

## Child Health Care Transformation, Nurturing, and Resilience: Developing Transformed Metrics for Young Children

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This particular working paper was authored by Charles Bruner and improved upon by comments from Kay Johnson. It is adapted from a shorter manuscript that started with the introduction and did not describe many of the references to and advancements made in child health measurement to date, which have been incorporated into this document in the foreword. While recognizing these advancements in the field, the Executive Summary and Core Messages makes the case for a fundamental and transformational shift in child health metrics to support child health care practice transformation. Many of the ideas expressed here derived from earlier work by the authors in a Technical Working Group of the Child and Adolescent Health Measurement Initiative focused upon social determinants of health for young children, made possible by funding to the Maternal and Child Measurement Research Network (MCH-MRN) supported by the Human Resources and Services Administration (HRSA) of the United States Department of Health and Human Services.

## Executive Summary and Core Messages

This working paper focuses upon the emerging challenges and opportunities to devise a metrics and measurement system for young children’s health and development needed to advance practice transformation. Like practice transformation, metrics transformation requires action research, development and validation of new tools, and continuous learning and improvement as these are put into practice. Metrics and measures are required at the practice level, the administrative level, the community level, and even the policy level. They only will be useful in practice to the extent they engage children and families in their use.

While innovative practices may continue to emerge and show evidence of achieving better results for children – even as measured by current child health outcomes – diffusion of such practice and adherence to the practice attributes that make them effective require concerted and equivalently transformational changes in the metrics and measures used related to:

1. Children’s health and developmental trajectories;
2. Family and community factors and determinants which impact those trajectories; and
3. Practice attributes and approaches which address those broader factors affecting child development.

**Children’s Health and Developmental Trajectories.** In terms of the first three years of life, neuroscience has emphasized the particularly critical area of social and emotional development – secure attachment to at least one caregiver and positive self-identity and acquisitiveness in exploration and approach to learning. Resiliency itself has been shown to be part nature but also strongly nurture.

Measuring a child’s healthy development in the earliest years involves measuring such concepts as attachment, resiliency, mindfulness, emotional connection, self-regulation, and self-identity.

**Family and Community Factors Which Impact Those Trajectories.** Science and research are clear that the major factors driving children’s health outcomes are not the result of bio-medical conditions or medical care responses, but the socio-ecological conditions that surround the child. Nurture matters, as much as nature. At an operational level, this means incorporating measures for the safety, stability, and nurturing in the home environment. At the relational level, this includes parental presence and the frequency and quality of intimate, serve-and-return child activities and the times of enjoyment the parent has with the child, e.g. the nurturing that goes on day-to-day.

**Practice Attributes and Approaches Which Address Broader Factors Affecting Healthy Development.** Lisbeth Schorr’s seminal publication, *Within Our Reach*, described the manner in which practices engaged children and families and worked with them to achieve their goals as “attributes of effective practice.” She drew from the study of a diverse set of exemplary programs that showed strong evidence of success working with children that other systems had failed. These attributes, rather than the specific programmatic interventions, protocols, or location or professional affiliation of the organization, represented the foundation for their success.

Measuring them in practice is key for monitoring and performance accountability systems, for quality improvement. and for embedding them within the organization’s own operation and culture of practice.

Charts and case records should reflect family voice and measures of satisfaction; training and selection processes for new staff should demonstrate attention to such attributes; office configuration and setting should be welcoming and supportive; and active solicitation of and response to feedback and ideas from parents should be evident in written records. All these have and can be measured, although most of the literature and research is found in the family support and not the health care field.

**Parent Engagement.** Parents have the most intimate and deep knowledge of who their child is, what the child can and likes to do, and how the child feels and relates. Gathering information and therefore metrics from the parents about the child and the child's relationship with the world represents a critical part of screening, assessment, and response. Moreover, gathering and using this information is part product and part process. If done in a manner that engages parents, where they see the information they provide as relevant to the practice's response to their child and to their own continued nurturing of that child, that information will be more completely provided and will help build a relationship of trust between practitioner and parent. The more this trust is established, the more the parent will share intimate information and be receptive to changing views and actions.

**Summary.** There are two adages about metrics that are particularly appropriate to supporting child health care transformation for young children to be more preventive, promotional, and relational – “You measure what you treasure” and “What gets measured gets done.” We know that children's healthy development in the earliest years is dependent upon secure attachment and bonding through a safe, stable, and nurturing home environment. Our task is to include, and often lead, with that in our measures of children's health and child health care practice.

