IDENTIFYING AND ADDRESSING DEVELOPMENTAL-BEHAVIORAL PROBLEMS:

A Practical Guide for Medical and Non-Medical Professionals, Trainees, Researchers and Advocates

Frances Page Glascoe, Ph.D.

Kevin P. Marks, MD

Jennifer K. Poon, MD

Michelle M. Macias, MD

(Editors)

CHAPTER 17: NORTH AMERICAN MODELS FOR PREVENTION, EARLY DETECTION, INTERVENTION AND PROFESSIONAL TRAINING

JOANNA BOGIN    PAUL DWORINKI    JEAN CIBOROWSKI-FAHEY
FRANCES PAGE GLASCOE    JOE HAGAN    PATRICIA HERRERA
PAMELA HIGH    MARGOT KAPLAN-SANOFF    DESMOND KELLY
JENNIFER K. POON    GREG PRAZAR    JILL ROSENTHAL
MONICA H. ULTMANN    JANE WITOWSKI
INTRODUCTION

In this chapter, we provide examples of the many different, innovative initiatives in the US and Canada that focus on early detection, collaboration across medical and non-medical services and measurement of outcomes. The many contributors are listed along with the projects they have described. The resources section of this chapter provides website addresses for the various initiatives with live links on www.pedstest.com/TheBook/Chapter17.

MEDICAL HOME PROJECT: AMERICAN ACADEMY OF PEDIATRICS


A Case Example

Children with special healthcare needs who live in rural areas face many challenges. Local expertise may be lacking. Care is usually fragmented. Getting there takes longer. Finding support and information is harder. Schools may have had little experience with unique and rare conditions. Ultimately, children with complex conditions and their families typically lack a medical home—leaving them with little continuity—if not a confusing welter of recommendations and treatment plans (or lack thereof).

We are doing something about this! Since 1997, our practice of seven physicians and three pediatric nurse practitioners has been involved with the Rural Medical Home Improvement Project. The project is funded by the US Maternal Child Health Bureau (MCHB) and by the Center for Medical Improvement at Dartmouth Medical School. Led by Carl Cooley and Jeanne McAllister, the intent of the project is to make systematic improvements in care given to children with special healthcare needs and their families. Our practice was one of four rural practices initially enrolled (the other practices are in Plymouth, New Hampshire; Randolph, Vermont; and Bradford, Vermont). We have now expanded to include nine more practices in New Hampshire, Maine, and Vermont.

How does the project work? First we were helped by project facilitators to identify areas in need of improvement (using the Chronic Conditions Management Practice Self-Assessment Tool, developed at the Hood Center for Children and Families at Dartmouth Hitchcock Medical Center). The tool identifies areas for manageable steps for improvement followed by outcome measures to make sure the results were effective. This helped us realize that our first task was to figure out which patients actually had special healthcare needs.

Of our 14,000 active patients, we have identified 1480 with complex needs (and we are still counting). The two most common complex conditions in our practice are asthma and ADHD—conditions with strong co-morbidities.

To address the needs of these children and their families, we began using a simple pre- and post-visit questionnaire. The pre-visit questionnaire asks parents to identify the two biggest concerns. This gives clinicians a sense of the parents’ needs and issues so that providers can help solve or at least address them. The post-visit questionnaire focuses on parent satisfaction with the encounter.

We also identified a care-coordinator. In our practice, this is a social worker, but the Project often uses nurses or administrative office person. The care coordinator helps with insurance eligibility, crisis intervention, locating mental health and other services, parent counseling, and also advocates for and with parents at Individual Educational Program planning meetings at the schools.

Integral to the success of this project is the involvement of parent-partners. In our practice, one is a parent whose child has had a liver transplant (s/p biliary atresia); the other parent has a child with Aicardi Syndrome (a congenital condition that includes partial or complete absence of the corpus callosum, retinal lesions, infantile spasms, and significant developmental delays). The parent-partners meet twice monthly at team meetings (90 minutes each). These also include the care-coordinator, the pediatrician and a facilitator (provided by the Center for Medical Improvement), and an office person (in our case, a medical assistant).
The meetings are very structured and focus on planning, implementing, and evaluating incremental improvements in care given to patients with complex conditions. One of the improvements is the use of a parent journal—essentially a hand-held health record with a clear action plan of treatment steps, which has space to record who is responsible for calling subspecialists. Another improvement is a practice bulletin board with information about services and other patient information. The efforts of the parent-partners facilitates family-centered care and enables true parent-professional partnerships.

At least twice a year, we also meet with other care-coordination teams to share our successes and brainstorm about better methods. We recently described our efforts at the National Summit on Children With Special Health Care Needs. It addressed national progress in establishing medical homes for children with complex conditions.

I hope you can feel my passion and excitement for our participation in this great program! As a result of involvement in this project, my attitude toward practice has changed. I enjoy going to work and believe that through the project we are making unique contributions to care of children with special healthcare needs.

© 2002 originally published in the American Academy of Pediatrics' Section on Developmental Behavioral Pediatrics Newsletter (www.dbpeds.org) and adapted with permission.

Comments on the Medical Home Project: Dr. Prazar highlighted the many delightful aspects of participating in the AAP’s Medical Home project. His non-medical colleagues in Exeter, New Hampshire’s IDEA programs cannot say enough good stuff about his office having a care-coordinator with whom they can share information about children’s developmental-behavioral evaluations and receive information about children’s medical needs. Clearly Medical Home has been a win-win situation for all involved. The AAP’s Medical Home project has a rich website (www.medicalhomeinfo.org) with links to webinars, training, and continuing medical education opportunities, tool kits, activities in each US State, etc. Also included is very helpful advice for families entering IDEA services (e.g., how to create a notebook for filing important documents).

THE AMERICAN ACADEMY OF PEDIATRICS’ BRIGHT FUTURES INITIATIVE
Joe Hagan, MD, Clinical Professor of Pediatrics, University of Vermont College of Medicine

In the United States, almost one century ago, pediatrics was founded as a unique medical discipline. From inception, the specialized pediatric care of infants, children, adolescents and young adults focused on preventive care. Ever since, pediatricians have been champions for improved public health, better nutrition, public hygiene, and reductions in childhood morbidity and mortality. Our predecessors recognized the importance of nutrition to healthy growth and development, and appreciated the magnitude of infectious disease in children. As a consequence we have specialized not just in the treatment of common child infections, but also in disease prevention.

The founders of pediatrics speculated wisely that the population of healthier children would in turn face “the new morbidities”—harms caused by problems in mental and behavioral health, including social stressors to families and communities that deter growth and development. Ability to address persistent threats to the health and well-being of children have also become core competencies in pediatrics.

Pediatricians and other clinicians who care for children—family medicine physicians, nurses in pediatrics sand family medicine, and physician assistants—rely on guidelines and other identified standards for preventive care. If preventive care is to be successful, it must be studied and make use of available evidence of effectiveness. Guidelines demonstrate standards of care for assuring that every child and adolescent and their families are provided quality guidance regarding nutrition, growth and development, oral health, behavioral health, injury prevention and other topics. The Bright Futures Guidelines for Health Supervision of Infants, Children, Adolescents and Young Adults is the contemporary standard for preventive care and defines the standard of care for youth in the United States under the
Affordable Care Act of 2010.

