

# Evolving Roles for Health Care in Supporting Healthy Child Development

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## Summary

Health care reaches more children under age three in the United States than any other family-facing system and represents the most common entry point for developmental assessment of and services for children. In this article, Adam Schickedanz and Neal Halfon examine how well the child health care system promotes healthy child development early in life. They also review children's access to health care through insurance coverage, the health care system's evolution in response to scientific and technical advances, and the shifting epidemiology of health and developmental risk.

The authors find that the health care system is significantly underperforming because it is constrained by antiquated conventions, insufficient resources, and outmoded incentive structures inherent in the traditional medical model that still dominates pediatric care. These structural barriers, organization challenges, and financial constraints limit the system's ability to adequately recognize, respond to, and, most importantly, prevent adverse developmental outcomes at the population level.

To achieve population-level progress in healthy child development, Schickedanz and Halfon argue that pediatric care will need to transform itself and go beyond simply instituting incremental clinical process improvement. This will require taking advantage of opportunities to deliver coordinated services that bridge sectors and focusing not only on reducing developmental risk and responding to established developmental disability but also on optimizing healthy child development before developmental vulnerabilities arise.

New imperatives for improved population health, along with the growing recognition among policy makers and practitioners of the social and developmental determinants of health, have driven recent innovations in care models, service coordination, and coverage designs. Yet the available resources and infrastructure are static or shrinking, crowded out by rising overall health care costs and other policy priorities. The authors conclude that child health systems are at a crossroads of conflicting priorities and incentives, and they explore how the health system might successfully respond to this impasse.

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Child health care professionals reach more American families with children under age three than any other family-facing system or service. Current national recommendations call for no fewer than 12 health care visits by a child's third birthday. These recommended clinical visits for children and their parents can provide access to developmental surveillance, screening for developmental delay, and referrals to developmental services.

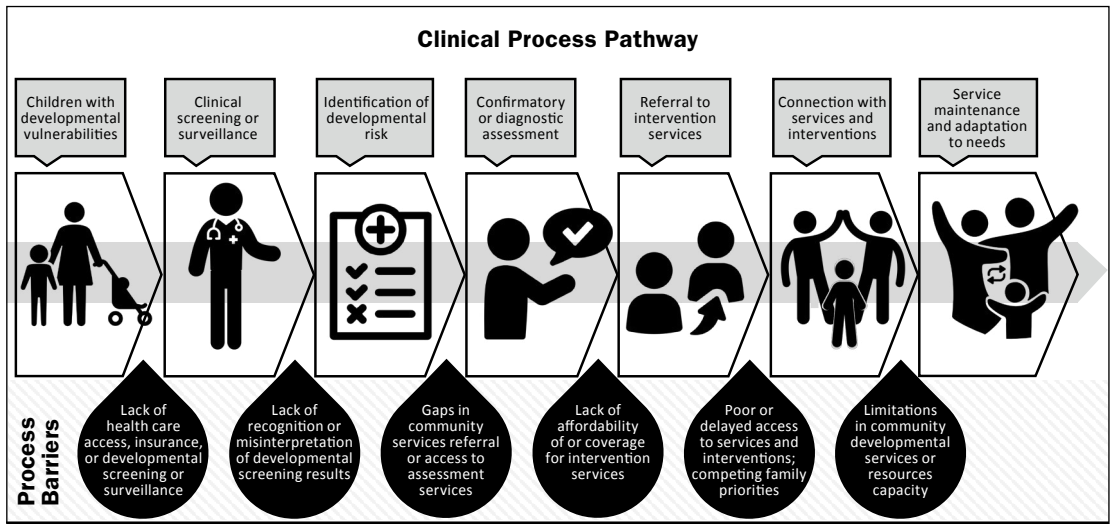
Pediatric clinicians support healthy child development in various ways. Developmental risk assessment, surveillance, and screening are recommended components of routine preventive health care for all children. Even though the American Academy of Pediatrics (AAP) Bright Futures prevention and health promotion guidelines were adopted by the Centers for Medicare and Medicaid Services as part of the Affordable Care Act (ACA) in 2010, developmental monitoring rates still vary widely across states, and the national rate of clinical developmental monitoring has been fairly static for the past decade.<sup>1</sup> Figure 1 depicts the current, conventional pathway that health care providers follow in attending to children at risk for developmental delays. This figure also shows key barriers to each stage of the pathway that impede the health system's ability to promote healthy child development.

Models of child health care have evolved substantially over the past century and continue to evolve today. Until the middle of the 20th century, infectious diseases ravaged children's health and led to high morbidity and mortality. Pediatric health care had focused primarily on acute illnesses and their medical aftermath, which often had multiple developmental consequences.

But widespread access to antibiotics, effective vaccines, and the postwar baby boom fundamentally reshaped pediatric health care. The profession adapted to new roles focused on monitoring the health of predominantly well infants and children (that is, those without serious acute or chronic diseases) and helping to define parameters of healthy child development.

