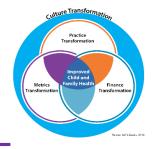
Inck Marks

Health Care Transformation for Young Children: The State of the Field and the Need for Action

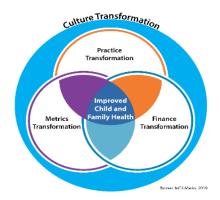
Overview Working Paper
InCK Marks Child Health Care Transformation Series

March, 2020 DRAFT

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Framework for Transforming Children's Health Care



Children's primary care providers include: pediatricians in solo or group practice, family practitioners in rural and urban clinics, nurse practitioners and physician assistants in community health centers, and others. All aim to be a family-centered medical home.

Research and professional guidelines such as *Bright Futures* point to a need for more family-centered medical homes that emphasize: 1) prevention, attachment, and healthy development, 2) meaningful family engagement, and 3) connections to other services in the community. In addition to providing high quality medical care, child health practitioners are being called upon to identify and initiate responses to social determinants of health, including stress and adversity (economic, social, and psychological). In short, they are being called upon to transform their practice.

Changing the culture of children's primary care will require transformation in practice, measurement, and financing. Most important, transforming child health care will require a culture of practice with emphasis on health equity and long-range outcomes, not short-term costs.

Across the country, exemplary practices demonstrate how to create high-performing medical homes, which deliver more team-based, relational, and family-centered primary and preventive services. We have the knowledge base to move toward broader diffusion and adoption of child health care transformation.

InCK Marks encourages child health practitioners, experts, advocates, researchers, and policy makers to help advance child health care transformation and promote health equity for all children.

- Practice Transformation Moving toward more high performing, family-centered medical homes with preventive, developmental, behavioral, and other services that respond to both bio-medical and social determinants of health. This includes reaching the standards set by *Bright Futures* and the expectations set by Medicaid's Early and Periodic Screening, Diagnostic, and Treatment (EPSDT) benefit.
- Metrics Transformation Using measures and measurement tools to guide performance and support practice
 transformation, including those related to the child, home environment, and family strengths and goals. Practicelevel measurement tools and system-level metrics are both needed.
- Finance Transformation Providing financing that recognizes how preventive and primary care for young children can have lifelong positive impact and long-term cost savings across multiple public systems, that rewards the greater value of high performing medical homes over existing practice. This is particularly true for Medicaid financing.
- Culture Transformation Advancing health equity via transformed medical homes that value and build from family
 culture, strengths, and goals and are connected to the neighborhoods and communities served. Assuring familycentered care focused on healthy development (cognitive, social/relational, emotional/behavioral, and physical)
 requires advancing equity and combatting bias in all its forms.

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Preface

Internationally, children in the United States ranked 37th in their well-being among 41 high and middle-income countries (above only Mexico, Bulgaria, Rumania, and Chile), according to a 2017 UNICEF report.¹ At the same time, the United States spends more per capita on health care than all of these countries. Health care is not the only factor contributing to child well-being, but it does play a role.

This overview working paper is part of a series of working papers about what we know about transforming child health care in the critical prenatal-to-three years to improve child health and well-being. Current research and practice innovations do not provide all the answers to how best to transform child health care, but this working paper series shows there is substantial consensus in the field on the key elements of child health care transformation – practice, metrics, financing, and culture – and substantial knowledge and experience upon which to build in deepening and broadening this transformation and moving it toward the standard of care.

This working paper series is just that; it is designed to elicit further comment and encourage those in the field to continue to revise, refine, and expand upon the evidence base provided from this state-of-the-field analysis.

This overview working paper is based upon the framework established by the InCK Marks National Advisory Team, including: Charles Bruner, Kay Johnson, Maxine Hayes, Kamala Allen, Mayra Alvarez, Melissa Bailey, Scott Berns, Christine Bethell, Elisabeth Burak, Paul Dworkin, Wendy Ellis, Jeff Hild, Shadi Houshyar, Nora Wells, and David Willis. Charles Bruner is the lead author of this overview.

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This resource brief was made possible with generous funding from the Robert Wood Johnson Foundation (RWJF) and the Perigee Fund for the establishment of InCK Marks. All opinions and views expressed are those of the author(s), however, and not necessarily of the funders. InCK. The purpose of InCK Marks is to support child health champions — child advocates, practitioner leaders, family and community voices, health experts, Medicaid agency staff, and policy makers — in advancing and transforming child health care to achieve health equity.

