



A HISTORY OF THE COMMONWEALTH FUND'S CHILD DEVELOPMENT AND PREVENTIVE CARE PROGRAM

CYNTHIA A. CONNOLLY

AUGUST 2013



The Commonwealth Fund, among the first private foundations started by a woman philanthropist—Anna M. Harkness—was established in 1918 with the broad charge to enhance the common good.

The mission of The Commonwealth Fund is to promote a high performing health care system that achieves better access, improved quality, and greater efficiency, particularly for society's most vulnerable, including low-income people, the uninsured, minority Americans, young children, and elderly adults.

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Abstract: The Commonwealth Fund has a nearly century-long role in the improvement of children's health in the United States. This historical monograph examines the foundation's more recent efforts to create an integrated model of well-child care capable of addressing children's cognitive, emotional, and social development needs. The author focuses on the creation and implementation of initiatives that began in the 1990s under the Child Development and Preventive Care Program.

Support for this research was provided by The Commonwealth Fund. The views presented here are those of the author and not necessarily those of The Commonwealth Fund or its directors, officers, or staff. To learn more about new publications when they become available, visit the Fund's website and [register to receive email alerts](#). Commonwealth Fund pub. 1693.

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ABOUT THE AUTHOR

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ACKNOWLEDGMENTS

I am very grateful for the opportunity to have studied The Commonwealth Fund's Child Development and Preventive Care (CDPC) program. Like most historians, I approached this topic with a skeptical eye, but the documentary evidence and stakeholders with whom I spoke revealed an innovative and cost-effective story that needed to be preserved and drawn upon as a useful template for making policy and practice change. I have appreciated my many conversations with Janet Golden, Ph.D., about the history of children's health. They have sharpened my analysis and broadened my perspective. The CDPC program's accomplishments are all the more impressive when considered against the backdrop of historical challenges to funding and delivering well-child care in the United States. I am grateful to the many scholars who made time to talk with me; my discussions with them amplified the documents and other primary sources that informed this project. I appreciate former Commonwealth Fund program associate Cara Dermody for helping me organize volumes of data. Finally, I am particularly grateful to Ed Schor, M.D., and Melinda Abrams, M.S. Each spent many hours talking with me, discussing the fine points of my analysis, pointing me toward new resources, and reading numerous drafts of this monograph.

Editorial support was provided by Joris Stuyck.

PREFACE

The Commonwealth Fund is proud to be among the U.S. philanthropic foundations that have for decades been a force for positive social change. One of the areas where the Fund's historical impact has been most visible is child health.

In the 1920s, The Commonwealth Fund developed and informed the new field of child guidance to provide mental health services for children. During this era, the foundation also supported the first fellowships in child psychiatry and established children's community clinics. And model public health clinics established by the Fund spurred initiatives to reduce maternal and infant mortality.

Much more recently, the Program on Child Development and Preventive Care—the subject of this historical overview—supported states in their efforts to expand the delivery of developmental and behavioral services, particularly to children in low-income families. As a result of the program's efforts in the 2000s, screening and referrals for developmental problems have now become standard features of modern pediatric practice.

In this monograph, Cynthia Connolly traces the history of one of The Commonwealth Fund's most successful endeavors. Through exhaustive archival research and interviews with the key movers in early child development and health policy, she explains how a group of committed individuals were able not only to effect wholesale changes in policy, but ultimately to make a real difference in the lives of children and their parents.

David Blumenthal, M.D., M.P.P.
President
The Commonwealth Fund

INTRODUCTION

In March 2010, President Barack Obama signed the Patient Protection and Affordable Care Act (PPACA) into law. Designed to reform the health insurance market in the United States and thereby improve access to care for more than 30 million uninsured Americans, its provisions were structured to become effective by 2014.¹ Along with broadening access to care, improving quality, and placing a new emphasis on care coordination, the act was celebrated by its champions for its focus on clinical preventive services, health screenings, and surveillance of well patients.²

The Affordable Care Act stands to transform children's health care delivery. Not only does it promise to provide greater stability to poor families with children by reducing the numbers of uninsured parents, for example, the law makes it impossible for private insurers to deny coverage to children because of preexisting conditions. However, many of the other concepts embedded in the PPACA are not new at all.³ More than a century before its passage, physicians, nurses, and other health care reformers had begun building a care delivery model for children that broadly emphasized health promotion and disease prevention for well children, in addition to caring for them when they were ill.⁴

Those ideas would later become the conceptual underpinnings of well-child care, and were considered important enough to be codified in publicly funded initiatives such as the 1920s Sheppard-Towner Act and the Early and Periodic Screening Diagnostic and Treatment (EPSDT) program, created in the 1960s to ensure that indigent youngsters received needed comprehensive developmental services, and, in the 1990s, the Children's Health Insurance Program (CHIP), which provided insurance coverage for poor and near-poor children. Now those principles would extend beyond pediatric practice into adult health care delivery.

One central feature of the Affordable Care Act is an expanded focus on measuring the quality and outcomes of care, a landmark change that was strongly influenced by the most recent reauthorization of CHIP. The 2009 Children's Health Insurance Reauthorization Act (CHIPRA) not only provided states with

significant new monies, programmatic options, and incentives, it also mandated the use of a core set of quality measures for all pediatric care covered by Medicaid and CHIPRA programs.

Among the measures chosen by the federal Centers for Medicaid and Medicare Services (CMS) was one that required "[s]creening using standardized screening tools for potential delays in social and emotional development." In order to be chosen for inclusion, each measure needed a sturdy body of evidence attesting to its importance and feasibility. The CMS had been convinced of the need for this measure based on the evidence presented by the Assuring Better Child Health and Development (ABCD) Screening Academy, a major initiative of The Commonwealth Fund.⁵

Why did The Commonwealth Fund create this initiative? What did the ABCD program discover about well-child care and providing developmental services to indigent infants and young children that helped it shape a major piece of legislation? This monograph traces the history of the ABCD initiative and of the program in which it was nested, The Commonwealth Fund's Child Development and Preventive Care (CDPC) program. Specifically, it considers how the CDPC worked successfully to convince parents, payers, health care providers, and policymakers of the importance of developmental screening in well-child care.

The emphasis of this monograph is on The Commonwealth Fund's recent efforts to improve the delivery of well-child care in the first years of the 21st century. However, these recent efforts should first be placed in the context of the foundation's involvement in pediatric health care and well-child care over the past century. Only in this way is it possible to fully appreciate the Fund's successes, the challenges it faced, and its development of the platform on which it mounted the program.

Part I explores the development of well-child care in the United States in the 20th century, focusing on turning points and emphasizing Commonwealth Fund initiatives and their contributions to child health care, from those of the 1920s through Healthy Steps for Young Children, in the 1990s. Part II traces the creation

of ABCD and the CDPC program, and provides an intellectual history of the theories and philosophies informing them. Part III examines how the CDPC program built momentum for change, engaged stakeholders, generated evidence, and, by so doing, was poised to capitalize on a particular policy window to effect sustainable change in well-child care in the United States. Finally, Part IV analyzes the lessons learned from ABCD and the CDPC program and considers them in the context of enduring issues in American society, children's health care delivery, and 21st-century challenges to effecting policy change.



PART I. MAJOR 20TH-CENTURY TURNING POINTS IN DESIGNING WELL-CHILD CARE

*There are few things more vital to the welfare of the nation than accurate and dependable knowledge of children.*⁶

—Theodore Roosevelt (1910)

Child Health Is Purchasable

The Fund’s nearly century-long role in children’s health began soon after its founding in 1918. At the time, there were no federal or state initiatives for children’s health. Those municipalities providing any such services at all did so in a fragmented fashion: school health services, municipal health departments, and private physicians almost always operated independently of one another. In this context, when the Fund announced a community-based pilot project focused on children’s health, the *New York Times* considered it worthy of mention.⁷

The Fund’s program was launched at a time when the nation was increasing its attention to children’s well-being. Theodore Roosevelt was one of the first presidents to envision the nation’s destiny in terms of its commitment to children. A few years before, he had devoted a White House conference to children’s issues, thus generating a national discussion on child health and welfare that had resulted in 1912 in the creation of the Children’s Bureau—a federal agency dedicated entirely to children and their well-being.

There was another national shift under way, as well—a major epidemiological shift caused by the rapid decline in infant mortality and child deaths from infectious disease.⁸ Leading scientists and health professionals agreed in attributing these gains to the work of public health departments, whose funding went to improve sanitation, to ensure the purity of milk and water, to educate the public, and to screen the public for diseases. The belief that fiscal investment could produce quantifiably improved health outcomes was summed up in the memorable statement of Hermann M. Biggs,

New York City’s activist general medical officer: “Public health is purchasable.”⁹

This sentiment resonated with reformers committed to improving the health and welfare of children in a nation experiencing the challenges of rapid growth, increasing urbanization, and the bureaucratization of previously informal mechanisms for providing health and social welfare services. The Fund’s new initiative also meshed with the philosophy of America’s leading pediatrician, Abraham Jacobi, who argued that pediatrics required a new paradigm, one that moved away from illness-oriented medical specialties focused on discrete organ systems or particular diagnostic technologies. Pediatricians, Jacobi admonished, needed to think about the “whole” child, addressing issues such as feeding and growth in addition to therapeutics for sick youngsters.¹⁰

Consequently, as World War I ended, The Commonwealth Fund strove to integrate the strategies of the 19th-century voluntary charitable organizations—which provided funds and services to “deserving” petitioners—with the organizational and epidemiological research ethos of the modern public health department.¹¹ Its Child Health Demonstration Committee ardently hoped to persuade the American public that health screenings, coordination of care, and other strategic societal “purchases” on behalf of children would be worthy, cost-effective investments: by improving health outcomes, they would strengthen the nation’s workforce and also its military.

In the 1920s, Commonwealth Fund pediatric efforts coincided with the evolution both of pediatrics as a medical specialty and of the beginning of American health policy. Pediatricians, public health nurses, and other reformers debated how best to translate into practice new concepts emerging from the field of psychology and how best to integrate the systems of child welfare and health care. These discussions led to major Commonwealth Fund initiatives in juvenile delinquency prevention and child guidance. Although an attempt to achieve compulsory national health insurance had recently failed, the Sheppard-Towner Act—the first federal health-oriented legislation—was enacted in 1921. This statute provided federal funds to states for

maternal and child health education and for disease-prevention and health-promotion campaigns, but there were as yet few accepted guidelines beyond those of tracking children's heights and weights.¹²

One of the Fund's initiatives was a child health demonstration that hoped to use its pilot locations—Fargo, North Dakota; Athens, Georgia; Rutherford County, Tennessee; and Marion County, Oregon—as laboratories for defining a model for preventive pediatrics. The most basic goal of the child health demonstration was to bring into the health care system all the children in each study area. The advisory committee also hoped to be able to make recommendations about ways in which communities could reduce duplication and poor communication among the diverse sites—including schools, health departments, and the offices of private physicians—at which children received health care.¹³

The Commonwealth Fund soon had in place a structured program of preventive services. At regular "health conferences," children could be weighed and benchmarked against new national normative data, and at the same time examined for defects and health problems. At the conferences, parents could be instructed on issues such as feeding and child-rearing, potentially resulting in material gains such as reduced rates of infant and child mortality. Over the course of the study, from 1923 to 1927, Fargo documented a 50 percent reduction in infant and child deaths from communicable disease in those families who participated in the demonstration. Marion County reduced its infant mortality rates by 22 percent, while the rest of Oregon saw a decline of only 13 percent. Importantly, each pilot community judged the demonstration to be so successful (and cost-effective, thanks to reduced expenditures in other areas, such as the treatment of communicable diseases) that local governments restructured to maintain the services it had established; this accomplishment was all the more impressive given that localities saw it through in the early years of the Great Depression.¹⁴