Though the establishment and widespread monitoring of developmental and behavioral norms through health care was seen by some as an overmedicalization of issues in children's lives previously left to the purview of parents and families, there was widespread demand for these services from the nation's parents. Standards for pediatric care that came with the passage of Medicaid in the mid-1960s further codified its diagnosis-based reimbursement structure, increased access for low-income children, and put new pressure on private health plans to standardize coverage as well. Pediatrics continued to expand the scope of diagnosis and treatment for a growing number of previously overlooked childhood conditions, and with this growth came more pediatric health professions and subspecialties that had to be integrated with the child health care system. The term *patient-centered medical home* was coined by pediatricians in 1978 to describe standards for improving the continuity of primary care and coordinating an expanded array of medical services within the health care system to deliver quality care.<sup>2</sup> The medical home model has continued to be disseminated and refined across all of health care since then, accelerated by the widespread adoption of managed care in the 1980s and 1990s. The ACA introduced new incentives for child health care to deliver better quality and shift to value-based reimbursement, opening the

**Figure 1.** Pathway of Developmental Risk Identification and Intervention in the Conventional Child Health Care Model



door to a greater focus on preventing disease in its social context and coordinating with services outside the health care system to promote population health.

Pediatric health care has improved in response to technical advances, changing epidemiology, and evolving demands for care, but the basic organization and structure of primary health care in pediatric offices and clinics has remained largely unchanged since the 1960s (if not before). Preventive and well-child health care services in the United States are provided in ways that are quite distinct from those of other advanced nations. In many other countries, including England, Australia, and most European nations, pediatricians predominantly care for sick children. Well-child and preventive care is largely managed by specially designated maternal and child health nurses, general practitioners, or well-child clinics. In the United States, where pediatricians generally provide these services for young children, the schedule of visits was initially built around immunization schedules and the routine monitoring of growth and developmental

milestones. Though there have been modifications over the past 50 years, this visit schedule and content remains largely the same today.

The approach to promoting healthy child development in primary care settings has nonetheless evolved in response to practice, norms, and needs; table 1 summarizes the changes that have occurred. Among the distinctive skills that pediatric practitioners possess, in addition to expertise in the diseases unique to childhood, is expertise in measuring and monitoring growth, child development, and nutrition. Several factors contributed to the growing role of pediatricians in identifying and managing child development. One was the advent of neonatal intensive care, which improved the odds of survival of many infants that were born prematurely. The host of developmental disabilities associated with what was initially a set of neonatal care interventions with limited clinical efficacy meant that pediatricians had to be trained not only to care for premature newborns with multiple medical problems but to manage the developmental delays

**Table 1.** Stages of Evolution of Health Care Delivery System Models to Support Healthy Child Development

	<b>1. Conventional Medical Care System</b>	<b>2. Expanded Medical Home and Coordinated Health Care System</b>	<b>3. Community Integrated Health System</b>
<b>Goals of the System</b>	Decrease Mortality and morbidity	Decrease morbidity and disability	Prevent developmental vulnerabilities; increase developmental capabilities; improve population developmental outcomes
<b>Developmental Focus</b>	Identify and treat developmental disability	Prevent developmental risks	Optimize developmental potential
<b>Health Care Model</b>	Acute and rescue health care; identification of disease; management of disability	Chronic disease prevention and management	Creation of integrated systems and sectors to promote healthy development
<b>Scientific Model</b>	Biomedical model disability	Biopsychosocial model	Biopsychosocial and life course health development models
<b>Organizational Models</b>	Offices, clinics, and hospitals without horizontal or vertical integration	Capitated accountable health care organizations	Accountable communities for healthy development
<b>Payment Models</b>	Fee for service; volume-driven	Capitated payments	Bundled services, value-based payment incentives for high quality, upstream care, and service care, and service coordination; value-driven
<b>Developmental Services</b>	Developmental screening for disabilities	Developmental surveillance; coordinated intervention from by community organizations	Provision of and linkage to services (parenting supports, early literacy materials, etc.) that promote healthy development
<b>Innovations in Developmental Interventions</b>	Nurse home visitation for high-risk infants	Integration of developmental services into health care; centralized access to resources and service coordination	Community-wide healthy development promotion networks; community service hubs

that followed. Other technical advances also meant that children with chromosomal abnormalities and other genetic conditions were also surviving, and their developmental needs likewise required attention.

As pediatrics ascended as its own specialty, the prevailing construct of child development was informed by biological maturation, consistent with developmental biology that undergirded the dominant biomedical

model and the explanatory model of growth that animated pediatric assessments. This thinking was highly influential in the creation of the Denver Developmental Screening Test (DDST), which was introduced into pediatric training and practice in the early 1970s. The DDST became a widely used tool, shaping the developmental understanding of many young pediatric trainees who were taught to see development through a maturational framework. Not until the introduction of a biopsychosocial alternative to the biomedical model was the role of adverse environments recognized, at which point approaches to child development largely driven by biological and neurological determinism began to be questioned.

In the early 1970s, leading pediatricians championed a set of transformative ideas that would change how pediatricians saw their roles. The promulgation of these ideas also encouraged the AAP to embrace the profession's role in addressing "new morbidities" of child health: learning, behavioral, and developmental disorders that were caused by social, family, and environmental conditions. As a result, pediatric practice shifted toward screening for developmental concerns in the context of a more holistic approach to young children's needs. This was codified in the early 1990s in Bright Futures, which established a new way to integrate child health, development, and family supports into each pediatric visit.

Children's health care has increasingly been held accountable for adherence to health care quality guidelines, including clinical guidelines for developmental screening and surveillance. But owing to how American health care is financed, it hasn't been possible to align clinical processes and pathways to ensure that most children

receive recommended care and have access to community-based early interventions or to guarantee that children with developmental risks are appropriately connected to services.