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Health Care Transformation for Young Children³: The State of the Field and the Need for Action

Introduction: The Imperative for a Focus Upon Young Child Health and Health Equity.

Children represents society's future; and Americans place ensuring the health and education of children at the top of the issues that they want public policy makers to address.⁴ Policy makers at both the state and federal levels increasingly recognize the foundational role that the first years of life play in a child's health trajectory and are describing that health broadly – across physical, cognitive, social, and emotional dimensions. Parents care deeply about their children; and with parenting comes a neurobiological change toward protection and parenting of that new life. ⁵ In short, families have hopes and dreams for their children that are powerful motivators and hey go to great lengths to find opportunities for their children to grow and develop.

Unfortunately, far too many of America's children start life at a disadvantage that places them in jeopardy. Whether through poverty, discrimination, isolation, stress, or other adversities, they and their parents face formidable barriers to ensuring healthy growth and development. By kindergarten entry, one-quarter of America's children are measurably and unnecessarily behind in two or more areas of development (physical, cognitive, social and emotional). In high poverty neighborhoods, more than twice as many are at risk, where "unreadiness" often is the norm. At all stages as they approach adulthood, profound racial gaps exist as to their opportunities to become "middle class by middle age." Early adversity and toxic stress produce lifelong consequences in health, productivity, and even life expectancy. Discrimination, segregation, and marginalization are devastating to the outlook for a large share of the diverse young child population, with inequitable opportunities due to race and place as well as poverty.

The first three years of life are particularly critical to healthy development, when brain development is most rapid and children are developing their sense of security and attachment, early self-regulation and identity, and responses to the world.¹⁶ It also is the time when children's primary care health practitioners – including pediatricians, family physicians, nurse practitioners, and physician assistants – see them most often outside their own families and can play the greatest role in prevention and healthy development.¹⁷

Over the last two decades, advances in neurobiology and social science have identified the critical importance of getting a good start in life to lifelong development. The P.A.R.E.N.T.S. science (Protective factors, Adverse childhood experiences (ACEs), Resiliency, Epigenetics, Neurobiology, Toxic Stress, and Social determinants of health is clear that the critical foundation of child health is the safety, stability, and nurturing in the child's home environment during these years. Emerging science also tells use about the long-term protective effects of positive childhood experiences (PCEs), even for those who face adverse experiences and toxic stress. While parents are their young children's first and most important teacher, nurse, safety officer, and guide to the world, they cannot do this without sufficient and tailored support and resources for them and their communities.

The Need for Identifying Child-Specific Approaches to Health Care Transformation.

This, in turn, has focused new attention on the role of the child health practitioner during these critical years. Definitions of child health²⁸ and health equity²⁹ now call for health care to be much broader than the treatment of illness and injury and physical health conditions. Guiding principles for medical homes³⁰ emphasize family-centered and holistic care which responds to the child in the context of the family and community. The latest edition of *Bright Futures*³¹ – the established, evidenced-informed guidelines for providing well-child visits – places emphasis upon practitioners identifying, discussing, and responding to social determinants as well as biomedical determinants of health.

At the same time, current child health care practice remains largely focused upon providing clinical care for medical conditions and focusing preventive efforts only on child- and health-specific conditions and diagnoses (e.g. immunizations, developmental screenings). Well-child health care falls far short of the guidance set out in *Bright Futures*, let alone offering the opportunity to extend responses to health-related and not strictly medical care services.

As medical costs in American society have continued to rise, without corresponding improvements in health, there have been calls for fundamental changes to health care delivery – an overall health care transformation. With various iterations, this has been framed as focusing upon "the triple aim" of improved health care quality for individuals, improved population health and well-being, and lower health care expenditures. In addition, there is a movement in support of building "a culture of health" and not simply treating disease, which aims to provide everyone in America a fair and just opportunity for health and well-being. In this context, the term "transformation" is not used lightly, representing far more than incremental changes to office protocols or the addition of subtraction of specific services. It is about fundamentally shifting the focus, activities, measures, and financing of health care.