There is another adage about metrics that also deserves attention, “garbage in ... garbage out.” We are not going to get the information we need unless those providing that information are informed, see its relevance, and are eager to provide it – and the people receiving that information value it and know how to make use of it.

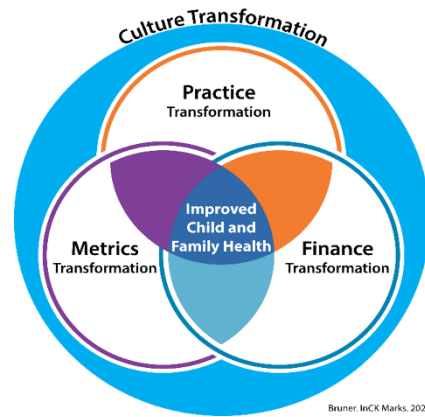
In overly simple but still relevant terms, improving young children's healthy development requires nurturing and fostering resilience. At least proximate measures for these must be part of a child health care system of metrics and measures. They are measurable, if we truly treasure them and want actions taken that support their “getting done.”

## Foreword

InCK Marks has developed a framework for child health care transformation which includes four aligned foci for that transformation – practice transformation, metrics transformation, finance transformation, and culture transformation.<sup>1</sup>

These all require fundamental changes to the current standard of child health care – and particularly primary, preventive, developmental, relational, and promotive health care for young children.

In terms of practice transformation, InCK Marks has described changes to primary child health care that build upon a broad definition of child health, which extends beyond providing medical care and places emphasis upon the principles of a family-centered medical home,<sup>2</sup> partnering with families to advance that child health. The InCK Marks working paper, *Young Child Health Transformation: What Practice Tells Us*<sup>3</sup>, describes this practice transformation and the evidenced-based and exemplary practices in the field which have shown the power of such transformation. COVID-19 has brought new challenges to providing child health services, but reaffirmed the opportunity to advance child health care transformation, as exemplary child health practices have shown in pivoting their response and expanding their outreach to address the impacts of social isolation.<sup>4</sup>



This working paper discusses the corresponding metrics transformation required to support such practice transformation. Metrics and measures are essential in child health care to determine the degree to which practices have engaged in transformation, to provide essential information on children and families to guide provision of child health care services, and to enable practices to continuously respond to and improve their responses to children and families.

Over the last decade, there have been significant advances to child health metrics and measurement to build upon. These have included a much greater emphasis upon practices screening for and responding to children’s developmental health (physical, social, cognitive, and emotional), including the use of developmental screening tools such as Ages and Stages, Ages and Stages SE, the Parents Evaluation of Developmental Status (PEDS) and the Survey of Well-Being of Young Children (SWYC) . Since 2007, screening with validated tools has been a recommended element of well-child visits and part of the standard of care based on the American Academy of Pediatrics *Bright Futures* Guidelines.<sup>5</sup> The recommended schedule for 2020 includes screening for: general development at the 9 month, 18 month and 30 month visits; social-emotional development at all 15 visits from birth to the 6<sup>th</sup> birthday; maternal depression screening in pediatric visits four times in the first year of infant life; and screening for social determinants of health (SDOH) at all 15 visits from birth to the 6<sup>th</sup> birthday.

Still, according to the National Survey of Children’s Health, even general developmental screening is conducted for only about one-third of children.<sup>6,7</sup> Not all practices, health plans, or states are measuring performance using the developmental screening measure for children in the first three years of life now part of the Centers for Medicare and Medicaid (CMS) Core Child Set,<sup>8,9</sup> or the parallel measure on developmental screening in the Title V National Performance Measurement (NPM) set.<sup>10</sup>

While CMS has other initiatives that relate to children’s quality measures, including a Pediatric Quality Measures Program (PQMP), these PQMP measures related to developmental screening are even less likely to be used by practices, health plans, and states.<sup>11</sup> Importantly, even if such measures are used, they often are not assessed along with other important information to guide improvement or action.

