needs.

Second, the health care system is the “800-pound gorilla” in the financing world and can be a significant source of financial support for developmental services, particularly under Medicaid and through EPSDT.

The potential is great, but realizing that potential will require significant changes in the way pediatricians' and other children's health practitioners' offices are structured and the way primary and preventive health services are financed.

One can imagine touch screens in waiting rooms where parents can complete self-diagnostic tools about their child's health and development, which can provide onscreen advice and referrals and can highlight issues the family should discuss directly with the health practitioner. These touch screens might be financed, in part, under Medicaid and could even be sources for determining Medicaid, SCHIP, WIC, and food stamp eligibility.

One can imagine similar self assessment tools in hospitals, for use at the birth of a child, which can identify family stresses that require follow-up services, potentially including home visiting programs whose services are covered under EPSDT and Medicaid as a form of care coordination.

One can imagine close working relationships between primary health care providers and special education, with special education developmental assessments, diagnoses, and follow-up services covered under Medicaid and EPSDT.

One can imagine pediatric visits that focus upon particular developmental issues appropriate to the age of the child, with specialized materials available on those issues and with parents provided background information even prior to their visits, so both parents and the practitioner are more likely to address developmental issues pertinent to the family.

At the heart of this work, one can imagine health practitioners and their office staff trained and supported in providing developmental assessments and guidance to parents, including identifying parental and family issues that can affect child development and well-being.

In fact, there is much in the pediatric literature that supports greater physician attention to developmental issues. There are a growing number of promising practices and model programs that have shown the potential for the health community to positively impact child development. There are pediatricians and other child health practitioners in every state who are willing and eager to advance policies and practices that will expand the health community's role in supporting young child development.

At the same time, however, current pediatric practice in general gives insufficient attention to child development issues. This has not been "front burner" work in most states' agendas for improving child health, nor has it been a significant topic of concern in most states' agendas related to child development and school readiness. Professionals, administrators, and advocates often have not drawn the connection between the related goals of improving child health and improving child development and school readiness.

Particularly with the continued policy focus in many states upon school readiness, however, there is an opportunity to focus attention on the health community's role in child development and school readiness -- and what policies and supports states might provide to help health practitioners fulfill this role.

This resource brief is a compilation of several different documents that provide an introduction to this topic and suggest possible policy actions, as well as highlight promising practices.

Chapter One, "Reasons and Strategies for Strengthening Childhood Development Services in the Healthcare System," makes the case for the health system's role in early childhood development, describes four components of basic child development services, outlines the challenges of integrating those services into the health care system, offers strategies for improving child development services in the health care system, and provides illustrations of promising practices.

Chapter Two, "Building a Bridge from Birth to School: Improving Developmental and Behavioral Health Services for Young Children," draws upon survey data and other reports to show that both parents and practitioners believe that developmental services should be a part of primary health care services for young children, but that current developmental services do not meet the needs of

most families. Like Chapter One, it identifies barriers to providing that care, and identifies current research findings and recommendations for action, as well as describing several promising approaches.

Chapter Three, "Partnering with Parents to Promote the Healthy Development of Young Children in Medicaid," reports on a survey of parents of young children enrolled in Medicaid in three states on their experiences in receiving developmental services. It shows the limitations of the current practices in meeting family needs, with specific recommendations on changes that states can make to their Medicaid systems to promote developmental services.

Chapter Four, "A Children's Developmental Health Model Act," provides one approach states could take in bolstering the developmental nature of health services to children – one which could lead to developing and enacting many of the recommendations made in the earlier chapters. It represents a learning approach that draws upon the leadership of the pediatric and child health community while drawing in broader systems which address child development issues and concerns.

In short, the message of this resource brief is that child health practitioners can be a strong ally in achieving the first National Educational Goal, that "all children start school ready to learn." To realize this potential, however, will require greater emphasis upon supporting those practitioners and seeing the health system as an integral part of a school readiness strategy. The most important role that child health practitioners can play is in their own work with children and families within health care settings, but they need support and partnership with others to assume this role.

Chapter One

Reasons and Strategies for Strengthening Childhood Development Services in the Healthcare System

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National Academy for State Health Policy
Prepared with support from the Commonwealth Fund¹

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Overview: The Case for Early Childhood Development

The concept of investing early in children, youth, and their families early in order to prevent health, education, and social problems in the future is not new. Studies have demonstrated the benefits and cost-effectiveness of prevention programs and efforts targeted to women, infants, and children, particularly those who are low-income.² In particular, early brain development research affirms the long-lasting impact that early experiences in the first five years of life have on young children and stresses the importance of maximizing investments in early childhood development.

Recent early brain development reports based on a decade of research confirm that child development is far more complex than previous notions of "nature versus nurture." As this research makes clear, human development is a dynamic and interactive process between genetics and experience that occurs rapidly from birth to age five but is also life-long. Early environments, nurturing relationships, human interaction, early experiences, and culture are among the factors that play a critical role in a child's development.³ Moreover, early emotional development and early learning are interrelated. Children who do not reach age-appropriate social and emotional milestones, such as a secure attachment with a parent or other primary caregiver, face a far greater risk of school failure.⁴

The critical foundations for learning, school success, health, and general well-being are established well before a child enters kindergarten. Children's physical health, cognition, social emotional development, and language development are essential underpinnings to school readiness. However, striking disparities in what

children know and can do are evident very early, are strongly associated with social and economic circumstances, and are predictive of subsequent academic performance.⁵ Children who are not successful early in school may also have greater problems with later behavioral, emotional, academic, and social development.⁶ Fortunately, early investments in young children and their families can make a significant impact on child well-being and reduce the need for more costly interventions. Early intervention efforts have been shown to improve school readiness, health status, and academic achievement, and to reduce the need for grade retention, special education services, and welfare dependency.⁷

The health care system plays a central role in promoting optimal child health and development and in contributing to school readiness. It is the one system with which nearly all families come in contact in a child's first five years of life and can intervene even before a child enters school. The health care system can help solidify a child's trajectory for academic success by assuring that infants are born healthy, that parents receive child development information and support, and that children meet their optimum developmental potential. Health care services that support a child's healthy development should begin as early in pregnancy as possible and continue throughout a child's first five years of life.

While many recognize the health care system's important role in early childhood development, routine child development services are not consistently provided in health care settings. Flexibility in federal programs such as Medicaid and the State Children's Health Insurance Program (SCHIP) provide an important opportunity to strengthen early childhood development services. This issue brief provides a framework for the provision of child development services in the health care system, offers strategies for strengthening child development services, and identifies examples of promising practices at the state, community, and primary care level. It is based on the research, key national policy reports, and state and local innovations that were featured at a national meeting of state health agency administrators, providers, and others interested in improving early childhood development services, policies, and practices.⁸

The Essential Role of the Health System in Early Childhood Development

Without the active and ongoing involvement of the health care system in child development, opportunities for assuring optimal development can be missed, and developmental problems can often go undetected until a child enters kindergarten or even later. Approximately 15 to 18 percent of children in the United States have a developmental or behavioral disability; however, only 50 percent of these children are identified as having a problem prior to starting

school.⁹ Preventive child health and development services address behavioral, social, and learning problems in the health care system and help improve trajectories for very young children, especially those who are low-income.

Nearly one in five young children (18 percent in 2000) live in poverty in the United States.¹⁰ Children who live in poverty are more likely to be at-risk for poor health, academic, and social outcomes. These children, including the children of the working poor, are more likely to be uninsured, have unmet medical needs, and have no usual source of care.¹¹ Parents who are low-income are more likely to have higher rates of mental health problems and report generally higher levels of stress.¹² They are less likely to engage in activities that help foster healthy child development, such as breast-feeding, establishing daily routines, and reading to their child.¹³

What Families Want From Health Care Providers to Support Their Child's Healthy Development. All families with young children need some type of support during their child's early years. Changes in family structure, work patterns, and other aspects of society are placing increased demands on families which, in turn, can have a negative impact on child development. These challenges are further compounded when families are low-income, headed by a teen parent, experience substance abuse and mental health problems, or have other issues. To navigate their child's first years of life, families want more information, services and assistance from health care providers on how they can help their children thrive and learn.¹⁴

Recent national surveys indicate that most parents understand the important role they play in their child's health and development. In fact, 71 percent of adults in a recent survey understand that brain development can be impacted very early and 76 percent realize that a child's early experiences have a significant impact on abilities that appear much later in a child's life.¹⁵ Many families, however, lack important knowledge and information about how they can best support their child's optimal development.

