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Building State Medicaid Capacity to Provide Child Development Services: *Early Findings from the ABCD Consortium*

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by

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Julie Olson	Public Health Program Manager Utah Department of Health
Susan Shepard	Public Health Nurse Specialist Office of Vermont Health Access
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Although we appreciate the input of these individuals, we note that the views presented here are those of the author. Any errors or omissions are ours.

INTRODUCTION: THE IMPORTANCE OF EARLY CHILD DEVELOPMENT

Research over the past decade confirms the importance of brain development and the day-to-day experiences of infants and toddlers in shaping their future health and well-being. The early years of life have an enormous impact on the child's development, health, readiness to learn, and potential for success in later years. From birth to age five, children develop at a rapid pace, making great gains in physical, cognitive, and linguistic functions, as well as progress in social and moral development. Their family environment and interactions with their parents (and other regular care givers) provide the positive context in which this development occurs.[1] [2]

Studies also suggest that children of low-income families face certain disadvantages that can compromise their health and development.[3] The disparities associated with social and economic opportunities at a young age are predictive of future health and well being as well as academic achievement. An issue brief published by The Commonwealth Fund in November 1998, summarized some of this research by noting: "Young children who experience the impact of poverty, stressful family circumstances, and inadequate health care services are at particular risk for poor health and developmental problems. Many of these children had low birth weights and suffer from malnutrition and lead poisoning, factors that are often associated with developmental delays, learning disabilities, and emotional and behavioral difficulties."[4]

Additional research has demonstrated that child health and development services—planned interventions—can promote positive outcomes for children's lives. Early childhood interventions can positively affect a child's emotional and cognitive development and education, as well as the overall health and economic well-being of the family. [5] [6] Recent surveys of parents of young children indicate

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1 Shore R. *Rethinking the Brain: New Insights into Early Development*. New York: Families and Work Institute, 1997.

2 Shonkoff JP and Phillips DA. *From Neurons to Neighborhoods: The Science of Early Childhood Development.* Washington DC: National Research Council and Institute of Medicine, 2000.

3 Carnegie Task Force on Meeting the Needs of Young Children, *Starting Points: Meeting the Needs of Our Youngest Children.* New York: Carnegie Corporation of America, 1994.

4 Collins K et al. Issue Brief: *Improving the Delivery and Financing of Developmental Services for Low-Income Young Children.* New York: The Commonwealth Fund, November 1998.

5 Regalado M and Halfon N. "Primary Care Services Promoting Optimal Child Development from Birth to Age 3 Years: Review of the Literature," *Archives of Pediatric and Adolescent Medicine* 155:1311-22. 2001.

6 Karoly L et al. *Investing in Our Children: What We Know and Don=t Know About the Costs and Benefits of Early Childhood Interventions.* Santa Monica, CA: RAND, 1998; Olds DH et al. "ALong-Term Effects of Home Visitation on Maternal Life Course and Child Abuse and Neglect: A Fifteen-Year Follow Up of a Randomized Trial,"

that parents understand the importance of early child development, have concerns about their child's development, and want to learn more from pediatric providers.[7] Studies of early intervention programs for low-income parents with young children have demonstrated positive results, including improved parent-child interactions, maternal confidence, and child health and behavior.[8] Early child health and development services usually encompass four broad domains: screening and developmental assessment of the child and family; education and health promotion, including anticipatory guidance; developmental interventions; and care coordination.

The scientific evidence about the importance of the early years of life in laying the foundation for healthy outcomes in later years, coupled with the sobering knowledge that children in low-income families are at disproportionate risk for developmental problems, have important implications for public policy and practice. State and local governments can take the responsibility for designing and implementing early child health and development services and programs for infants and young children. Improving early child development is a shared responsibility among the multiple programs and agencies that address the needs of young children: education, social services, health, and mental health. The Medicaid program, however, is a cornerstone in the delivery system for young children because of its breadth of coverage and scope of services. It is the single largest insurer of children of all ages in the nation, providing coverage to 23 million low-income children.[9] The program covers 35 percent of all live births and provides coverage to 27 percent of children under age six. [10] [11]

Medicaid programs offer a regular point of contact with low-income children and their families. The Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) benefit provides coverage for a comprehensive array of preventive services that are designed to ensure healthy growth and development. In collaboration with other programs for children, state Medicaid programs have the

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Journal of the American Medical Association 278 (August 1997) 637-643.

[7] Young KT, Davis K, Schoen C, Parker, S. "Listening to Parents: a National Survey of Parents with Young Children," *Archives of Pediatric and Adolescent Medicine.* 152:255-62. 1998; Halfon N, Olson L, Inkelas M. *Summary Statistics from the National Survey of Early Childhood Health 2000.* Washington, DC: National Center for Health Statistics, Centers for Disease Control and Prevention, USDHHS, 2001.

[8] Achenbach TM et al. "Nine-Year Outcome of the Vermont Intervention Program for Low Birth Weight Infants," *Pediatrics* 91(1993):45-55; Kaplan-Sanoff M et al. "Enhancing Pediatric Primary Care for Low-Income Families: Cost Lessons Learned from Pediatric Pathways to Success," *Zero to Three* 17 (June/July 1997): 34-36.