Now in its third edition, *The Bright Futures Guidelines* describe preventive care visits from the prenatal visit to 21-years of age. Each well-child visit attends to disease detection, disease prevention, health promotion and anticipatory guidance. To achieve these outcomes, health care professionals employ techniques to screen for disease, screen for risk of disease, and provide advice about healthy behaviors. These activities lead to the formulation of appropriate anticipatory guidance and health advice.

Clinical detection of disease in the well-child encounter is accomplished by a complete physical examination which is augmented by surveillance and screening. In well-child care, surveillance occurs in every health encounter and is enhanced by the opportunity for repeated visits and observations with advancing developmental stages. It relies on the experience of a skilled clinician over time. Screening is a more formal process utilizing some form of tool, which has been validated and has known sensitivity and specificity. Even so, validated screening tools can serve in the capacity of both screening and surveillance, i.e., evidence-based longitudinal measurement with clinical decision-support, engaging parents’ concerns and observations, under the watchful eyes of pediatric providers who are experienced in child development.

*The Bright Futures Guidelines* includes screening for various conditions in every visit. Some screening is universal, for all children at that visit (e.g., anemia screening by hematocrit or hemoglobin testing is a universal screen at the one-year-old visit). Screening can also be selective, based on risk assessment (e.g., anemia screening is selective at other visits based on risk assessment questions found in the Bright Futures Visit or in the Pre-visit questionnaire). Developmental-behavioral screening and surveillance should be both routine and selective (e.g., at sick or return visits if a family has missed a prior well-visit).

**The Bright Futures Toolkit**

The second essential action of the well-child encounter, disease prevention, may include both primary prevention activities applied to a whole population and secondary prevention activities aimed at patients with specific factors of risk. For example, counseling about reducing fat intake is appropriate for all children and families. Counseling is intensified for overweight and obese youth or in the presence of a family history of hyperlipidemia and its sequellae. Disease prevention strategies are individualized to specific families, patients and their communities.

Health promotion and anticipatory guidance activities distinguish the well-child health supervision visit from all other encounters within the healthcare system. Disease detection and disease prevention activities are germane to all interactions of children with physicians and other healthcare providers, but health promotion and anticipatory guidance shift the focus to wellness and to the strengths of the family, for example, what is being done well and how this might be improved.

Although not all well-child care activities have been evaluated for efficacy, lack of study does not imply lack of benefit. *The Bright Futures Guidelines* utilized available evidence. When evidence was absent, the rationale for well-child care activities was based on a balance of evidence from research, expert opinion, clinical practice guidelines, professional recommendations, experience, habit, intuition, and preferences or values. Effective preventive services require sound clinical and counseling decisions that are responsive to family needs and desires, and support “patient-centered decision-making.” It would be proper to describe *The Bright Futures Guidelines* as “evidence-informed.” Work on the Fourth Edition has begun with a careful analysis of the rationale and evidence that will support any new guideline components.

Strategies to improve the preventive services delivered to children and youth follow AAP Recommendations for Preventive Pediatric Health Care (http://brightfutures.aap.org). Practice strategies to complete this work include screening schedules and flow sheets, registries, and the use of parent and youth pre-visit questionnaires and handouts for parents and older youth. Such tools are available in *The Bright Futures Guidelines Toolkit*. A coordinated team approach via use of continuous measurement to improve
techniques has been an effective method for helping clinics adopt new preventive care practices. Stay tuned at www.brightfutures.org.

**National Academy for State Health Policy (NASHP) and Assuring Better Child Health and Development (ABCD)**

Jill Rosenthal, MPH, Program Director, National Academy for State Health Policy

The Assuring Better Child Health and Development (ABCD) Program is a grant from The Commonwealth Fund and administered by the National Academy for State Health Policy (NASHP). Several multi-year projects under the ABCD umbrella have supported State efforts to develop or expand service delivery and financing strategies aimed at enhancing healthy child development for low-income children and their families. Early detection of developmental delays has been a central theme of these efforts.

Since 2000, four States (North Carolina, Utah, Vermont, and Washington) have participated in the ABCD-I Learning Collaborative focused on general development. Five States (California, Illinois, Iowa, Minnesota, and Utah) have participated in the ABCD-II Learning Collaborative focused on social and emotional development; and 20 States and Territories* participated in the ABCD Screening Academy to implement policies and practices that move the use of standardized screening tools as part of well-child care from a ‘best practice’ to a ‘standard of practice.’

More than half of all States have participated in an ABCD initiative. The ABCD experience demonstrated that Medicaid and other State agencies, in collaboration with primary care partners, can play an important role in promoting policy- and practice-level change. ABCD participation improves routine identification of young children with developmental delays (or at risk of delays) by promulgating use of validated screening by pediatric primary healthcare providers.

The ABCD approach features three common elements: (1) public/private partnerships to enable state teams to use their resources most effectively; (2) demonstrations to develop, test, and refine plans for statewide with improvements; and (3) measurement to plan, incentivize and monitor system-wide policy improvements. Fostering change at the office-based primary care level, community level, and State policy level has been found to be critical to success. Private sector involvement and pilot testing allowed the ABCD projects to ground proposed policy and systemic changes in real-world experience. This approach has been critical to identifying and making the case for specific changes, as well as gaining provider acceptance of (and adherence to) the changes.

ABCD leaders across various US States reported significant progress in helping primary care practices better identify children by incorporating validated screening tools into regular well-child care. In all States that reported baseline and follow-up data for their demonstration sites, the proportion of children screened using a standardized tool increased during the course of the initiative.

ABCD State teams used various combinations of methods to support changes in the demonstration sites and statewide spread of their practice improvements. A variety of training formats support providers’ efforts to incorporate screening into standard office practices, along with leadership by physician champions in the State. Formats included in-office trainings, learning collaboratives, workshops, and presentations at grand rounds and/or conferences focusing on child health and development. Training also included development of web-based curricula for providers and staff designed to integrate screening tools into primary care.

In terms of State policy, ABCD States clarified existing policies and established new policies, changed claims processing systems, provider handbooks and contracts with managed care organizations, and conducted workshops and other activities to inform providers of the new policies. Policy improvements can be categorized into three groups:
1. **Program coverage**: An example is improving Medicaid’s coverage of services by adding developmental screening with a validated screening tool to the benefit package or clarifying that the service was already covered. Some States added the 30-month visit to their EPSDT periodicity schedules as recommended by the AAP.

2. **Reimbursement**: An example is establishing, modifying, expanding or clarifying the conditions under which Medicaid pays for CPT code 96110 (developmental testing: limited) or increasing the reimbursement rate for this code.

3. **Program performance**: An example is conducting Medicaid managed care quality improvement activities or facilitating exchange of information between primary care providers and IDEA Part C providers through standardized referral and feedback forms.

NASHP and The Commonwealth Fund are currently implementing the ABCD-III learning collaborative, through which five States (Arkansas, Illinois, Minnesota, Oklahoma, and Oregon) are tackling the next set of challenges that arise after appropriate early detection of developmental delays. These States are identifying, implementing, testing and then spreading the policy and system changes that create and support efficient linkages between primary care clinicians and providers of child and family services; the collaboration needed to optimize child health and development (e.g., mental health, Early Intervention, early care and education programs such as Head Start, family support such as WIC, and specialty health services). Participating States are targeting policy improvements through these approaches: (a) maximizing the use of personnel to assure effective linkages; (b) undertaking quality initiatives that engage clinical practice settings and networks of providers, along with other mechanisms for assuring and monitoring quality related to referrals; (c) improving data, information and technology (e.g., common referral forms and data linkages); and (d) supporting individualized care plans and cross systems planning.