There have been some emerging state initiatives to expand screening to include some social determinants of child health. At the federal level, CMS explicitly has supported screening for maternal depression within Medicaid, one social determinant recognized to impact child health. Several states have begun to incorporate other social determinants, including household economic concerns and the presence of Adverse Childhood Experiences (ACEs). With nearly 1 in 4 children with mothers whose mental health is less than very good and over 45 percent experience ACEs (as assessed on the NSCH), these are especially important advancements.<sup>12</sup> While there is growing recognition of the importance of screening for social determinants of health, however, this concept is defined differently in the field. As will be discussed later, most screens incorporate only a portion of the elements related to social determinants of health (and often not developed with specific reference to children).<sup>13</sup>

In short, the advances which have been made in metrics have not yet become standard among practices. Moreover, and t Transformed metrics and measures are required at the practice level, the administrative level, the community level, and even the policy level. They only will be useful in practice to the extent they engage children and families in their use. The major focus of this working paper, they also do not fully cover the practice transformation components that need to be measured as part of the metrics system.

This working paper focuses upon the emerging challenges and opportunities to devise a metrics and measurement system for young children’s health and development needed to advance practice transformation. Like practice transformation, metrics transformation requires action research, development and validation of new tools, and continuous learning and improvement as these are put into practice.

It may be possible for individual practices committed to embracing transformation to do while still operating within current measurement systems. At the same time, without metrics transformation, such practice will not move to become the standard of care. Two relevant adages

about metrics are that you should “measure what you treasure” and “what gets measured, gets done.” While practice transformation can and will proceed, it will be bolstered by metrics system transformations that are aligned and recognize the value and focus of such transformation. There can and should be just as much rigor and precision in measuring children’s overall health and the factors impacting that health as in measuring specific medical components of that health.

Transformed metrics and measures are required at the practice level, the administrative level, the community level, and even the policy level. They only will be useful in practice to the extent they engage children and families in their use.

## Introduction

**HEALTH PRACTICE PRINCIPLES:** Family-centered (driven) services, relational care coordination, coaching and mentoring, community health navigation, trauma-informed care, two-generation strategies, strength-based services, preventive/promotive/developmental/ecological/whole-child primary care

**HOME AND FAMILY CONDITIONS:** Protective factors, love and nurturing, social determinants of health, ACEs, toxic stress, inequity

**CHILD OUTCOMES:** Bonding, secure attachment, security, resilience, self-regulation, social/emotional/relational health, school readiness, mindfulness/flourishing

All the above terms have come into increasing use in the child health care literature – particularly for young children. The first set of terms describes health practice attributes which respond to the whole child in the context of family and community. The second set describes the focus of such practice upon responding to home and family conditions. The third set speaks to the goals for that practice in terms of children’s own health.

As the InCK Marks review of exemplary practices leading child health transformation has described, there is substantial research and science showing the validity of the resulting pathway/equation to improved child health:

More family-centered, strength-based, relational child health care practice **STRENGTHENS +** Family protective factors (improved safety, stability, and nurturing in the home environment), which **IMPROVES =** Children’s healthy development and school readiness (physical, cognitive, social/relational, and emotional/behavioral).

At the same time, these terms are not always used precisely or in the same way. While exemplary and evidenced-based practices see their distinction from mainstream health practice with reference to these terms – in identifying children in need of attention, in responding to them and their ecology, and in producing improvements – such practices are only beginning to develop metrics to measure them and what they do. Screening and surveillance tools often are very limited in their measures of social determinants and protective factors, let alone being administered in ways that engage and support families.<sup>14 15 16</sup> Practice and performance monitoring and accountability tools are not geared to measuring how family-centered or relational is the health care that is provided. Overall, child outcome measures themselves largely are confined to ones related to clinical health conditions and disease and infirmity. At the same time, however, a few studies are emerging that assess child flourishing and school success factors among children, and these show strong associations with family resilience, parent-child connection and the cultivation of positive relational experiences in childhood.<sup>17 18</sup>

While innovative practices may continue to emerge and show evidence of achieving better results for children – even as measured by current child health outcomes – diffusion of such practice and adherence to the practice attributes that make them effective require concerted and equivalently transformational changes in the metrics and measures used at these three levels:

4. Children’s health and developmental trajectories;

5. Family and community factors and determinants which impact those trajectories; and
6. Practice attributes and approaches which address those broader factors affecting child development.<sup>19</sup>

In short, the above terms must be operationalized at the child, family and community, and practice levels. This working paper describes the current state-of-the field in doing so, with particular emphasis upon work at the cutting-edge in developing new tools and metrics.