[9] Congressional Budget Office, *An Analysis of the President=s Budgetary Proposals for Fiscal Year 2001* (April 2000), Table 2-2.

[10] National Governors Assn, *Income Eligibility for Pregnant Women and Children.* Jan 20, 2000.

[11] Paul Fronstin, "Sources of Health Insurance and Characteristics of the Uninsured: Analysis of the March 1999 *Current Population Survey*," Employee Benefit Research Institute, Issue Brief 217, January 2000.

potential to provide coordinated developmental services as part of the comprehensive quality health care delivered to children through Medicaid. These services, in turn, have the very real potential to improve the long-term health and well being of millions of young children.

ABCD CONSORTIUM

In 1999 The Commonwealth Fund launched the Assuring Better Child Health and Development (ABCD) Program, an initiative dedicated to strengthening the capacity of the health care system to support the early development of children from low-income families. As part of the ABCD Program, the Commonwealth Fund awarded a grant to the National Academy for State Health Policy (NASHP) to help states improve the delivery of early childhood development services to children through their Medicaid programs.

The specific activities of the NASHP initiative include:

- providing grants to four state Medicaid agencies to develop or expand service delivery and financing strategies that enhance child development for low-income children and their families;
- creating a laboratory of innovation and interagency collaboration comprised of the selected states;
- providing technical assistance to participating states to assure success; and
- using the results of the state demonstrations to inform and inspire replication in other state Medicaid programs.

The ABCD Consortium States

Medicaid agencies in four states are funded by The Commonwealth Fund to participate in the ABCD Program: North Carolina, Utah, Vermont, and Washington. Together, these states form the ABCD Consortium. Their projects focus on a range of early child health and development services and on strategies for delivering them, including developmental screening and assessment, home visiting, parent education, provider education, collaborative partnerships, and financing mechanisms.

Table 1: ABCD State Project Objectives

	Design and/or implement standardized develop-mental assessment or screening tools	*Identify and recommend improve-ments and/or changes in state Medicaid policy or procedures*	*Establish or expand home visiting program*	*Improve service coordination across agencies*	*Enhance parents' knowledge of child development*	*Improve pediatric clinicians' assessment and counseling skills*
North Carolina	■	■		■	■	■
Utah	■	■	■	■	■	
Vermont	■	■	■	■	■	■
Washington	■	■		■	■	■

North Carolina

The North Carolina project is developing a "best practices" model for integrating child health and 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 parents and clinicians serving Medicaid children. To help achieve its goals, the North Carolina ABCD project has convened a state policy group to address policy, reimbursement, and implementation issues that can hinder or facilitate the expansion of the delivery model throughout the state.

North Carolina's initiative is closely integrated with a community-based Medicaid demonstration plan called Guilford ACCESS Partnership (GAP), one of eight such plans across the state. The model has been tested at a large GAP pediatric practice, Guilford Child Health, which has two sites in Greensboro and one site in High Point. Specifically, a developmental screen (the Ages and Stages Questionnaire (ASQ)), has been integrated into the practice workflow at these health centers. The ASQ is a parent-completed screening tool that identifies infants and young children who may have developmental delays or disorders. Tested as valid and reliable, the ASQ reviews communication, gross and fine motor skills, problem-solving, and social development as many as 15 times between birth and age three. The ABCD Project has replicated the model at three family practice sites within GAP. As of September 2001, over 2,000 children had been screened in Guilford County and approximately 8% of those children were referred to early intervention services.

Utah

The Utah ABCD project is implementing a statewide targeted case management (TCM) program for Medicaid newborns. The TCM initiative uses home visiting as the vehicle by which to provide case management. The intent of the service is to facilitate the identification of developmental issues for the infant and of social and environmental factors within the family. Home visits are conducted through the state's local public health departments. The nurse who performs the case management function assesses families' needs, links them to the most appropriate services, provides education and information about early child development, and encourages them to seek comprehensive care in a medical home. With input from the local health departments and the Early Intervention Research Institute, the state's evaluation consultant, project staff have developed an assessment tool to be used during the initial visit. The state amended its State Plan to add targeted case management to its Medicaid-covered services and established rates of reimbursement for the service. As of September 2001, eleven of the state's twelve health districts had implemented the program.

Vermont

The Vermont ABCD project is expanding the scope of services currently provided through two different home visiting programs that serve families with Medicaid eligible children ages zero to five. The Healthy Babies program provides home visits to children ages zero to one, and the One to Five Program provides visits to high risk children who fall within that age group. The goal of the project is to create one program serving all Medicaid children ages zero to five to provide preventive services related to early child development. Service options in the integrated program include home visiting with case management, phone consultation, targeted educational material that highlights child development, and group education for parents and caregivers.

To improve provider practice in childhood development services, the Vermont ABCD project is conducting training in Touchpoints. Developed by T. Berry Brazelton, M.D., Touchpoints is a model for practitioners that emphasizes the building of supportive alliances between parents and professionals

around key points in the development of young children. As of September 2001, over 200 providers and agency officials in Vermont have participated in the Touchpoints training.

Washington

The ABCD project in Washington is using multiple approaches to facilitate improvement in EPSDT outcomes, including the provision of early child health and development services. Its strategies are focused on the following: the linkage of existing developmental health services for children and families, outreach to Medicaid families to ensure that they receive EPSDT services, review and promotion of developmental screening tools, provider training, parent education, and improved EPSDT screening rates.