The achievements of the demonstration cities, in tandem with a host of child health campaigns sponsored by the Children's Bureau and voluntary

organizations, resulted in a growing demand by parents for preventive care for their children. By the 1930s, one-third to one-half of children's visits to physicians were for what pediatricians classified as well-child care.¹⁵ Although the benchmarks for child health in that era largely constituted measuring height and weight and identifying physical anomalies, the Fund also committed significant resources to its juvenile-delinquency and child-guidance programs in the hope of promoting positive family functioning and improving children's social and psychological well-being.¹⁶

Children's care in the United States suffered a serious setback in the late 1920s when Congress failed to reauthorize the Sheppard-Towner Act. The passage in 1935 of the Social Security Act created Title IV, which offered states financial assistance to support needy children. Through Title V, the law resurrected many of the programs from the Sheppard-Towner Act, authorizing funding to states for health promotion for poor mothers and children. However, unlike other components of the Social Security Act, such as the pension plan that included all retirees regardless of income, children's benefits, with a few exceptions, were limited according to social class, available to indigent children only. Moreover, while the retirement entitlement was enacted as a federal initiative, children's programs under the Social Security Act were to be provided by a complicated matrix of federal and state responsibility.¹⁷

By this time, nearly all political discussions surrounding children's health were class-based, a perspective that would profoundly influence the contours of ensuing child health policy in the United States. While education for all children, poor and nonpoor alike, had been a recognized responsibility of government as early as the mid-19th century, there was no discussion of a similar universal approach to children's health. Indigent children's health was examined through the limiting lens of social welfare and poverty policies, while policymakers assumed that the health needs of middle-class children could be flexibly met by parents and health care providers as they saw fit. This segregation of medical benefits made it virtually impossible to create a comprehensive national approach to the needs of children.¹⁸

The Postwar Era: Growth and Development of the Well-Child Care Concept

By the end of World War II, the importance of well-child care had been established in the minds of the American public; parents expected their children's doctors to offer preventive as well as curative care. The postwar period presented another opportunity for professionals and policymakers to consider what a coordinated care system for children should look like. By the late 1940s, American children as a group were healthier than ever before. Ongoing improvements to the public health infrastructure, together with the advent of antibiotic therapy, meant a steep decline in the number of children hospitalized or placed in convalescent wards for recuperation from such diseases as tuberculosis and rheumatic fever.

Now, many youngsters who contracted acute bacterial infections such as pneumonia could be cured, and those with chronic conditions such as cystic fibrosis or sickle-cell anemia could survive the infections that often accompanied the disease. Immunizations for communicable diseases such as smallpox and diphtheria were available, and one for polio was on the horizon. The nation's leading pediatricians, relieved that the United States had survived the Depression and World War II, now set out to address the health needs of the well child and consider how best to make quality health services available to all children. In 1947, Yale University pediatrician and psychologist Arnold Gesell pressed his colleagues to think about the new era upon them. At the annual meeting of the American Academy of Pediatrics, Gesell spoke about the "vast domain" of preventive pediatrics and the central role it needed to play in pediatricians' practice going forward.¹⁹ But there was one major obstacle facing the vision of Gesell and others: the nation had too few pediatricians—the existing 2,600 board-certified pediatricians oversaw the care of only 10 percent to 20 percent of American children. Worried that this situation would hamper children's health and national strength in the postwar era, the American Academy of Pediatrics sought to partner with the government to address it.²⁰

In 1949, The Commonwealth Fund published the results of a two-year collaborative study by the American Academy of Pediatrics, the Public Health Service, and the Children's Bureau.²¹ The report, *Child Health Services and Pediatric Education*, called for better training of physicians in the provision of well-child care, more pediatric education for all medical students, an increase in the number of pediatricians, and a more holistic, coordinated approach to well-child care. Pediatric leaders celebrated the report for its exhaustive accumulation of data, which quantified known problems such as lack of access to care.

By "turn[ing] opinions into facts," wrote Katherine Bain, director of the Division of Research in Child Development at the Children's Bureau, the report provided important information about problems in pediatric health care delivery. But Bain presciently warned that addressing the inadequate supply of physicians and the maldistribution of services would be much easier than assuring the quality of that care: "Any system devised to meet the deficiencies in 'quantity' of services rendered to children, which merely succeeded in spreading mediocre 'quality' services more evenly, would be of questionable benefit."²²

Bain and other pediatricians also considered the report especially important because it documented what many of them had feared: children's access to care varied significantly by race, socioeconomic status, and geographic region. Although more and more middle-class children were being covered through the emerging voluntary insurance programs, poor children were not; they lacked access not just to the latest medical and surgical therapeutics, but to such basic preventive services as immunizations and dental care.²³

The definition of "quality care" remained elusive. Moreover, at a time when American society was embracing hospital care and private-practice medicine as its preferred care model, the idea of the planned, coordinated network of health resources that had defined the Fund's 1920s child health demonstration fell out of favor. The emerging framework, for child as well as for adult care, was disease- and technology-based, focused on acute care for complex

chronic illnesses such as cancer or disabilities such as cerebral palsy. The funding streams that once went to the Children's Bureau to support public health innovations increasingly went toward hospital-based training for physicians, who finished their educations with little experience in providing well-child care, even though much of physicians' time in practice went to providing preventive pediatric care.²⁴

The postwar interest in children evinced by policymakers crystallized during the 1960s as the cultural effects of the population surge of the baby boom on American society increased.²⁵ The growing scientific and political interest in early-life development and its implications for later outcomes led to an explosion of interest in the factors that shape children's growth, development, and learning. In 1961, President Kennedy's sister Eunice Shriver persuaded him to propose the creation of the National Institute of Child Health and Development (NICHD), the first NIH institute not focused on a disease or organ system. Although several foundations, among them The Commonwealth Fund, were managing long-standing research programs that had significantly increased knowledge of infant and child development, the NICHD now pumped large sums of new money into the field. With the NIH replacing foundations as the primary funder of research, the Fund shifted its attention not only to the training of physicians, but also to emerging roles such as that of nurse practitioners.²⁶

By the mid-1960s, tectonic shifts had also occurred in the financing of health care. The old, largely self-pay or charity-supported care model had been firmly supplanted by private, employer-sponsored health plans that covered most working Americans and by Medicare and Medicaid, the new government programs intended to cover the elderly and the poor, respectively.²⁷

Although Medicaid was almost an afterthought when it was enacted in 1965, it would grow to have profound influence over the health of America's most vulnerable children, becoming the template upon which subsequent health policies for indigent children would be layered. In addition to those Medicaid programs designed to advance access to basic health care for

indigent children, there were new initiatives aimed at improving their cognitive and emotional development and educational outcomes (e.g., Head Start). Also, the new Supplemental Nutrition Program for Women, Infants, and Children (WIC) provided nutritious food to pregnant women and young children. These social welfare programs now supplemented those enacted decades earlier through the Social Security Act.

Although these programs were funded and put in place, little attention was paid to making sure that they cohered with one another or collectively addressed the needs of very young poor children. In 1967, Congress amended Medicaid legislation to authorize a major program aimed at bringing together the programmatic silos dividing the educational, health care delivery, and social welfare sectors. It was called the Early Periodic Screening, Diagnosis, and Treatment (EPSDT) Act. This statute required state Medicaid agencies to provide developmental services for all low-income youngsters, to screen them for potential handicapping conditions, and to make sure that identified conditions received the necessary treatment.²⁸ The middle and late 1960s presented one of the most public discussions of child poverty and its concomitant ill health, lack of opportunity, and malnutrition that the nation had ever seen, brought into American homes by the cameras following Senator Robert F. Kennedy through the Mississippi delta in 1967.²⁹

Most pediatricians of the era addressed considerations of "development" less through health-promoting interventions than by diagnosing and treating disorders that were defined as "organic," such as cerebral palsy or genetic disorders resulting in mental retardation. This approach was actualized by new funding streams aimed at the cognitive sequelae of these conditions. Little research was undertaken into how and when to screen children for development-related conditions and how to integrate into clinical practice the emerging body of evidence coming from the new field of developmental psychology. Although pediatricians agreed in principle on the importance of developmental screening, it wasn't until 1967 that the American Academy of Pediatrics published its first "periodicity"

schedule, establishing the first significant standards and recommendations for the sequence and timing of childhood immunizations.³⁰

The goal of bringing services for poor children together under one umbrella and expanding Medicaid services beyond the field of illness care remained elusive. The legislative language for EPSDT was vague in key areas, so lines of responsibility remained unclear. Statutory language, for example, mandated evaluating children for “physical or mental defects” and required states to take corrective action, but offered little in the way of guidance, leaving the states to define how best to achieve this goal.³¹ Additionally, many states felt they lacked the resources to implement the statute as intended, that is, by providing a full range of multidisciplinary, interagency services for all infants and toddlers with developmental delays or disabilities. As a result, states and municipalities interpreted their roles independently, resulting in a patchwork of services with wide variability according to place and time. The law’s full potential was limited by confusion about implementation, by ambivalence on the part of legislators and policymakers about funding poverty-related programs, and by the complexity of many children’s needs.³²

In the early 1970s, another attempt to enact national health insurance, led this time by President Nixon, failed. So did the Comprehensive Child Development Bill (CCDB), designed to draw together initiatives interspersed throughout the health care, education, and social welfare sectors. There was little support for CCDB’s goal of providing developmental services through a coordinated national framework for all children, not just those who were poor. A few years later, the Carter administration’s Medicaid expansion proposal (the Child Health Assessment Program), which was intended to expand coverage to 700,000 poor children under the age of six years, did not even come to a vote in Congress.³³

Despite these failures, reformers could claim a number of legislative victories in the 1970s and 1980s. The 1975 Education for All Handicapped Children Act (Public Law 94-142) mandated a free public education for all young people ages 3 to 21, even those with

disabling conditions. (It was amended in the 1980s to include children under age 3.) Legislation in the late 1980s broadened the types of services available through EPSDT. Its success was limited, however; the evidence suggested that only 25 percent to 35 percent of all eligible children received a well-child visit.³⁴

Within pediatric medicine, as subspecialties such as cardiology, endocrinology, and neonatology matured in the 1970s and 1980s, there were also a number of attempts to shift the focus in health care toward more and better preventive care for children and a more holistic approach to pediatrics.³⁵ One model for achieving these ends was the notion of “community-oriented primary care” (COPC). The tenets of COPC were similar to those laid out by Abraham Jacobi, which had informed the Fund’s child health demonstration in the 1920s and 1930s. COPC reflected a recognition that the social factors underpinning health and illness needed just as much attention from pediatricians as did targeted disease-based intervention.³⁶ Those pediatricians who supported COPC believed not only in better organization for pediatric primary care services, but also in the need for pediatricians to engage more with child development. Physicians, following the lead of Julius Richmond, M.D., the first national director of Head Start, saw the field of child development as the “basic science” that should undergird the practice of pediatrics; this perspective was all the more vital, they argued, given the recent emergence of “new morbidities” rooted in developmental, behavioral, educational, or psychosocial problems caused by family stressors and social and economic pressures such as poverty.³⁷

“Healthy Steps” to a New Model for Pediatric Primary Care

By the 1990s, the federal government had continued to expand its role in, and its funding for, the provision of health care for children. Growing numbers of youngsters of the working poor and new populations of disabled children benefited from successful attempts to extend income eligibility criteria for targeted groups. Between 1979 and 1996, for example, the rate of diagnosis of attention deficit hyperactivity disorder and

autism increased dramatically.³⁸ Clinicians believed the severity of many of these conditions could be reduced with early identification and intervention, but pediatricians were increasingly reporting that they lacked evidence to justify the type and substance of their preventive care interventions.³⁹ This situation was in stark contrast to the growing body of rigorous evidence that supported disease-related decision-making.⁴⁰

Meanwhile, well-child care remained mostly tradition-bound. It was scheduled according to the immunization timetable, not according to the critical moments in child growth or the identified periods of parental vulnerability.⁴¹ As pediatrician and child health services researcher Neal Halfon, M.D., M.P.H., later noted, the potential for early intervention based on developmental screening was largely untapped:

*[W]e were beginning to talk about the fact that most well-child care followed the periodicity schedule established decades ago when infectious disease prevention still needed to be the major focus for pediatricians. But by the 1990s, we lived in a more “psychosocial” world. While residents learned how to treat an ear infection, they didn’t know what to do about a child who couldn’t read on schedule or one whose parents couldn’t pay the rent*⁴²

Like the 1920s and the early post–World War II era, the 1990s represented a fresh opportunity to reframe the way in which child health care was delivered in the United States. An explosion of new science in the areas of developmental psychobiology, neurobiology, genetics, and social science revealed that very early experiences affected later development in ways previously unrecognized. These findings attracted bipartisan political interest in early-childhood growth and development. Republican president George Herbert Walker Bush proclaimed the 1990s to be the “Decade of the Brain,” while a few years later Democratic president Bill Clinton’s health care reform proposal attempted to address the large numbers of uninsured children

and the great variability of developmental screening availability.⁴³

The importance of containing the cost of American health care assumed new urgency as the percentage of the gross domestic product (GDP) devoted to health care increased rapidly. Consequently, the 1990s brought heightened discussions about health care quality per dollar expended, which, despite Katherine Bain’s suggestions of 40 years earlier, had not been captured for either children or adults. The fledgling debates surrounding health care quality focused mostly on adult care, however, while failing to address the needs of the developing child. Those few leaders in the nascent pediatric quality movement argued that assessing the benefits to children of preventive pediatrics required a new paradigm, one that would move beyond quantifying immunization rates to incorporate robustly measured best practices of care for those youngsters with developmental vulnerabilities, and would provide the evidentiary base for those practices.⁴⁴

Ambitious attempts were under way to translate into practice the new evidence emerging from the developmental sciences, chief among them the Bright Futures campaign, which was sponsored jointly by the Maternal and Child Health Bureau and the American Academy of Pediatrics (AAP). Bright Futures expanded the traditional periodicity schedule with a set of guidelines that included more psychosocial and developmental services. Important obstacles, however, stood in the way of incorporating those guidelines into routine pediatric practice for all children. Many clinicians perceived developmental screening as too time-consuming, and few believed they could be reimbursed for these services through Medicaid or even private insurers. And, if they did identify a problem, many pediatricians lacked guidance on how to proceed.⁴⁵

In 1994, Commonwealth Fund president Margaret Mahoney announced an ambitious multi-year, multisite \$4.5 million demonstration, the Healthy Steps for Young Children program. Built on a successful pilot program at Boston Medical Center, Healthy Steps added a new health professional, the Healthy Steps Specialist, to the health care team. He or she

would monitor the child's development, attend closely to growth-related issues, and respond to parental concerns through a menu of services such as home visits, telephone support, and support groups. Mahoney, who became chair of the National Advisory Committee for Healthy Steps the next year when she retired from the Fund, stressed that the time was auspicious for Healthy Steps:

Fresh insights are emerging from science about the importance of the first three years of life; mothers and fathers are saying they want to know more about fostering their young child's well-being [I]t is a time when a promise of better care at good value can be tested.⁴⁶

Kathryn Taaffe McLearn, Ph.D., an early-childhood health and development specialist, was recruited by Mahoney to lead Healthy Steps. Unlike previous demonstrations, Healthy Steps was designed as a cooperative venture that encouraged collaboration; it ultimately attracted \$16 million in contributions from more than 50 funders linked together in creative local and national partnerships.⁴⁷ Healthy Steps was also innovative in that it incorporated an evaluation mechanism, overseen by researchers from the Johns Hopkins Bloomberg School of Public Health.⁴⁸ But the Healthy Steps program was especially novel because it harkened back to the 1920s Commonwealth Fund demonstrations in that it examined the issue of designing an integrated model of pediatric primary care through a lens that focused on all children, both wealthy and poor, instead of considering needs based on social class.

In 1997, the first 15 evaluation sites chosen for the Healthy Steps demonstration began to implement a curriculum designed by Barry Zuckerman, M.D., and his colleagues at the Boston University School of Medicine. Simultaneously, the Fund embarked on a study that was the first of its kind, a survey proposed by the Fund's new president, Karen Davis. Davis had served under the Carter administration in the Department of Health and Human Services as a health

economist and deputy assistant secretary for health policy. Now she wanted to generate information about what help parents felt they needed from their children's health care providers in order to function more effectively as parents. The study was called the National Survey of Parents with Young Children.

It took as its base a representative sample of 2,000 parents with children under the age of three years. The findings reinforced the significance of stressors faced by families in the 1990s, an era in which there was wide recognition that, with the majority of mothers now working outside the home, American society had undergone a fundamental change.⁴⁹ The survey also yielded a finding that surprised many professionals: from the perspective of parents, there were crucial ways in which the health care delivery system was not meeting their needs.

Only 58 percent of parents, for example, reported that they received enough help from their child's health care provider to be able to translate into daily life the new research on brain development in young children. Most had questions about nonmedical issues such as discipline, feeding, and toilet training but were uncertain as to whom to ask for advice. Only one of five reported receiving information on topics such as injury prevention, nutrition, and child development, all considered by the AAP to be important areas for parents to understand. Screening for conditions such as maternal depression that were known to impact family functioning and child development was addressed in a widely variable fashion. At a time when cost-reduction strategies resulted in mothers being discharged from many hospitals only a few hours after childbirth, many new parents reported feeling overwhelmed by their new responsibilities. Finally, the survey revealed that lower-income families felt the financial and emotional strain of child-rearing more severely than those at higher socioeconomic levels. This finding bolstered already strong evidence that lower-income children were at the highest risk for growth- and development-related problems.⁵⁰

The survey's findings supported the ideas underpinning Healthy Steps: parents needed and

wanted more than just disease diagnosis from their children's care providers. They sought guidance on child-rearing and advice regarding how best to help their child develop physically, emotionally, cognitively, and socially in the context of a healthy and stable family life.

Spurred by Fund-sponsored training seminars and other dissemination strategies, by the late 1990s 21 practices around the nation had Healthy Steps Specialists on staff, and both parents and care providers were reporting widespread satisfaction with the program. Nonetheless, from the very beginning Healthy Steps supporters recognized a major challenge facing the Healthy Steps model: how to sustain its benefits after the external funding expired. Who would pay the salaries of the Healthy Steps Specialists in a health care system coming under more financial pressure with each passing year?

Despite its cooperative and coordinated nature, built-in evaluation, and ambitious goal of bringing a universal, evidence-based model of pediatric preventive care, Healthy Steps faced formidable obstacles to permanence. The lack of a built-in and stable funding stream to reimburse clinical agencies for the Healthy Steps Specialist's salary and services ultimately became the greatest challenge to the Healthy Steps program's reproducibility and growth on a national scale. The Fund and others interested in infusing a broader set of services, such as sophisticated developmental screening and child-rearing advice, into well-child care knew that in order to achieve sustainability in American health care delivery, payers—not just practitioners and parents—needed to become stakeholders in developmental services for young children.

PART II. NEW SOLUTIONS FOR OLD PROBLEMS: ABCD AND THE CHILD DEVELOPMENT AND PREVENTIVE CARE PROGRAM

Until The Commonwealth Fund's Child Development and Preventive Care Program, everyone was stuck. Despite decades of trying, no one knew how to incorporate developmental screening for children into practice in a systematic, coordinated, cost-effective, evidence-based fashion. The CDPC program showed a way of doing it, importantly, one that didn't take a lot of money or an act of Congress.

—Kay Johnson, M.P.H., M.Ed. (2011)

A Radical Idea: Private Funding to Encourage Innovation Within State Medicaid Agencies

In the early 1990s, public attention to emerging scientific evidence about brain development had facilitated the development of the Healthy Steps initiative. In the late 1990s, a second new policy window appeared. In the most significant change to health and social welfare policy since the 1960s, reformers called successfully for devolution of power from the federal government to state authorities. In 1996, President Bill Clinton signed two pieces of legislation that radically reshaped the social safety net for children and families. The Personal Responsibility and Work Opportunity Reconciliation Act of 1996 terminated the open-ended federal commitment to ongoing financial assistance for poor families, while Title XXI of the Social Security Act, known as the State Children's Health Insurance Plan (SCHIP), created a new \$20 billion funding stream designed to expand access to health insurance for indigent youngsters whose families did not qualify for Medicaid.⁵¹

Before 1997, Medicaid paid for half of all health care delivered to infants and for almost one-third of care for children ages 1 to 5. SCHIP now added more children to the rolls of publicly funded insurance

programs. Also now in transition were models for health care financing. Going forward, more children, both publicly and privately insured, would receive medical services through managed care. By the late 1990s, this change was having a major effect on children, since more than 85 percent of all Medicaid managed-care enrollees were either children or women of childbearing age.⁵²

Commonwealth Fund president Karen Davis wanted the Fund to take a leadership role in shaping policy to respond to this new health care delivery context. Davis, an economist, believed that policy formulation must be based on data. She stressed the importance of the Fund's own Survey of Parents with Young Children and the forthcoming National Survey of Early Child Health. Davis saw that these questionnaires not only would capture health care issues from the perspective of the parent consumer, but could also serve as a basis on which to translate complex social science data into actionable information that policymakers could appreciate. For instance, data emerging from the surveys indicated that indigent mothers were more likely to suffer from depression, a known risk factor for developmental problems in children. Also, the Survey of Parents with Young Children revealed that while breastfeeding rates were lower among poor mothers, they could be raised by timely counseling from a physician or nurse. Even "simple" recommendations from clinicians to parents about practices to promote their children's brain development—for instance, that they could help their children by reading to them—worked.

By 1998, The Commonwealth Fund team included senior vice president Brian Biles, M.D., M.P.H., the former staff director of the Subcommittee on Health of the House Ways and Means Committee, and Melinda K. Abrams, M.S., a recent graduate in health care policy from the Harvard School of Public Health. Along with Patricia A. Riley, executive director of the National Academy for State Health



Melinda K. Abrams, M.S., vice president, Patient-Centered Coordinated Care

Policy (NASHP), they developed an implementation strategy for an intriguing idea.

NASHP, a voluntary group, had been founded in the late 1980s by health policy leaders seeking a vehicle to share policy challenges and best practices across states. The NASHP and Commonwealth Fund working group considered states an untapped resource, believing that if their Medicaid agencies were given the right sets of tools, they could create sustainable new models for developmental health care services to children. They thought that improved access to care, increased rates of screening and referral, and better integration of care could be achieved cost-effectively at the state level given the right support systems and the freedom of each state to tailor its programs to its own needs.

Their idea resulted in the Assuring Better Child Health and Development (ABCD) initiative. It aimed to build on Healthy Steps but in a more targeted way by focusing on poor children. By now, as was clear from the evidence, indigent youngsters suffered from overwhelmingly high rates of preventable growth and developmental problems, and early intervention stood to benefit them financially in the form of fewer health expenditures and enhanced economic well-being in the future. The Commonwealth Fund and NASHP group recognized that while Medicaid had improved access to disease-based care for children, its potential to enhance screening and developmental care was not being fully realized. It was decided to fund this initiative through Medicaid.