In a post-ACA system, the next stage of the child health care system's evolution and transformation should focus on preventing the upstream causes of children's developmental vulnerabilities, integrating community-based services, creating incentive structures that support these functions for improving developmental capabilities, and optimizing healthy development and developmental capabilities.<sup>3</sup> Right now, however, the health care system is still constrained by funding streams that distribute more resources to medically complex patients at the end of their lives, by short-term insurance coverage time horizons that limit opportunities to focus on long-term investments in healthy development and recoup on those investments, and by siloed services and barriers to collaboration between health care and other child-facing systems concerned with promoting healthy lifelong development. All of these constraints are layered onto volume-driven clinical care delivery and reimbursement models that leave insufficient time and resources for doctors to identify those at risk for developmental disability, that fail to provide incentives for preventing developmental disability in the absence of a medical condition to diagnose and treat, and that fail to capitalize on opportunities to optimize healthy child development for the many children who may be medically well but are at risk for developmental delays and deficits due to early childhood adversity and socioemotional risks in their homes.

It's no wonder that the US child health care system has a long way to go to substantially

improve its care practices, processes, and coordination to support healthy child development. The best available data from the National Survey of Children's Health suggest only one-third of children from nine to 35 months old receive the recommended developmental screening.<sup>4</sup> Among children with identified developmental risks, referral from a health care setting to appropriate early intervention services is inconsistent, as is successful connection.<sup>5</sup> And even when referral and connection are successful, early intervention agencies and health care providers rarely share information about children's progress. As a result, the effectiveness of both sectors in promoting healthy child development is limited.

These operational and structural shortcomings are largely a legacy of health care's historical conceptions of developmental disability, which focused on medical, disease-related causes of physical and cognitive impairments. Such a view grew out of clinicians' focus on prematurity, low birth weight, or other perinatal complications that affected only a small percentage of children with significant medical issues. Yet it has become increasingly clear that adversity due to social, economic, and environmental conditions is a major source of developmental risk common for children at the population level. For the large and growing number of young children whose developmental vulnerabilities are a consequence of their social conditions, clinical monitoring and response lack sufficient resources to address the scope of their needs. Through advances in our understanding of how childhood economic and interpersonal adversity threatens health outcomes and achievement over the life course, we know that early adversity increases and compounds developmental vulnerability as well.

The gap between the child health care system's potential to improve population-level developmental outcomes and its current performance is alarmingly wide. The disconnects are occurring at the clinical practice level, the community level, and the policy level. There's a mismatch at the clinical practice level between population-level needs, processes, and financing of care. In the community, the health care system faces barriers in integrating its services with other resources and services to achieve optimal developmental outcomes for populations of children. And, finally, policy dictates the flow of funding and resources to the child health system embedded in its community of aligned partner organizations in other sectors. Opportunities exist at each of these levels to transform the way we provide care and ensure that child health care lives up to its potential to promote healthy child development.

## Health Care Access and Insurance Coverage

In the US system, pediatricians and other child health care professionals are parents' primary source of information about healthy child development in the preschool years, making medical insurance and access to the health care system critical for families.<sup>6</sup> After decades of gains in insurance coverage rates nationally, leading to a peak child insurance rate of 95.3 percent in 2016, insurance rates for children have shown an alarming decline in the past four years. Since 2016, more than 400,000 children have become uninsured, raising the total to over four million.<sup>7</sup> This decline in health insurance rates was driven by loss of coverage among children under age six, white and Hispanic children, those in the low to moderate income range, and those with Medicaid and CHIP coverage.<sup>8</sup>



States that failed to expand Medicaid saw threefold increases in their uninsured rates compared to those in expansion states. Young children and those on public health insurance are at particularly high risk for developmental delay and are also likely to find it difficult to access early intervention services. Given that health care access is the primary point of entry for identifying developmental disability and linking to early intervention services for children in the age and demographic groups where insurance coverage rates are eroding, adverse impacts on developmental outcomes for these children are of great concern (see figure 1).

Insurance coverage for child developmental services in health care became standard two years after the establishment of Medicaid in 1965 when Congress added the Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit. This assured that children from lower-income families would receive appropriate preventive services, with the goal of reducing the burden of disabling chronic health conditions in adulthood. Under the EPSDT benefit, state Medicaid agencies are required to cover childhood preventive screenings, resultant referrals, and medically necessary services for conditions revealed by screenings during clinical encounters. The timing of EPSDT-mandated, Medicaid-reimbursed preventive encounters and preventive screenings is now based largely on the Bright Futures guidelines and periodicity schedule, which includes developmental screenings with validated tools. Reimbursement for developmental screening through Medicaid may be bundled with age-specific well-child visits or may be a separate payment depending on the state, and neither bundled nor separate payments appear to yield superior rates of childhood developmental screening.<sup>9</sup> Medicaid fee-for-service rates for

developmental screening vary by an order of magnitude across states (\$4.95 in Michigan to \$61.51 in Iowa), while managed care plans now covering most children under Medicaid have wide latitude to set their own reimbursement rates that may not adhere to the state fee-for-service rates.<sup>10</sup> In addition to adopting these conventional approaches to reimbursement for clinical developmental screening, state Medicaid agencies have implemented a variety of statewide performance improvement projects, incentives for collaboration across state agencies, public-private partnerships, and training initiatives for health professionals to increase developmental screening and early intervention rates.<sup>11</sup> For children covered by private insurance, developmental screening under age three became an essential covered health benefit with passage of the ACA. This patchwork of funding approaches contributes to the great variation in developmental screening rates across states.