As part of the project's work, the Medicaid agency developed and piloted a standardized health screening form for providers to use during EPSDT visits. The EPSDT charting tool incorporates age-specific developmental information and a checklist for providers and parents to use during the well-child visit. The tool is now available for use by all pediatric providers in the state.

The project has also contracted with three counties in the state to develop site-specific initiatives to improve early child health and development services. These pilot sites are focusing on the following:

- Whatcom County is developing an interdisciplinary model of early child health and development services, through partnerships with family practice and pediatric physicians, agency providers, and other children=s services. It has convened a developmental screening workgroup to develop recommendations for screening practices and the use of Bright Futures protocols.[12] The Whatcom pilot is conducting training for early childhood providers on Bright Futures protocols and on EPSDT services, specifically well-child visits.

- Snohomish County is focusing on outreach to and enrollment of Medicaid-eligible children in the Healthy Kids Access Program (Medicaid). Once enrolled, staff are contacting families to encourage well-child visits and to assist with parents= concerns. The local project is also working with other providers and agencies in the county to facilitate well-child/EPSDT exams and developmental health services for Medicaid-eligible children.

- Southwest Washington Health District (Clark and Skamania Counties) is using its existing programs to develop an emphasis on early child health and development services and the importance of regular EPSDT screening. The Women Infant and Children's program (WIC) is offering classes to parents about preventive measures, how to access EPSDT services, child development issues, and tips for communicating with providers. The local public health nurse

[12] Bright Futures is a comprehensive initiative to promote maternal and child health and improve the quality of well-child visits, with specific guidelines endorsed by the Federal Maternal and Child Health Bureau.

for the Vaccine Distribution Program is incorporating the state's CHILDProfile materials and other information about EPSDT services in her visits and educational sessions with providers' offices, to encourage service delivery by these providers.[13]

[13] CHILD Profile (Children=s Health, Immunizations, Linkages, and Development) is a health promotion and tracking system to help assure children, ages birth to six, receive needed preventive health services. It provides timely, developmentally based, age-specific information by mail to all parents of young children.

EARLY FINDINGS FROM YEAR ONE

The ABCD Projects have completed their development phase and are in the implementation stage. Individually and collectively, they have identified several issues and challenges in improving early child health and development services through their states= respective Medicaid programs. All four projects have focused on how to improve developmental screening for infants and toddlers and two projects have incorporated home visiting in their approach to early child development services. As the projects have undertaken their respective initiatives, they have begun to address issues of collaboration and coordination with other providers and agencies, services and supports for uninsured parents, and financing mechanisms to support their programs. The following describes several of the early findings in these areas from the states' first year of participation in the ABCD Consortium. These early lessons may be instructive to other states that are considering similar issues, opportunities, and activities.

Developmental Screening

Developmental screening is identified as an important component of early child health and development services, leading to early detection of possible developmental concerns and disabilities. Approximately 15% to 18 % of children have some form of developmental delay or disability, yet only 50% of these children are identified prior to starting school. Most providers rely on clinical judgement instead of screening tools to detect a developmental problem. Clinical judgement alone, however, results in under-detection of learning disabilities, language impairments, other developmental disabilities, and emotional and behavioral problems. [14]

Despite this evidence there is little agreement on a universal approach to screening. Each screening tool has its limitations, leading to controversy among the pediatric community as to the most appropriate approach to screening for developmental delays. Further, each test must be administered according to unique and specific instructions for the results to be valid. Multiple variables affect the provider=s choice of screening tool. As a 2001 American Academy of Pediatrics (AAP) policy statement notes, that choice Amay depend on risk factors in the population, time allotted for the procedure, availability of other sources of developmental screening in the community, and personal preferences of the pediatrician.@[15]

Medicaid regulations stipulate that an EPSDT visit should include a physical and mental health

[14] Glascoe FP. Early Detection of Developmental and Behavioral Problems. *Pediatrics in Review*. 2000: Vol. 21, No.8: 272-279.

[15] Policy Statement: Developmental Surveillance and Screening of Infants and Young Children. *Pediatrics*. 2001: Vol. 108, No.1: 192-196.

assessment, developmental screening, and developmentally-based health promotion services. Data from state and national studies as well as anecdotal evidence suggest that the prescribed screening and assessment do not occur routinely, nor are the results of the screening reported uniformly.[16] Screening instruments can be time-consuming for the pediatric provider to administer and interpret, and the activity may not be reimbursed adequately.[17]

Each of the ABCD Consortium states has taken a slightly different approach to incorporating and encouraging developmental screening in its service delivery for Medicaid-enrolled children. As with other components of a state=s Medicaid program, each state's approach is defined by a number of factors that often include the existing health care delivery system, the receptivity of the physician community, potential partnerships and collaboration with other agencies and providers, and the demographics of the state.