Families overwhelmingly indicate that they want accessible child development information and guidance from credible and knowledgeable sources. Outside of their own family, parents most frequently rely on and turn to their pediatric provider¹⁶ for information about parenting and child development.¹⁷ In spite of what families clearly want from their pediatric provider, child development services are not consistently provided in health care settings. In a national survey of parents with young children, parents were least satisfied with the extent to which their child's regular doctor helped them understand their child's development.¹⁸

In addition to child development information and guidance, parents want support from providers in other areas that can affect child health and well-being.

For parents of young children:

- 89 percent believe that health care providers should ask about alcohol or drug use in the home; however, only 44 percent of parents have been asked this by their provider,
- 85 percent believe providers should ask whether a parent has someone to turn to for emotional support, but less than 50 percent of parents have been asked by their provider,
- 56 percent believe providers should ask about violence in the community but less than 22 percent have been asked this by their provider.¹⁹

The Role of Primary Care Providers. Child development services are provided by a variety of primary health care providers such as pediatricians, family physicians, and nurse practitioners, and in settings including local health departments, community health centers, and private physician practices. Regardless of the setting, it is important that children and their families have a medical home: accessible, continuous, comprehensive, and coordinated health care provided or directed by well-trained physicians who are able to manage all aspects of a child's pediatric care.²⁰

Primary care providers play a central role in child development, particularly in the first five years of a child's life and even before a child is born or conceived. They have regular access to women, infants, young children, and families, providing an important window of opportunity to assess and positively influence child health and development. For instance, providers can educate women of child-bearing age about the importance of folic acid intake to prevent neural tube defects²¹ and promote proper nutrition and adequate prenatal care to lower the risk of having a low-birthweight infant.²² For very young children, pediatric providers recommend and help assure that children receive nine to ten well-child visits within the first 24 months of life.²³

In addition to placing greater focus on child development, pediatric providers can address family, psychosocial, and community issues during general health supervision. They can use child health and development visits as an opportunity to inquire about the health of the mother or primary caregiver. For women with maternal depression or other mental health concerns, pediatric providers can serve as an important link to other services and supports. Finally, a clear link exists between a mother's use of health services for herself and her use of

services for her child, a fact that may encourage providers to use a two-generational approach to child health services.²⁴

The Impact of Parental Depression on Child Development

Depression is the most prevalent mental disorder nationally. It occurs twice as frequently in low-income groups as compared to others and is the leading cause of disability among women.²⁵

Infants and toddlers of depressed parents are:

- less attentive, more fussy, and experience lower activity levels,
- 6-8 times more likely to be diagnosed with a major depressive disorder, and
- 5 times more likely to develop conduct disorders.²⁶

Parental depression can lead to harsh or negative interactions with the child, lack of interest or follow-through on important prevention activities such as use of car seats and child-proofing, and limited school readiness for children.²⁷

When asked about child development assessment, most pediatricians (93%) agree that pediatricians should inquire about child development during health supervision; however, few (36%) think that their time is sufficient for developmental assessments and still others (65%) report having inadequate training in assessment.²⁸ The emphasis in many pediatric visits continues to be on more traditional preventive health topics such as immunizations and nutrition.

Preventive Child Development Services: Promoting the Optimal Development of Young Children

Child development services should be a routine part of preventive pediatric care and an integral component of general child health supervision. However, the degree to which they are regularly provided by primary care providers is inconsistent. Numerous factors and competing priorities for preventive pediatric care mean that child development services can get shortchanged. When child development services such as developmental assessments and anticipatory guidance are delivered, they are often a small and indistinguishable piece of general primary pediatric services. This makes it difficult to target services for quality improvement and enhanced service provision strategies that are separate from other components of health supervision.²⁹ Fortunately, early brain research reports have prompted health care providers and others to more clearly define the scope of routine child development services and take measures to improve the quality and consistency of services.

Child development services can be categorized in the following four key areas:

- **developmental surveillance, screening and assessment** services that include gathering information from the parent, developmental monitoring including screening for developmental problems, parent-child observation, and assessment of child development and behavior;
- **developmentally-based health promotion and education** including anticipatory guidance and parent education that addresses areas such as the parent-infant relationship, sleep patterns, discipline, injury prevention, and language development, and literacy programs that encourage reading to young children;
- **developmentally-based interventions** that provide families with services and support within or outside of the health care setting and through mechanisms such as phone consultation and home visiting. Interventions include problem-focused counseling and speech, language, and physical therapies for children who have or are at-risk of developmental delays; and
- **care coordination** to manage and monitor the ongoing care of young children and link families to community agencies and services not provided in the health care setting.³⁰

Levels of Early Childhood Development Detection³¹

Developmental surveillance or monitoring includes eliciting and attending to parental concerns, obtaining a relevant developmental history, making accurate and informative observations of children, and sharing opinions and concerns with other relevant professionals.³² It means assessing risk factors for negative developmental outcomes, including prenatal and perinatal conditions, nutritional deficiencies, environmental toxins, sensory impairments, and poverty.

Developmental screening refers to a brief assessment procedure designed to identify children who should receive more intensive diagnoses or assessments.³³

Developmental assessment or evaluation refers to a more in-depth evaluation of children and may lead to a definitive diagnosis, plan of remediation, determination that there is no problem, or further observation.³⁴

Child Development Surveillance, Screening, and Assessment. Routine developmental surveillance, screening, and assessment are important components of child development services for infants and young children. The American Academy of Pediatrics (AAP) recommends that all infants and young children be screened for developmental delays and that screening procedures be

incorporated into the ongoing health care of the child as part of the provision of a medical home. Developmental screening should be part of routine preventive pediatric care that is culturally sensitive and family-centered, and connected to community-based resources and programs.³⁵

Numerous evidence-based child development and behavioral assessment tools are available for screening and identifying developmental delays in young children. However, no single universally accepted tool currently exists. Each tool offers its own unique strengths and weaknesses for detecting developmental delays and application in a primary care setting.

The availability of multiple screening and assessment tools—combined with multiple factors such as limited physician training and time constraints—can impede the consistent use of standardized tools and the ability to implement assessment systems. For these and other reasons, many pediatric providers continue to rely on clinical judgment for detecting developmental delays rather than on standardized tools. In fact, only 44 percent of pediatricians report using a developmental screening instrument and 38 percent report using a formal assessment.³⁶

Developmental screening tools that use parent report are increasingly being examined for use in health care settings because they may remove some of the time burden on pediatric providers. Structured mechanisms for eliciting parents' concerns have been shown to be fairly accurate and reliable in detecting children at risk of developmental problems.³⁷ Screening tools that rely on parent report such as the Ages and Stages Questionnaire (ASQ) and the Parents' Evaluation of Developmental Status (PEDS), are often favored because of their utility for integration in a primary care setting.³⁸ (See Table on page 32 for an overview of developmental screening tools.)

Developmentally Based Health Promotion and Education. Anticipatory guidance for parents and other caregivers is an important part of child development services and has been shown to improve child development outcomes. It includes preventive counseling to promote optimal growth and development, parenting education and developmental advice, and motivation to adopt healthier practices. Anticipatory guidance appears to be most effective when education efforts are directed toward increasing positive interaction between parent and child. It can also be effective when targeted to specific issues such as sleep habits, discipline, and promoting children's learning.³⁹

Typically, anticipatory guidance acknowledges the importance of early emotional development, reinforces the parent-child relationship, and addresses those areas most conducive to early intervention. Topics for discussion often include:

- parent-child interaction,
- discipline,
- infant and toddler sleep habits,
- child temperament, and
- child learning.⁴⁰

Ideally, anticipatory guidance might also address other topics that can have a major impact on child and family health, among them injury prevention, maternal depression, and domestic violence.