Beyond requiring coverage for developmental screening, EPSDT mandates coverage for an array of medical services necessary to address identified developmental disability. For children with isolated developmental delays or disabilities without other medical conditions, Medicaid's benefits for children under age three also include physical, occupational, and speech therapy, as well as services such as hearing and vision assessment, behavioral health care, and case management. Children other than those in low-income families are also eligible for Medicaid (though with marked or severe limitations) if they have special health care needs, defined as those who "have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and also require health and related services of a type or amount beyond that

required by children generally.<sup>12</sup> This allows Medicaid to fill gaps in private insurance service coverage for many children with such needs and makes coverage of services for developmental disabilities more affordable for families. Though developmental and medical services are covered benefits under Medicaid for the most medically complicated children with special health care needs, the health care system is not as responsive to families whose children have isolated developmental delays or disabilities in the absence of other medical conditions, nor to the large proportion of children at risk for developmental delay because of psychosocial adversity. These gaps become especially important when we consider the evolving epidemiology of developmental risk.

## **Epidemiology and Recognition of Developmental Risk**

Physical, cognitive, and language impairments and disabilities have steadily become more prevalent over the past few decades. Currently, according to national estimates, just under 18 percent of all children have diagnosed developmental-behavioral disabilities.<sup>13</sup> Rates of diagnosed developmental disability, excluding behavioral disabilities, have increased even more markedly, from an estimated 4 percent of children in 1994 to nearly 7 percent in 2016.<sup>14</sup> Speech, cognitive, and other developmental disabilities have grown faster than nearly all other conditions, with the most recent estimates showing growth of 40 to 60 percent for each between 2001 and 2011.<sup>15</sup> For children under age three, these speech, cognitive, and motor issues represent the most common types of delays.<sup>16</sup> Though emotional and behavioral disorders like attention deficit disorder and autism can be identified through clinical screening

before age three, they are more commonly diagnosed in later preschool and the early school-age years. Early manifestations of behavioral disorders in the first three years of life are also increasingly seen as antecedents of later emotional, behavioral, and psychiatric problems, but without better screening they aren't commonly recognized, diagnosed, or treated.<sup>17</sup>

A number of factors lie behind changes in the epidemiology of childhood developmental risk. For one, advances in medical care in the prenatal and neonatal periods have led to better diagnosis and treatment and reduced mortality for children who are born with or develop serious illness, children born extremely prematurely, and children with perinatal complications, who now survive with higher rates of developmental disability. Though medical advances are often mentioned as a key factor, most of the growth in childhood developmental risk appears to be caused by other things. First, rates and sensitivity of developmental and behavioral screening, assessment, and diagnoses have increased moderately, meaning that more children are identified who would likely not have been diagnosed before.<sup>18</sup> Second, the extent of socioemotional developmental problems is just beginning to be understood. Until recently, socioemotional vulnerabilities were often overlooked or downplayed as minor complications of more consequential language and cognitive delays, and they are still underappreciated by child health care professionals, who aren't trained to recognize them, assess their origins, or intervene. Because such vulnerabilities often require complex family interventions and must be delivered by service providers who are few and far between, there is also a disincentive to identify these problems, which require extensive case management and coordination



to address. Third, psychosocial and socioeconomic developmental risk factors have increasingly been recognized, leading to heightened awareness of how the nested interplay of neighborhood, household, family dynamics, parenting practices, and early relational and interpersonal supports and attachment affects brain development, cognitive functioning, and developmental outcomes.<sup>19</sup>

Advances in understanding the developmental consequences of various forms of childhood adversity—including social determinants such as poverty, low education, and racial and ethnic discrimination—have brought more vulnerable children to the attention of the health care system than ever before. In particular, because of the growing evidence that early psychosocial adversity becomes biologically ingrained in physiology and health behavior, the health care system increasingly recognizes severe stress and emotional trauma due to childhood abuse, neglect, household violence, mental illness, or substance abuse, together termed adverse childhood experiences (ACEs), as threats to children's developmental outcomes and also their mental and physical health.<sup>20</sup> Parents' own ACEs may influence child developmental risk intergenerationally.<sup>21</sup> The growing recognition that common social risk factors for adverse developmental outcomes must be addressed through the health care system is now leading to a mismatch between the health care system's aspirational goals and its actual capacity to mitigate these widespread, traditionally nonmedical developmental hazards.

The challenge we face is how to create a more comprehensive approach to assessing and intervening in developmental

vulnerability caused by complex social and relational risks embedded in family socioeconomic conditions, resources, and behavioral adaptations and community ecosystems. To better meet the needs of children who are developmentally at risk, a host of policy and health care practice changes are needed, particularly for children in disproportionately vulnerable sociodemographic populations.