The **North Carolina** ABCD Project has developed a model for integrating child health and development services in local health care delivery systems. One of the essential elements of the project's approach is incorporating the Ages and Stages Questionnaire (ASQ) into provider practice. The project selected this instrument because of the ease with which it can be administered and its validation in clinical trials. In North Carolina's project, the ASQ is completed by the parent at certain well-child visits, while the child and parent wait to be seen by the child's primary care provider.[18] The physician or nurse practitioner then scores the questionnaire. This gives the clinician immediate feedback on a child's strengths as well as any need for further assessment. The North Carolina project's Early Intervention Specialist coordinates follow-up, if indicated, including developing a service plan with the family, coordinating referrals to other providers and services, and assisting families with obtaining information and resources.

The **Utah** ABCD Project has developed an assessment tool to be used in its statewide home visiting program for Medicaid families with newborns. The tool is not a developmental screening instrument, but rather an assessment of the mother's pregnancy and birth experience, the baby'ss habits, the family environment, and parent-child interaction. After reviewing existing screening instruments, project staff determined that they needed to develop one that included an assessment of social and environmental factors and family strengths and weaknesses. The tool is administered by local public health department staff during initial visits that are conducted with mothers of newborns enrolled in Medicaid.

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[16] Perkins J et al. *Children=s Health Under Medicaid: A National Review of Early and Periodic Screening, Diagnosis and Treatment*. National Health Law Program, Los Angeles CA: 1998; *Building State Medicaid Capacity to Improve Early Child Development Services:* Proposal to National Academy for State Health Policy from Washington State; October 1999.

[17] Policy Statement, *Pediatrics*. Op. cit.

[18] The GAP practices have chosen to use the screen at 6, 12, 24, 36, and 48 months. Providers have the option to use the form at other intervals as they deem necessary.

In recognition that this assessment, while useful in identifying potential risk factors, does not necessarily improve developmental screening of children (ages zero to three), the Utah ABCD project plans to incorporate the use of the ASQ in its project protocols in the future. The project is investigating the feasibility of introducing the ASQ to the parent during the initial home visit, having them complete the questionnaire and return it in a stamped, self-addressed envelope. Findings from the ASQ would then be relayed to the appropriate providers and incorporated into the child's pediatric care.

The **Vermont** ABCD Project has focused much of its attention on improving the skills of the state's pediatric providers to provide early child health and development services and to develop enduring relationships with the parents of young children. The project is offering training in Touchpoints, Dr. T. Berry Brazelton's model for practitioners that emphasizes supportive alliances between parents and professionals around key points in the development of young children. As a companion to this approach the project is offering training to a limited number of clinicians in the use of Dr. Brazelton's Neonatal Behavioral Assessment Scale (NBAS) for developmental screening. The tool is targeted for use with newborns and their parents, with the goal of actively involving parents in observing their baby as a unique individual with a variety of skills and abilities. Pediatric providers report that they find the tool useful in helping parents get to know their babies. Because the NBAS requires providers who administer it to undergo intensive training in its use and because the screen is limited to newborns, the project is also examining other approaches to improve developmental screening.

The **Washington** ABCD Project is addressing developmental screening through promotion of comprehensive EPSDT exams. Data collected through the state'ss study of EPSDT performance in managed care indicates that only 11% of infants from birth to 18 months received the recommended schedule of visits (six) in 1998 and that developmental screening, particularly for social and emotional development, was performed less than 75% of the time.[19] The Washington Project is promoting the use of an EPSDT charting tool, developed by the State Medicaid agency, to improve provider performance in completing comprehensive EPSDT exams, including developmental screening. Unlike other tools for delivering EPSDT services, the charting tool addresses age-specific issues in child development, providing guidance to both primary care providers and parents. The project is also encouraging the use of the Bright Futures guidelines so that providers deliver comprehensive care when seeing children at their well-child visits.

The Washington ABCD Project also convened a panel of physicians to assess the usefulness of various developmental screening tools administered via three different approaches: in the primary care office, by community personnel, and by community or statewide distribution. Although the panel developed recommendations for screening tools appropriate to each of the three settings, it concluded that there is

[19] *Building State Medicaid Capacity to Improve Early Child Development Services:* Proposal to National Academy for State Health Policy from Washington State; October 1999.

no one perfect tool to assess the broad range of individual differences among young children.[20]

Each of the ABCD Projects has identified that—regardless of who conducts the screening (a physician, a nurse, a social worker, or a parent)—effective communication of the results of the screening is essential. A feedback loop must be established so that the appropriate provider can incorporate the information into pediatric practice , whether providing care to the child, making referrals as necessary, or providing anticipatory guidance to the parents.

Home Visiting

Home visiting is not an early child development service, per se, but rather a vehicle by which to identify developmental issues, address family concerns, and provide education and support to families. Home visiting programs can have a wide range of purposes, including improvement of pregnancy outcomes, postnatal education and support, prevention of child abuse and neglect, promotion of early child development and school readiness, and parent education. As noted in a 1999 report on the effectiveness of home visiting programs: "Despite their varied goals, these programs share a focus on the importance of children=s early years, a belief that parents play a pivotal role in shaping children=s lives, and a sense that one of the best ways to reach families with young children is by bringing services to them, rather than expecting those families to seek assistance in the community.@[21]

Although the notion of home visiting suggests a positive influence on the intended recipients, the literature suggests that there is limited conclusive evidence about home visiting=s long term or consistent benefits. Considerable variation exists among program models for home visiting, and the results of one model cannot be generalized to another. The most compelling findings among the evaluations of the six home visiting models summarized in The Packard Foundation report are those of the Nurse Home Visitation Program (NHVP).[22] The NHVP is a 20-year old program of intensive home visiting targeted to needy families, beginning during the mother's pregnancy and continuing through the child's second birthday. Findings from the Elmira (NY) and Memphis (TN) trials indicate that the program helps reduce childhood injuries and child abuse and neglect and has a positive impact on women delaying subsequent pregnancies and entering the workforce.