Anticipatory guidance is maximized when effective and productive relationships exist between practitioners and parents. Families should feel comfortable addressing child development issues with their pediatric provider. In turn, providers need effective communication skills and techniques in order to elicit critical information about child development, to counsel parents, and to provide important developmentally-based education. In establishing relationship-based practices, providers focus their efforts on promoting the parent-child relationship and, at the same time, recognize that the relationship between the parent and practitioner is fundamental to quality services.⁴¹

Developmentally Based Interventions. Developmentally based interventions provide families with young children with some of the services and supports that they need to assure their child's healthy development. These interventions may be provided within or outside of the health care setting and through such vehicles as phone consultation or home visiting. They may include such interventions as problem-focused counseling for excessive crying or the management of colic, or more intensive services such as speech, language, and physical therapies for children who have or are at-risk of developmental delays.

Among these interventions, home visiting is a long-standing prevention strategy used by states and communities to improve health outcomes for women, children, and their families, and a mechanism that is being used in many early childhood development efforts.⁴² Home visiting is used to strengthen parenting skills, prevent child abuse and neglect, improve child health, and enhance child development services. It can serve as an important vehicle for providing or connecting families with additional supports such as smoking cessation services and additional parenting education.

Care Coordination. Care coordination involves managing and monitoring the ongoing care of young children and their families and linking families to health and developmental services (e.g., behavioral and psycho social services) in the

community. Since developmental interventions are outside of the pediatric office, linkages between pediatric settings and community based systems can be inconsistent and incomplete.⁴³ Care coordination is highly dependent on effective outreach and referral mechanisms, well-integrated systems of preventive care and early intervention services and supports, and efficient feedback loops between community agencies and providers.

Challenges to Integrating Child Development Services in the Health Care System

In spite of national reports, policy statements and nationally-recognized child development guidelines such as Bright Futures,⁴⁴ the inclusion of routine child development services in the primary care setting remains highly inconsistent.

Key barriers include:

- time limitations for providers,
- lack of appropriate provider training to use developmental screening and assessment tools,
- inadequate reimbursement amounts and administrative barriers to billing,
- lack of bi-lingual providers, and
- graduate medical education programs that lack comprehensive training on early childhood education and development.

When families must be referred to services outside of the health care setting, insufficient community resources, inadequate provider referral mechanisms, and fragmented linkages between pediatric providers and community agencies provide further challenges.

These challenges are not limited to private pediatric providers and managed care organizations. Local health departments and community health centers may have more flexibility in determining the amount of time spent during well-child visits or in obtaining outside grants to support greater integration of child development services into their efforts. However, high client caseloads, insufficient resources, and administrative barriers to billing that outweigh relatively low reimbursement amounts present other challenges.

In addition to system and provider barriers, there are inherent challenges to early detection of developmental delays. Because child development is a dynamic and interactive process, children can develop at different rates making it difficult to fully assess whether a child is experiencing problems or just developing more slowly. Many families may not be aware of what a developmental screening will

tell them and if a developmental delay is detected, where to take their child for services. In addition, some families may find it difficult to consider that their child is experiencing a developmental delay. For these and other reasons, many young children are often screened or given a more in-depth developmental assessment only when significant developmental delays are evident.⁴⁵

Addressing the social and emotional health of young children and their families poses a particular challenge for the health care system. Children at risk for emotional and behavioral problems may be difficult to identify through routine pediatric care, and services and resources are difficult to find and coordinate, despite the fact that this aspect of early child development is a widespread concern. The mental health system does little for children ages 0 to 5, so the burden of responsibility falls to primary child health care providers. These providers may not have the expertise to address mental health issues for such young children and their families.

Strategies for Improving Child Development Services in the Health Care System

Multiple strategies, including improved financing mechanisms, quality improvement and standard setting, and provider training and education, can be used to improve the integration and implementation of child development services in health care settings. Numerous federal programs including Medicaid and SCHIP, TANF, Child Care, Head Start, and Early Head Start recognize and support the importance of intervening early with young children and their families. Through state innovations and the flexibility provided under these federal programs, unique opportunities exist to create comprehensive systems of care that assure the optimal health and development of all young children and their families.

Maximizing the Delivery of Child Development Services Under Medicaid and SCHIP. Medicaid and SCHIP are the largest sources of federal support for health coverage for low-income children, and the largest source of financing for child development services. Medicaid provides insurance coverage to approximately 23 million low-income children or more than one in four children in the United States.⁴⁶ SCHIP provides coverage to approximately 4.6 million children who are not eligible for Medicaid because family incomes and resources are too high to qualify.⁴⁷

In Medicaid, eligible children are entitled to a defined set of health care benefits under the Early and Periodic Screening, Diagnostic and Treatment (EPSDT) benefit. Preventive services under EPSDT include a thorough health and

developmental history including a mental and physical development assessment, age-appropriate immunizations, and health education and anticipatory guidance.

In SCHIP, eligible children are not entitled to a defined set of health care benefits. Rather, children qualifying for SCHIP receive health care services as

Using EPSDT Assessment Tools to Improve Developmental Screening

State Medicaid agencies can encourage the provision of child development services through the use of comprehensive encounter and screening forms for EPSDT visits. For example:

- Arizona's Health Care Cost Containment System (AHCCCS) developed an age-specific EPSDT tracking form to insure that all EPSDT components are met during each well-child visit, with input from the MCOs and the medical community. The form is completed by the provider, one copy is kept in the medical record and one copy is sent to the MCO. The MCOs are responsible for ensuring that EPSDT screens are performed and that the tracking form is completed.
- Maine adopted the encounter forms based on the Bright Futures Guidelines for Health Supervision of Infants, Children and Adolescents for use during EPSDT well-child visits. The series of 19 health assessment forms provides age-specific information about services to be provided, such as immunizations, and outlines suggestions for anticipatory guidance.
- Washington developed a well-child exam form for all primary care providers to use during well child visits. The form furnishes guidance and information to both physicians and parents and addresses age-specific issues in development.

determined by the state and subject to certain federal requirements.⁴⁸

States can strengthen the child development services provided to young children in Medicaid and SCHIP by:

- providing screening tools for primary care providers to use during the well-child visit that contain a specific focus on early child development;
- enhancing the service settings in which covered services will be delivered and broadening the range of health professionals who can be reimbursed under state programs;
- redefining classes of covered services to create an early childhood development benefit; and
- requiring a "preventive standard" of medical necessity to determine when

covered Medicaid and SCHIP benefits will be available.⁴⁹

Capitalizing on States' Roles as Insurance Regulators and Public Health Care Purchasers. States have the opportunity to use their role as insurance regulators and health care purchasers to strengthen child development services in health care systems. States can have an impact on whether public and private health care purchasers expect early childhood development competency from the health services that they purchase. They can also influence whether purchasers pay for services offered by non-traditional professionals and in non-traditional settings.

State governments, relevant state agencies, and purchasers can capitalize on their respective roles in health care purchasing and insurance regulation by:

- providing financial incentive arrangements that encourage provision of early childhood development services;
- requiring that pediatric networks demonstrate the use of practice guidelines that incorporate early childhood development and that they also demonstrate core competencies in early childhood development;
- using the contracting process with managed care organizations and other health systems to require or encourage inclusion of child development services;⁵⁰
- implementing quality improvement interventions with contracting managed care organizations by using the External Quality Review Organization (EQRO);⁵¹ and
- expecting managed care organizations to measure the early childhood development performance of their contract networks.⁵²

An Example of Using the EQRO to Improve Preventive Services for Young Children

Washington state has incorporated provisions in its contract with the EQRO to conduct an EPSDT Quality Improvement Project. Focused patterns of care (FPOC) studies are being used to assess utilization patterns, quality of care, and patient outcomes for the EPSDT population. The EQRO contractor is required to:

- conduct a FPOC chart review study of infants (up to 18 months), children (2 to 6 years), and adolescents (12 to 20 years);
- calculate clinic and provider level performance measures using chart review data; and
- develop and implement quality improvement interventions with clinics and/or providers based on findings from the chart review study, historical EPSDT studies, and focus sessions with providers and parents of children.