The ABCD Electronic Resource Center (ERC) ([www.nashp.org/abcd-welcome](http://www.nashp.org/abcd-welcome)) provides State policymakers, primary care providers and other child and family service providers with easy access to research and resources they can use to promote early childhood health and development. The resources in the ERC include tools and materials developed by each of the States participating in the ABCD initiative. The ERC also features clinician toolboxes containing information for primary care providers interested in promoting the use of structured developmental screening in their office practices. Each toolbox contains information about key activities related to developmental screening, such as a discussion of screening tools, coding and reimbursement, and practice guidelines. NASHP has synthesized lessons and recommendations from each ABCD project to maximize adoption in other States. These are included in a variety of reports also available on the ERC website.

Providers and State provider association chapter representatives who participated in ABCD State activities cite a number of reasons for involvement, including opportunities to shape State policy, improved office efficiency and patient/family satisfaction, better care coordination and awareness of partners in the community, potential financial incentives (through enhanced reimbursement), and public acknowledgment of efforts to strengthen the quality of care for young children. Providers also cited increased involvement of parents in their children’s care, time saved by using standardized screening tools, and satisfaction in knowing that children are referred to appropriate services.

For primary care providers and other community service providers interested in becoming involved in State ABCD initiatives, contacts include the State Medicaid office, the State AAP Chapter ([www.aap.org](http://www.aap.org)) or the National Academy for State Health Policy to identify local contacts ([www.nashp.org](http://www.nashp.org)).

[*] (AK, AL, AR, CA, CO, CT, DC, DE, KS, MD, MI, MN, MT, NJ, NM, OH, OR, PR, VA, WI)
The Help Me Grow initiative began in 1998 in Hartford, Connecticut, based on the following assumptions: (a) that children at risk for developmental and behavioral problems were escaping early detection; (b) that despite capacity issues and gaps in services, a variety of community-based programs existed to address children's developmental needs; and (c) that children and their families would benefit from a comprehensive, systems approach to the early detection of at-risk children and the linkage of children and their families to community-based programs and services. Research demonstrates that health care, early care/education, and human service providers often have difficulty recognizing the early signs of developmental or behavioral challenges. Meanwhile, we also know that early detection and connection to services lead to the best outcomes for children with developmental delays or behavioral issues. Research also suggests the unique benefits of identifying and linking at-risk children (meaning those likely to have delays in the future) to appropriate community-based supports whenever possible, thus reducing or even preventing the subsequent need for more intensive services. While the importance of early screening and detection is frequently cited in the literature, screening without a referral mechanism is unacceptable. Perrin emphasizes that detection without referral and intervention is certainly ineffective, and may even be judged unethical (although it may still be helpful for needs assessment, service development, etc.).

The Help Me Grow system creates a statewide infrastructure that efficiently and effectively links children at risk for developmental and behavioral problems to existing, community-based programs and resources. Core components of Help Me Grow include: (a) the training of health care and early education providers along with families, in the early detection of at-risk children through the process of developmental screening and surveillance; (b) the compilation of an accurate and informative inventory of community-based programs and services; (c) a centralized information and referral center serving as a point of access to such programs and services; and (d) data collection to ensure the effectiveness of the system and to document gaps and capacity issues to inform advocacy. Engagement of healthcare clinicians is a critical component of the Help Me Grow system. Outreach to medical providers promotes developmental screening and surveillance according to AAP policy, and encourages the use of a centralized call center. A key message is that healthcare professionals are ideally suited to promote cross-sector collaboration with early care and education and family support providers, which is so important in promoting children's healthy development.

The Help Me Grow National Center, established in 2010 and based at Connecticut Children's Medical Center in Hartford, supports the building of Help Me Grow statewide systems throughout the country. Orange County, California replicated HMG with guidance from the Connecticut team in 2007. In 2008, a two-year grant from The Commonwealth Fund enabled a team of Connecticut HMG leaders to provide technical assistance to five States in their efforts to develop Help Me Grow systems. In 2010, a three-year grant from the W.K. Kellogg Foundation supported the establishment of HMG National that enabled continued support to the five initial HMG States and the recruitment of ten additional States as HMG affiliates for system development. The goals of HMG National are to ultimately support HMG system development in all States; to ensure that all families have knowledge of and easy access to statewide systems that support them in addressing their children's developmental needs and finding appropriate services. States affiliated with HMG National use the Help Me Grow system to implement effective, universal, early screening and surveillance for all children and then link them to existing programs and services. By 2013, sixteen States and organizations will be Help Me Grow affiliates, actively engaged in the planning and implementation of Help Me Grow systems throughout the country. The National Center is poised to support additional States and create even greater nationwide impact.

Help Me Grow affiliates collect and analyze data on client calls and outreach to healthcare providers, communities, and families. Centralized call centers assist families with identifying their children's needs.
and connecting them to relevant services. Call centers collect a wide range of data including: How callers learn about the call center; caller demographics; facts about the child and/or family in need; the specific assistance being requested; referrals provided and other actions taken to assist callers; and the outcomes of the contacts with the call center. Call centers are in a unique position to collect data that reflect system-level issues and regularly identify gaps and barriers to services.

An annual analysis and summary report of available data assess how well the HMG system is working and what is needed to improve or enhance the service. In addition, the data is shared with funders and policy makers to inform their views on service delivery and to demonstrate how to best use resources to promote optimal child development. For example:

- Connecticut Help Me Grow was established in 2002 as a statewide entity. Data (2006-2007) shows that 86% of families calling the centralized center (Child Development Infoline) are successfully connected to services.

- In 2009, the Orange County, CA annual evaluation report states that the two top concerns of families focused on their child's behavior and communication skills.


**Promoting Resources in Developmental Education (PRIDE)**

*Desmond Kelly, MD, Medical Director of the Division of Developmental-Behavioral Pediatrics at the Children’s Hospital of the Greenville (South Carolina) Hospital System; Jane Witowski, PRIDE Program Coordinator.*

Promoting Resources in Developmental Education (PRIDE) began in 2004 in Greenville, SC as a pilot program to involve the medical, education, and early intervention communities in ensuring that children birth to 3-years of age with developmental delays are identified as early as possible, and that they are connected to appropriate services. The program targets the key players in a young child's life: Parents, primary care physicians, and early childhood providers and educators. Over six years, the program has expanded its reach from a single county to eight counties, and expanded its focus on the developmental-behavioral concerns of children birth to 5-years of age.

The program builds a greater awareness of developmental milestones among parents and child care providers through training and education activities. Physician outreach focuses on creation and maintenance of a system for routine standardized developmental screening.

The PRIDE program was developed as a community collaboration, and this is the key to the program’s success. The Gardner Center for Developing Minds at Children’s Hospital-Greenville Hospital System University Medical Center serves as the program’s fiscal agent, and Dr. Desmond Kelly, Developmental-Behavioral Pediatrics Division Director, serves as the program’s medical director. The program is funded by grants along with significant in-kind support from Greenville Hospital System.