To date, most of the actual exploration and support for such transformation has been directed to adults and to populations with high-cost, chronic care needs, which represent the locus for the lion's share of health care expenditures. While the seminal article describing the triple aim emphasized that achieving that aim requires more upfront investments in primary and preventive health services, the primary focus has been on transforming health care specifically to contain medical health care expenditures. Since most children, including very young children, are not high-cost users of medical care, they often have been left out and their unique needs and developmental status absent in health transformation efforts.³⁴

The Core Elements of Child Health Care Transformation for Young Children.

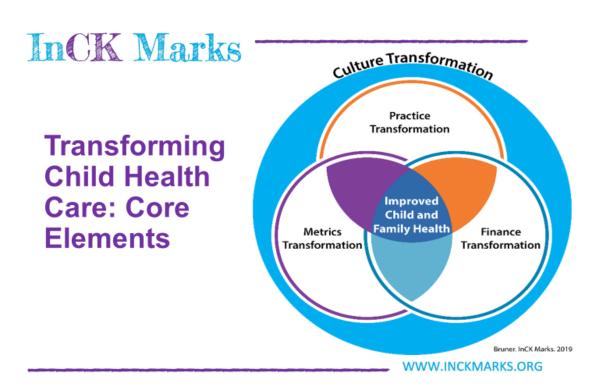
This working paper focuses on health care transformation for young children (birth to three), starting with primary health care services. During these first three years, primary care child health care practitioners represent the one nearly universal point of professional contact with them and their families. Over 90 percent of all very young children see a practitioner at least annually for a well-child visit and virtually all have contact with health practitioners for some illness or injury. When children reach school age, almost all have regular contact with teachers and other school staff on almost a daily basis. By contrast, in the earliest years it is the child health practitioner who most often sees the child, with the parent, in a setting that can identify and explore the child's health condition and developmental needs and at least provide an initial discussion and response. There is no other system

with close to this reach. Subsidized child care, TANF, early intervention (Part C of IDEA), and housing subsidies reach less than 1 in 20 young children; the Early Head Start, Maternal, Infant, and Early Childhood Home Visiting (MIECHV) program, and foster care reach around 1-2 percent each.^{36 37}

The guidelines in the fourth edition of *Bright Futures* lay out a broad set of activities for these visits, going well beyond a physical examination, the provision of vaccines, and anticipatory guidance around child medical health issues. The guidelines entail much more care coordination and relational health care — and the referral to and then provision of health-related services — often focused upon strengthening and empowering the family to advance healthy child development. In short, the guidelines describe what a transformed primary care child health care practice would do as part of a transformed child health care system.

Achieving such transformation, however, requires more than promoting such change among child health care practitioners and health related services. It requires complementary transformations in the metrics and measures used to define children's health, the financing structure for advancing and sustaining transformed practice, and the foundational commitment to a culture of practice that is developmental, ecological, and equitable. These elements of child health care practice transformation are shown graphically in Chart One.

CHART ONE



Achieving such transformation in child health care does not have to start from scratch. In fact, through many innovations and their early adoption, adaptation and diffusion, there is much to build upon. This working paper briefly describes the "state of the field" regarding each of these elements of transformation, with upcoming working papers going into more depth on each.

The Practice Transformation Element.

Young children are not little adults, and research long has shown that fostering young children's health and development is different from maintaining an adult's health status. Moreover, the health of a young child cannot be viewed outside the safety, stability, and nurturing the child receives in home and community.³⁸ Over the last thirty years, a number of enhancements to well-child care, starting with Reach Out and Read in 1989, have shown their value in advancing children's healthy development. More recently, this has included high visibility programs such as HealthySteps, DULCE, Centering Pregnancy and Parenting, Help Me Grow, Medical-Legal Partnerships, and an array of new health-related care coordination and home visiting programs connected directly to child health care practice. While there has not yet been an exhaustive meta-analysis of such programmatic efforts, several different reviews of evidenced-based programs for young children related to child health³⁹ have identified more than fifty such evidenced-based programs, many identified by multiple reviews.⁴⁰ These reviews compare favorably with the reviews of home visiting and early learning and preschool programs that have given rise to major expansions in public funding for those fields of practice.⁴¹

In addition to these programmatic enhancements to primary child health practice, a growing array of pediatric systems – particularly federally-qualified health centers (FQHCs), large public health systems, and clinics linked to children's or teaching hospitals – have taken systemic approaches to child health care transformation, often incorporating several new programmatic features while seeking to reconfigure the overall health care system and setting to be more family-centered, preventive, and developmental. They have begun to develop population-based responses, particularly within high poverty neighborhoods and communities, where the needs are greatest.⁴²

In short, taken together, these exemplary practices, evidenced-based programs, and systems change initiatives point to a primary care practice - e.g. a high performing medical home⁴³ - that involves transformation in what the practice and practitioner do, what immediate care coordination and relational health is provided to engage families and enhance their agency, and what additional health-related services are then embedded within or linked to that practice. Chart Two shows this schematically.