## **Developmental Screening and Services Standard of Care**

Health care professional societies, clinical practice guidelines, and national targets for health and health care improvement recommend developmental surveillance, screening, and referral to appropriate services as standard of care in the early childhood years.<sup>22</sup> The AAP recommends screening all children regardless of risk for developmental delay at nine, 18, and 24 or 30 months of age using standardized, age-specific screening tools completed by their caregivers. Screening tools have advanced considerably since those that focused squarely on motor, language, and cognition; new tools assess a broader swath of emotional, behavioral, and social developmental vulnerabilities. The AAP also recommends that health care providers surveil and monitor development at all child preventive health care visits before age five by asking parents about their concerns, observing children, and assessing risk. Other AAP recommendations include 1) referring patients to appropriate developmental and medical assessments and services, 2) coordinating care for patients to help them connect to such assessments and services, and 3) developing and maintaining working relationships with state and local programs and resources that serve children with

developmental-behavioral concerns.<sup>23</sup> The Centers for Disease Control and Prevention has endorsed these recommendations, and they form the basis for the widely used Bright Futures clinical practice guidelines. Other health care quality targets and improvement initiatives nationally, including Healthy People 2020 and the Core Set of Child Health Quality Measures for Medicaid and CHIP, have likewise been guided by these recommendations. A measure for standardized developmental screening for children under age three was endorsed by the National Quality Forum and subsequently recommended by the Core Quality Measures Collaborative for all public and private insurance payers. Currently, states voluntarily report the measure, but in 2024 the Centers for Medicaid and Medicare Services will begin requiring them to do so.

While the AAP recommendations have been widely adopted and cited to support developmental screening and surveillance as a standard of care, the US Preventive Services Task Force found insufficient published evidence that the benefits of universal clinical developmental screening outweigh its potential risks in situations where neither caregivers nor clinicians are concerned about delays or disabilities. This determination reflects a lack of studies on the potential for universal clinical developmental screening to mediate risk and produce long-term benefits. The American Academy of Family Physicians cited this lack when it recommended against universal screening for developmental delay by family physicians, who conduct roughly 20 percent of childhood preventive visits.

Increases in the proportion of children who receive clinical developmental screening have been bolstered by initiatives such as the

Commonwealth Fund's Assuring Better Child Development (ABCD) program and the Administration for Children and Families' "Birth to Five, Watch Me Thrive" and the Center for Disease Control and Prevention's "Learn the Signs. Act Early" campaigns.<sup>24</sup> At the same time, the rate at which pediatricians employ standardized developmental screening tools in their practices has risen; it was estimated at just under 50 percent in one national study published in 2011.<sup>25</sup> Yet outside of pediatrics, standardized screening tools are used much less, and the national rate of clinical developmental screening among young children appears to have plateaued at around 30 percent over the past half decade.<sup>26</sup> The major barriers appear to be time constraints in the clinical encounter itself and the fact that physicians seem to prefer to rely on clinical observation and surveillance rather than screening.<sup>27</sup>

Compared to pediatrician surveillance alone, standardized, validated screening tools have been shown to increase referral for further developmental evaluation.<sup>28</sup> Nevertheless, nearly half of children who screen positive for developmental delay are either never referred for further assessment or face other barriers to reaching early intervention services. The reasons for this disconnect appear to be different from the barriers to screening. They include inefficient clinical practice referral processes, clinicians' perceptions that a family doesn't want a referral, and notions that families lack the health literacy to correctly interpret positive screening results and therefore wouldn't follow through on a referral.<sup>29</sup> This may not be surprising, given that health care visits are time limited and clinicians and parents alike are often focused on other priorities. Also, in the absence of a concurrent medical diagnosis, no financial incentive exists for

most clinicians to respond to an identified developmental delay.

## **Workforce, Training, and Clinical Process Improvement**

Even within the confines of the more traditional medical model and conventional visit structure, clinicians can become better at recognizing and responding to developmental risks and outright disabilities (see figure 1). Education and training for providers in health professions that play integral roles in children's health care can improve their ability to recognize developmental problems. Currently, over 80 percent of preventive health care visits for children under age two take place in general pediatricians' offices, which thus represent the largest opportunity to increase developmental screening and referral rates. Since 1997, when the Accreditation Council for Graduate Medical Education (ACGME) began requiring that pediatric residents receive training in developmental and behavioral pediatrics, pediatricians and other members of child health care teams have been routinely trained to identify children with or at risk for developmental delay and those in need of therapeutic intervention. But there are still many practicing pediatricians who were trained before then. And this training is not required for family physicians. Evidence from the single national cross-sectional study available on the topic clearly supports the conclusion that the 1997 change in ACGME requirements led to higher rates of clinical recognition and management of pediatric developmental and behavioral issues among practicing pediatricians.<sup>30</sup> However, according to one medium-sized study, only two-thirds of pediatricians certified after the 1997 change reported that their developmental and

behavioral pediatrics training was adequate, and the result was that they appropriately identified and managed developmental issues less than 30 percent of the time.<sup>31</sup> Moreover, few pediatricians are aware of the agencies and services available in their communities to address developmental risks and disabilities. Pediatricians also tend to have little practical experience in coordinating care with early assessment and intervention services.

Beyond general pediatricians, the workforce in the field of developmental and behavioral pediatrics is especially critical for definitively assessing and managing developmental issues in children, especially in cases of greater developmental and clinical complexity and risk that require specialized expertise to manage. This critical workforce mostly consists of subspecialist developmental-behavioral pediatricians who require years of additional training beyond that of general pediatricians. A recent survey of developmental-behavioral pediatrics clinicians found that their capacity is being severely squeezed under the pressure of higher rates of developmental issues at the population level and the greater developmental and medical complexity of the patients they see. Perhaps most alarmingly, one-third of these clinicians anticipate retiring in the next three to five years.<sup>32</sup> Thus it will be critically important not only to invest in strengthening the existing workforce but also to expand and restructure it to include a wider array of professionals, such as developmental specialists, care coordinators, parent coaches, and partners in key community organizations.