Improving Accountability, Quality Measurement and Improvement, and Data and Tracking Systems. Health care providers, state health agency administrators, policy makers and others can improve the quality of child development services by strengthening accountability and quality improvement systems and improving data collection and tracking systems. With regards to quality improvement measures, few exist that assess health care system performance in child development services. Many measures rely heavily on medical record or administrative data and provide information about children's access to preventive care but not the *quality* of such care.⁵³

A recently developed quality improvement measure, the Promoting Healthy Development Survey (PHDS), assesses preventive developmental services for children ages birth to four years and is based on national guidelines from the American Academy of Pediatrics and Bright Futures. PHDS is designed to help providers, consumers, purchasers and others assess the degree to which health plans and providers provide recommended developmental services. The survey measures seven areas of preventive child development care:

- anticipatory guidance and parental education from providers;
- health information;
- follow-up for children at risk;
- assessment of family well-being and overall safety;
- assessment of smoking and substance abuse in the family;
- family-centered care; and
- the helpfulness and effect of care provided.⁵⁴

PHDS has many uses in health care settings. It can complement and supplement states' reporting requirements under EPSDT. Some states have used PHDS to strengthen purchasing and contracting by assessing the quality of care at the health plan and practice levels. In addition, PHDS has been used for quality improvement efforts to strengthen implementation of child development services in areas such as use of reporting forms, referral services, and coverage of developmental screening.⁵⁵

In addition to quality improvement measures, data systems that effectively track and assess the provision of child development services in public health care settings are also important. Many state health agencies have existing data systems that track and assess the provision of child health services in health departments and in public programs such as Medicaid and SCHIP. However, many of these systems may not include specific measures covering the provision of child development services such as child development screenings and

assessments. Finally, some states are using EPSDT reporting forms and charting tools to address age-specific issues in child development and provide guidance to primary care providers and parents.⁵⁶

State agencies, purchasers, health care providers, health plans, and others can enhance quality improvement efforts, and data and tracking systems by:

- integrating child development quality improvement measures in health care practices and settings;
- utilizing quality improvement data to strengthen practice and purchasing;
- compiling quality improvement data to educate key stakeholders about the benefits and importance of child development services;
- incorporating or obtaining measures of child development services, such as the provision of child development screening and assessment, in existing health care tracking and assessment systems; and
- using enhanced reporting forms to track child development services and charting tools to address age-specific issues in child development.

Creating Comprehensive, Coordinated Systems of Care for All Children, Including Those Who Have or Are At-Risk for Developmental Delays. States have certain flexibility under federal programs to establish comprehensive systems of early childhood care for all children, including those who have or are at-risk of a developmental delay. By maximizing key federal programs such as the Maternal and Child Health Services Block Grant (Title V of the Social Security Act) and the Early Intervention Program for Infants and Toddlers (Part C of the Individuals with Disabilities Education Act) and fully coordinating these programs with Medicaid and SCHIP, states can help assure stronger and more efficient systems of early childhood development services and supports at the state and community level.

Under Title V, states must spend 30 percent of their federal block grant allocation on preventive and primary care for children and youth, and 30 percent on services for children with special health care needs (CSHCN). State Title V programs work to assure the health of all women, children, and youth – including those with special health care needs – through a variety of programs and initiatives. The flexibility of Title V allows for it to be an originating and supportive source for child development programs, including direct care for mothers and children as well as interventions for an entire family.

Through the Early Intervention Program, *all* children ages birth to three who are experiencing developmental delays or who have a diagnosed mental or physical

condition that is likely to result in a developmental delay, are entitled to a range of services and supports. States may also elect to serve children who are *at-risk* of having substantial developmental delays if services are not provided.⁵⁷ States must establish an Early Intervention Program that includes several key components including a definition of developmental delay, a comprehensive child find (i.e., outreach to potentially eligible families) and referral system, a timely and comprehensive multidisciplinary evaluation of children's needs, and services and service coordination.

The unique complexities of federal programs, which are often administered by different state agencies, can pose significant barriers to seamless integration, particularly at the community level, but the challenges are not necessarily insurmountable. States can strengthen coordinated systems of early childhood services and supports by:

- assuring that programs such as Title V and Early Intervention are maximized and coordinated with Medicaid and SCHIP;
- fostering effective feedback mechanisms between community agencies and pediatric providers;
- educating pediatric providers about the availability of Early Intervention services and supports, and where they can refer children who have or are at-risk of a developmental delay;
- assuring that children in the Early Intervention program are assessed for eligibility for Medicaid or SCHIP; and
- coordinating data systems between Early Intervention, Medicaid, SCHIP, and other relevant programs.

Building Strong Linkages With Programs That Serve Low-Income Families and Support Children's Social and Emotional Development. There are numerous federal programs that provide family support and can be used to promote child health and development. For instance, Temporary Assistance for Needy Families (TANF) provides federal funding to support low-income families in achieving maximum self-sufficiency and decreasing adult dependency on public assistance. Federal TANF regulations and recent guidance clearly support use of TANF funds to assure the well-being and healthy development of children and youth, particularly those in low-income families. As a result, states are using TANF to promote quality child care, early childhood education, teen pregnancy prevention, and other related efforts.⁵⁸

Families with young children, particularly those who are low-income, come in contact with a variety of programs during their child's early years, providing an important entry point for providers to assure that child development needs are

being met. Head Start and Early Head Start, Child Care, Family Planning, and the Special Supplemental Nutrition Program for Women, Infants and Children (WIC) are some of the federal programs that either have explicit child health and development components or can serve as key contact points for connecting families with young children to child development services. Several states are exploring innovative approaches to child development service integration through these programs such as training public health nurses to conduct child development screens in child care settings, connecting families in the WIC program with child development services, and using these settings to educate parents about the importance of child development.

Strengthening Health Profession Education, Accreditation, and Licensure.

Health profession education, accreditation programs, and licensure systems have a significant impact on the degree to which health professionals possess competencies in early childhood development and are trained to incorporate early childhood development concepts into professional standards of practice. They can also influence pediatric standards of practice and whether public and private purchasers consider child development services as important components of what they purchase.

State agencies, health providers, and purchasers can influence early childhood development health profession competencies and practice standards by:

- examining current medical profession licensure policies and practices and requiring pediatric health professionals to demonstrate early childhood development competency as a condition of licensure;
- strengthening and expanding early childhood development training in medical education;
- incorporating the indirect and direct costs of publicly-funded graduate medical education and training programs into early childhood development services reimbursed by Medicaid and SCHIP; and
- dually certifying early child development specialists and social service/education professionals as health professionals in order to help them qualify for public and private insurance payments.⁵⁹

Creating Public Awareness and Education Campaigns. Increased public awareness and education of parents, caregivers (e.g., grandparents, aunts and uncles), and others about the importance of early childhood development and the role that health systems play is needed. While many parents indicate that they want child development services and support from their pediatric provider, many may not know how or whether to ask for these services. Increased public awareness and education that child development services are an important part

of primary health care may result in more requests for these services from families. In turn, this may help influence and shift the health care system towards more consistent and routine provision of child development services.

Putting It All Together: Promising Practices at the Primary Care Practice, Community, and State Level

Efforts to improve child development services in health care systems through service integration and care coordination, better financing mechanisms, partnerships at the state and community levels, and quality improvement measures are being implemented at the state, community and primary care practice level. These promising practices provide important insights and strategies for strengthening child development services in the health care system.

Primary Care Setting. Primary care settings are tackling the barriers to integration of child development services through evidence-based preventive standards, the strengthening of internal office systems, the implementation of performance monitoring and tracking systems, and the improvement of community-based referral and follow-up systems between providers and community agencies.

Effective practice delivery systems include:

- strong leadership;
- guidelines about preventive services that are well-known and used;
- structured assessments of child and family needs at every office visit;
- structured methods and forms to prompt physicians;
- methods to prompt patient involvement;
- linkages with community resources; and
- performance monitoring and feedback.⁶⁰

Guilford Child Health and the North Carolina ABCD Project^{61, 62}

The North Carolina Assuring Better Child Health and Development (ABCD) project is developing a “best practices” model for integrating child development services into local health care delivery systems, targeting children from birth to five years of age. The model includes developmental screening, referral, service coordination and the provision of educational materials and resources for both parents and clinicians serving Medicaid children. It was first piloted at Guilford Child Health – a large pediatric practice that is part of Guilford ACCESS Partnership, one of the state’s community-based Medicaid demonstration plans.