## Measuring Child Outcomes: Young Child Health

The definition of child health<sup>20</sup> and of health equity<sup>21</sup> now clearly reflect the multidimensional nature of health, extending well beyond bio-medical conditions [see insert]. Even when looking at the medical dimension of health, the Institute of Medicine has recognized that treatment effectiveness not only should be assessed as to whether the treatment reduces or eliminates the biomedical disease or infirmity; it also should be measured as to whether the functional life of the patient improves and, perhaps most importantly, how the patient views the effectiveness and quality of their life as a result of that treatment.<sup>22 23</sup> In this context, a person with a debilitating or terminal health condition may still be seen to be “healthy” and made “healthier” by health interventions to the degree other aspects of the person’s life are fulfilling and enhanced. Alternatively, while a person may have no biomedical disease or infirmity, that does not mean the person is healthy, particularly in a social, relational, or emotional context. The disability community has emphasized that the goal for children (and adults) should be defined as “optimal development,” and not the absence of infirmity or disease.

**CHILD HEALTH** is a state of physical, mental, intellectual, social and emotional well-being and not merely the absence of disease or infirmity. Healthy children live in families, environments, and communities that provide them with the opportunity to reach their fullest developmental potential. *WHO*

**HEALTH EQUITY** is achieving the highest level of health for all people. Health equity entails focused societal efforts to address avoidable inequalities by equalizing the conditions for health for all groups, especially for those who have experienced socioeconomic disadvantage or historical injustices. *Healthy People 2020*

Since 1995, the National Education Goals Panel has defined “school readiness” in a similarly broad fashion, as including five domains: (1) physical health and motor development; (2) social and emotional development; (3) language and literacy; (4) approaches to learning; and (5) general cognition.<sup>24</sup> These have been widely adopted, and states have increasingly established kindergarten entry assessments that cover these five domains. The Race to the Top Early Learning Challenge grants placed major emphasis upon establishing metrics for measuring school readiness at kindergarten entry for the 21 states receiving those competitive grants. Even before then, the School Readiness Indicators Initiative, supported by the Packard, Ford, and Kauffman Foundations, worked with 17 states to develop school readiness indicators to help guide state actions in developing their state early childhood systems.<sup>25</sup> While applied to children at the time of school entry (age 5 or 6), these domains also hold for younger and older children, although the developmental expectations are different at different ages.



Drawing upon the National Survey of Children’s Health (NSCH), both the Child and Adolescent Health Measurement Initiative (CAHMI) and Child Trends have developed frameworks to define health, using very similar domains to those established for school readiness.<sup>26</sup> The Maternal and Child Health Bureau has built on this work to formally create a Healthy and Ready to Learn indicator, with it showing fewer than 50 percent of young children meet criteria for being ready for school.

CAHMI has emphasized the importance of incorporating and integrating both measures of child flourishing and family resilience and connection with measures of medical complexity, social complexity, and relational complexity in assessing children’s healthy development.<sup>27</sup> Child Trends, in collaboration with the Health Resources and Services Administration (HRSA) Maternal and Child Health Bureau (MCHB), CAHMI, and others, has developed a National Outcomes Measure (NOM) for children three to five that covers areas very similar to the school readiness domains: (1) early learning skills; (2) self-regulation; (3) social-emotional development; and (4) physical well-being and motor development.<sup>28 29</sup> The NOM uses 22 items from the NSCH.

The overall child development literature similarly has placed a major emphasis upon social and emotional as well as cognitive development in the early years, recognizing the key role of bonding and secure attachment as a foundation and scaffolding for future growth and development. Advances in neuroscience over the last two decades have reinforced the critical importance of the first years of life – particularly in terms of bonding and secure attachment, early self-regulation, and beginning socialization (playing well with others).

Importantly, while these different domains of health/school readiness often are interrelated, they constitute distinct domains – and therefore all should go into assessing a child’s health. In particular, relational health like healthy attachment or exposure to ACEs is distinct from social factors like food insecurity or economic hardship. Moreover, since children develop at different rates and in different areas, the composite is not simply the sum of its parts.