As part of the ABCD Program, focus groups were conducted with mothers of very young children

[20] Tekolste K et al. Washington State Developmental Screening Committee Recommendations. April 2001.

[21] "Home Visiting: Recent Program Evaluations," *The Future of Children*. The David and Lucile Packard Foundation. Vol. 9, No. 1 (Spring/Summer 1999).

[22] Ibid.

enrolled in Medicaid in the four ABCD Consortium states. The purpose of the groups was to learn what parents think about childhood development services and how they feel about the health care that their young children receive. The focus groups also examined mothers= attitudes and responses to home visiting. The findings suggest that home visits can be helpful for mothers of newborns and toddlers in providing information and support about early child development, but that they are not a universal approach for all families. Mothers said that sometimes they feel as though they are being inspected instead of helped by home visitors. They would like the home visitor to check with them about the best time for arranging a visit and the frequency of contact that would be most helpful. When in the home, mothers suggested that the visitor show respect for the family's circumstances and the mother's expertise and opinions instead of just telling the mother what to do.[23]

The ABCD Projects in Utah and Vermont are using home visiting in their respective strategies to improve early child health and development services. Both projects have incorporated the findings of the focus groups conducted in the four states in the design and implementation of their home visiting components.

Utah is implementing a statewide targeted case management program for all families with newborns enrolled in Medicaid. Public health nurses conduct the initial visit in the child's home but have the freedom to meet the parent at another location if the parent prefers. As noted above, the home visiting is conducted by nurses who work in the local public health departments throughout the state. The state has developed a newborn report that allows the staff at the local public health departments to identify families in their service area with newborns. The purpose of the initial home visit is to assess the needs of the newborn and family. Through the home visit, the nurse determines the need for parent education, follow-up services, linkage with a pediatric provider, and/or referral to other community resources. Subsequent contacts and/or home visits are conducted, as necessary, to determine whether services are being furnished and are appropriate and whether the needs or status of the child and family have changed.

Vermont is redesigning its existing home visiting services that have been conducted through the Healthy Babies and One to Five programs. With input from parents and providers, the Vermont ABCD project is promoting a new approach to home visiting, viewing it as a component of a larger service package. The resulting model will offer a combination of services and a range of interventions, from the simple to the intensive, depending on the needs of the child and family. Service options include: basic and intensive home visiting, case management, parent education (both one-on-one and group), and phone consultation.

As noted in a previous section, Vermont's project has incorporated the Touchpoints model in its approach to providing early childhood development services to young children and their families.

[23] Perry M et al. *Child Development and Medicaid: Attitudes of Mothers with Young Children Enrolled in Medicaid.* New York: The Commonwealth Fund (March 2001).

Touchpoints provides a model for timely and appropriate interventions with newborns, toddlers, and their families. Large numbers of providers who care for children—pediatric physicians, nurses, and social workers—are completing training in Touchpoints. The project anticipates that, as these providers incorporate Touchpoints in their care of young children, families, in turn, will engage in and utilize home visiting and other community services to support their child's development.

One of the goals in providing an effective home visiting program is ensuring that findings from the home visit are conveyed to the child's primary care provider and/or other providers who are involved with the child's care. A home visit in isolation, unrelated to the child's overall care, is not particularly helpful to the child or family and can, in fact, be counterproductive. Both Utah's and Vermont's projects are developing mechanisms for communication with the physician and other appropriate providers so that the intervention does not simply end with the home visit.

- In Utah, the local public health department nurses are collecting contact information for the child's primary care provider when they conduct the home visit so that they can relay their findings and recommendations following the visit. Over time the public health departments anticipate developing a relationship with the primary care provider that permits exchange of pertinent information, within the requirements for confidentiality. Utah's provider manual for EPSDT informs the primary care provider about the targeted case management service focusing on child development and directs the provider to contact the local public health department if a child may benefit from targeted case management services.

- The Vermont project is developing a more streamlined system so that communication between providers and the family is more timely, pertinent, and non-duplicative than in the past, as well as reflecting a more unified approach to service delivery. Project staff are working with partner agencies to develop new intake and referral forms for use by all providers involved with the child's care, in keeping with confidentiality and documentation requirements.

As noted above, home visiting is a popular approach for addressing a variety of issues with families who have young children and, consequently, multiple home visiting programs may be operational in a given state or locality. Both Utah and Vermont have had to address this issue by working collaboratively with other agencies and programs to ensure that they either make a distinction between programs or combine their approaches so that the available services are clear and understandable to the family. This issue is discussed in more detail in the next section.