The ABCD team sought to build on the lessons learned from Healthy Steps. Bringing payers in early in the process facilitated an ongoing dialogue between clinicians and state Medicaid officials in ways that stood to improve the chances of sustainability. The approach being developed by the Fund was not, however, without risk, not least because there was little in the way of precedent. The idea of private funding for state Medicaid agencies was not just novel; for some, it was revolutionary. In the past, state Medicaid agencies had contracted with managed care organizations to oversee care; the new model would ask them to engage more directly with practitioners both to change practice

behaviors and to design public policy. Some questioned the wisdom of a foundation providing a grant to a government agency. A number of issues needed to be considered. If the grantee were a government agency rather than an individual researcher or community program, could it, for example, be held accountable in the same way? Moreover, how much money was needed to make a difference and seed innovation? Was \$100,000 enough? Too much? Others worried that states would use Fund monies as a substitute for federal revenue, thus diverting existing resources to ends other than improvement of child health care. In order to prevent such an outcome and maximize the likelihood of success, The Commonwealth Fund invited NASHP, as experts in state-level policy, to choose four demonstration states to receive three-year grants.⁵³

One of the first tasks before launching the ABCD program was to draft a uniform definition of “developmental care.” What did this concept really mean? For this effort the team turned again to Neal Halfon, M.D., M.P.H., as well as to developmental pediatrician Michael Regalado, M.D. The definition Halfon and Regalado proposed was quickly adopted for the ABCD initiative. It included clinical assessment, follow-up surveillance, screening and referral, developmental health promotion and intervention, coordination of care, and ongoing monitoring of all these functions.⁵⁴

Before now, developmental screening had usually been bundled with other well-child services such as immunizations; one of the challenges of the study was therefore to break it out discretely in order to quantify its availability. Another challenge would be to engineer reimbursement for care that many clinicians assumed was not covered. One thing that would help in this regard was the existing EPSDT mandate stipulating that states screen indigent children for developmental conditions. The team also reasoned that if ABCD were structured in a way that quantified the quality of developmental services and their outcomes, Medicaid would be more likely to reimburse for those services.⁵⁵

The ABCD planning strategy sought to build on data emerging from Healthy Steps regarding the importance of developmental screening and early referral. In addition to revealing the importance of

collaboration between providers and payers, and paying attention to payment and sustainability from the beginning, Healthy Steps had demonstrated the benefits of targeting poor children. The initiative also capitalized on events such as two White House conferences on child health in the late 1990s that spotlighted the ongoing accretion of scientific evidence revealing the importance of early brain development to subsequent health and well-being and the opportunities offered by early-intervention programs that enabled early identification of developmental risks. The Fund's attention to the quality of children's health services also coincided with that of other voluntary initiatives now under way nationwide. The Child and Adolescent Health Measurement Initiative (CAHMI) aimed to develop meaningful measures for assessing the quality of pediatric health care. Another organization, the National Institute for Children's Healthcare Quality (NICHQ), began instituting collaborative learning aimed at quality improvement.

The pilot states would be required to create models that promoted the provision of quality child development services (screening, surveillance, and referral) for all Medicaid-eligible children from birth through the age of three years; identification of family risk factors likely to impede children's healthy development; and policies and programs to ensure that pediatric providers and health plans would have the necessary knowledge and skills to furnish those services. It was critically important that states receiving ABCD funds would be able to match these private Commonwealth Fund dollars with federal Medicaid dollars.

But the states would be given flexibility to develop financing models that worked for them individually. They were also encouraged to be creative, to experiment, and to take informed risks. And they would be required to share information with one another about what worked, and what did not. As such, each state needed to commit to participating in a cross-state learning consortium, or "think tank," that Commonwealth Fund and NASHP leaders believed would seed innovation, replication, and the spread of best practices and new ideas. As with the Healthy

Steps initiative, a monitoring and assessment process for ABCD was embedded in the program design. This evaluation, though modest, led to the use of comparable measures by participating states, and eventually contributed to advancements in the measurement of development screening and care coordination.

A number of thought leaders in children's health care were asked to provide consultation in the early phase of ABCD (which later became known as ABCD I). Pediatrician Neal Halfon, M.D., M.P.H., had been addressing the state of pediatric developmental science and convened an advisory group to provide ongoing guidance and technical support for ABCD. Sara Rosenbaum, J.D., of George Washington University, provided policy analysis to help state Medicaid agencies better understand how to leverage the resources available to them through statutes such as EPSDT and how best to draw on them to advance ABCD. Christina Bethell, Ph.D., of the Foundation for Accountability (FACCT), created a variety of measures, among them the Promoting Healthy Development Survey, to help state Medicaid managed-care organizations collect and interpret the wealth of data to be generated in the ABCD states. Bethell also developed tools aimed at evaluating health system performance in providing quality education to parents regarding their children's growth and development, identifying the barriers that needed to be overcome in order to bridge the gap between guidelines and practice, and tracking what parents thought about the services their children received.⁵⁶

NASHP selected the states of Utah, Vermont, North Carolina, and Washington to participate in ABCD. All were judged to have stable, committed state Medicaid staffs, and their grant applications had all revealed strong statewide collaboration. Each had provided a detailed outcome plan and thoughtful mechanisms to promote sustainable practice and policy changes. North Carolina, for example, outlined the way in which its innovative statewide pilot program, Community Care of North Carolina (CCNC), with its system of data-based case management, would provide

a sturdy template on which to layer ABCD-related initiatives.⁵⁷

Almost immediately, all four states crafted improvement models that enhanced developmental screening rates and clarified Medicaid policies and procedures, changes that stood the test of time (see box for a full summary). No state was more enthusiastic about ABCD than North Carolina.⁵⁸ Developmental pediatrician Marian Earls, M.D., F.A.A.P., medical director of Guilford Child Health (GCH) Inc., a large pediatric safety-net practice in Greensboro, saw the combination of ABCD and CCNC as creating a “perfect” opportunity that would allow her to achieve her long-standing goal of improving developmental services and well-child care for children in North Carolina.⁵⁹

Most of the children in Earls’ practice were poor, as were 44 percent of North Carolina’s children. The North Carolina ABCD group quickly realized that the program’s resources brought people together to talk with one another as they had never been able to in the past, and in ways that made change possible. For example, up to now the lack of clarity in EPSDT language had left practices, and sometimes individual care providers, to interpret the concept of “developmental screening” for themselves. Reimbursement forms were unwieldy and confusing.⁶⁰ With the support and infrastructure provided by ABCD, payers (state Medicaid agencies) and physicians could now together develop standardized definitions and streamlined processes

that mandated screening as part of an EPSDT visit, a change that saved clinicians considerable time.

At the beginning, Earls and her team used ABCD as a quality-improvement pilot for a single network of practices, but within two years its procedures were being applied across the entire state. Systematized screening with follow-up interventions and close coordination with managed care organizations improved physician satisfaction almost immediately. The intellectual and technical resources provided through the program led to work-flow mapping that identified for individual practices the most effective and replicable ways to integrate developmental screening and surveillance into primary care. The need for more practice-level standardization quickly became clear, and a proprietary developmental screening instrument, the Ages and Stages Questionnaire (ASQ), became integrated into primary care practices across the state.⁶¹

A major advantage of ASQ was that it was a validated instrument that could be reliably completed by parents based on their home observations of their child. Earls had long considered screening processes based only on in-office observations made by clinicians to be invalid, because children behave differently away from their home surroundings. In addition to the better assessment outcome, the ASQ model greatly increased parents’ satisfaction with their children’s primary care provider. The parent-completed tools, which were inexpensive and required little staff time, engaged parents directly in their children’s care and opened up

EXHIBIT 1. ENDURING CHANGES OF ABCD I STATES

State	Lasting Improvement
North Carolina	Community Care of North Carolina’s developmental screening practices have spread to all 14 networks across the state. The state requires standardized developmental screening, but the service is not reimbursed.
Utah	The state has maintained its pre-natal-5 nurse home visiting program for children at risk of developmental delay.
Vermont	Healthy Babies, Kids, and Families home visiting program was expanded across the state as part of children’s integrated services. The state also reimburses for standardized development screening, though it is not required.
Washington	State continues to use EPSDT forms developed during ABCD I to facilitate structured developmental surveillance. State requires providers that offer screening for children in foster care to use the forms and pay an enhanced fee for the screens.

new lines of communication between care providers and parents. The improvements in screening rates in North Carolina were astounding. When ABCD was launched in the state in 2000, 15 percent of eligible children were receiving EPSDT screening by the age of two years. By 2001, screening rates for those children in the ABCD pilot practices were greater than 70 percent.⁶²

As a result of the ABCD and CCNC effort, physicians, in partnership with state agencies, amended state Medicaid policies for North Carolina. The new rules mandated the use of a standardized, validated tool for developmental screening at specified intervals. Within a short time, more than 90 percent of primary care facilities serving Medicaid-eligible children had integrated developmental and behavioral screening into practice.⁶³ Evaluations of ABCD I categorized it as a successful collaboration among Medicaid and other state agencies, noting that “interagency barriers were broken down and often intractable bureaucracies changed their behaviors.”⁶⁴

Setting the Stage: A New Partnership for a New Program

In 2001, the Institute of Medicine released a landmark report calling for a redesign of the American health care system to improve the quality of care through evidence-based practice, and to identify those gaps in services that precluded the provision of first-rate health care to all Americans.⁶⁵ That same year, the AAP issued new health supervision guidelines that maintained the focus on developmental services by calling for the integration of health, educational, and social variables throughout children’s programs.⁶⁶ And, in July 2001, The Commonwealth Fund’s board decided to bring all of its child development activities under the single programmatic umbrella of the new Child Development and Preventive Care (CDPC) initiative. With a dedicated annual budget of nearly \$2 million, the CDPC program would support projects to:

1. Develop state-of-the-art, evidence-based curriculums for pediatric residency training in early child development.

2. Articulate the evidence base for the efficiency and effectiveness of preventive and developmental services.
3. Complete the evaluation of the Healthy Steps and ABCD initiatives.
4. Extend the work of the ABCD initiative to more states.
5. Identify federal and state policy options for promoting the universal incorporation of preventive and developmental services into pediatric practice.
6. Expand parents’ and clinicians’ access to reliable information on child development through the use of information technology.⁶⁷

At this juncture, the Fund began looking for a director for the new program. Throughout the search, Melinda Abrams managed the child health portfolio while continuing to bear primary responsibility for the ABCD initiative. Abrams’ experiences before graduate school as a community organizer had convinced her of the importance of combining a “top down” approach (such as enacting new federal policies) with a “bottom up” strategy that engaged those “on the ground” to effect social change. She believed strongly in a problem-solving approach that identified a problem and, often, the seemingly intractable barriers to addressing it, but also believed in the importance of generating the evidence necessary to craft a meaningful solution.⁶⁸



Edward L. Schor, M.D., former vice president, State Health Policy and Practices

Edward L. Schor, M.D., a member of the ABCD Advisory Committee and a nationally respected leader in the field of pediatrics, was chosen to take over direction of the CDPC program and Abrams’ efforts with ABCD in 2002. Schor was trained in general pediatrics and behavioral sciences and had a long-standing interest in the psychosocial and economic variables that shaped how child health care was delivered in the United States. As a resident in training in the 1970s, he had realized that he was “learning a

great deal about children's diseases, but not as much as I wished to learn about children." He believed strongly in community-oriented primary care with a strong developmental focus.⁶⁹ Schor had been a program officer for the Kaiser Family Foundation, had served as medical director for family and community health and director of health policy in Iowa's Department of Public Health, had directed a pediatric residency program, had done research on the family context of child health, and as a medical director for a managed care organization had coordinated health care services for children in foster care. His new role brought together the many strands of his career.

Like Abrams, Schor wanted to capitalize on the growing quality-improvement movement and the trend toward evidence-based medicine. He was well aware that the effectiveness of pediatric preventive services was difficult to "prove" scientifically. The EPSDT legislation had improved access to care, but in Schor's view it remained "a wish unfulfilled" because the law lacked specificity. Developmental screening, for example, could be, and often was, interpreted differently by clinicians. For some, it included a formal developmental assessment. For others, it meant a summary of the clinician's overall impression captured through a routine well-child visit.