**Medical Outreach**

Physician outreach began in a single county with 19 pediatric practices. In 2011, more than 65 practices in eight counties benefited from initial training with ongoing technical support and academic detailing on best methods of incorporating standardized developmental screening into their practices. While physician practice has been slow to change due to perceived and real barriers such as electronic medical records, coding and reimbursement, and lack of time, 52% of area pediatricians responding to a recent survey indicated an interest in making changes to their current screening practices.

It is evident that the successful implementation of a sustainable model of developmental screening in a primary care office is dependent on education and involvement of all staff members, starting
with the physicians. Our findings confirm previously published recommendations. Because changing circumstances within offices, including changes in staff or the financial structure of the office can contribute to attrition, there is a clear need for “booster” visits by a representative of the program to uncover and to help address emerging problems. Another implementation challenge is the reluctance of physicians to identify problems for which there are no easy solutions, but providing information about community resources has been very well received.

**Parent Outreach**

PRIDE’s parent outreach builds a greater awareness of developmental milestones through an educational series called “Mind Your Milestones.” Informative cards are mailed periodically to parents from their baby’s birth through 5-years of age. Parents learn about typical development, activities to promote achievement of milestones, and warning signs of possible delays. Families are enrolled in a variety of ways; through their child’s health provider, through community agencies serving at-risk families, and through the hospital’s women’s education program (labor and delivery). More than 15,000 families benefit from this free service. Not only do parents report an increased knowledge of child development, but say this knowledge has improved communication with their child’s health provider by opening up dialogues on specific developmental topics or concerns. One example shared on a recent survey describes a parent with limited formal education who took a milestone card to her child's doctor to use as a conversation starter about concerns she had about her child. The integration of information provided to parents with the education and support of physicians is a unique aspect of the PRIDE program. Parents facilitate the process of developmental screening by being educated consumers and raising their own concerns with physicians regarding their child’s development.

**Early Care and Education Outreach**

PRIDE’s outreach to child care providers includes a five-hour training that focuses on early childhood development, identification and assessment of developmental delays, parent-teacher conference strategies, and positive disciplinary techniques to use in the classroom. Participants receive a customized toolkit with developmental guides, curriculum support, and community resource information. More than 900 child care providers have completed our training, and referral rates from developmental screening increased an average of 25% annually. Early care providers report that the program's training and materials provide legitimacy to their observations and support their conferences with parents. Changes in teacher behaviors and classroom activities are also reported as a result of PRIDE’s training.

**Lessons Learned**

- PRIDE demonstrates that an integrated approach to early detection and intervention for developmental problems is more likely to be an effective model than reliance on a single group of professionals.
- The chance that children with problems will be missed is greatly reduced by involving parents, early care/education and healthcare providers in developmental screening and surveillance.
- A truly family-centered healthcare model provides parents with tools for taking a more active role in evaluating their child's development and collaborating with professionals. Through education, parents are more informed consumers and better advocates for their child's optimal development.
- Educators have largely been neglected as key observers of children. Our experience indicates that child and early care providers are eager to embrace a role in the effort to improve early identification of children at risk for developmental or behavioral delays.

**Planned Outcomes Study**

A two-year program evaluation study is underway by the University of South Carolina Health Sciences Research Core located within the School of Public Health.
Head Start (www.nhsa.org) is a Federally funded program under the United States Department of Health and Human Services. Created in 1965 and focused on low income children ages 3- to 5-years-old, Head Start promotes education, nutrition, health, and social-emotional well-being. Head Start emphasizes parents as primary interventionists in helping children.

Early Head Start was created by a Congressional Act passed in 1994. Early Head Start provides services for expectant mothers and children birth to 3-years of age. Each of the 50 States is responsible for determining eligibility criteria, including services for children of American Indians and Alaska Natives as well as migrant and seasonal workers. Family income is one of the eligibility factors, but each program determines who their target population is, depending on the needs of their community. Early Head Start also includes children with disabilities, eligible for Part C services under IDEA. Because Head Start and Early Head Start Programs are tailored to each community, program settings are diverse, and may include schools, child-care programs, or home-based services.

Research on Head Start and Early Head Start is voluminous. Head Start research spans almost 50 years and is summarized at www.acf.hhs.gov. Highlights of findings are that a structured curriculum with an emphasis on language development (e.g., High Scope) is particularly effective. Although many Head Start graduates remain behind their more advantaged age-mates and may still struggle in school, they are nevertheless far more likely than equally low SES but unenrolled peers to graduate from high school, become employed, avoid teen pregnancy and criminal behavior. In short, Head Start confers a huge benefit to tax payers. More information about parent-training, progress monitoring and other efforts by Head Start/Early Head Start can be found on the website. Of note: IDEA services collaborate well with Head Start/Early Head Start, meaning that enrolled children can also receive physical, speech or other therapies through IDEA.

Healthy Steps for Young Children: Supporting Young Children and Their Families Using Primary Care as a Vehicle for Service Delivery

Margot Kaplan-Sanoff, EdD, Associate Professor of Pediatrics, Director, Healthy Steps National Office, Boston University School of Medicine

Parents often come to well-visits with one passionate question: “How is my child doing?” Parents are often unsure how their child’s learning and behavior measure up. In answering this question, well-child care becomes a critical impetus for determining a child's developmental status and families' need for assistance. But this same question also reflects this underlying issue: “How am I doing as a parent raising this child?” As practices attempt to answer this second question, they expand the scope of developmental well-child care to include both the social-emotional development and behavioral health of young children and the well-being of the family: Do they have enough food?; How do parents handle conflict within the family?; Do families feel safe in their home/community? Parents often feel more comfortable having these issues addressed in the context of well-child care (as opposed to a neighborhood early childhood program) because healthcare offers protection, individual attention, and confidentiality so that families can more easily explore their worries about their children or themselves.

Rationale: Healthy Steps for Young Children

Healthy Steps for Young Children (www.healthysteps.org) is a national initiative emphasizing a close relationship between pediatric clinicians and parents that focuses on physical, emotional, and intellectual growth and development of children from birth to 3-years of age. In a traditional pediatric practice, there may be only one clinician who tries to address all of the child’s health and developmental needs, often without much success. Healthy Steps expands the model of a solo pediatric clinician to add
a new member to the healthcare team—the Healthy Steps Specialist who enhances the information and services available to parents. The Healthy Steps Specialist can be a new team member or a nurse, child development specialist or social worker already working in the practice. Healthy Steps Specialists have training in child development, early intervention, child care, social work, counseling or nursing and can address major behavioral and developmental issues, focusing on the child within the context of the family. Healthy Steps Specialists co-manage families with pediatric clinicians, ensuring that the practice has the time and expertise to address each family's need for information and support.

Healthy Steps provides relationship-based practice by using a team approach, allowing both the pediatric clinician and the Healthy Steps Specialist to interact together in the same exam room with the family when they come in for well-child visits. As a team, they build on each other's knowledge and resources, responding to parents' questions and concerns with both a medical focus and a developmental perspective. For example, when a family expresses concerns about their toddler's limited language, the pediatrician will check for recurring ear infections, hearing problems and parents' use of language to the child—ending the visit with a discussion of how to use books to support language and then giving a developmentally and culturally appropriate book from Reach Out and Read. Then the Healthy Steps Specialist might ask about the family's routines for talking and sharing books with their toddler, their expectations about the child's use of language at this age, and whether this concern is based on feedback from other family members, child care providers or friends.