Process improvements in the current preventive child health care delivery model would also likely help increase identification of developmental risk and early

intervention. A handful of rigorous studies that focused on interventions to standardize or automate developmental screening in clinical settings found improvements in screening rates, rates of identification of children as developmentally delayed, rates of referral to early intervention services, and rates of children ultimately being ruled eligible for early intervention services and receiving those services more quickly.<sup>33</sup> In a cluster randomized trial of a computerized decision support system to determine and assign children to standardized screening for developmental delays, screening at recommended ages increased more than threefold and developmental surveillance at other visits rose by 75 percent.<sup>34</sup>

Unsurprisingly, experimental evidence supports the notion that rigorous and uniform implementation of a standardized tool will result in measurable improvement in screening and referral rates and efficiency. This is consistent with abundant evidence suggesting that the leading threat to the quality of medical care for children, unlike for adults, is underutilization of recommended preventive services and screening. The key factors behind this problem are resource and time limitations during the medical visit.

Underutilization impairs the effectiveness of early intervention services, too. Population-level estimates indicate that roughly 10 percent of eligible children under age three actually receive early intervention services.<sup>35</sup> These early intervention services are mandated by part C of the federal Individuals with Disabilities Education Improvement Act (IDEA), which covers services from birth through age three for children with developmental delays who meet state-defined eligibility criteria or who have conditions

that automatically qualify because of high risk for future developmental, emotional, or behavioral impairments. Services potentially offered under the umbrella of early intervention include community-based and publicly funded programs such as developmental therapies (for example, speech, physical/gross motor, or occupational/fine motor therapies), audiology and hearing services, socioemotional and behavioral therapies, nutritional services, specialized medical or nursing services, preschools designed to deliver therapies, home-based therapies, and many others, all tailored to needs identified in initial and ongoing developmental assessments. Both the criteria for receiving services and the services offered vary considerably from state to state, limiting evidence on early intervention effectiveness nationally. Lack of health insurance and structural racism have been shown to predict poor access to early intervention services for African American children.<sup>36</sup> Indeed, at the population level, the largest barrier to children receiving early intervention services is either that they're not referred or that even if they are, they aren't able to use those services. Though empirical evidence largely suggests that early intervention services are effective for older children, evidence is limited and at best mixed for children under age three. This may be because the issues picked up in infancy and toddlerhood are a combination of severe disease-related delays, mild speech delays related to the language environment, and everything in between, making it hard to standardize service assessment. Indeed, reviews of evidence on early intervention under age three find that multifaceted early intervention services have the greatest impact. But, paradoxically, that multifaceted nature makes it hard to determine which specific components of those services are most effective.<sup>37</sup>

How could clinical systems and structures increase rates of preventive developmental screening and referral? One possibility would be for the health care system to realign clinical resources, processes, and structures to provide services that promote and maintain healthy development early in life rather than waiting for healthy development to erode in a way that might have been fully predictable and preventable earlier on. The health care system could also invest in upstream services that would safeguard healthy development by minimizing predictable and known risks.

Vulnerabilities such as exposure to maternal depression, lack of stable caregiver relationships, and various other forms of economic and interpersonal early childhood adversity are now known to drive a large proportion of adverse developmental outcomes early in life; they are also linked to conventional medical disease outcomes in adulthood.<sup>38</sup> Well-documented developmental vulnerabilities, including poverty, early childhood emotional trauma, and various other forms of childhood adversity, are also beginning to be recognized and measured by health systems interested in addressing such experiences and the social determinants of health.<sup>39</sup> These social determinants are already understood by many health professionals to account for most of the variation in population health outcomes related to the most common causes of illness and death in the United States and other developed nations.<sup>40</sup> Screening for these social risk factors is becoming more routine and could be a way for the health care system to intercede in the upstream determinants of developmental risk as well. Pediatric practices have substantially increased their social risk screening owing to recognition that poverty-related social

needs predict a host of health outcomes, including risk of developmental delay.<sup>41</sup> This approach is beginning to gain traction for clinical screening and identification of and interventions for ACEs and early childhood trauma, which also have clear associations with children's socioemotional, language, and cognitive developmental outcomes within and across generations.<sup>42</sup> This growing focus on social and economic root causes of most developmental vulnerability, along with new care models designed to address those root causes and respond to socioemotional needs, offers an opportunity for the health care system to proactively promote healthy development rather than reactively treating developmental problems as they arise.

### **Promising Health Care Models to Improve Child Development**

The shortfalls of current models of health care designed to promote healthy child development have not been studied rigorously, but barriers at each step of the screening-referral-intervention process can limit their success. Also, these models haven't been able to coordinate with nonmedical systems that are involved in addressing developmental delays. Successful models will need to improve performance within the health care system regarding its scope of services and, at the same time, coordinate with and facilitate the success of other service systems for evaluating and treating developmental issues.