Nevertheless, Schor wanted to use EPSDT's mandate to fund "medically necessary" developmental services for very young children as the basis for organizing the new program's goals. He also argued that in order for the CDPC program to make real change, it needed to be more than just an assemblage of good ideas and demonstrations: it must push the horizons of research, identify concrete program targets, and nest them in existing funding streams.⁷⁰

Schor also wanted to engage the research, practice, and policy initiatives undertaken through the CDPC program, envisioning it as an opportunity to address the long-standing policy challenge of quantifying the benefits of well-child care. In 1988, the Office of Technology Assessment, the scientific advisory body to Congress, had concluded that "evidence on the effectiveness of components of well-child care other than

immunization is more remarkable for its limitations rather than its findings."⁷¹ In other words, while most people would consider that well-child care provided a social benefit, there was little evidence at the level of individual child outcomes to support the claim of a significant return on such a major investment of resources.

Schor's and Abrams' strengths complemented each other unusually well. Although both were passionate and informed about children's health care and committed to data-driven change, Schor brought a vision grounded in his many years of clinical and policy experience, while Abrams possessed the ability to take big ideas and turn them into action, in part by effectively creating partnerships between the Fund and grantees, as well as other influential stakeholders.⁷² By summer 2002, they and their Fund colleagues had a broad outline in place for infusing developmental services into well-child care in a structured, sequential, and standardized fashion. First, they had aggregated all of the available data about developmental screening. Then they planned to structure funding for diagnostic tools and best practices; tracking systems to identify successes and failures; apparatuses for the dissemination of data and new practices; and support of leading pediatric consultants and other stakeholders.⁷³

In October 2002, Schor convened a panel of seven of the nation's leading pediatricians to review the work so far and make recommendations for moving forward. The group endorsed Schor's approach, agreeing that child development care should be better anchored within the well-child care framework, that low-income children should be targeted because they were the most at risk, and that better measures to assess development were a key to building professional support. The group agreed with Schor that the Fund needed a clear strategy to achieve more than just further documentation of the problem and an intellectual argument for change. One panel member, Julius Richmond, M.D., a former surgeon general, defined the problem forcefully and eloquently: "The landscape is littered with reports. ... A report isn't enough, we have to have a social strategy of how we get there from here."⁷⁴

In another contribution to the meeting, Paul Dworkin, M.D., professor and chairman of pediatrics at the University of Connecticut School of Medicine and physician-in-chief of Connecticut Children's Medical Center, described his innovative care coordination model, ChildServ. Dworkin created the program in 1998 in Hartford, Connecticut, a city whose 41 percent child poverty rate placed an overwhelming number of children at high risk of serious developmental problems. Dworkin's research suggested that 25 percent to 30 percent of Hartford's kindergarten students lacked the emotional, behavioral, and/or developmental resources to succeed in the first grade.

Dworkin had long believed that developmental screening was largely overlooked in American pediatric medical education and, consequently, undervalued in clinical practice. Dworkin's work through ChildServ revealed that it often took three to four office visits and 12 to 13 telephone calls to connect parents with developmental resources, if the resources even existed. He designed ChildServ to identify the services available in the community, to provide an organized referral system, and to track children in a streamlined fashion.⁷⁵ Thanks to ChildServ, when a clinician caring for a Medicaid-insured child suspected a developmental problem, he or she could call a care coordinator at a toll-free telephone number. After the provider and the coordinator together identified appropriate services from the ChildServ inventory, the care coordinator facilitated referrals to those services. Families themselves could also contact ChildServ directly to be linked to services. A major strength of ChildServ was that it used existing resources such as Title V and Part C. With new funding from CDPC, ChildServ evolved into the "Help Me Grow" initiative. Fund support not only helped Dworkin to link to NASHP, NICHQ, and the ABCD program, it provided resources for him to create a dissemination strategy that could be adapted by other states.⁷⁶

In June 2004, the journal *Pediatrics* published a supplemental issue focused on an analysis and discussion of results from the 2000 NSECH, developed with support from The Commonwealth Fund, the AAP,

the Gerber Foundation, and Neal Halfon's Center for Healthier Children, Families & Communities, at UCLA. The matrix of intersecting tools that Abrams, Schor, and the ABCD Advisory Board had wanted to develop was becoming a reality. The National Survey of Early Child Health, for example, was strengthened by adapting several of Christina Bethell's Commonwealth Fund-supported Promoting Healthy Development Survey (PHDS) topics for inclusion in the new survey. Like the Survey of Parents with Young Children, the National Survey of Early Child Health revealed that many parents wanted more information about child-rearing, as well as about growth and development. The new survey spotlighted once again the great variability in the quality and quantity of developmental services available to families.⁷⁷

Later that year, Schor published a landmark article in *Pediatrics*. The paper, "Rethinking Well-Child Care," summarized his many years of thinking about the subject. Schor reminded his fellow pediatricians of several facts: existing policies and practices had failed to generate universal access to developmental services for children; the widely accepted periodicity schedule, which guided payment by Medicaid and other insurers, remained driven by the timing of immunizations; and the nascent but growing movement in support of evidence-based preventive guidelines, such as those recommended by the U.S. Preventive Services Task Force, measured interventions only in terms of morbidity and mortality reduction. Clearly, pediatric clinicians had a lot of work ahead of them if they were to generate an evidentiary basis for well-child care. The article had a strong impact, stimulating a number of follow-up letters and discussions around the country, and was cited by other scholars in medical journals more than 40 times in the next few years.⁷⁸

Schor's article, together with early Fund grants to Bethell, Dworkin, and the research center Child Trends, helped to synthesize the extant data about child development, to identify key gaps in knowledge, and to set examples of best practices that could be adapted for national use. In the excitement surrounding ABCD I, it and other projects addressing child development

“primed the pump” for more knowledge generation, and attracted a new level of attention to the field of developmental screening. So did the publication in 2004 of a new study sponsored by the Institute of Medicine. The report, titled *Children’s Health, the Nation’s Wealth*, updated the discussion begun in the 1990s regarding early brain development and the importance of a national commitment of resources to youngsters in early childhood. The IOM report was peppered with information from Commonwealth Fund–supported research projects, a reflection of the growing visibility of the CDPC program.⁷⁹

PART III. RETHINKING WELL-CHILD CARE: HOW THE COMMONWEALTH FUND PROVIDED THE TOOLS FOR CHANGE

*What is the role of the primary health care system in promoting children's development, and how can we promote its effectiveness?*⁸⁰

—Edward L. Schor, M.D. (2002)

A Foundation for Change

The ABCD program had built tremendous momentum for positive change; an evaluation of its efforts would laud it for the fact that “interagency barriers were broken down and often intractable bureaucracies changed their behaviors.”⁸¹ Looking forward, Commonwealth Fund staff wanted to develop a new initiative to pursue three areas that both Healthy Steps and ABCD had shown to be of major importance: developmental screening, quality improvement, and care coordination.

ABCD II would be the laboratory to test further initiatives in these areas. But while the states would still have extensive freedom to individualize their efforts, ABCD II was designed to be less exploratory than ABCD I had been. Abrams, who led ABCD II, wanted a more specific focus on developmental screening, a direct outcome of North Carolina’s ABCD I successes. The number of applicant states suggested that the Fund’s ABCD initiative was finding a receptive audience. Twenty-five states applied for three-year ABCD II grants, and California, Illinois, Iowa, Minnesota, and Utah were selected to participate. Clearly, the answer to the question raised at the beginning of the ABCD project as to whether a relatively modest grant to states of less than \$100,000 could make a difference was a resounding yes. And, like the model states for ABCD I, these applicants had strong state leadership already guiding their Medicaid and SCHIP child health programs. Moreover, their proposals included ambitious, yet clearly defined, strategies to address problems related to providing developmental

screening and mental health promotion for very young children.

ABCD II was launched in January 2004. Central to the ABCD model was its flexibility in permitting each state to define its own approach based on its own needs. Illinois, for example, wanted to improve Medicaid reimbursement for developmental screening as well as to promote maternal depression screening. In its applications, California’s Medicaid officials proposed to convene a statewide working group to develop new policy with managed care programs in two counties, as the first stage in making policy changes statewide.⁸²

Program staff and NASHP incorporated into ABCD II the key strategies that had worked well in ABCD I: planning for dissemination early on; putting in place strong advisory committees; supplying technical assistance; and requiring states to match grant funds. Neva Kaye, the NASHP senior program director responsible for ABCD, had realized by now that the shared learning consortium was the program’s single greatest strength. The learning collaborative created an intellectual space to bring together professionals who had not previously had a forum for interaction—Medicaid directors, academic researchers, and clinical practitioners now had the time and place to discuss issues in depth and to agree together on taking informed risks. This interaction not only built goodwill, it forged practical solutions.⁸³

In the years 2004 to 2011, Fund grantees studied strategies for improving screening, quality of care, and care coordination; for integrating these advances into mainstream clinical practice; for disseminating them statewide; and for anchoring them in sustainable policy. The Fund’s approach was targeted and strategic, with a funding strategy that maintained an iterative, ongoing relationship between itself, its grantees, and the entire CDPC grant portfolio. Abrams, for example, went on regular site visits, reminding grantees and NASHP of the “big picture” by keeping them apprised of other CDPC and Fund initiatives germane to ABCD.

The Fund decided to start with screening for a number of reasons. As a pediatrician, Schor knew

that identification of a problem through screening was one of the first steps in a clinician's thought process. Most pediatric health care providers were already doing some kind of screening, but usually it was a subjective appraisal that entailed observing the child and asking the parent a few questions, rather than drawing on a standardized instrument. Screening was also a logical place to start because Schor knew it would be important to parents whose top priority for a well-child visit was to learn how their child was progressing developmentally. Moreover, compared to other types of practice changes, introducing a simple screening instrument was relatively concrete. Schor hoped that once a practice figured out how to collect developmental data in a standardized fashion, it could more easily adopt data-gathering devices for other issues, such as maternal depression screening.⁸⁴

Developmental Screening

Clinical practice is nested in a professional context that requires a defined body of knowledge and a trained pool of individuals authorized to do the work. The CDPC generated information valuable for guiding practice, but it went beyond that to help expand the specialty of developmental and behavioral pediatrics for the 21st century.⁸⁵ The infusion of resources helped shift the focus of well-child care toward developmental service, and also forged a better understanding among developmental-behavioral pediatricians regarding how they could promote the inclusion of appropriate developmental services, such as screening, in primary care practice and training.⁸⁶

Mapping the Literature. The program's team funded a number of projects that aimed to identify barriers to screening, to develop screening tools, to publicize examples of best practices, and to embed developmental screening in standards maintained by the AAP and other professional organizations. One such project was headed by Michael Regalado, M.D., director of developmental pediatrics at Cedars Sinai Medical Center in Los Angeles, who mapped the extant literature in order to define and examine the evidence base supporting the value of developmental services.