Components of Healthy Steps

A team approach to primary care offers families enhanced well-child visits that emphasize the promotion of children's development, including strategies to improve “the goodness of fit” between parent and child, closer attention to parental questions and concerns, and the use of “Teachable Moments” to support better parental understanding of their child's behavior. An enhanced Healthy Steps visit may be conducted jointly or sequentially by the pediatric clinician and Healthy Steps Specialist (HSS). Other critical components of Healthy Steps include:

- Home visits by the HSS, timed to specific developmental needs in young children.
- A dedicated child development telephone information line.
- Child development and “family health checkups,” including developmental screening of the child and a review of adult strengths and risk factors which impact the child's development.
- Written materials for parents that emphasize prevention and health promotion within the context of their relationships with family, pediatric and community resources.
- Facilitated linkages and referrals to community resources.

Well over 500 pediatric clinicians, family physicians and pediatric and family medicine residents participate in Healthy Steps. The Johns Hopkins University's Bloomberg School of Public Health rigorously evaluated Healthy Steps using medical record review, parent and provider satisfaction and knowledge questionnaires, telephone interviews and contact logs. Three year follow-up data reported in the Journal of the American Medical Association indicates that for all children, not just those at high-risk, the quality of pediatric care in the first three years of life dramatically improved because of Healthy Steps. By changing the structure and process of pediatric care, Healthy Steps significantly improved the delivery of pediatric developmental services. The evaluation found that families involved in the Healthy Steps program were more likely than non-participating families to:

- Discuss concerns with someone in the practice about the importance of routines, discipline, language development, child's temperament, and sleeping patterns, etc.
- Be highly satisfied with care because someone in the practice went out of their way for them.
- Discuss feelings of sadness following screening for maternal depression.
- Are 27% less likely to report using severe physical discipline (slapped a child in the face or spanked him with a belt or other object) at 3-years of age.
Identifying and Addressing Developmental - Behavioral Problems

- Are less likely to rely on other harsh strategies such as yelling, threatening, slapping a child’s hand or spanking with their hand at 3-years of age.
- Ensure that infants slept on their back to help reduce the risk of Sudden Infant Death Syndrome.
- Receive timely well-child visits and vaccinations.
- Remain with the practice until the child was at least 20-months-old

Healthy Steps helped parents better understand children’s behavior and development, thereby producing more favorable disciplinary practices. Pediatric clinicians were highly satisfied with the program and viewed Healthy Steps as a valuable service that helped to keep families in their practices. The research team at Johns Hopkins analyzed data from a five year follow-up study of Healthy Steps children and families focused on school readiness: Researchers followed Healthy Steps children from birth to 5½-years and found that families continued to use more appropriate disciplinary methods and remain more sensitive to the child’s behavioral cues. Parents tended to remain with the Healthy Steps practice, ensuring continuity of care.

Based on the strength of these program evaluations, Healthy Steps was selected as an approved evidence-based practice for both the Substance Abuse and Mental Health Services Administration and the Maternal Infant and Early Childhood Home Visiting Programs funded under the Affordable Care Act Federal initiatives.

**Healthy Steps Strategies that Support the Development of Both Young Children and Their Families: Teachable Moments**

To help pediatric clinicians provide effective information and support for parents within the time constraints of a typical office visit, the use of “Teachable Moments” represents a highly effective strategy. By using the basic assessments of the pediatric visit—history taking, physical examinations, and developmental screening/surveillance—as potent Teachable Moments, providers can exploit the educational opportunities they present for intervention. The strategy of Teachable Moments is to use the behavior of the child during the visit and the clinician–parent interactions in the office as compelling, shared experiences that further parents’ insights into their child and enhance their sense of competence as parents. Using everyday questions and experiences in the office as a shared context for discussion while the visit progresses are efficient ways to address issues without appreciably lengthening the visit. The goals of Teachable Moments are to:

- Enhance parents’ understanding of the child’s needs.
- Promote “goodness of fit” between parent and child.
- Conduct developmental screening/surveillance using both observed behavior and evidence-based tools.

**Using Behavior in the Office as a Teachable Moment.** Discussions of the infant’s or child’s behavior in the office provide a fruitful context for Teachable Moments. Newly emerging and developed skills and behaviors can challenge the equilibrium between parent and child. Frequently a specific behavior that parents find disturbing (e.g., mouthing toys at 6-months of age, throwing blocks or food at 8-months, refusing to lie down to be diapered at 10-months, irrepressible exploration at 18-months) is developmentally normal and predictable yet can activate a parent’s anger, confusion or anxiety. Parents’ concerns about these issues create a special opportunity to promote parental understanding of typical health and development. Concerns that new parents bring to pediatric visits in the first months of a child’s life provide a wealth of Teachable Moments. The infant’s behavior creates a special opportunity to promote parental understanding and support. For example, if the infant cries inconsolably during the visit or her cues are difficult to read, the clinician can explore how parents feel and empathize with their frustration at not being able to calm or read their baby. The goal of this Teachable Moment is to blend information about development with knowledge about possible “red flags,” which the pediatrician will note for future observation, further assessment or for making a referral to early intervention.
When a child’s behavior in the office provides a Teachable Moment, it is up to the pediatric clinician or HSS to capitalize on it. During these Teachable Moments, one might infer or “read” the child’s behavior or temperament together with the parents, and offer constructive interpretations of its significance. The clinician should then ask parents how they feel about the behavior or use their own reactions to explore parental concerns.

**Creating Teachable Moments.** If a child’s behaviors do not produce Teachable Moments spontaneously, the clinician may employ specific strategies to engage the child and discuss the implications for behavior and development. Parents tend to watch carefully as a pediatric clinician engages the child in activities (e.g., handing the child a toy or a book, rolling a ball back and forth, listening to the heart or looking into the ears) that demonstrate a particular behavioral or temperamental quality or developmental skill. In some cases a pediatric clinician can remark on a child’s unsteady gait or inability to follow a point as an introduction to the screening process using an evidence-based tool. By observing and commenting on the child’s behavior, the pediatric clinician encourages the parents to step back and speculate about its meaning. Unrealistic expectations, which can contribute to parental frustration and lead to child abuse or neglect, can be gently corrected. The clinician can create a Teachable Moment by narrating the child’s actions, reframing them as acts of exploration rather than as deliberate attempts to make life difficult for the parent. The clinician can explain how seemingly unimportant tasks, like using a pincer grasp to pick up a Cheerio, are important windows into a baby’s development and learning.

**Asking Questions and Shared Dialogue**

Questions about children’s behavior and development give parents a chance to discuss concerns in these areas. Especially useful in the early years are questions about children’s temperamental characteristics, developmental milestones, behavioral and family issues, and how parents feel about these issues. Evidence-based methods are superior to informal lines of questioning for determining which concerns are predictive of developmental-behavioral problems (and thus need further screening or referral). Clinical judgment should be used to decide when it is appropriate to expand, and when to narrow, the content of the discussion, but should not be used to over-ride the evidence behind screening measures. In any case, the well-child visit can also serve as a natural springboard to elicit more information or concerns from the observing parent. Neutral, nonjudgmental comments about children’s behavior (e.g., “He certainly is a busy guy, isn’t he?”) may trigger a host of parental concerns, elicited all the more easily by the stimulus provided when providers share their own observations.