To see how the child health care system could better promote healthy child development it is helpful to understand broadly how it's currently evolving and how its developmental services are conceived, organized, and funded. Table 1 describes a stepwise evolution of the health care system from



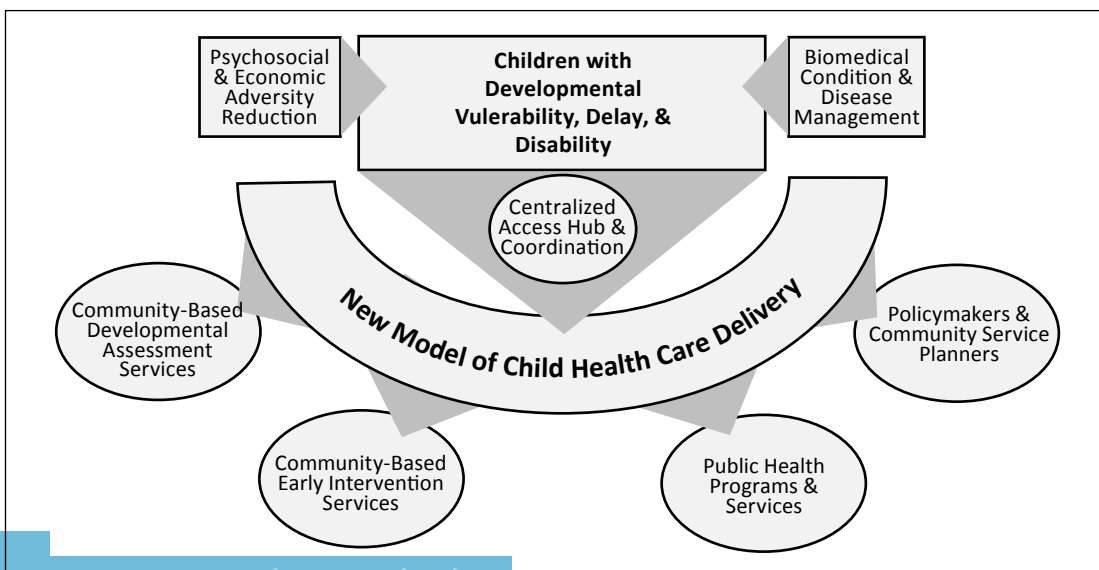
acute care whose goal is to minimize the number of deaths and mitigate illness to care focused on managing chronic conditions to a new delivery model focused on optimizing health by ameliorating adversity and emphasizing upstream prevention. The table outlines how the system for healthy child development evolves through these stepwise shifts. The rest of this section mirrors the progression in the table.

The primary approaches that have been used to improve developmental monitoring and response in the conventional child health care delivery model (stage 1 in the table) have been focused on making incremental changes in the clinical process. Despite the fact that clinical guidelines recommend standardized developmental screening and intervention, that pediatricians have been trained in developmental assessment, that developmental screening is being reimbursed through public payers in every state, and that the federal government has set national surveillance and screening

rate targets, the health care system has made little progress in ensuring that children are monitored for developmental issues and referred to early intervention services. Most of the progress that has been made has been in just the very first step (increasing screening rates) of a multistep process designed to connect children with heightened developmental risks to appropriate developmental services. It appears that we need new approaches, along with new models of child health care delivery and integration with the ecosystem of developmental services, depicted visually in figure 2.

Child health care systems may be more ready for these new approaches than ever before. Providers are increasingly aware of children’s developmental and behavioral needs in family and community context, especially the ways that individual-, household-, and neighborhood-level adversity are linked to childhood developmental hazards.<sup>43</sup> The ACA ushered

**Figure 2.** Evolution of Child Health Care Delivery to Prevent Developmental Vulnerability and Integrate with Community Developmental Services





in a shift in reimbursement emphasis from volume to value that has paved the way for new models of care that emphasize preventing disease and disability rather than awaiting their onset before responding, as in the fee-for-service framework. Yet limited payment reform alone hasn't brought about clinical practice improvements in areas like developmental screening and response. The solution doesn't appear to be attempting further changes in the clinical process in the hope that it can squeeze more productivity out of clinicians who are already short of time and resources and find it hard to coordinate with other services. Instead, a better option would be to restructure the child health care delivery model and to make developmental assessment and early intervention services available across key sectors in the community.

Innovative health care delivery models based on this kind of restructuring have thus far been successful in promoting healthy development while identifying and connecting more children to early intervention. Adding more resources for coordinating care with the existing clinical delivery model is a starting point. A study that examined what happened when electronic centralized referral tracking, clinical patient navigators, and a postreferral tracking system were added to one practice showed that such resources can substantially increase the rate at which children with identified developmental issues are connected to early intervention.<sup>44</sup> Embedding developmental specialists and enhanced developmental services into the child health care system has also been shown to help providers prevent developmental risk and delay and not just respond more effectively to delays once they appear. The HealthySteps model,

which tested this approach, led to sustained improvements in children's communication and language skills, fewer parental concerns about their children's behavior, and less use of severe discipline and other parenting practices known to be linked to adverse developmental outcomes.<sup>45</sup> Not only do HealthySteps and other programs like it support development by improving parenting, they also improve parents' sense of wellbeing and competence and increase their satisfaction with health care as well as advance preventive well-child care and anticipatory guidance in other areas beyond development.<sup>46</sup> Clinicians participating in HealthySteps also report improvements in the quality of care delivered, especially in low-income communities.<sup>47</sup> Such improvements were also seen in a similar enhanced pediatric care model that integrated lay parent coaches, as opposed to developmental specialists, demonstrating that some of the benefits can be achieved at a lower cost than in HealthySteps.<sup>48</sup> The spread and scaling of enhanced child health care models have been stymied by a lack of standardization, a range of different conceptual and implementation approaches, incomplete parental uptake, and the need for follow-up to measure impact. Yet such models demonstrate short- and medium-term impacts on identification and referral for developmental risk, promote parenting and clinical practices that should prevent developmental risk, and provide more evidence of their effectiveness than is required for most medical advances to be adopted and reimbursed.<sup>49</sup>