CHART TWO

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Design for High Performing Pediatric Medicaid Homes in Medicaid

Well-Child Visits

- Comprehensive well-child visits as required under EPSDT.
- Adherence to AAP Bright Futures scope and schedule.
- Screening for physical, developmental, social-emotional-behavioral health, maternal depression and other social determinants of health.
- Anticipatory guidance and parent education, as required in EPSDT and Bright Futures.
- Family engagement, focused on two-generation approaches to ensuring child health
- Other primary care practice augmentations (e.g., Reach Out and Read).

Care Coordination / Case Management

- Individualized, with intensity commensurate with need.
- Routine care coordination for all as part of medical home.
- Intensive care coordination/ case management for those with higher needs identified.
- Structured, family-focused approach to assess and respond to medical and non-medical health-related needs.
- Linkages to community resources, with active identification and engagement of those resources.

Other Services

- Child/family support programs, including those designed to be collocated in primary care (e.g., Healthy Steps, Project DULCE).
- Integrated behavioral health in primary care setting.
- Referrals to and integration with other services such as home visiting, family support, early intervention, early childhood mental health, and other programs.

Suggested citation: Johnson K and Bruner C. A Sourcebook on Medicaid's Role in Early Childhood: Advancing High Performing Medical Homes and Improving Lifelong Health. Child and Family Policy Center. October, 2018.

WWW.INCKMARKS.ORG

In terms of the diffusion of innovation literature,⁴⁴ such transformation already has produced innovations directed toward this transformation, enlisted earlier adopters, and even become recognized by the pediatric community as a high value practice change. Champions for transformation have emerged. At the same time, however, it is far from the standard of or expectation for practice. To become so requires further spread of practice transformations and complementary transformations in child health care metrics and child health care financing.

The Metrics Transformation Element.

The great majority of children are born without a major congenital abnormality, hereditary condition, or other immediate major medical care condition that calls for immediate intervention. At the same time, many children are born into circumstances that jeopardize their health and early development, with lifelong consequences. Currently, however, the measures in broad use to screen for, diagnosis, and then treat young children for their health and well-being focus upon child-specific medical conditions. The measures used to determine impact or improvement of children's health status similarly generally are medical and child-specific in their nature.

The practice transformation described above, however, requires practitioner attention to much more than the medical health of the child. It requires identification of and response to social determinants of health, e.g. to both social complexity and medical complexity.⁴⁵ For accountability and continuous improvement efforts, it requires ongoing tracking of children and their families in terms of their social and medical complexities and their overall development (physical, cognitive, social/relational, and emotional/behavioral).

A partial step to doing this has been spurred by the findings regarding Adverse Childhood Experiences (ACEs), with greater attention to identifying specific adversities in the home environment. A broader formulation has been around "toxic stress" experienced by young children, whether or not this relates to specific experiences or events. Definitions of social determinants of health and protective factors related to young children describe a broader array of factors which include household material well-being, family social well-being, parental personal well-being, and parent-child relational well-being. These are shown in Chart Three and are also very much aligned with the National Educational Goals Expert Panel's definition of "school readiness."

CHART THREE

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In particular, transforming such measures to correspond with practice transformation also involves looking for child and family strengths and assets and forging relationships which advance family resiliency, hope, mindfulness, and simply time spent with the child in fostering child development.

In this respect, the Child and Adolescent Health Measurement Initiative (CAHMI) has done much to advance both the actual metrics for use by practitioners and health systems and the process for using them with and through family engagement. CAHMI's Well Visit Planner⁵⁰ provides a platform that advances family engagement and partnering with practitioners in identifying and responding to child health, development, and well-being. While more work needs to be done in the field to further test and refine specific screening questions to families and related observations by practices, the platform for such efforts has been established. Moreover, other analysis has shown that the scope for enriched and transformed child health care applies to at least 30 percent of the young child population.⁵¹ CAHMI, in particular, also emphasizes the importance of mindfulness, hope, and nurturing as core to thriving – and moves to operational definitions of these terms.⁵²

The Finance Transformation Element.