Collaboration and Coordination

One of the major challenges for any state or local agency that has responsibility for children's services is to coordinate with the many other services, resources, agencies, and providers that also serve children. As described in NASHP's recent publication, *A Coordination Challenge for States: A Snapshot of*

Major Federal Programs for Children, there are at least 23 major federal programs that provide services to children, and they are administered by numerous offices within seven federal departments.[24] Each has its own eligibility criteria, definition of service, funding source, and protocols. An individual child can be eligible for services from multiple programs, focusing on everything from health to child care to education to child welfare to nutrition. Within the domain of early childhood development alone, health, education, child care, behavioral health, and social service programs all may be supporting services, research, and resources to benefit the development of young children.

In order for their work to succeed within their state Medicaid programs the four ABCD projects, are working to identify existing resources for early childhood development, seeking collaborative relationships with other stakeholders, and coordinating their efforts with other programs and providers. Each has been quite successful in developing a shared vision among certain key players and/or entering into specific collaborative agreements, but the effort has been a time-consuming process and has presented challenges and obstacles along the way.

The **North Carolina** ABCD project participates in an existing consortium of providers and agencies at the county level to coordinate early childhood development services. This local consortium was developed in response to the passage of Public Law 99-457, also known as the Individuals with Disabilities Act (IDEA). It is comprised of clinicians and professionals in public health, behavioral health, childcare, and education who meet weekly to initiate the development of the Individual Family Services Plan (ISFP) and to ensure that at-risk children and their families receive appropriate referrals and services. Project staff also participate in Early Intervention Management meetings at the state level. This group consists of representatives from such key state agencies for children as child development, public health, Smart Start, and Head Start. Public health and Head Start have been particularly interested in evaluating the tools that they have used, historically, to screen children and have asked the ABCD Project to share their experience with the ASQ.

The North Carolina project has also been successful in establishing a relationship with the state=s chapter of the American Academy of Pediatrics and with individual pediatricians because of the active involvement of a developmental pediatrician who is associated with the project. Her leadership and credibility have enabled the project to attain visibility within the pediatric community and to promote the importance of the project's integrated model of developmental services in pediatric practice. This physician has conducted initial ASQ training for pediatricians at statewide AAP meetings. Additionally, the project is developing a curriculum on developmental screening for pediatric providers, in collaboration with the state chapter of AAP, the Early Intervention Program, and the State Interagency Coordinating Council.

The ABCD project in **Utah**, based within the Division of Health Care Financing (Medicaid), has

[24] Wysen K et al. *A Coordination Challenge for States: A Snapshot of Major Federal Programs for Children.* Portland, ME: National Academy for State Health Policy, October 2001.

worked in collaboration with a sister agency, the Division of Community and Family Health Services (DCFH), and the local health departments to develop its home visiting initiative. Both divisions are within the Utah Department of Health. The process has not been without its challenges; DCFH provides home visiting services to children from birth to age five with special needs and therefore, staff have had concerns about the potential overlap and distinction between the two home visiting approaches. At the local level, health department nurses have had similar concerns. The Utah project has worked with these two partners to 1) clarify the distinction between the ABCD targeted case management home visiting to all Medicaid newborns and the home visiting to at-risk children provided by DCFH, and 2) ensure that the system of care is understandable and as seamless as possible for children and their families.

The **Vermont** ABCD project is a partnership between the Office of Vermont Health Access (Medicaid) and the Department of Health and is built on a history of collaboration between the two agencies in the administration and provision of health services in the state. The Department of Health, through its district offices and contracts with home health agencies and parent-child centers throughout the state, provides Medicaid services for the Healthy Babies and One to Five programs. The Vermont project has convened a 30-member *Healthy Babies/One to Five Expansion* advisory committee, with representation from state and local health, mental health, education, corrections, child care, and social services agencies as well as pediatric clinicians, to guide the Department of Health and the Medicaid agency in the development and implementation of the project.

In addition, the project has sought coordination and collaboration among providers by approaching early childhood development through Touchpoints. The Touchpoints training brings clinicians, social workers, and other child care providers together to learn about the touchpoints in newborns' and toddlers' lives and to gain a common language and purpose in providing early childhood development services.

Similar to Utah, Vermont has faced certain challenges in working with other home visiting initiatives. The Family Partnership Program is a three-county pilot program of home visiting for at-risk families that was approved by the Vermont legislature at the same time that the ABCD grant was awarded to Vermont. The Healthy Families America initiative is also conducting a home visiting program in a single community in northern Vermont. These multiple initiatives prompted the formation of an intensive home visiting workgroup to examine the commonalities among Healthy Babies, One to Five, Family Partnership, and Healthy Families America. The workgroup is making recommendations as to how to integrate the best elements of each program into a single collaborative team approach, as well as how to build on other national protocols and best practices for families who need ongoing and intensive support.

The **Washington** project has brought key staff from the Medicaid and public health agencies together to coordinate their respective efforts and communication regarding early child development. The project team is working with programs and initiatives such as CHILD Profile, the Medical Home

Training and Resources Project, Bright Futures, the Infant Toddler Early Intervention Program (ITEIP), and Child Health Notes to ensure coordination and consistency among programs and materials that address early child development.[25] At the local level the pilot sites have involved physicians, WIC service providers, public health nurses, and Early Head Start and Head Start providers in a concerted effort to focus on the importance of early child development in all communication and interventions with families with young children.