It's feasible to enable the health care system to respond to growing family needs for interventions that promote healthy child development. And it makes sense to do so, considering that multiple randomized

studies of nurse home visitation programs have demonstrated positive impacts on children's developmental outcomes, including improvements in communication and language, motor, and cognitive developmental risk over the period of the visitation program. Several studies have shown that children continued to see improvements in their cognition, language, and achievement years after the intervention ended.<sup>50</sup> One study of a statewide home visitation program in Oregon found improvements in rates of parents reading to their children and developmental screening and even in rates of developmental delay.<sup>51</sup> Providing additional developmental supports and services for coordination with the medical home through the vehicle of home visitation may be particularly effective as a tool for optimizing healthy child development, especially when home visitation nurses have enough resources, their visits are sufficiently frequent, and they're able to reach at-risk families.<sup>52</sup>

One promising strategy for improving healthy development in which the health care system figures as a key partner is to increase resources and opportunities for service coordination. The national Help Me Grow initiative is a good example of such a community-oriented approach. Help Me Grow creates a single, centralized access point for assessing and responding to developmental delay; it also reaches out directly to families and encourages health care providers to offer developmental screening and referral. By 2018 it had grown to 92 sites in 28 states.<sup>53</sup> Elements of this community-oriented model have demonstrated impact in experimental studies, though no experimental studies of the model as a whole have been published (only nonexperimental studies have been

carried out to date).<sup>54</sup> In a trial in which a trained staff coordinated with pediatric clinics from a centralized hub designed to link developmental services, rates of developmental screening, referral, and receipt of services markedly improved.<sup>55</sup> Community-integrated approaches like this have been recommended for decades. Given growing need for developmental supports and services, as well as the appetite for such programs among health professionals, it's likely an excellent time to begin developing such community-integrated models.

## **Evolving Practices and Horizons in Care**

Despite the current large mismatch between developmental needs and the health care system's ability to identify developmental risk or delay, provide supports, and connect vulnerable children with services, the system is evolving, albeit incrementally, to meet the health and developmental needs of the nation's children through innovations in care models, service coordination, and coverage designs (see table 1). For instance, a group of care models for children has been developed to clinically screen for poverty-related material hardships and adversity (for example, food insecurity, housing insecurity, transportation problems, etc.) and to link children and parents to community resources when such risks are identified.<sup>56</sup> Though a handful of experimental and quasi-experimental studies of such models have shown higher rates of social resource connections and improvements in quality of life, none have yet examined child development. Similarly, screening for ACEs in the clinical setting is gaining traction in pediatrics and has been made reimbursable

in California for children on Medicaid. Though it's far from clear whether rigorous studies of ACEs screening and subsequent intervention via the child health care system will affect developmental outcomes, few factors influence children's development more than early exposure to trauma. If the health care system can effectively identify and respond to ACEs without further stigmatizing or marginalizing the families that experience them, this approach could help prevent developmental risk.

To meaningfully improve the health system's performance in identifying, responding to, and preventing developmental risk, transformative change may be required. Various transformative models have been proposed, all of which show promise for helping health care systems build meaningful partnerships with key community services and agencies, coordinate services to achieve efficiency and scale, and reach families that would otherwise be left behind. This is especially urgent at a time when the resources and infrastructure available to address children's health development are static or shrinking, crowded out by rising overall health care costs and other policy priorities. New models of payment are needed to match these new models of care delivery and coordination.<sup>57</sup> We also need more research that evaluates the effectiveness of such payment reforms. A handful of alternative payment programs under state Medicaid agencies offer possible roadmaps for funding both direct provision of an expanded set of services and capacity-building programs for integrating community services and health care. These might be adapted to the child health care system.<sup>58</sup>

We'll need rigorous evidence to guide the evolution of innovative, integrated health care models. Measures of success will need to reflect the full scope of health care, education, early intervention, and community resources required to support healthy child development. These measures must capture rates of screening at the population level and rates of referral or receipt of early intervention services and must ultimately track the extent to which early interventions lead to decreasing rates of developmental delay.

## **Conclusions**

The child health care system is at a crossroads of competing and conflicting priorities and incentives supporting patchwork approaches carried over from outmoded, overly medicalized conceptions of how to address and promote healthy child development. Substantive systemwide improvement is currently elusive, and no clear reduction in developmental risk or increase in developmental capabilities has been achieved at the population level. Instead, the child health care system continues to apply its existing tools to the shifting epidemiology and swell of newly recognized developmental vulnerabilities, deploying a push broom against a flood.

As US inequality continues to grow, the number of children with developmental needs is likely to increase as well. We need transformational changes in health care delivery if we are to recognize and prevent a broader set of developmental vulnerabilities, foster clinical-community service coordination and facilitation of access to developmental services expertise, and develop payment models that encourage upstream intervention to mitigate a range

of psychosocial and medical developmental vulnerabilities and lead to improvements in population-level developmental capabilities. A growing number of pediatric clinicians and child health delivery systems recognize the need for such transformations and are more

ready to implement new models of upstream care than at any time in recent memory. Through this evolution, the child health care system can realize its potential to serve as a catalyst of healthier development among America's children.

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