Just within the young child health practice setting for the well-child visit, practice transformation requires much more time and therefore reimbursement than is currently provided by most child health care payers, particularly Medicaid. Medicaid is critically important in this financing, as it provides health care coverage to over half of all young children, and a greater proportion of children who are most vulnerable.⁵³ While Medicaid includes a preventive and developmental framework that is entirely aligned with child health care practice transformation – the Early, Periodic, Screening, Diagnosis, and Treatment (EPSDT) benefit⁵⁴ – Medicaid financing in most states falls far short of stimulating or sustaining such transformed practice.

Health care financing transformation in the adult and chronic care world has focused upon moving away from a fee-for-service and "volume-based" payment system to a managed or accountable care "value-based" payment system. Although sometimes based upon achieving the triple aim, most of the financing transformations toward value-based care has narrowly defined this as, first and foremost, containing or reducing overall health care costs through reducing episodes of high cost medical treatments. This moves toward identifying and then responding to patients with medical complexities and imminent treatment costs, generally through some form of care coordination, to better manage and stabilize their conditions and therefore minimize high cost episodes of care. While this gets at the heart of where there are disproportionate costs in America's health care system (often involving treatments with limited actual value), it does not get to the heart of improving children's health and the value of doing so.

Transformed financing for child health care requires a different approach – more investment-based and less cost-avoidance – than for adult health care transformation. It requires compensating high value (e.g. transformed) young child health care at a rate to advance and sustain it, commensurately greater than what is reimbursed for the current general standard of care. In many respects, "value" is "volume," e.g. much enriched care, when it comes to primary child health care practice, and needs to be financed as such.

While child health care financing transformation has not received the same attention that overall health financing transformation has, that is changing. A consensus document of leading child health care organizations has identified the levers for such transformation, which can be incorporated into both feefor-service and managed or accountable care financing systems.⁵⁵

The Culture Transformation Element.

The Robert Wood Johnson Foundation has emphasized the need to "build a culture of health" which focuses upon family engagement and agency and achieving health equity.⁵⁶ Nowhere is this more important than with respect to child health, and nowhere does the health care system itself play a greater role than in the earliest years of life.

The principles undergirding a medical home include "partnering with families" and providing ecological care that is relational and team-based.⁵⁷ Stress, discrimination, and the social gradient all are recognized as core factors in the social determinants of health.⁵⁸ Providing "culturally competent" care has been expanded to providing "culturally responsive" or "culturally reciprocal" care, with a greater emphasis

upon a concerted, intentional anti-bias approach and a commitment to building racial and cultural diversity into the organization itself.⁵⁹ ASCEND at the Aspen Institute has placed emphasis upon two-generation models for improving child health and well-being that build upon assets and strengths.⁶⁰ Relational health and health care⁶¹ have emerged to emphasize the foundational importance of valuing families and where they come from and building upon their hopes for their children as essential to engaging them.

This culture of health transformation in many ways describes a fundamentally different relationship between the system and its practitioners and the families being served. While child health practitioners still must be recognized and valued for their expertise on clinical health care, they serve in much more of a facilitating and partnering role with the child and families they serve in advancing overall child health. This also leads to their often providing a space for community-building, ⁶² as well as individual service provision, particularly as families themselves seek to create healthy environments not only for their own children but for others in the community. ⁶³ This recognizes that adverse community experiences as well as adverse home experiences jeopardize healthy child development and require community-level and community-led actions to address, ⁶⁴ as Chart Four shows.

CHART FOUR

The Pair of ACEs Adverse Childhood Experiences Maternal Physical & Depression **Emotional Neglect Emotional &** Divorce Sexual Abuse Mental Illness Substance Incarceration Abuse Homelessness **Domestic Violence** Adverse Community Environments Violence Discrimination **Poor Housing** Quality & Community Lack of Opportunity, Economic Affordability Disruption **Mobility & Social Capital**

Such culture transformation obviously is not confined to the child health care system; it also is required in all systems serving young children and their families.⁶⁵ Yet the child health care system often can play a leading and facilitating role, particularly by providing the time, space, and opportunity for peer support, mutual assistance, and affinity-based networking (often around child-specific and health-related needs).