**Recommendations and Conclusions from Healthy Steps**

The challenge for all pediatric practices is the mandate to “do more in limited time.” In recent years, as parent expectations and expert recommendations for pediatric primary care have increased, so have the demands on pediatric clinicians. Currently, during brief 10- to 15-minute encounters, clinicians are expected to provide a complex set of health, developmental and behavioral assessments, therapies, and counseling services. Yet it has been reported that in 60% of all routine well-child visits, providers ignored parental concerns or provided no developmental or behavioral information or guidance.10

By adding a new professional to the healthcare team, Healthy Steps provides a vehicle for enhancing well-child visits and moves practices toward becoming patient-centered Medical Homes. Healthy Steps Specialists have the opportunity to observe parents and children during physical exams and to comment on the affect of babies and/or parents. By describing how children and families might be feeling or thinking during visits, Healthy Steps Specialists become a very tangible symbol for the potentially charged issues of development and parenting that can surface within the context of pediatric care.
REACH OUT AND READ: ENSURING CHILDREN ENTER SCHOOL PREPARED TO SUCCEED

Monica H. Ultmann, MD, Director, Center for Children with Special Needs and Division of Developmental-Behavioral Pediatrics, Floating Children’s Hospital/Tufts Medical Center; Jean Ciborowski-Fahey, PhD, Early Literacy and Research Specialist, Reach Out and Read National Office

The Need for Reach Out and Read

Studies demonstrate that young brains are highly malleable and are shaped by an infant’s day-to-day interactions with the important people in their lives. Given that 96% of all children younger than 5-years of age see a pediatric healthcare provider, Reach Out and Read clinicians are in a strategic position to coach parents about the impact that reading aloud can have on the development of the young brain. Reading aloud, even to the tiniest of babies, helps build crucial central nervous system connections for language and literacy learning. Infants are soothed by the rhythm and tone of the spoken language around them and may even try to ‘mimic’ the melodic contour of the mother’s voice to attract her attention.11

At the same time, too many children begin school ill-prepared to learn. Children raised in poverty, children whose second language is English, children whose parents struggled with learning to read, and toddlers who experience language delays are highly represented in groups of children who experience early difficulties in learning to read.12,13

The learning gap begins in infancy, especially for low-income children. A nationally representative sample of 1100 infants born in 2001 were studied using data from the Early Childhood Longitudinal Study-Birth Cohort, gathered by the National Center for Educational Statistics along with the US Department of Education. Children from low-income families scored lower on cognitive assessments, were in poorer health and had more behavior problems at 9- and 24-months than their counterparts from higher-income families.14 Mendelsohn and colleagues studied babies after coaching low-income parents (with video and modeling) to read to and otherwise stimulate their newborns once they brought them home. Differences were already present at 6-months between babies whose parents were coached and those who were not.15

Vocabulary development at 3-years of age predicted future reading achievement. By age 3-years, children from more educated families have typically heard 30 million more words than children from low-income and undereducated families.16 Furthermore, while a record number of young children are being cared for outside their homes, studies also show many children are in daycare settings of poor quality.17,18 Half of all kindergarten teachers across the US report that at least half their students have problems such as difficulty following directions, working independently, and beginning knowledge of books, letters and numbers. When children begin kindergarten with fewer language and cognitive skills they often fall further behind, while the children with higher skills make gains in reading and math with increasing velocity.19,20 As they reach first grade, the consequences of reading failure are so profound that without intervention children are not on course to make the necessary transition from “learning-to-read, to reading-to-learn.” The 2010 Annie E. Casey Kids Count data show that 83% of low-income 4th graders score “Below Proficient” reading levels vs. 55% of middle income cohorts.21

The Evidence for Reach Out and Read

Since 1991, this model has been researched by academic investigators in a variety of settings, culminating in several independent, peer-reviewed studies showing positive effects on children and families whose primary care practices provided books and literacy anticipatory guidance. As a result of Reach Out and Read, preschool children make gains in vocabulary and comprehension. They also have parents more likely to read aloud to them on a regular basis. As a result of increased parental investment in nurturing early literacy, children gain a 6-month developmental edge over children who do not participate in Reach Out and Read before they start school.
Among Reach Out and Read programs across the US, a number of peer-reviewed studies point to the effectiveness of the program. The Reach Out and Read model has been shown to be effective in:

- Increasing the number of days per week parents read aloud to their children.
- Enriching the home literacy environment by increasing the number of books in the home.
- Improving the language skills of older toddlers at risk for reading difficulties.\(^{22-26}\)

**Going Beyond the Reach Out and Read Model: Using Books as Tools for Developmental Surveillance**

Giving a book to a child during a routine health maintenance visit allows healthcare providers a unique opportunity to relate to children and families. When a child picks up a book, opens it, and begins to interact with its content, the healthcare provider can view the child through a different lens. Though not considered a screening tool because of its inherent lack of standardization, books can serve as a unique way to observe children’s developmental skills and interactions with caretakers.

During a well-child visit, depending on each child’s age and developmental level, a provider who offers a book may be able to:

- Assess eye contact: normal, brief, sustained.
- Assess attention to tasks as well as joint attention and focus.
- Observe a child bringing items for shared enjoyment.
- Consider language development.

Note skills in various domains such as:

- Verbal (babbling, words, phrases, rhyming, spontaneous conversation).
- Nonverbal communication (gestures, pointing).
- Observe receptive language skills (understanding directions, pointing to pictures, etc.).
- Discern pragmatic skills, i.e., the social context of language such as responding to speaker's facial expressions, affect, and gestures (e.g., “head shaking”).
- Identify atypical language such as excessive repetition, dysfunctional language or echolalia (immediate and delayed).
- Observe fine motor skills such as holding the book, turning pages, pointing, and tactile abilities.
- Note the presence of positive parent-child interactions such as turn-taking between the adult and child.\(^{27}\)

Giving a book to a child during the healthcare visit elicits spontaneous language from many children. Gross and fine motor skills can be observed: a 6-month-old sitting alone, reaching for the book, grasping it in his/her whole hand, and transferring it to his/her mouth; a 12-month-old pointing to pictures; an 18-month-old holding the book, turning it right-side up, and walking around holding it; and a 3-year-old turning paper pages without difficulty. The provider and parent enjoy listening to a 2-year-old who is beginning to name animals. Practitioners hear pronoun use or complex sentences as an older child comments on illustrations.

The Reach Out and Read model relies on the trusting relationship formed between the pediatric primary care providers, children, and families. This relationship is facilitated by the gift of a developmentally and culturally appropriate book and literacy anticipatory guidance provided at each well-child checkup. The observations in the examination room of how a child relates to a book and the parent-child interactions are extremely helpful in encouraging families to incorporate books and reading into their everyday lives.
Effective child advocacy requires strong and reliable data, both to inform direction and to effectively make a compelling case for policy makers and for the community at large. One organization that has dedicated itself to collecting high quality data on the status of American children on a national, State and local basis is the Annie E. Casey Foundation. This private charitable trust was created in 1948 by Jim Casey, who built the United Postal Service. He named the Foundation after his mother and it continues to be directed by the Casey family and UPS executives. The primary mission of the Foundation is to foster public policies, human service reforms, and community supports that meet the needs of today’s vulnerable children and families. The foundation also makes grants that fund initiative with potential to demonstrate innovative policy, service delivery, and community supports for disadvantaged children and families within the United States.