Finally, and particularly in recent studies on child flourishing, school success and family resilience and parent-child connection represent continua. It is not just a matter of reaching an acceptable threshold to be considered healthy or ready for school. In fact, when children truly flourish, even within one domain, it enriches their overall health and well-being.<sup>30</sup>

In terms of the first three years of life, neuroscience has emphasized the particularly critical area of social and emotional development – secure attachment to at least one caregiver and positive self-identity and acquisitiveness in exploration and approach to learning. Resiliency itself has been shown to be part nature but also strongly nurture.

Measuring a child’s healthy development in the earliest years involves measuring such concepts as attachment, resiliency, parental presence and mindfulness, emotional connection, self-regulation, and self-identity. Many of these relate to the foundation or scaffolding for all future growth and development. At age three, it is possible to begin to assess the child’s life course trajectory – and much of the period from birth to three sets that trajectory in terms of that child’s bonding, attachment, early



Measuring a child’s healthy development in the earliest years involves measuring such concepts as attachment, resiliency, parental presence and mindfulness, emotional connection, self-regulation, and self-identity.

self-regulation, and patterns of exploration and connection with others.<sup>31</sup> CAHMI and partners have focused on advancing measurement constructs such as mindfulness,<sup>32</sup> resilience,<sup>33 34</sup> hope,<sup>35</sup> and thriving to assess and drive developmental directions in a positive way and not to focus (primarily or exclusively) upon weaknesses or deficiencies or adversities in development.<sup>36</sup> Research has shown that positive growth on one dimension of development often can support development in other areas and certainly can compensate for weaknesses. Focusing upon positive growth also is effective in engaging families and encouraging their participation.<sup>37</sup> There now are decades of measurement advances to integrate measurement of early development across the domains of physical health, cognitive development, social/relational development, and emotional/behavioral development.

While many measures require parent-reported information, metrics relying on observational approaches to surveillance and practitioner-administered screens or assessments also are important to employ. The practitioner or child development professional will not have the extent of knowledge and experience with the child that the parent does, and young children are subject to wide variations across the day in the behaviors they express. At the same time, parent-reported information, while most valid and important (both to determination of the child's development and to engaging in actions to advance that development), is not always sufficient to understand the child's developmental on specific dimensions of cognitive, social or emotional development or their medical status and needs.

Currently, while practices sometimes screen for a child's developmental status using such tools as Ages and Stages Social-Emotional or the Survey of Well-Being of Young Children<sup>38</sup> through parental completion of those tools, these seldom become part of the metrics which are employed in overall measures of the child's health. At an operational level, to do so really requires integration of data, which is possible by administering comprehensive assessments using parent report and integrating with results from observational assessments of a parent-child attachment and other measures assessing children's attention, inquisitiveness in exploring the world and ability to deal with set-backs, positive sense of self, and other elements of early self-regulation and response associated with resilience, mindfulness, and hope.

## **Measuring Family and Community Factors: Social Determinants**

By the time a child reaches age 18, it is possible to identify most health vulnerabilities (physical, cognitive, social, emotional/behavioral) by talking with and examining the youth, but that is not the case with infants and toddlers. Particularly when children are very young, measuring their development simply by examining them is likely only to identify very substantial anomalies outside the range of appropriate development. Identifying these anomalies is important, but only begins to identify children who may be on compromised trajectories or at risk of compromised development.

Science and research are clear that the major factors driving children's health outcomes are not the result of bio-medical conditions or medical care responses, but the socio-ecological conditions that surround the child. Nurture matters, as much as nature.

These often are referenced as "social determinants of health," and are posed as having three to four times the impact as medical care on medical morbidity and mortality. Different people may describe such determinants differently – with some concentrating primarily upon economic factors related to meeting basic needs (food, clothing, housing, safety from violence or environmental toxins). Generally, however, these social or environmental factors go beyond simply meeting basic needs to include the

safety, stability, and nurturing in the home environment and the social environment of family, relatives, and friends. A CAHMI technical workgroup defined these in terms of household material well-being, parent personal well-being, family social well-being, and parent-child relational well-being, as depicted in the chart.



Child and Adolescent Health Measurement Initiative (CAHMI) Maternal and Child Health Measurement Research Network Social Determinants of Health Working Group Consensus Framework (2018).

Simply through observation (surveillance), practitioners sometimes can identify, at least at a general level, families who are struggling to provide that safe, stable, and nurturing home environment. Such activities as Reach Out and Read also enable the practitioner to obtain a picture of parent-child interactions and attachment. This surveillance, however, is no substitute for more formal screening. Screening for social determinants of health with an objective tool is recommended by the American Academy of Pediatrics and other professional experts, as well as being integrated into *Bright Futures*.