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Ellis, W., Dietz, W. (2017) A New Framework for Addressing Adverse Childhood and Community Experiences: The Building Community Resilience (BCR) Model. Academic Pediatrics. 17 (2017) pp. S86-S93. DOI information: 10.1016/j.acap.2016.12.011

In reviewing transformational efforts in early childhood across health, early care and education, and family support, *Village Building and School Readiness* described this underlying culture as a DNA of

effective programs,⁶⁶ as shown in Chart Five. The two interconnecting DNA strands in the double helix relate to staff and family roles embedded in those transformational efforts.

CHART FIVE

The DNA of Transformed Practice

STAFF DNA Strand	PARTICIPANT DNA Strand	DESCRIPTION of Interconnecting Strands
ASSET-BASED APPROACH	RECIPROCITY	Staff recognize and work to build upon family strengths. Participants reciprocate by using their assets to help others and the community.
FACILITATED NETWORKING	MUTUAL ASSISTANCE	Staff facilitate participant groups and support development of affinity-based networks. Networks and groups provide support to one another and community.
INDIVIDUAL TAILORING OF SERVICES	PERSONAL RESPONSIBILITY	Staff work with participants and respond to individual needs in providing services. Participants take personal responsibility for addressing family needs.
PASSIONATE SKILLED STAFF	ACTIVATED PARENT LEADERSHIP	Staff are passionate and skilled in what they do, with expertise in own areas and a collaborative mentality. Participants assume leadership roles and build skills, often leading to new roles and careers.
MUTUAL ACCOUNTABILITY FOR SUCCESS		Both staff and participants hold themselves accountable for their roles in personal and community growth and success.
PARTNERSHIP	OWNERSHIP	Staff partner with families, including planning activities and services. Participants take ownership and make commitment for sustaining the program.
CULTURAL CONGRUENCE	EMBRACE DIVERSITY	Staff reflect the culture of the community they serve and value diversity and inclusion (race, gender, disability, sexual orientation, age). Participants advocate for inclusion and model that behavior with family and community.
COMMITMENT TO EQUITY		Achieving equity and eliminating "isms" is embedded in the work.
FAMILY FOCUS	WHOLE FAMILY INVOLVEMENT	Staff maintain a family focus and an environment that is welcoming to all family members. Families strengthen their involvement with their (and others') children and with other families.
COMMUNITY EMBEDDEDNESS	FOCUS UPON COMMUNITY BUILDING	Staff are connected to the community as more than a place to work. Participants act to strengthen and build their community. Staff maintain a family focus and an environment that is welcoming to all family members. Families strengthen their involvement with their (and others') children and with other families.

Clearly, this cultural transformation is about something much more basic than program, practice, protocol, metrics, or financing. At the same time, when embedded into transformation efforts it also leads to those transformations in practice, metrics, and financing. It undergirds – and it sustains – the work. While it often can be intimidating or scary to move outside the bounds of one's professional expertise and the exercise of only that expertise, it also is ultimately rewarding and powerful.

Moving Forward.

Transforming child health care certainly can seem a daunting challenge (let alone transforming the whole system of services and supports during early childhood). At the same time, there is much more to build upon in doing so than there was even a decade ago. There is ample expertise for advancing child health care transformation both within each of the elements and across them, as a whole. There is much more consensus in the field on the value, and for achieving health equity the imperative, of doing so.

This, in turn, requires concerted public education, policy advocacy, and mobilization of the health practitioner community to move beyond small-scale innovation and testing to broader and deeper investment in transformed child health care. It ultimately is not whether we can afford to act and make transformational investments in young child health care; it is that we cannot afford not to act.

NOTE: Comments and edits to this document are welcome. People can contact Charles Bruner by email (bruner@childequity.org) to provide comments or edits or to schedule a call to discuss the framework. This represents an overview of the framework and additional working papers are being developed around each of the four transformation elements — practice transformation, finance transformation, metrics transformation, and culture transformation. Each seeks to provide a state-of-the-field analysis and synthesis of the work.

Endnotes

11 .

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³ The term "transformation" is used to mean "a thorough or dramatic change in form or appearance." While the elements of transformation in this document apply to children of all ages, the focus here is upon the particular developmental period from birth to three, where the primary child health care practitioner plays a particularly prominent role.

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