One major initiative of the Casey Foundation is Kids Count. The Foundation provides funding and technical assistance for a national network of Kids Count projects. There is one in every State, the District of Columbia, the US Virgin Islands, and the Commonwealth of Puerto Rico. Each site is charged with measuring and reporting on the status of children at both the State and local level, so that this data can inform public debate and encourage public action that improves the lives of children. Each State Kids Count site publishes a State data book, special reports, and issues briefs and fact sheets. More information about the Kids Count grantee network, as well as local level data can be found at www.kidscount.org.

Each year, often in early autumn, Kids Count publishes the Data Book containing updated State profiles of child well-being. Ten key indicators have been tracked in the Data Book over the past two decades. These indicators demonstrate a decline over time in infant mortality, death rates for children and teens, some decreases in high school dropout rates and teen births, but they also point to increases in proportions of children born with low birth-weights, living in single-parent families, and living in low-income families. Compelling analysis in the 2011 Data Book on effects of the recent recession shows a significant jump in numbers of children living in families with at least one unemployed parent and reveals that millions of children have been affected by housing foreclosures.

Online resources sponsored by Kids Count are even more extensive and accessible. The Kids Count Data Center provides access to hundreds of child well-being indicators in areas of education, employment and income, health, poverty and youth risk factors. Data are not only available for the US as well as for States, but also on a city, county, congressional district and school district level. The Data Center also offers many tools to customize and share indicators, including national and local rankings as well as mapping and graphing tools. The center can be found at datacenter.kidscount.org. Mobile browsers can access Kids Count via Mobile.kidscount.org.

An example of a successful advocacy effort informed by the Casey Network is Rhode Island Kids Count’s involvement with lead poisoning. Thirty-three of 100 children entering kindergarten in the core cities in Rhode Island had a history of elevated blood lead levels in 1998, compared with 4 out of 100 core city children entering kindergarten in 2012. This 88% decrease in the percentage of children entering kindergarten with a history of elevated lead levels in 14 years was monitored closely by Kids Count, and the frequent use of Kids Count data provided momentum to maintain continued change over time. Currently Rhode Island Kids Count is using the goal of reading at grade level by the end of third grade to advance the birth- to third-grade policy agenda in the State. A high level leadership group of public and private sector partners are regularly tracing third-grade reading proficiency as a “proxy indicator” of success. A Kids Count Issue Brief has specific recommendations for birth to 5-years, and for kindergarten through third grade; policy changes that are evidence-based and achievable.
THE HANEN CENTRE
Frances Page Glascoe, PhD, Professor of Pediatrics, Vanderbilt University

Started in Canada in 1975, The Hanen Centre (www.hanen.org) focuses on early language intervention, parental guidance, and aiding speech-language pathologists and educators to develop language and literacy skills in preschool children. Based on abundant research, Hanen’s guiding principles are that parents’ involvement in their child’s early intervention is critical and that the earlier parents are involved, the better the outcome for the child. Investigators found that children learn best in their natural environments, where they are motivated to communicate with the important people in their lives. Professionals at the Hanen Centre have now focused on changing the way speech-language therapy is offered to young children.

The Hanen Centre provides research-based parent programs and resources as well as professional development within four areas of expertise: general language and literacy development; language delays; autism spectrum disorder (ASD) including Asperger syndrome.

The Hanen Centre is not only a North American initiative but also an international one. It offers training workshops (in English) to parents and professionals in Canada, the United States, the United Kingdom and Ireland, Australia, New Zealand, Singapore, and The Netherlands.

Research support is both abundant, current and peer-reviewed for the various target groups: children with delays and ASD. The Hanen website (www.hanen.org) offers e-seminars to professionals, DVDs, as well as classes for parents.

211 LOS ANGELES (211LA)
Patricia Herrera, MA, Project Director Developmental Screening, 211 LA County

In July of 2000, the Federal Communications Commissions assigned an expedited telephone number enabling citizens of the United States and Canada to access community information and referral services. Thus was born the 211 “warm-line.” Developed by the Alliance of Information and Referral Systems in partnership with the United Way Worldwide, 211 addresses a wide range of non-emergent crises including loss of housing, inability to pay utility bills, food insufficiency, and domestic violence. As of January 2011, 211 had served more than 246 million Americans (more than 82% of the entire population) and covered all or part of 47 States plus Washington, DC and Puerto Rico. In Canada, more than 56% of the population has access to 211.

Los Angeles County is home to 10 million people, with 16% living below the Federal poverty level and more than 50% who do not speak English at home. Ten years ago in California, IDEA early intervention enrollment rates were far lower than the national average. These dismal statistics led to the 2003 creation of the Early Identification and Intervention Collaborative for Los Angeles County (EII Collaborative), whose members quickly began to advocate for accurate developmental screening through the 211 helpline. The EII Collaborative is discussed further in Chapter 21, along with the personal narrative of its director who engaged in grass-roots as well as State and Federal legislative advocacy.

As the 211LA Developmental Screening Project began in 2009, bilingual parenting support specialists were hired to receive call transfers from families willing to participate in screening, enter the parents’ responses into PEDS Online and help parents, especially those whose children scored at-risk, get additional services. In the first two years more than 2800 children received early developmental screening via 211LA and were then connected with needed services.

Families calling 211LA are disproportionately low-income and have limited education. More than 80% are enrolled in California’s Medicaid program (MediCal) but use of healthcare services is extremely low. This means that many 211LA children do not otherwise come under professional scrutiny for health and
developmental-behavioral issues.

Not surprisingly, 211LA children are four times more likely to score at high-risk on PEDS Tools as compared to national norms: 28% (N = 803) were identified as high-risk and in need of further developmental evaluation; an additional 28% were at moderate-risk (for which additional screening is recommended); while 16% (N = 463) were at risk for mental health problems. Only 28% had limited risk (as compared to 60% in PEDS standardization studies). Not all of the 2800 families had time for the additional measures offered by PEDS Online (or were within the targeted age-range) but 1605 (57%) agreed to complete the Modified Checklist for Autism in Toddlers (M-CHAT). Of those completing the M-CHAT, 21% (N = 341) failed—more than twice the expected rate compared to national norms.

To deal with the extensive follow-up needed to ensure families receive services, a thorough case management component was developed including referral/consent partnership agreements between 211LA, the families served, and referral resources. Capitalizing on the database created by PEDS Online screening, every family is tracked to determine whether recommended services were received or other services were needed. Referrals were made to a range of health care, parenting, Head Start and other early childhood programs for the 67% of children failing screens, and 16% were referred to IDEA services. To ensure families connected with services, case-coordinators often had numerous follow-up contacts: 37% of families required three or more contacts. In the first two years of the 211LA Developmental Screening Project, 53% of children were enrolled in services or had services in progress, with 38% scheduled for additional screening, and only 8% lost to follow-up.