At Guilford Child Health, parents complete the Ages and Stages Questionnaire (ASQ) at intake when their child is 6, 12, 24, 36, and 48 months old. The ASQ is scored by a physician or nurse practitioner and used as a teaching tool to reassure parents and reinforce their understanding of their child’s healthy development. The practice’s Early Intervention Specialist reviews each child’s ASQ score. When a problem is detected (i.e., one or more developmental scores are below the ASQ cutoff score) a referral is made to the state’s local Early Intervention Program. In addition to routine developmental screening, Guilford Child Health provides families with referrals for necessary services, parenting classes, the Reach Out and Read literacy program,⁶³ and educational materials covering such age-specific developmental issues as managing tantrums and time-out guidelines.

For more information about the North Carolina ABCD initiative contact: Sherry Hay, ABCD Project Coordinator at sherry.hay@ncmail.net, or Marian Earls, Medical Director Guilford Child Health, Inc. at mearls@gchinc.com

Community Level. Community agencies play an important role in child development services because they can serve as a bridge and conduit between state programs and policies and what occurs in primary care practices. Efforts at the community level to strengthen child development services in health care settings include:

- creating critical linkages with physicians, hospitals, and other providers, that can strengthen child development services and referral mechanisms;
- fostering partnerships by involving providers, community organizations, families and other caregivers, and schools in coalitions and networks designed to improve early childhood development outcomes;
- strengthening systems for tracking and assessing the provision of child development services in public programs;
- educating providers about available Early Intervention services and other resources in the community;

- becoming educated about real or perceived confidentiality barriers that can prohibit community agencies and providers from sharing critical information; and
- working to improve referral and feedback loops between agencies and providers.

The San Mateo County (California) Prenatal to Three Initiative⁶⁴

The San Mateo County Prenatal to Three Initiative (Pre-to-Three) is a collaboration between the San Mateo County Health Services Agency, the Health Plan of San Mateo, the Peninsula Partnership for Children, Youth and Families, and other community organizations. Key program components include home visiting, parent support groups and education classes, linkages to community providers, provider training, literacy programs, and a central registration and referral system. Pre-to-Three serves Medicaid-eligible low-income families with pregnancies and newborn children.

Home visiting is a core component of the program. Home visitors are a multidisciplinary team from the county and community-based organizations that contract with the county. Home visitors address child development, nutrition, child safety, family planning, mental health issues, substance abuse, and special health needs.

Pre-to-Three partner organizations assist families with navigating managed care procedures, obtaining child care, and seeking transportation to and from appointments. Linkages with health care clinics and physicians offices are facilitated through the Program's central registry and referral system. The Initiative also collaborates with providers of family and mental health, nutrition, social services, libraries, education, and child care in order to improve service coordination. Three committees meet regularly to discuss program issues and inform policy making for the prenatal to age three population.

A recent evaluation of Pre-to-Three reveals, among other outcomes, that:

- Women in the program at high-risk of a mental health disorder received therapeutic services more often than their counterparts.
- Pre-to-Three children had on average one more well-child visit than children seen before the program began.
- Pre-to-Three parents showed picture books to their infants 45 percent more and visited the library 33 percent more than non-program families.
- Foster care placements in San Mateo County amongst children age birth to five years decreased from 46 percent to 33 percent after the Pre-to-Three Program.

For more information about the San Mateo County Prenatal to Three Initiative contact Mary Hansell, Prenatal to Three Initiative Director, at mhansell@co.sanmateo.ca.us

State Level. Efforts to strengthen child development services at the state level often involve multiple and complex funding streams, competing priorities for child

health and education among agencies, and different federal program requirements. States can strengthen child development services and support communities and primary care settings by:

- creating comprehensive and coordinated systems of care that integrate relevant federal and state programs for young children and their families;
- maximizing and using multiple federal financing streams, particularly Medicaid, SCHIP, Early Intervention, Title V, and TANF;
- building effective partnerships between state health, education, human service, mental health and substance abuse agencies; professional associations representing physicians, hospitals and other providers; child advocates; parent and family groups and others;
- using multiple public programs such as child care, WIC and Family Planning as key entry points for linkages and referrals to child development services;
- fostering and supporting innovative child development service practice models at the community level;
- conducting training and continuing education on early childhood development and child development services for providers, community agencies, and others;
- creating public awareness campaigns to educate parents and caregivers about the importance of early childhood development;
- developing model child health and development reporting forms for use in public programs and settings; and
- building and strengthening data systems that track the provision of child development services.

Kentucky Invests in Developing Success (KIDS) Now⁶⁵

Kentucky Invests in Developing Success (KIDS) Now is the state's early childhood initiative designed to assure maternal and child health, support families, enhance early care and education, and establish the state infrastructure to carry out these goals. The initiative began in 1998 with a gubernatorial creation of the Office of Early Childhood Development and the subsequent appointment of an Early Childhood Task Force, which presented a 20-year plan. The plan formed the basis for legislation which was passed in April 2000. Evidence from early brain research, recognition of the economic development potential to invest in children early for later substantial returns, and education reform all served as catalysts for the development and passage of the initiative.

KIDS Now is comprised of several work groups covering prenatal, early care and education, in-home supports, professional development, and public awareness. Several community forums have been held to elicit community and family input, and challenges and needs in early childhood care, education, and well-being. Among other activities, state conferences addressing infant/toddler health and development, early childhood care and education, and school-age issues have been held. Public awareness and education activities have also been conducted for such key stakeholders as legislators, families, and members of the media.

For more information about KIDS Now, contact Kim Townley, Executive Director, Governor's Office of Early Childhood Development, at kim.townley@mail.state.ky.us.

Conclusion

During early childhood, children develop at a rapid pace, forming the foundations for physical, cognitive, and social and emotional development that are predictors of school success, health, and overall well-being. While early childhood is a critical time for influencing and impacting children's life-long trajectory, all is not lost after children reach the age of five. Investments to support families in promoting their child's optimal health and development must also carry children through adolescence and into young adulthood.

Health systems have a clear role to play in promoting child development, educating parents and caregivers, screening and assessing children for potential developmental delays, and assuring that children and their families receive the necessary services and supports that they may require. States, communities, policy makers, health plans, pediatric providers, and others have an unprecedented opportunity to shape and strengthen child development services and numerous options and flexibility with which to do so. Promising practices at every level of health care service delivery provide important lessons for effecting

change and assuring that all young children achieve their optimal healthy development.

Overview of Developmental Screening Tools

	ASQ ¹	BINS ²	DDST ³	PEDS ⁴	CDI ⁵	BRIGANCE ⁶	PSC ⁷	GAPS ⁸
Type/Ages	Parent questionnaire (2 mos-5 yrs)	Direct elicitation (3-24 mos)	Direct elicitation	Parent questionnaire (0-8 yrs)	Parent questionnaire (3 mos-6 yrs)	Direct elicitation (21 mos-7.5 yrs)	Parent questionnaire	Child & parent Questionnaires (11-21 yrs)
Staff required	Para-professional	MA or equivalent	3.5 hours of training	Para-professional	Para-professional	Professional	Para-professional	No Scoring
Time to score	5 minutes	10-15 minutes	20-30 minutes	5 minutes	10 minutes	10-15 minutes	7 minutes	20 minutes
Cost (per kit)	\$190	\$195	\$91 kit \$185 training materials	\$39	\$41	\$249	Free download	Free download from AMA
Refills	OK to copy	Needed	\$26-\$100	\$30-\$50			OK to copy	OK to copy
Languages	English/Spanish	English	English	English/Spanish	English/Spanish	English/Spanish	English	English/Spanish
Reading Level	4 th - 6 th Grade	NA	NA	5 th Grade	NA	NA	NA	NA

¹ Ages and Stages Questionnaire. Paul Brooks Publishing Co., PO Box 10624, Baltimore, MD 21285-0624. 1-800-638-3775. www.pbrookes.com

² Bayley Infant Neurodevelopmental Screen. The Psychological Corp., 555 Academic Court, San Antonio, TX 78204. 1-800-228-0752. www.psychcorp.com

³ Denver Developmental Screening Test. Denver Developmental Materials, Inc., PO Box 371075, Denver, CO 80206-0919. 1-800-419-4729

⁴ Parents Evaluation Developmental Status. Ellsworth & Vandermeer Press, PO Box 68164, Nashville, TN 37206. 1-888-729-1697. www.pedstest.com

⁵ Child Development Inventory. Behavior Science Systems, Inc., PO Box 580274, Minneapolis, MN 55458.