Regalado's work consolidated all the available information and provided a typology of developmental services that was used in developing the CDPC program. He ran focus groups with pediatricians and found them to be very interested in providing more child-rearing guidance to parents, while at the same time they felt that they faced numerous barriers to doing so, among them inadequate training, time constraints, and lack of knowledge regarding community resources.⁸⁷

In the course of cataloguing the available developmental screening instruments, Case Western Reserve psychologist Dennis Drotar, Ph.D., also documented the lack of consensus in clinical practice regarding what the best tools were, and a dearth in the literature regarding their validity.⁸⁸ Another pediatrician, Laura Sices, M.D., reviewed the research on developmental screening. While her study showed that there was very little research into its impact, there was empirical evidence to be found for its benefits: in those states that did little screening or did not make screening uniformly available, there was a higher incidence of developmental problems in children.⁸⁹

Models. Program staff challenged investigators to think big. While attending a conference on health care quality in 2003, for example, Schor asked David Bergman, M.D., of Stanford University the question that he put to many of his grantees: "What would a 'perfect well-child care' system look like?" He did so to capture their imaginations and challenge their inventiveness, even as he asked them to undertake a definable project with tangible outcomes. Bergman's project produced a practical, authoritative physician guide to best office practices in well-child care, including research-based, technology-driven strategies to achieve them. Bergman articulated and promoted the idea of "tiered care," that is, of providing pediatric primary care visits that varied in frequency, length, and scope, based on a needs assessment.⁹⁰

Bergman and his colleagues consolidated information on the latest health care innovations and consulted with pediatric experts to generate the blueprint for a continuum of primary care services. The resulting guide was widely disseminated by the Fund to

pediatric practices through AAP and NICHQ meetings and publications.⁹¹ After a Fund-sponsored conference suggested broad support for the tiered-care concept, Bergman and his colleague Arne Beck received funding to implement the model. Children in Colorado Kaiser and Denver Health plans were tracked into one of four periodicity schedules on a continuum from low risk to high risk. Risk assessment was based on a number of factors, among them a Web-based form that parents completed prior to their child's visit.⁹²

The CDPC funded subsequent projects related to the idea of tiered or individualized well-child care. In 2005, J. Lane Tanner, M.D., of the Children's Hospital and Medical Center in Oakland, California, Martin T. Stein, M.D., of Rady Children's Hospital at UCSD, and Lynn M. Olson, Ph.D., at the American Academy of Pediatrics, documented the importance of well-child care to pediatricians and parents, suggesting ways of how practice might be redirected to support a greater focus on child development.⁹³ Another grant, to Children's Hospital of Philadelphia pediatrician Christopher Forrest, M.D., Ph.D., and Susmita Pati, M.D., M.P.H., of Stony Brook University, analyzed how to use risk factors to tier care. This project not only revealed the impracticality of a one-size-fits-all approach to well-child care, it also was an early example of the potential use of electronic data-gathering in health care delivery and quality improvement.⁹⁴

Diffusion/Dissemination. Fund-sponsored seminars such as workshops at the annual meetings of the Society for Developmental and Behavioral Pediatrics helped to spark interest in and enhance knowledge about promoting developmental screening by general pediatricians. Interest proved strong: the sessions were filled every year. The CDPC team also recognized the importance of leveraging connections with the AAP. In 2004, as part of the implementation of Bright Futures, it provided a large grant to the AAP to test developmental screening and other practice changes in a number of pediatric practices.⁹⁵ Capitalizing on North Carolina's success in ABCD I, the Fund also supported Marian Earls in bringing her expertise to states who were already contacting her for advice. Finally, they

provided assistance to individuals trying to harness the Internet in novel ways, funding Henry Shapiro, M.D., of All Children's Hospital in St. Petersburg, Florida, to enable him to turn his electronic resource on growth and development into a substantial tool for pediatricians and parents. The site ultimately became a permanent responsibility of the Section of Developmental and Behavioral Pediatrics of the AAP and took up its home on AAP's website.⁹⁶

In 2007, the ABCD Screening Academy was launched to spread the best practices, experiences, and successes of the original eight ABCD states to more than 20 other states and U.S. territories. The Screening Academy was a 15-month project for which states received no money except funding to attend a conference run by NASHP and to participate in an ongoing network of webinars. Unlike the two ABCD phases, which had each included a small number of states and required three years of involvement, the aim of the Screening Academy was to efficiently engage as many new states as possible in promoting structured developmental screening. The ABCD I and II states, NASHP, and the Fund had learned a great deal regarding how best to engage Medicaid and other state agencies. A major goal of the Screening Academy was to spread that information, as well as state success stories such as Earls' in North Carolina and Dworkin's in Connecticut, beyond the eight participating states. This low-cost dissemination strategy worked very well. Every state improved its tracking of children receiving developmental screening and made meaningful changes to policies and procedures that resulted in improved quality and reduced costs. By 2009, the Screening Academy states were reporting significant improvements in rates of developmental screening. Changes to Medicaid program provider manuals and websites clarified expectations regarding structured developmental screening, while new requirements mandated standardized developmental screening as part of EPSDT visits. Provider education and revised claims-processing systems also improved rates of screening. This broad stakeholder engagement represented an innovative and inexpensive

spread strategy; in every instance, changes were made without the need for new funding or legislation.⁹⁷

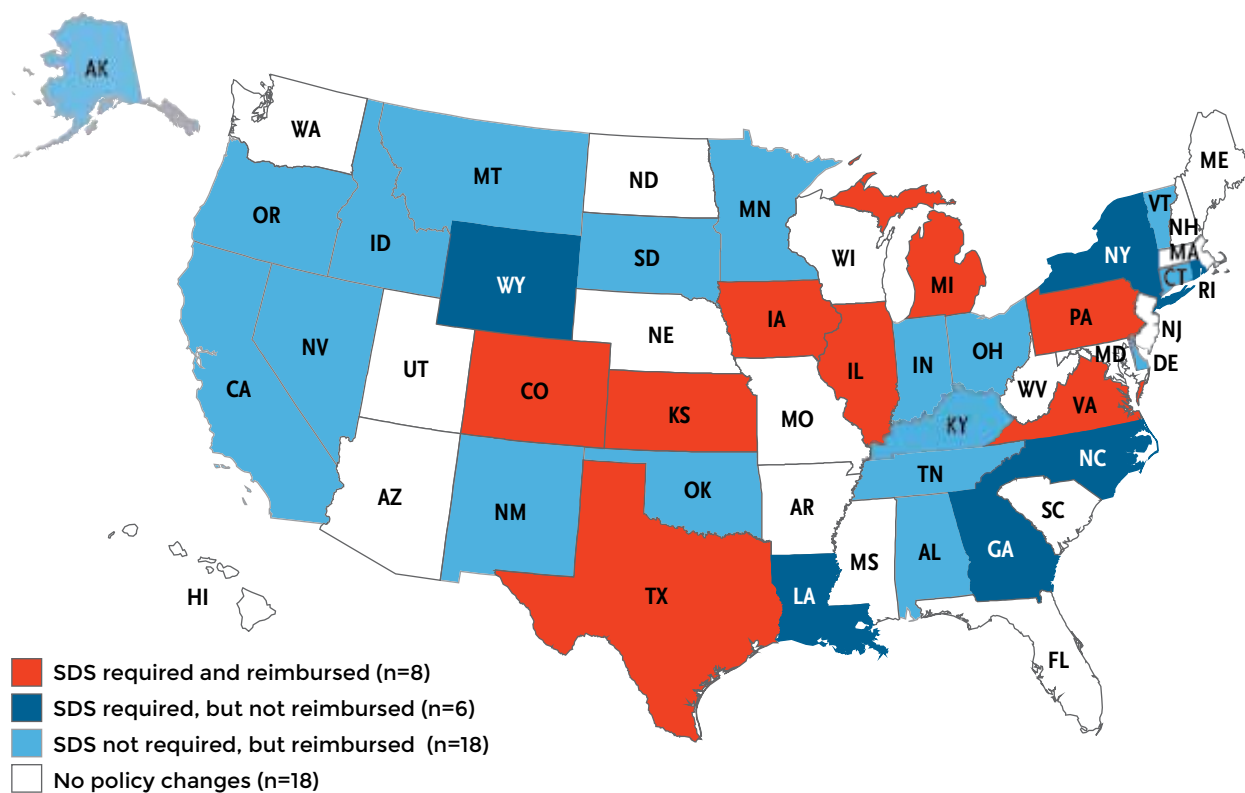
In addition to providing tools and ideas to policymakers, administrators, and clinicians at the state level, the Fund maintained a great interest both in supporting young, promising investigators and in training the next generation of pediatric health care professionals. Karen Davis was especially committed to these areas. Few academicians studied the care delivery system as it related to well-child care. In an effort to create a cadre of investigators whose careers might focus on preventive care, Schor asked the Academic Pediatric Association to run a small-grant program for junior investigators. By 2011, the initiative had funded 12 young investigators. The small-grant program was so appealing that, shortly after its initiation, the federal government's Maternal and Child Health Bureau chose to support a sister program, the Bright Futures Young Investigator project, which focused more broadly on preventive care. These funding streams, as well as the CDPC program's commitment to funding early career

academicians such as Arvin Garg, Susmita Pati, and Laura Sices, helped to expand the field by strengthening their potential to get large federal research grants.⁹⁸

The CDPC team also funded Arizona State University's Bernadette Melnyk, Ph.D., R.N., a leading nurse researcher in child mental health. Her project was designed to study ways of revising the ambulatory pediatric nurse practitioner (PNP) curriculum to strengthen its behavioral and developmental components. Just as with physician training, national surveys of PNP programs indicated that knowledge and skills requirements for treating psychosocial and behavioral health issues varied widely, and that screening tools and early evidence-based interventions for these problems did not have any definite place in the curriculums. Educating faculty and furnishing teaching resources could increase teaching time and provide students with organized, in-depth knowledge about development and screening methods.⁹⁹

Changes to Screening Rates and Standards for Screening in the U.S. ABCD I had identified barriers to

**EXHIBIT 2. MEDICAID-ABCD POLICY CHANGES:
32 STATES PROMOTE STANDARDIZED DEVELOPMENTAL SCREENING**



developmental screening such as nonreimbursement. But the Fund also plumbed existing statutes under which new efforts to enhance developmental screening might fit. The Fund's study group brought together two skilled policy entrepreneurs: Kay Johnson, M.P.H., M.Ed., a nationally known leader in Medicaid and children's health policy; and Sara Rosenbaum, Harold and Jane Hirsh Professor of Health Law and Policy at the George Washington University School of Public Health and Health Services. Johnson and Rosenbaum studied ways of maximizing the potential of Medicaid, EPSDT, CHIP, and other programs to deliver a full range of preventive care and developmental services to young children. Their efforts were very useful to the ABCD work groups in rethinking policies and procedures.¹⁰⁰

The Fund-sponsored screening-related initiatives resulted in a number of changes. All five of the ABCD II states were able to show that health care providers could be reimbursed through Medicaid for conducting developmental screening. The intensive work of the ABCD II states resulted in increases in screening rates to 43 percent to 95 percent, depending on the state, with all but one state reporting total screening rates of about 75 percent.

The ABCD II program validated the importance of assessing parents' mental health, while also providing assessment tools and reimbursement strategies. The technical assistance, learning consortium, and consultation provided by NASHP and the Fund encouraged the ABCD II state Illinois, for example, to identify a way to pay for maternal depression screening through Medicaid. As a result of the state's participation in ABCD II, depression screening through Medicaid resulted in a 96 percent increase in paid claims for the condition. Parents' mental health was one area where the keen synergy between support-oriented ABCD and research-oriented CDPC was clearest. For example, CDPC grant recipient Ardis Olson, M.D., of Dartmouth College developed a model that demonstrated that maternal depression screening could be feasibly made a routine part of well-child care visits, and could be reimbursed in that context. She also showed that patients would accept such routine screening,

relieving the fears of many physicians that mothers would resist being screened for depression.¹⁰¹

These ABCD state efforts made a difference. Research by CAHMI revealed that children with public insurance were more likely to receive developmental screening than uninsured children or even those with health insurance. In addition to the improved rates of screening seen in the ABCD states for Medicaid families, by 2011 private insurers in Alabama, Rhode Island, Texas, and Massachusetts had added coverage for developmental screening to their benefit plans. Large national insurers such as United Health Care, Aetna, CIGNA, and HealthNet also began to pay for screening under their standard benefit plans. Indirect evidence of the positive results of ABCD and CDPC efforts was found in the 22 percent increase between 2003 and 2010 in the proportion of children from birth through age three who were served by state early-intervention (Part C) programs. This figure meant that, in 2010 versus 2003, 68,911 more children in the United States were receiving services designed to minimize the impact of a recognized disability.¹⁰²

Among health care providers, not only did the CDPC-funded initiatives challenge the beliefs of many that screening was nonreimbursable and extremely time-consuming, they also succeeded in making their changes sustainable by embedding their findings in recognized professional standards for well-child care programs such as Bright Futures. The grant to the AAP in 2004, for example, engaged it in the Fund's work and led to enhancements of the screening provisions of Bright Futures while simultaneously prompting the AAP and a cohort of others to act as champions for developmental screening around the country.¹⁰³

Changes to AAP screening statements in the years 2001–2010 reflected the growing sophistication of new professional standards for developmental screening. The 2001 statement had simply provided a list of recommendations and advocated the use of standardized screening tools. The 2006 policy statement called for more screening uniformity, crediting the CDPC program for providing the evidence to support this change. In 2008, the AAP's new well-child care

standards emphasized child development more heavily than in the past, again acknowledging CDPC's leadership. Comparing the policy statement of 2010, the most recent, with that of 2001, there is not only much more detail and nuance in the organization's recommendations, there is a sophisticated synthesis of the growing body of evidence, along with an algorithm, strategies, and critiques of the tools available to guide clinicians.¹⁰⁴

By 2009, the pediatric community was paying new attention to well-child care and its components. For example, Lewis R. First, M.D., the editor of *Pediatrics*, took note of a Fund-sponsored national survey of pediatricians in a blog entry titled "How Well Are Our Well-Child Care Visits?" The survey had found a substantial increase in the proportion of pediatricians who reported regularly screening young children using a structured screening instrument. A comparison of pediatricians' use of standardized developmental screening tools for the years 2002–2009 found that the percentage who did use them had more than doubled.¹⁰⁵

By now, significant advances had been made in the quality and quantity of developmental screening, and the CDPC program had accreted evidence, strategies, and tools confirming its importance to children's well-being. But the Fund and other stakeholders saw the need for an even broader discussion about the ways in which well-child care was viewed in the United States, one that would fully recognize Jacobi's vision of supporting children's health not only by preventing morbidity, but also by maximizing children's physical, social, cognitive, and emotional growth and development.