Services and Support for Parents

As documented in the Institute of Medicine's report *Neurons to Neighborhoods* and other research, healthy early development depends on nurturing and dependable relationships, primarily with parents and other regular caregivers. As the IOM report notes, these relationships "are 'active ingredients' of environmental influence during the early childhood period."[26] And healthy relationships are dependent, at least in part, on the health of both adult and child. Research supports the notion that the health and well-being of the parent has a direct impact on the child's health. There is evidence that a parent's health-related problems have an adverse impact on his or her ability to care for an infant or child. Problems such as maternal depression, family substance abuse, and other parent mental illness have a particular impact on the parenting capacity of parents with young children. As one report notes, children of "depressed or otherwise mentally ill parents are at risk for adverse outcomes in social, emotional, and cognitive development during early and later childhood and beyond."[27]

Parents of Medicaid-eligible children are often without health coverage and, therefore, unable to access care and services. As a NASHP issue brief on access to care for uninsured parents has noted, these low-income adults "are without coverage, not because they choose not to enroll in available plans, but because they have no access to either any or affordable health insurance."[28] Many work in jobs where health insurance is not offered as a benefit; others don't enroll because of the high premium costs. Consequently, their physical and mental health needs go untreated, affecting their ability to care for an infant or young child.

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[25] The Medical Home Training and Resource Project supports medical home teams (comprised of a physician, public health nurse, early intervention resources coordinator, and a parent) to provide training for primary care providers, office staff, and others who see children with, or at risk for, developmental delays and chronic health problems. ITEIP is responsible for coordinating and implementing early intervention services to infants and toddlers with disabilities and their families, as defined in IDEA. Child Health Notes is a one-page newsletter for primary care providers that focuses on developmental issues for young children.

[26] Shonkoff, Op. cit.

[27] Hendrick V et al. *Parental Mental Illness*. Policy Brief: UCLA Center for Healthier Children, Families and Communities, California Policy Research Center (June 2000).

[28] Rosenbaum S. *Options for Assisting Uninsured Parents to Secure Basic Health Services: Issue Brief*. Portland, ME: National Academy for State Health Policy, February 2002.

Early findings from the ABCD projects, although largely anecdotal, corroborate the lack of coverage and services for parents and the potentially detrimental effects on young children. Each of the projects has noted the difficulty of providing continuing services to most mothers, once they are 60 days postpartum and no longer eligible for Medicaid. These mothers and other caregivers are in need of basic health care coverage as well as of an array of supports and ancillary services to help them stay healthy and provide a healthy environment for their children.

Among the issues faced by mothers of young Medicaid children, project staff within the four states note that maternal depression is one of the more serious and prevalent problems. Mothers are often without adequate supports or resources and find that their basic self-steem is jeopardized by the multiple pressures and demands they face. Findings from the focus groups in the four states corroborate this concern. According to participants, pediatric providers rarely ask mothers how they are coping. These mothers would appreciate it if the doctor would ask about their own health and well-being and provide advice about how to cope with the pressures of raising a small child.[29]

A survey of Medicaid parents conducted in three of the ABCD Project states by the Foundation for Accountability (FACCT) supports the more anecdotal concerns about maternal mental health.[30] It found that approximately 20% of the mothers responding to the survey were at risk for depression. In identifying what kind of psychosocial assessment was conducted by the child=s pediatric provider, many parents (46%) reported that doctors never ask them how they are feeling as a parent. Additionally, they reported that they are rarely asked how parenting works into their daily activities (16.6%).

In addition to concerns about maternal mental health, the four ABCD states have identified the following issues and needs of parents:

- family planning services,
- smoking cessation services and support,
- literacy and other educational services for parents who are unable to read the materials they are provided,
- translation services for parents who do not speak English, and
- adequate, safe housing.

So as the ABCD projects identify and develop mechanisms to strengthen the early childhood development services provided to children on Medicaid, they are also seeking ways to provide a range

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[29] Perry, Op. cit.

[30] Bethell C et al. *Medicaid Parents= Experience with the Health Care System: Summary of Findings from a Survey of Parents of Young Children Enrolled in Medicaid in Three ABCD States*. Prepared for the Commonwealth Fund by FACCT, The Foundation for Accountability (June 2001).

of supportive services to the parents, particularly mothers. The Utah project links a mother with smoking cessation services, if appropriate, at the time that the nurse conducts the home visit. The state is also in the process of expanding the availability of family planning services to mothers through submission of a 1115 waiver request to the Centers for Medicare and Medicaid Services (CMS). The North Carolina project offers parenting classes to mothers of young children through its Guilford Child Health site and assists individual parents in accessing services such as domestic abuse support, housing assistance, and employment opportunities.

In addition to providing supportive services to parents, each project has developed specific products and materials to facilitate the parents' understanding of their child's physical, emotional, cognitive, and behavioral development.

- North Carolina has developed parent education materials that address developmental issues at specific age increments as well as brochures on specific topics, such as managing tantrums, shopping with your children, time-out guidelines, and ten guidelines for living with children.

- Utah has developed a new booklet for Medicaid parents that describes how to access services in the Child Health Evaluation and Care Program (CHEC, Utah=s EPSDT benefit). It includes a section on early childhood development and how parents can take an active role in the healthy development of their children.