⁶ Brigance Diagnostic Inventory of Early Development. Curriculum Associates, Inc., 153 Rangeway Road, North Billerica, MA 01862. 1-800-225-0248. www.curricassoc.com

⁷ Pediatric Symptom Checklist. Child Psychiatry, Bulfinch 351, Massachusetts General Hospital, Boston, MA 02114. 617-724-3163.

⁸ Guidelines for Adolescent Preventive Services. American Medical Association. www.ama-assn.org

¹ This chapter is based on the research, key national policy reports, and state and local innovations that were featured at a national meeting of state health agency administrators, providers, and others interested in improving early childhood development services, policies, and practices. "Improving Early Childhood Development: Promising Strategies for States and the Health Care System" was held January 30–February 1, 2002, in Jacksonville, Florida. The national meeting was co-sponsored by the Agency for Healthcare Research and Quality User Liaison Program, Centers for Medicare and Medicaid Services, The Commonwealth Fund, and the American Academy of Pediatrics, and administered by the National Academy for State Health Policy. Senior state and local health officials from across the country

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- participated in presentations and discussions to address ways to strengthen early childhood development services in the health care system.
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- ⁶³The Reach Out and Read Program consists of three linked interventions: 1. Anticipatory guidance about reading aloud provided as an integral part of health supervision visits, along with modeling and observation of parent-child book use. 2. Developmentally and culturally appropriate picture books given by the doctor at each health supervision visit, so that parents have both encouragement and the tools they need. 3. Community volunteers who read to the children in the waiting room, modeling developmentally appropriate techniques for the parents. Source: Needleman R, Klass P, Zuckerman B. "Reach Out and Read: A Practical, Proven Strategy to Promote Learning," submitted to *Contemporary Pediatrics*.
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Chapter Two

Partnering with Parents to Promote the Healthy Development of Young Children Enrolled in Medicaid

Results from a Survey Assessing the Quality of Preventive and Developmental Services for Young Children Enrolled in Medicaid in Three States

September 2002

The Commonwealth Fund¹

Christina Bethell, Colleen Peck, Melinda Abrams, Neal Halfon, Harvinder Sareen, and Karen Scott Collins

Partnering with Parents to Promote the Healthy Development of Young Children Enrolled in Medicaid...Executive Summary

A child's environment and experiences in the first six years of life have lasting effects, even through adulthood. Brain development, social development, physical well-being, readiness for school, and, ultimately, a child's success in life are all linked to these critical first years of life.² For children to flourish, families and their communities must work together to support the achievement of the cognitive, social, emotional, behavioral, and physical milestones essential to the healthy development of children.³

Among the most important partners for parents of young children are physicians and other health care providers. Guidelines recommend that children see a pediatric clinician approximately 12 times during the first three years of life for routine, well-child care services.^{4,5} Given the frequent contact that most parents have with their children's health care providers, pediatric clinicians are in a unique position to ensure that children get the healthy start they deserve.

This chapter summarizes findings from the Foundation for Accountability's (FACCT's) Promoting Health Development Survey-PLUS (PHDS-PLUS), a survey of parents of children under age 4 who were covered by Medicaid.⁶ For this report, responses from a

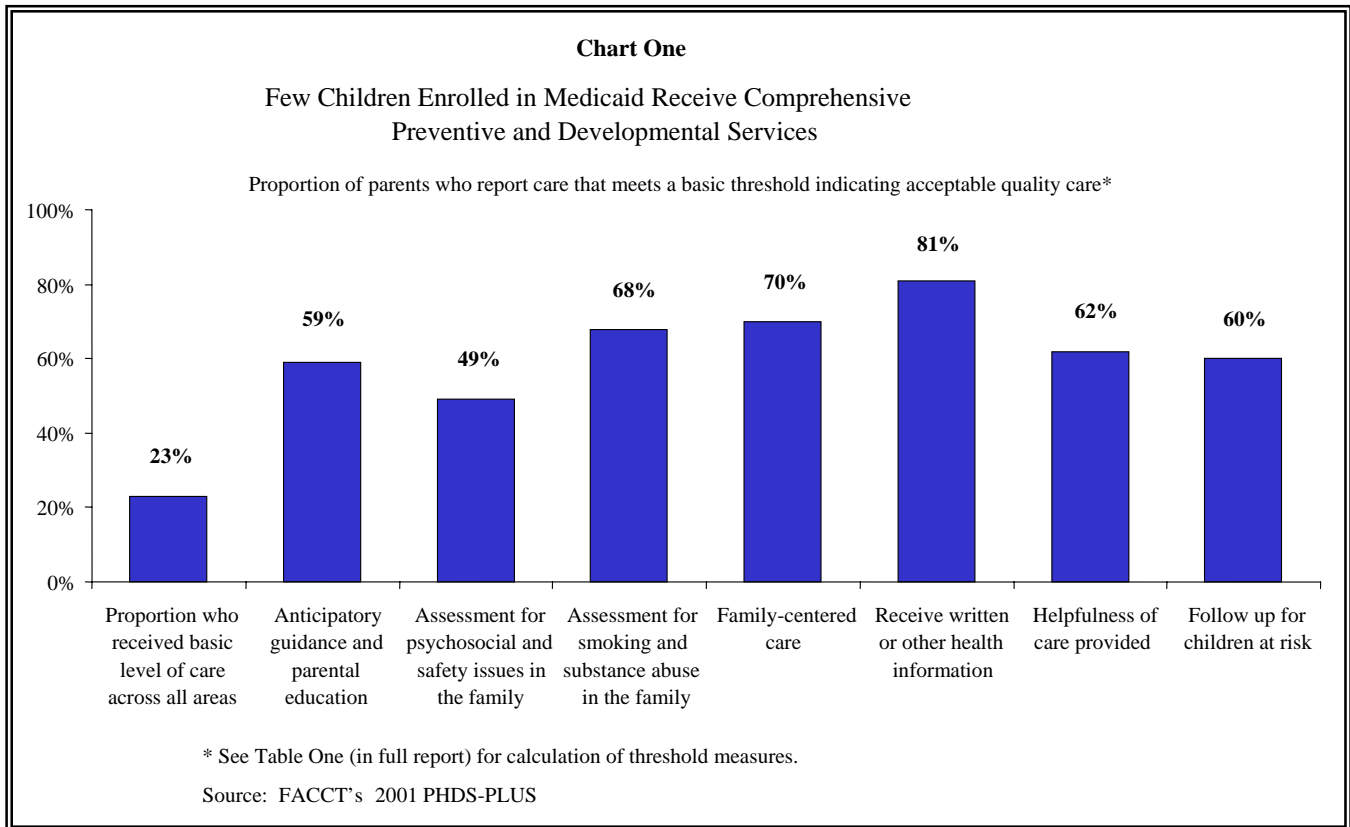
core sample of 1,900 parents (approximately 630 per state) were analyzed. The PHDS-PLUS provides a wealth of information about the provision and quality of preventive and developmental services to low-income children insured through Medicaid. These services include:

- Anticipatory guidance and parental education;
- Assessment of parental health and well-being and safety within the family;
- Assessment of parental concerns and follow-up with children identified as being at risk for developmental, behavioral, or social delays; and
- Family-centered care that promotes trust and partnerships with parents.