Robert Sege, M.D., Ph.D., of Boston University School of Medicine, for example, was among those convinced that favoring the randomized clinical trial (RCT) did not serve children well when it came to critiquing the evidence for pediatric primary care, especially care focused on prevention and health promotion. Received notions of "evidence" needed to be modernized in order to assess interventions for well-child care. Sege argued for an alternative set of criteria that did not merely analyze outcomes in sick

children at the individual level. The RCT worked well for risk-benefit analyses of therapeutics for ill children, and it was a powerful tool for assessing the worth of one drug over another. However, it did not work for designing evidence-based well-child care because it was intended to study therapeutic interventions in ill children. Interventions proposed for pediatric primary care required an assessment model designed to study health promotion in well children situated in their normal home, community, and societal settings.

Sege stated that it was both unfeasible and unethical to deprive children and their parents of education, screening, and anticipatory guidance merely because the value thereof could not be captured by the RCT. It would be even less justifiable to deliberately impoverish them in order to submit these variables to research testing. He identified a hidden bias in policy formulation arising from the illness-oriented RCT approach. The traditional model should be mitigated by the use of alternative approaches for obtaining and evaluating evidence scientifically. Sege's Commonwealth Fund-supported work alerted pediatric health care providers to the risk of relying on a too-narrow definition of "evidence," and warned them against adopting any particular method as the sole measure of "quality," a concept of growing importance in early 21st-century health care in the United States.¹⁰⁶

Quality Improvement

The CDPC program funded numerous projects linking child development to the burgeoning Quality Improvement (QI) movement. The ABCD II states were encouraged to include a quality evaluation measure in their proposals, and the issue was a major element of the Screening Academy. But even before it reorganized to put all child programs under the CDPC umbrella, the Fund had invested resources to support NICHQ in finding ways to foster quality improvement by the use of incentives for developmental screening.¹⁰⁷ The CDPC team recognized NICHQ's potential to extend QI initiatives nationwide and to broaden its then illness-oriented focus to embrace a prevention-oriented

approach. To these ends, they funded and participated in NICHQ's annual meetings.¹⁰⁸

The Fund also supported a learning collaborative to improve child development services. Peter Margolis, M.D., Ph.D., at the University of North Carolina refined a "Breakthrough Series" curriculum developed for physicians and office staff to provide infants and toddlers with developmental services. Fifteen pediatric practices in Vermont, under the guidance of Judith Shaw, Ed.D., M.P.H., R.N., drew on the curriculum tools and materials, implemented innovations in their practices, and achieved improvements in the quality of the child development services they provided.¹⁰⁹

With Fund support, Christina Bethell built on her PHDS measure for care quality. The PHDS had already employed the innovation of parent reporting to create a validated measure of care quality. CAHMI and the Fund considered parent reports and surveys to be keys to investing parents in developmental screening and turning them into consumers and partners who were informed enough to critique its quality.¹¹⁰

For many years, Schor had dreamed of developing a universal system of parent education similar to the model of prenatal education already being used in the U.S. Like Paul Dworkin, Neal Halfon, and other leaders in the field, Schor had long argued that parents were a huge untapped resource, since most pediatric health care recommendations must be translated into action by parents, especially in the case of very young children. At stake was the difference between an adversarial system and a cooperative one. Any model that referred children for developmental services only when a problem arose was in effect punitive and sent parents the message that the physician or nurse practitioner held them responsible for having done "something wrong."¹¹¹

Following up on the development of quality measures for the PHDS, in 2004 Bethell began to study the psychometrics of a new PHDS to capture quality at the level of the individual practice. Her efforts aimed to strengthen the partnership between parents and health care providers and to access parents' opinions about the resulting quality of care. In this same area, the Fund

supported Yale health services researcher Paul Cleary, Ph.D., in his collaboration with the American Board of Pediatrics, the AAP, and other leading organizations in revising the ambulatory care version of the Consumer Assessment of Health Plans Survey (CAHPS), the nation's most widely used and well-respected tool for measuring parents' experience with their children's care. The new version included questions on the preventive and developmental services delivered to children.¹¹²

Sarah Scholle, Dr.P.H., at the National Center for Quality Assurance (NCQA), a private nonprofit organization dedicated to improving health care quality, spearheaded another major Fund-sponsored attempt to engage with the QI movement. Before Scholle began working with the Fund, the NCQA had directed little of its attention to children. Scholle was especially concerned about the measures of quality maintained by NCQA, known as the Healthcare Effectiveness Data and Information Set (HEDIS), which focused on providing care at recommended intervals, not on guaranteeing the substance and quality of the care provided. The HEDIS standards were especially important because they were used by most private and public health plans in the U.S. to track quality. Scholle created new pediatric preventive measures that captured quality and that were designed to replace or supplement those used by HEDIS. As they had done for Paul Cleary, CDPC program staff put Scholle in touch with NASHP, the AAP, and other interested organizations to create a collaborative network that coordinated all of their efforts.¹¹³

The Fund recognized that usually there were no mechanisms to assist practitioners in adapting to the changing nature and improving the quality of pediatric care, including developmental screening. One model of direct support to pediatric practices was found in the Vermont Child Health Improvement Program (VCHIP). Founded by Judith Shaw, Ed.D., M.P.H., R.N., and her colleagues at the University of Vermont School of Medicine, VCHIP worked closely with Vermont's Medicaid program, reaching out to individual practices to implement pediatric QI initiatives. All Medicaid agencies are required to track the quality of

health care delivered to Medicaid managed-care enrollees. The VCHIP initiative had served the crucial function of External Quality Review Organization (EQRO) for Vermont's Primary Care Case Management Program, and demonstrated that EQROs were an effective vehicle for improving the quality of poor children's preventive care. The Fund supported dissemination efforts to replicate the VCHIP model which, as of 2011, was operational in 17 other states.¹¹⁴ The Fund sponsored several other researchers, such as Henry Ireys at Mathematica Policy Research Institute, who were exploring ways of employing EQROs in this hands-on role to improve quality.¹¹⁵

In 2007, the reauthorization debate for the State Children's Health Insurance Program (SCHIP) took up the issue of developmental services and the challenge of ensuring quality of care. This new focus of attention resulted in part from the work of Scholle, Bethell, and Cleary, and from other Fund-supported projects. The latter included the work of Lisa Simpson, M.B., B.Ch., M.P.H., F.A.A.P., who studied strategies for improving the quality of care provided through SCHIP and Medicaid, and Charles Bruner, executive director of the Child and Family Policy Center, who convened a group of child health experts and health policy advocates to raise the profile of these issues among stakeholders.¹¹⁶

As a consequence of all these efforts, when President Barack Obama signed the Children's Health Insurance Program Reauthorization Act (CHIPRA) into law in January 2009, a number of quality measures with links to the Fund were embedded in the statute. CHIPRA stipulated that an initial core set of children's health care quality measures for voluntary use by Medicaid and SCHIP programs be posted for public comment by January 1, 2010. By 2011, the NCQA had accomplished the difficult task of obtaining National Quality Forum endorsement for measures related to developmental screening. NQF endorsement represented an especially high benchmark because, to obtain it, a measure not only must demonstrate scientific rigor, but must also be supported by evidence of its importance, feasibility, and replicability. NCQA's attainment

of these challenging metrics had been made possible by Fund-sponsored projects on quality. Building on the ABCD II efforts related to quality, the 10 states awarded CHIPRA quality grants by the Centers for Medicare and Medicaid Services (CMS) have worked actively since 2010 to enhance well-child care-related quality measures.¹¹⁷

Care Coordination

Those invested in intensifying the focus on development in well-child care knew that screening tools and quality improvement, important as they were, would amount to little in the absence of systems for referral and care coordination once a health care provider had identified a problem. This issue had been identified by the ABCD II states as a prime barrier to the extension of screening.¹¹⁸ Moreover, just as in the cases of screening and quality improvement, the evidence base and best practices for care coordination were in short supply. Program staff understood the need for a series of projects that would define care coordination and develop approaches to providing it. In 2006, Amy Fine, M.P.H., a child public health consultant, and Rochelle Mayer, M.Ed., Ed.D., director of the National Center for Education in Maternal and Child Health, published their Fund-supported work in which they reviewed current approaches to linking pediatric primary care practices with community-based developmental services and in providing recommendations on how to improve those linkages.¹¹⁹

In 2009, the Fund reached out to Richard Antonelli, M.D., M.S., medical director of Children's Hospital in Boston's Integrated Care Organization and a Harvard Medical School faculty member, and Jeanne W. McAllister, B.S.N., M.S., M.H.A., director and cofounder of the Center for Medical Home Improvement, in Concord, New Hampshire. Antonelli was a long-standing ABCD faculty member who also served on one of the NASHP working groups on care coordination. Committed to the concept of care coordination, in the 1990s he had set out to demonstrate that what kept chronically ill children and very ill technology-dependent children healthier was not a care model

based on unlimited access to expensive physician subspecialists, but rather a family-centered team approach. Creating structures of care that allowed nurses to fully employ their care-coordination skills, Antonelli and McAllister demonstrated that this model resulted in healthier children, more satisfied parents, and cost reductions.¹²⁰ Antonelli believed that children needed to be triaged not only by medical diagnosis, but by quantified estimations of their care coordination needs. His efforts in the 1990s coincided with the AAP's embrace of the idea of the "medical home," meaning that every youngster's care would be managed by one health care provider.¹²¹

Other CDPC projects aimed to identify barriers perceived by policymakers and health care providers that hindered implementation of care coordination and to identify and disseminate best practices. Edward Wagner, M.D., director of the MacColl Institute, and his colleagues developed a tool kit for coordinating care. In another instance, the Illinois chapter of the AAP developed a training model of approaches for putting pediatric practices in touch with early intervention programs so that children who needed referral or follow-up could receive it seamlessly.¹²²

Paul Dworkin's successful "Help Me Grow" program in Connecticut was one of the few defined models of care coordination, and with Fund support he evaluated and then replicated it in five other states; the replication process continued with support from the W.K. Kellogg Foundation. Sharon Silow-Caroll, M.B.A., M.S.W., of the research and consulting firm Health Management Associates, studied promising models of care coordination in a number of states.¹²³ And, in order to find ways of embedding care coordination in Medicaid funding streams, the Fund again drew on the expertise of Sara Rosenbaum and Kay Johnson.¹²⁴

ABCD III

These projects generated substantial new information about care coordination, and in October 2009 the Fund and NASHP were ready to launch ABCD III, under whose aegis state Medicaid programs would develop policies and programs to improve care coordination in communities. The goals of ABCD III were the most ambitious yet. The chosen states, Arkansas, Illinois, Minnesota, Oklahoma, and Oregon, were charged with building on ABCD I and II using sustainable policy and systems improvements to develop working models of community-based care coordination, linking primary care practices with other community service providers, much as was laid out in the earlier work by Fine, Mayer, and Antonelli.