- Vermont has designed a parent book to accompany its integrated program for children from birth through age five. The book provides basic but comprehensive child health and development information for parents, incorporating Touchpoints language into the presentation. The Vermont project is also producing a series of newsletters for parents, to be sent to families at ten touchpoints, beginning at 28 weeks gestation and continuing to age five.

- Washington=s new EPSDT charting tool includes a section for parents that identifies age-specific developmental progress signs as well as parenting and safety tips. Parents are given a copy of the form so that they can have a reminder of what to watch for in their child=s development. The Project has also collaborated with the Department of Health in the development of a CHILDProfile Development Chart for children, 18 months to age four, to be distributed to parents of young children in the state.

Financing Mechanisms to Support Early Childhood Development Services

Strategies for financing child health and development services are a critical component of the ABCD Consortium. As the ABCD Projects build capacity within their state Medicaid programs to improve the delivery of early child health and development services, they are also identifying mechanisms for

sustaining the delivery system. The individual ABCD Projects have yet to finalize their approaches or recommendations for financing; their primary focus, to date, has been on the development and implementation of their respective initiatives. Some of the projects have begun to address these issues and their status, to date, is summarized below.

To support **Utah's** new program, the Medicaid agency has amended its State Plan to add targeted case management as a covered service for Medicaid eligible children from birth to age four. The targeted case management service includes a range of activities, all of which can be provided as part of a home visit. The state established two different rates of reimbursement for the targeted case management service, one for the initial assessment and a second for follow up and ongoing case management. The actual rates were determined by comparing similar services and providers and evaluating current rates of reimbursement, geographic area, population density, cultural diversity of the population served and the differences between urban and rural service areas. State local health departments are paid for delivering the new targeted case management service, and these agencies currently provide the federally-required state share of the reimbursement, matching the federal financial participation (FFP).

In **Vermont**, the home visiting conducted through the Healthy Babies Program has historically been reimbursed on a fee-for-service basis as an EPSDT covered service. Home visiting conducted for the One to Five Program has been reimbursed under the Medicaid program's targeted case management policy. As part of the redesign of the two programs, the Vermont project is developing a new reimbursement system that will accommodate both individual and group service provision and will facilitate a team approach to service delivery. A case rate was under consideration but, subsequently, rejected. Project staff, with input from service providers, are considering other fee-for-services alternatives and/or a per case cap to promote case planning and coordination among providers.

The **North Carolina** project included its Early Intervention Specialist in its integrated services model to provide case management, referral, and support services to children and their families who have been identified as needing additional services. This position is currently supported with grant funds. With the assistance of a State Policy Advisory Group, comprised of leadership from several state agencies that provide services to children in North Carolina, the project will determine how to incorporate this pivotal position in the infrastructure of ACCESS networks throughout the state.

CONCLUSION

The ABCD Projects have considerable potential to improve the delivery and financing of early child health and development for Medicaid-eligible children in their respective states. And over the course of the past year, they have made significant strides in addressing the issues and challenges that will lead to that improvement. In summary, early lessons from the ABCD Consortium include:

- Developmental screening is an important component of delivering comprehensive early child health and development services, but its effectiveness is largely dependent on the integration of screening with pediatric practice. If the screening occurs within the clinical setting it must be easy to administer and incorporate into the existing practice setting. If the screening is administered separate from the pediatric practice, the results must be communicated to those providers involved in the child's care so that they can incorporate the findings into a comprehensive plan of care.

- Home visiting can be an important strategy in identifying a child's and/or family's risk factors and concerns, but the service should be delivered with sensitivity to the family's circumstances and be responsive to the family's particular needs. As with developmental screening, it is important to communicate the results of a home visit to the child's providers so that the findings can be used effectively. When multiple home visiting services exist within a state, it is incumbent upon the responsible agencies to work together so that families receive optimum benefit from the services.

- Parents' health and well-being are integral to the healthy development of young children, yet there are limited opportunities and resources to provide consistent and continuous support and services to those parents who lack health insurance. Mental health issues for mothers are particularly critical. The ABCD Projects are developing multiple approaches to providing support to mothers and fathers through one-on-one consultation, group education, parent support groups, and educational materials.

- Collaboration and partnerships are key to improving developmental services for children. The building blocks to support early child development have been laid by multiple agencies and disciplines: health, maternal and child health, child care, education, social services, mental health, and others. Coordination among these diverse players can be challenging but the ABCD Projects are working in their respective states to create collaborative initiatives and coordinate approaches so that children and their parents receive comprehensive services and a consistent message.

- Financing of early child health and development services can be approached in several ways, through modifications to existing reimbursement systems, incorporation of administrative and service functions into an existing infrastructure, the addition of additional resources to improve

the delivery system, or the pooling of resources across agencies and systems. The ABCD Projects will work with their respective Medicaid agencies and other state partners to determine the most effective approach for their particular delivery system and state environment.

The intent of the ABCD Consortium is to disseminate its findings and lessons learned to other states, national associations, and organizations that focus on early child development, to facilitate an understanding of the importance of early child development and to inspire replication of successful program models. As the ABCD Projects in the Consortium continue their work, the National Academy for State Health Policy will issue policy briefs, reports, and other products that demonstrate further findings and lessons learned in improving the delivery and financing of early child health and development services.