The 211LA Developmental Screening Project serves as a national model for 211 services in other States in terms of early detection, care-coordination, and database support. 211LA is also evidence that:

- “It takes a village,” i.e., coordination among agencies is crucial.
- Some of our nation’s most vulnerable families do not access services such as primary care.
- Novel approaches to early detection are needed.
- Vulnerable families require extensive support to ensure access to and enrollment in needed services.

OTHER INITIATIVES BRIEFLY NOTED OR IN PROGRESS

Text4Baby (T4B)

In recognition that more than 85% of Americans own a cell phone and 72% of cell users send or receive text messages, T4B is an initiative launched by the National Healthy Mothers, Healthy Babies Coalition (www.text4baby.org) in partnership with the technology business, Voxiva. T4B is the first free text messaging service in the US in which parents are provided age-paced information about health, safety and developmental promotion. T4B works in collaboration with many professional societies such as the AAP, government agencies (including the White House Office of Science and Technology Policy, the US Departments of Defense, Agriculture, Health and Human Services, and the US Consumer Product Safety Commission), and with charitable foundations established by cell phone carriers. Expansion plans, via advocacy and grant-writing, include adding to T4B a quality age-paced developmental-behavioral screening tool (described in Chapter 21).

Safe Environment For Every Kid (SEEK)

Safe Environment For Every Kid (SEEK) created by Dr. Howard Dubowitz and colleagues at the University of Maryland, provides training and in-clinic, hands-on support for detecting and addressing risk factors for child maltreatment. Training consists of a one-time, small-group session lasting four or eight hours, followed by periodic “booster” sessions. In-office support includes use of the Parent Screening Questionnaire (PSQ) to identify risk factors (completed while families are waiting to be seen), customized educational handouts for parents, and “cheat sheets” for health professionals, including a social worker to support health professionals and parents. The project’s website provides references on SEEK’s effectiveness (www.umm.edu/pediatrics/seek_project.htm).
The State Of Delaware
With advocacy and support from Delaware’s Lt. Governor Matt Denn, almost every State agency involved with children [e.g., private payers such as United Health Care, Nemours Foundation (the state’s largest child health system), the Delaware Chapter of the AAP, the public library system, school nurses, Autism Delaware, the Delaware Speech-Language Association, etc.] banded together, asked for, and received a funded mandate to provide free developmental screening and referral services for all children in the State. Directed by the Delaware Division of Public Health, providers in Delaware have access to Peds Online without cost to clinics. Help Me Grow (HMG) is directing the State’s 211 call center to assist professionals in referring children to needed services. The initial goal is to engage healthcare professionals in using Peds Online and 211HMG, to detect problems and facilitate needed referrals. The next step is to make Peds Online available directly to families so they can elect to complete screening on their own (with results sent to their healthcare provider).

American Academy of Pediatrics’ State and District Chapters
Many of the AAP chapters have effective and unique hands-on initiatives to assist providers in detecting and addressing developmental-behavioral problems (e.g., Illinois, Delaware, Oklahoma, Arizona, Georgia, Pennsylvania, etc.). The national AAP website has links to all chapter and district websites (www.aap.org).

Resources and Links for North American Models
Below are descriptions of programs discussed in this chapter along with their websites. Links are live at www.pedstest.com/TheBook/Chapter17.

Medical Home  www.medicalhomeinfo.org
From the American Academy of Pediatrics, the Medical Home website provides webinars, training, continuing medical education opportunities, practice improvement tool kits, etc.

Bright Futures  http://brightfutures.aap.org
From the American Academy of Pediatrics, the Bright Futures Initiative website provides practice recommendations and strategies along with pre-visit questionnaires, workflow sheets, registries, and parenting information.

National Association for State Health Policy (NASHP)  www.nashp.org
NASHP houses information on the Assuring Better Child Development (ABCD) project. The site includes “how-to's” for practitioners and guidance for State policy advocates.

HMG’s national center provides information on establishing programs, use of call centers to coordinate services, etc.

Promoting Resources in Developmental Education (PRIDE)  www.unitedwaygc.org
Offers details about PRIDE; additional information can be found on the HMG website.

Head Start/Early Head Start  www.nhsa.org
Describes both Head Start programs and provides guidance on finding local services. Outcomes research on both programs can be found at www.acf.hhs.gov.

Healthy Steps  www.healthysteps.org
Provides technical assistance on training, staffing needs, and administration.

Reach Out and Read (ROR)  www.reachoutandread.org
Offers guidance on establishing ROR in pediatric clinics, guidance for parents, and research on program effectiveness.
Kids Count  [www.aecf.org](http://www.aecf.org)
From the Annie E. Casey Foundation, Kids Count provides advocacy for families’ issues by providing national and State-by-State data on the well-being of children in the United States.

Hanen Centre  [www.hanen.org](http://www.hanen.org)
The Hanen Centre provides research and advice for speech-language pathologists, educators and parents on building literacy and language skills.

211LA  [www.211LA.org](http://www.211LA.org)
Describes the value of crisis call centers to provide online developmental-behavioral screening and care-coordination for families at high psychosocial risk.

Text4Baby  [www.text4baby.org](http://www.text4baby.org)
Covers use of a cellphone text-messaging service funded by the Maternal Child Health Bureau to promote development, prevent injuries, and provide screening for developmental-behavioral problems.

Safe Environment for Every Kid (SEEK)  [www.umm.edu/pediatrics/seek_project.htm](http://www.umm.edu/pediatrics/seek_project.htm)
Devoted to reducing child maltreatment, SEEK provides hands-on training, measures focused on parents’ well-being, educational handouts for parents, and research updates.

Delaware Division of Public Health (DDPH)  [http://dhss.delaware.gov](http://dhss.delaware.gov)
The first State initiative to receive mandated legislative funding, DDPH serves as a model of advocacy supported by diverse professional groups. Delaware provides high quality online screening tools—without cost to providers.

State and District Chapters of the American Academy of Pediatrics  [www.aap.org](http://www.aap.org)
AAP Chapters have a variety of initiatives and proven successes. The site provides links for finding information about each State.

**Chapter Comments:** The above is hardly an exhaustive list of initiatives including those of many professional societies [e.g., the Ambulatory Pediatric Association’s efforts to establish curricula for medical students and residents; the National Association of Pediatric Nurse Practitioners (NAPNAP)’s focus on childhood literacy and developmental-behavioral pediatric care.] We’ve neither covered foundations nor government agencies that fund proposals in early detection and intervention (e.g., Robert Wood Johnson, Lucille and David Packard Foundation, Commonwealth Fund, etc.). So just know there is lots out there to help.

We should also view the screening and surveillance measures we use, as initiatives in their own right. Accurate tools shape our decision-making, clinical acumen, and willingness to find resources. Often the use of quality tests are and should be at the heart of each initiative designed to detect and address children’s and families’ difficulties.

The diverse projects described in this chapter provide evidence-based examples of how to care for the developmental-behavioral needs of families and children. Professionals designing new initiatives are encouraged to capitalize on existing ones by viewing them carefully, and by contacting those involved to gather details on what worked.

National, State and local initiatives are inextricably engaged, not only in creating and testing models for early detection and intervention, but also with training and implementation. As a consequence, such initiatives also serve as fundamental sources for advocacy on various ways to do the best for children and families.
REFERENCES