Looking back at ABCD I and II, and observing ABCD III as it unfolds, the many ways in which the initiative has changed the delivery of developmental services for young children are apparent. It has fostered numerous policy and practice improvements. Thirty-two states have instituted new policies that support developmental screening, for example. Eight of them have created mechanisms that foster communication between primary care providers and educators that previously were not possible. At least three other states have standardized diagnostic nomenclatures across systems, thereby facilitating Medicaid billing.

The effects of ABCD endure, and the initiative continues to produce results. Thanks to the success of ABCD, NASHP has been asked to represent child development-related issues for the National Early Childhood Systems Working Group, a networking organization for foundations interested in child health. It has continued to provide a vehicle for ABCD alumni states to advise CMS about ongoing ways to improve the health and well-being of young children through EPSDT. And, in 2012, when CMS proposed a billing code change that would make it harder to bill for

developmental screening through Medicaid, NASHP galvanized ABCD alumni states to successfully communicate the potential negative impact of this ruling.¹²⁵

Finally, other sustainable changes have been wrought through ABCD. Four states, for example, are creating developmental screening and care coordination continuing education initiatives that physicians can complete in order to maintain board certification.

But perhaps the most telling marker of its success is that many alumni states continue to refer to themselves as “ABCD states,” supporting initiatives that improve child development. Colorado, for example, secured state funds to continue its ABCD efforts. Thirty-five states as well as Washington, D.C., and Puerto Rico continue to participate in the alumni listserv and webinars.¹²⁶



PART IV. “PURCHASING” CHILD HEALTH IN THE 21ST-CENTURY UNITED STATES

The field was begging for leadership... Even though the “research engine” was making the need clearer and clearer, the health system had to be made to see that it made sense.

—David W. Willis, M.D., F.A.A.P.

The Presence of the Past

In 2011, the Fund restructured its programmatic initiatives to widen its focus from a single group defined by age to the population at large, aiming to improve the total health care system. The quality and care coordination initiatives that defined the CDPC program were merged into these new, broader programs. The strategies that had proved successful in the ABCD program, such as bringing stakeholders together at the state and local levels, would now be applied to other issues and set in the context of the Affordable Care Act.¹²⁷

History suggests that this kind of a shift entails both jeopardy and opportunity for children. The Affordable Care Act offers tremendous potential for positive change. For example, it is fitted with measures tying provider reimbursements to quality metrics and with measures to promote health care coordination and efficiency. And, to the extent that the Fund will be using its formidable set of resources to achieve a reorientation of the delivery of health care in the U.S., it can be expected to maintain the momentum gained from the CDPC program.

The move away from a targeted focus on children does not come without risk, however. The investigators funded through the CDPC program built a powerful argument and generated convincing evidence for Abraham Jacobi’s argument that children are not just small adults. Their health care needs are different, and so is the evaluation template for an intervention’s success or failure: children’s health is predicated not on disease prevention alone, but on maximizing all children’s emotional, physical, and social health with the aim of

helping them to achieve their highest potential. The Fund’s successes in creating the model for well-child care in the 1920s followed from its designated focus on children, its recognition of their special place in American society, and the national rhetorical consensus that children deserved special attention. A move away from this kind of stand-alone program for children risks neglecting their unique needs.

The CDPC program’s many successes may also have been a result of its choice to home in on one target issue—developmental screening for very young children, a group for whom there were already statutory mechanisms in place through EPSDT that might be subject to fuller exploitation. This kind of targeting may not be so easy for other groups, even other subpopulations within pediatrics. For instance, although science continues to reveal the dynamism of the adolescent brain, it will be a more complicated challenge to improve developmental surveillance of this group because, relative to young children, there are fewer existing legislative mechanisms to be leveraged and fewer community programs with which to collaborate.

Another potential challenge to continuing the trajectory set by the CDPC program is the growing political polarization in the United States. A lack of agreement, or even civil discussion, about what society “owes” children and poor families means that these groups are constantly threatened with federal, state, and local budget cuts to the safety net they rely on. Provisions for child health are being undermined despite the florid rhetoric pervading American political discourse to the effect that all children are “deserving.” Studies demonstrate the economic benefits to society of enhancing children’s development, while policy decisions are too often made based on the political advantages of the moment. Nor have the strides that have been made in developmental screening for indigent children actually reached all of those children; 10 percent of children remain uninsured and almost a quarter are underinsured, meaning that many lack access to preventive services, including developmental screening.¹²⁸

Because health care financing in the United States is a complex, class-based mixture of public and

private initiatives, what we as a society mean by “child health policy” continues to vary depending upon what set of children are under discussion. Most nonpoor children receive health benefits assigned by their parents’ employers. Poor children are the topic of debate as to which needs should be addressed by the “medical” system, which through “educational” programs, and which through “social welfare” mechanisms. It will be very difficult to carry forward Abraham Jacobi’s vision of focusing on the “whole” child because health care funding and structures have yet to support this ethos, and child welfare and education initiatives arising from those legislative arenas are not easily integrated into initiatives for health care.¹²⁹ Also, the silos isolating the health, educational, and social welfare sectors from each other remain firmly in place, and are likely to persist until the U.S. shifts away from its class-based system of health care. Despite these obstacles, however, the CDPC has shown that parent, payer, and care provider partnerships can be constructed regardless of the system’s structure. And long-standing beliefs and practices about well-child care can be improved in cost-effective ways, as Oregon behavioral and developmental pediatrician David Willis, M.D. (not a Fund grantee), observed in his characterization of the Fund’s contributions to children’s health in recent years.¹³⁰

Lessons Learned

Despite all the challenges, The Commonwealth Fund has succeeded in improving child health in the United States again and again. The Fund’s enduring legacy to children’s health is its nearly century-long attempt to create an integrated model of well-child care. Through the CDPC program, the Fund created a model for fulfilling the promise first made to poor children by the federal government in 1935, and reinforced in 1965 and 1967 with Medicaid and EPSDT legislation. It did so in much the same way that its first child-focused demonstration project had in the 1920s, by knitting together programs that already existed and demonstrating their worth.

History cannot be reduced to ready lessons that can be deployed to immunize us against making decisions for the future that might be considered “bad.” But knowing what happened in the past, and why, can lead to a more informed appraisal of both the intended and unintended outcomes of previous actions and policies and, as a result, a better discussion for future planning. Studying the Fund’s approach to children’s developmental services also offers suggestions for how to bring about change not just in the area of children’s well-being, but in other areas where complicated and enduring issues persist in American society.

1. Generate solid and meaningful evidence.

Generating evidence is an important first step toward engaging stakeholders. The CDPC staff were aware from the beginning that to be effective in the long term, their models would have to be self-sustaining. Consequently, the program’s focus on screening, quality, and care coordination was accompanied by equal attention to the political and social contexts in which their efforts were situated, and resulted in a coherent, ongoing strategy for policy improvement. This accomplishment can be attributed to careful grant-making; a commitment to ongoing, iterative dialogues with investigators; and regular review of projects to make sure they facilitated one another.

2. Use the evidence to engage payers and policymakers.

Engaging stakeholders cannot by itself create the necessary political will to effect policy improvements, but it lays the groundwork for change. Also helping to build engagement are translating findings into language and frameworks that are usable to stakeholders, having credible thought leaders and groups evaluate and promulgate evidence, and capitalizing on policy windows.

3. Address the problem from the top down and the bottom up. The place of developmental screening and follow-up referral in pediatric primary care had been discussed for decades. The Fund’s work integrated and optimized the existing knowledge base in order

to generate a critical mass of new information in ways that ultimately improved the quality and increased the extent of developmental screening. The top-down, bottom-up strategy was more than the sum of its parts in that it created a synergy of efforts. Work from the top resulted in child development being embedded in national initiatives such as Bright Futures and securing a place in the quality measures of the NQF and CHIPRA. Work from the bottom, or practice level, produced standards and measures for tracking quality improvement (and identifying gaps in care) that served as a guide for ongoing, meaningful policy improvement. In its efforts to actually change practice, the Fund relied on a learning collaborative on the ground, at the practice level. The collaborative brought together health care providers and state Medicaid and EPSDT directors, letting them talk directly to one another about the component parts of a developmental screening system and brainstorm about how to fix system issues that stymied reimbursement. These initiatives dramatically bridged the scientific, professional, and financial silos that exist between and within the health, education, and social welfare systems. By building new coalitions, generating new knowledge, and creating new discussions, the Fund's collaborative model achieved breakthroughs in all directions.

4. Focus simultaneously on building blocks and dissemination. Supplying support to develop exemplars such as Bergman's tiered-care model, Earl's work with CCMC in North Carolina, and Dworkin's "Help Me Grow" initiative is a vital task, but it is equally important to plan carefully early on for dissemination of results and transfer of best practices to other settings. Generating innovative tools and quantifying the health benefits of developmental screening are but a part of the battle; the same is true of publishing findings. The ultimate goal must be to change practice and build systems, and to do so, the instruments for dissemination must be created.

5. Use what you already have. Was the health care system the right place from which to address developmental screening for young children? The answer was clearly yes, because more than 95 percent of children come into contact with a health care professional sometime during the first three years of life.¹³¹ Other approaches might have been taken, but the Commonwealth Fund chose to build on its traditional object of focus—health care—and consequently, that was the "system" that Schor, Abrams, and their grantees leveraged. In a parallel way, the Fund engaged its pilot states' existing Medicaid, Title V, or EPSDT revenue streams, and aligned itself with burgeoning movements such as quality improvement and evidence-based managed care.

6. Depoliticize the issues. Over the course of the past generation, American society has grown more divided economically and socially, and more diverse culturally. Children and families have been the topic of many debates, as when politicians took sides on the view of First Lady Hillary Rodham Clinton that it took a "village" to raise a child and the view of Senator Rick Santorum of Pennsylvania that it took a "family."¹³² Commonwealth Fund colleagues deftly navigated these waters, refusing to be diverted by the question of whether it was right to invest in children because it was the moral thing to do, or because it made economic sense. Their data-driven message about developmental screening was simple and powerful—but politically neutral—and spoke to everyone. The Fund's efforts validated a core conservative belief that new money is not the solution to every problem, while also placing the emphasis on the progressive value of caring for poor children, one of the nation's most vulnerable groups.

7. Focus on the task, not the turf issues. The CDPC's leaders kept the focus on their program's goals, not least by disregarding conventional wisdom about how to make change. They built in local flexibility and discouraged professional squabbles over who "owned" the field of developmental screening.

8. Find the right people. The CDPC program would not have succeeded as it did without the very particular gifts and qualifications of individual Fund staff, the NASHP leadership, and the committed cadre of investigators who crafted the new tools and measures

that transformed policy and standards of practice. The ABCD laboratory suggests that, absent the CDPC tools, the status quo would have been much harder to challenge.

The Child Development and Preventive Care program and The Commonwealth Fund's almost 100-year history point up the unique role that foundations can play in policy improvement. Foundations possess the freedom to be creative, even provocative, in their strategies. They can commit in the long term to addressing complicated problems, and accelerate change that is already under way.

The 1990s saw a groundswell of political, professional, and scientific support for investing in young children's growth and development. The Fund built on that opportunity with clearly defined goals and a specific set of outcomes in mind. Through the research and dissemination activities sponsored by CDPC, the Fund not only facilitated the "rethinking" of well-child care that Ed Schor had challenged American health care providers to engage in, but put forward a successful model for bringing about sustainable and cost-effective change.

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