The survey also examines issues surrounding the health of young children and their parents and family health behaviors and routines. The survey was administered in three states participating in The Commonwealth Fund's Assuring Better Child Health and Development (ABCD) program: North Carolina, Vermont, and Washington.^{7,8,9,10} The ABCD program supports selected state Medicaid agencies' efforts to improve preventive and developmental services for young children and their families.^{11,12}

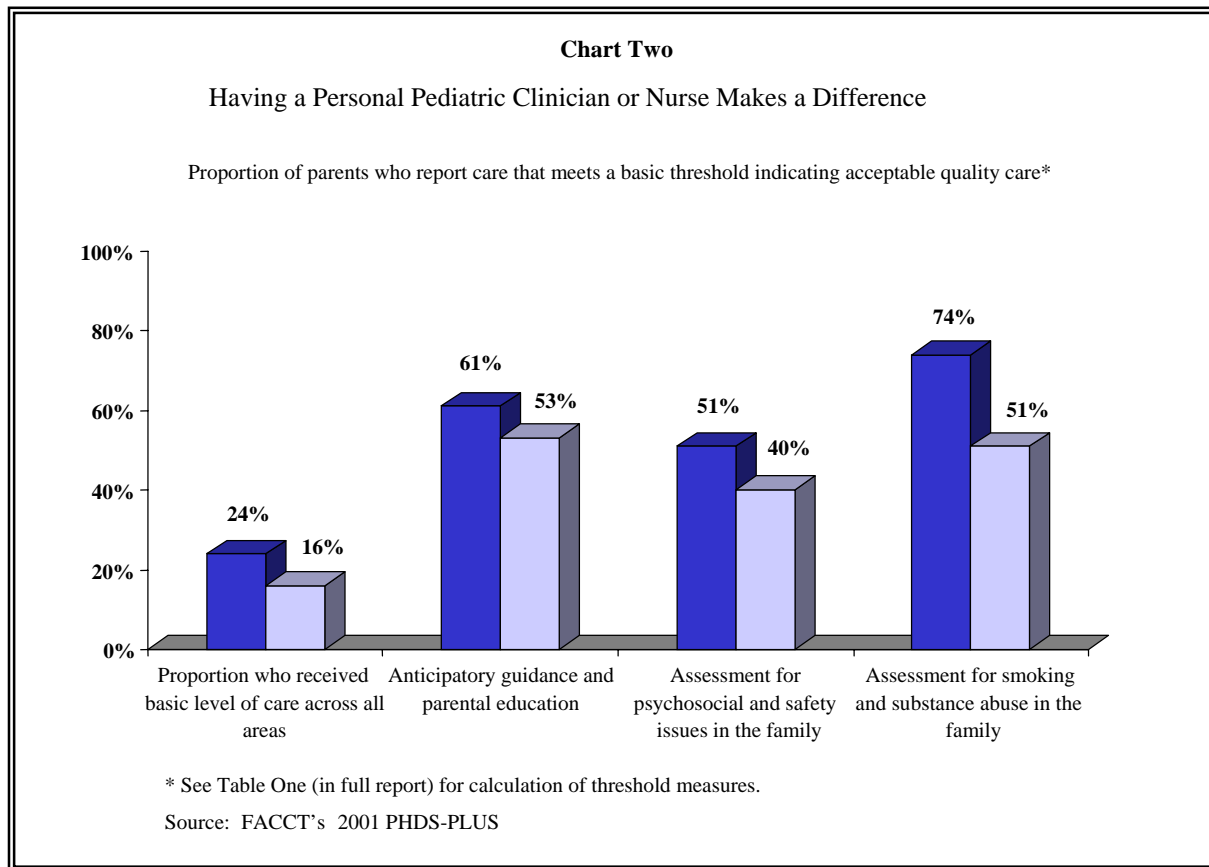
Key Findings. Among this population of low-income families with a young child under age 4 covered by Medicaid, key findings include:

- **A significant number of children are at risk from developmental, behavioral, and/or social delays.** Two of five parents reported at least one concern about their child's social, emotional, behavioral, and/or cognitive development (40%). The concerns of approximately one of five parents were significant enough to indicate that their child is at high or moderate risk for behavioral, developmental, or social delays based on the Parents' Evaluation of Developmental Status (19%).¹³
- **Few children receive recommended comprehensive preventive and developmental services.** Only about one of five children received preventive and development services that met a basic threshold of quality across each of the seven aspects of care assessed (23%). Among the range of preventive and developmental services the American Academy of Pediatricians recommends pediatric clinicians provide, pediatric clinicians were least likely to provide a basic level of assessment on the psychosocial well-being and safety within the family (49%) (Chart One). These findings are not surprising given that earlier studies have shown significant gaps between the preventive and developmental services that are both recommended and needed and what is actually provided.^{14,15,16,17,18}



- Parents have concerns that are not addressed by pediatric clinicians.** Two of five parents reported that their child's pediatric clinician did not routinely ask whether they had concerns about their child's development and well-being. Less than half of parents who reported potentially serious concerns also reported getting the information they needed to address these concerns (46%). More than three times as many parents who were asked by pediatric clinicians about their concerns reported that they got the information they needed, compared with those who were not asked (66% vs. 20%).
- Having a personal pediatric clinician or nurse makes a difference.** Nearly one of five children lacked a personal pediatric clinician or nurse who knew the child well (17%). Children with a personal pediatric clinician or nurse were one-and-a-half times more likely to receive a basic level of comprehensive care than children without a personal pediatric clinician or nurse (24% vs. 16%). Parents of children who had a personal pediatric clinician or nurse were nearly one-and-a-half times more likely than parents of children without a personal pediatric clinician or nurse to report receiving family-centered care (74% vs. 51%). Parents of children with a personal pediatric clinician were also one-and-a-half more likely to report being asked about their own health and the health of their family,

compared with children without a personal pediatric clinician or nurse (30% vs. 20%) (Chart Two).



Other Important Findings

- One in ten children did not get needed care or got delayed care (10%). In half these cases, this downfall was due to a lack of pediatric clinician appointments that would not disrupt parents' ability to meet work responsibilities.
- One of seven parents of children with special health care needs reported problems paying for that care despite having Medicaid coverage for their child (14%).
- Nearly one of three parents reported problems paying for their own health care needs (30%).

- Children at risk for developmental or behavioral delay were about half as likely as other children to receive comprehensive services than those not at risk for such problems (14% vs. 25%).
- Only one of five parents of young children received information or counseling on basic parent education and counseling topics that the American Academy of Pediatrics recommends be routinely discussed, such as reading to children, nutrition, injury prevention, and child behavior and communication.¹⁹
- More than two-thirds of parents not receiving anticipatory guidance in key areas wished their child's pediatric clinician discussed specific issues that were not addressed (67%). Topics of greatest interest were injury prevention, child communication and behavior, and the achievement of developmental milestones such as toilet training.
- Half of mothers who reported symptoms of depression were never asked about their mental and emotional well-being (50%).
- Parents who reported family-centered care were nearly twice as likely to receive anticipatory guidance and parental education (67% vs. 38%).

Implications for State Medicaid Agencies. Results from the PHDS-PLUS reveal areas where state Medicaid agencies can improve the health of low-income young children enrolled in Medicaid. While recent expansions in insurance coverage for children are critical, findings suggest that this coverage is not sufficient to ensure that children receive even a basic level of preventive and developmental services.

Implications of this finding for state Medicaid agencies include:

- **State Medicaid agencies need policies to monitor and improve quality.** Preventive and developmental services are the most basic aspects of health care for all children. State Medicaid agencies need to routinely monitor health care quality for children, set performance expectations for health plans and pediatric clinicians, and work with these plans and clinicians in efforts to improve care.
- **States can influence key factors that support quality care.** Promoting quality preventive and developmental services for young children enrolled in Medicaid may require state Medicaid agencies to evaluate and consider changes in:
 - The availability and distribution of pediatric clinicians and community-based developmental services;
 - Reimbursement policies and the use of performance incentives for health plans and pediatric clinicians; and
 - Strategies to inform parents about a child's need for preventive and developmental services and how to learn about and play a role in ensuring high-quality care for their children.

- **States should work for more transparency and accountability to consumers.** This conclusion is echoed by the emerging national consensus that measuring and reporting on health care quality to the public must be a priority in order to improve health and health care delivery in the United States.^{20,21}

Implications for Pediatric Clinicians. These conclusions indicate that pediatric clinicians should form stronger partnerships with parents to learn about parental concerns and assess children’s development and well-being. The study also suggests that pediatric clinicians are not meeting needs in educating and referring parents to services that could improve their ability to care for their children, as well as help them address other issues that directly affect their children, such as maternal depression, smoking or alcohol abuse in the home. To better equip them, clinicians need practice-based techniques, methods, and information about:

- What topics are important for the education and counseling of parents;
- How to ask parents about their concerns and follow up with information and support to prevent or address problems;
- How to assess a young child’s development; and
- Where and how to refer parents for help that is beyond clinicians’ ability to provide.

Finally, results of this study demonstrate the value of surveying parents about the quality of health care their child receives and the richness of information that can be obtained through the methodology used in this survey (see Appendix). The information is essential to understanding the degree to which health care is meeting the needs of children and whether efforts to improve the quality of care are making a difference. Findings emphasize that parent-reported assessments of preventive and developmental services for young children provide valid and valuable information to guide efforts to improve the quality of their health care.

¹ This chapter is the Executive Summary of a larger report published by the Commonwealth Fund. The full report is available at www.cmwf.org

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³ Morris Green (ed.) *Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents* (Arlington, VA: National Center for Education in Maternal and Child Health, 1994).

⁴ *Guidelines for Health Supervision III* (Elk Grove Village, IL: American Academy of Pediatrics, 1997).

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⁶ Christina Bethell, Colleen Peck, and Edward Schor, “Assessing Health System Provision of Well-Child Care: The Promoting Healthy Development Survey,” *Pediatrics* 5 (May 2001): 1084-94.

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- ⁸ Ibid.
- ⁹ Ibid.
- ¹⁰ Ibid.
- ¹¹ Deborah Curtis and Helen Pelletier. *Building State Medicaid Capacity to Provide Child Development Services: An Overview of the Initiative* (Portland, ME: National Academy for State Health Policy, March 2000).
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- ¹⁴ K.T. Young, K. David, and C. Schoen, "Listening to Parents: A National Survey of Parents with Young Children," *Archives of Pediatric and Adolescent Medicine* 152 (1998): 225-62.
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- ¹⁶ Frances Page Glascoe, "Parents' Concerns About Children's Development: Prescreening Technique or Screening Test?" *Pediatrics* 99 (1997): 522-28.
- ¹⁷ A.C. Gielen et al., "Injury Prevention Counseling in an Urban Pediatric Clinic," *Archives of Pediatric and Adolescent Medicine* 151 (1997): 146-51.
- ¹⁸ E.N. Goldstein, P.H. Dworking, and B. Bernstein. "Anticipatory Guidance in Pediatric Practice: Are We Doing More or Less?" *Ambulatory Child Health* 159 (1997):3.
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Chapter Three

Building a Bridge from Birth to School: Improving Developmental and Behavioral Health Services for Young Children

May 2003

The Commonwealth Fund¹

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Building a Bridge from Birth to School: Improving Developmental and Behavioral Health Services for Young Children...Executive Summary

Most American infants and young children receive adequate, often excellent, well-child 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 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 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 that 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 based 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.

¹ This chapter is the Executive Summary of a larger report published by the Commonwealth Fund. The full report is available at: www.cmwf.org

Chapter Four

Children's Developmental Health Model Act

Charles Bruner and Ed Schor

May 2003

Health care providers are often in an ideal position to identify young children's developmental needs and to provide parents with guidance and support in addressing developmental issues. At the same time, health care practitioners serving young children will need support in strengthening their capacity to serve in this role, as the preceding three chapters show.

This Model Act represents one way that states might focus attention on this issue and help build that capacity. Rather than mandating specific actions, it creates an office within state government to work with the health care community in this respect. It also could be used to establish a task force either legislatively or by Executive Order.

Section One. Office of Children's Developmental Health Established. There is established an Office of Children's Developmental Health to improve the capacity of health professionals and the child health care system to:

- conduct developmental screens and surveillance of children to identify developmental needs and problems;
- provide anticipatory guidance and counseling to parents on children's developmental issues and concerns; and
- coordinate with other service systems, including early intervention, special education, early childhood education, and other health and human services to address identified child developmental needs.

Definitions:

Developmental health includes physical, emotional, social and cognitive capacity of children relative to their potential for living fully in their social environment.

Developmental services include developmental surveillance, screening and assessment, anticipatory guidance, parent counseling, developmental interventions, referral for other remediation services, and care coordination.

Section Two. Duties of Office. The Office of Children's Developmental Health shall perform the following duties:

1. Recommend and disseminate screening and assessment tools for broad-based use by health professionals while providing preventive pediatric health care and providing EPSDT services that incorporate age-appropriate screening for developmental problems and risks, based on recommendations for best practices.
2. Develop training and continuing education opportunities in developmental screening and assessment activities for health professionals, including physicians, nurses and allied health professionals.
3. Identify and encourage the use of parent-completed screening tools and reports regarding child development issues.
4. With the Medicaid agency and health insurance regulatory agency, identify or develop and adopt quality assurance systems to ensure that developmental services are part of preventive pediatric health care and EPSDT practices.
5. With the Medicaid agency, design financing systems that ensure that Medicaid fully participates in and adequately supports health services that foster healthy child development, including parent-completed screening instruments and other developmental services.
6. With state and private agencies and professional and community organizations, promote access to developmental services for uninsured children and children whose families face geographic, cultural, and other barriers to appropriate developmental care and information.
6. Collaborate with other systems serving children and their parents, with a particular focus upon systems serving young children, to better achieve the goal that "all children start school ready to learn."
7. Perform such other duties as are necessary to build the capacity described in Section One.

Section Three. Advisory Board. There is established an Advisory Board to the Office of Children's Developmental Health to support the Office in establishing programs, practices, resources, and policies. The Advisory Board shall include:

1. The Administrator of the Office of Children's Developmental Health or his designee
2. State and local early intervention and special education representatives

3. A representative from the state chapter of the American Academy of Pediatrics
4. A representative from the state chapter of the American Academy of Family Practice
5. A representative from the state nursing society
6. Representatives from the private health insurance industry and a health maintenance organization
7. A representative from the state Title V program
8. A representative from information, resource and referral agencies
9. Four parents, two of whom have children with developmental disabilities, the Administrator of Medicaid Services or designee

Section Four. Duties of Advisory Board. The Advisory Board shall have the following duties:

1. Provide advice and guidance to the Administrator of the Office of Children's Developmental Health in carrying out the duties of the office.
2. Enlist or provide technical support in the development of specific procedures, tools, protocols, curricula, rules, proposals, or other materials necessary to carry out the duties of the office.
3. Serve in the role of disseminating the work of the Office of Children's Developmental Health to other organizations and systems in the state.

Section Five. Board Selection and Operation. Method of selection of Board members (e.g. Gubernatorial appointment, appointment by specific organizations, etc.), terms of service, compensation (per diem and expenses, if any), and other criteria or boilerplate language, consistent with other state advisory boards,

Additional Section(s). Memberships. Amendments to existing statutes in order to include Administrator of Developmental Health or his designee as a member on other relevant state boards and coordinating committees (e.g. Medical Assistance Advisory Council, Special Education Commission, etc.

About the State Early Childhood Policy Technical Assistance Network (SECPTAN)

State decision-makers face awesome challenges in developing public policies. They must balance competing demands across broad issue areas, with finite resources. They must respond to diverse political pressures while seeking solutions that ultimately best reflect societal values. They must be good stewards of public resources, requiring accountability based upon efficiency and effectiveness.

State decision-makers must do all this under time and resource constraints that often make securing credible information to inform their decision-making problematic. Particularly for early childhood issues, there often are not recognized and easily available sources for the most current evidence in the field.

The State Early Childhood Policy Technical Assistance Network (SECPTAN) was created to assist these state decision-makers in the important area of accessing the best available information and evidence about effective policies and practices on early childhood issues.

The Child and Family Policy Center administers SECPTAN, which is funded through the joint efforts of the Ford Foundation, the Kauffman Foundation, and the Packard Foundation. SECPTAN currently operates in the seventeen states that are part of the School Readiness Indicators Initiative, a companion grant administered by Rhode Island Kids Count.

For more information on SECPTAN, please contact: Charles Bruner, Network Director, or Sheri Floyd, Network Manager, State Early Childhood Policy Technical Assistance Network, 1021 Fleming Building, 218 - 6th Avenue, Des Moines, IA 50309.



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