If the practice is equipped to respond, practices can use screening tools to secure information from the parent(s) or primary caregiver across the different dimensions of social determinants. These also are best and most accurately gathered when they are part of a process of establishing trust and a relationship. A screen that simply involves a parent or caregiver responding to a set of questions, particularly when most focus upon whether or not there are risks or deficits (such as the presence of adverse childhood experiences or ACEs), may help identify vulnerable children but may not provide a good starting point for doing something to address them. When parents do not have trust in the practice or feel involved in the process, they may be less forthcoming in providing sensitive information about themselves and their children. In addition, while there may be challenges or adverse social conditions in the family's home environment, the most effective way to respond to or mitigate their impacts often is to focus upon and build upon strengths that do exist.

The protective factors and strengthening families framework developed by the Center for the Study of Social Policy (CSSP) as a basis for working with families (first to prevent child abuse or rectify its impacts and then more broadly to advance healthy development) presents social determinants as they relate to young children in a more positive construct, with less an emphasis upon diagnosis and labelling of

problems and more upon identifying areas to take action and build upon.<sup>39</sup> The inclusion of questions related to “greatest excitement about being a parent,” “what you love in your child,” and “what you hope for in what your child can aspire to,” all represent ways to engage parents in a positive manner and to identify strengths/interests/desires upon which to build.

The use of such screening tools also helps establish a baseline for subsequent practitioner activities, as well as providing some assessment, when conducted for the population of children served, of the overall status of the children and families being served and the degree to which different concerns present themselves.

At an operational level, this means incorporating some measures for the safety, stability, and nurturing in the home environment. At the relational level, this includes the presence and frequency of intimate, serve-and-return child activities and the times of enjoyment the parent has with the child, e.g. the nurturing that goes on day-to-day.<sup>40</sup> The HOPE – Healthy Outcomes from Positive Experiences – initiative applies this and related knowledge to advance new ways of seeing and talking about strengths and positive experiences that support children’s growth and development into healthy, resilient adults.<sup>41</sup>

The prevalence of such social determinants or risk and protective factors also can be assessed at a population level – not only in terms of the population served by the practice but in terms of the geographic area or areas served. Data from the American Community Survey (ACS) provides sufficient information on social determinants to provide a picture, at a neighborhood level (usually a census tract or aggregation of several census tracts) to identify areas of high need or opportunity.<sup>42</sup> This is particularly important when recognizing that some responses to social determinants require actions at the community level as well as the individual service response level. Even when families in poor and disinvested neighborhoods can establish some economic stability in their own lives, their access to social ties and community resources may remain problematic. In such neighborhoods, there may need to be both qualitatively and quantitatively different responses in order to strengthen the safety, stability, and nurturing in young children’s lives.

[S]ome responses to social determinants require actions at the community level as well as the individual service response level. ... [I]n poor and disinvested neighborhoods ..., there may need to be both qualitatively and quantitatively different responses in order to strengthen the safety, stability, and nurturing in young children’s lives.

At an operational level, this involves defining and gathering information at the neighborhood level both about the overall economic, social, health and educational environment for children (at an overall level available through the ACS down to the census tract level), bolstered by

other information (including community mapping of assets and resources present for young children and their families).<sup>43 44</sup>

The National Research Council has advanced an ecological model of child development that encourages measures at the level of: individual children and families, the community and environment, and the socio-political context and support for families.<sup>45</sup> The emphasis is on promoting equity and addressing the social determinants of health. As part of the Infant Mortality Collaborative Innovations and Improvement (COIIN) project, the Johnson Group and others developed a measurement framework for maternal and infant health equity, including an array of existing population level measures. Building Community Resilience has emphasized the need to focus upon community-level as well as individual-

level needs to address issues of inequity, with their “pair of ACEs” including both adverse childhood experiences and adverse community experiences.<sup>46</sup>

## Measuring Practice Attributes: Relational Child Health Care

The health practice principles enumerated at the outset call for a high performing medical home – family-centered (driven) services, relational care coordination, coaching and mentoring, community health navigation, trauma-informed care, two-generation strategies, strength-based services, preventive/promotive/developmental/ecological/whole-child primary care. These elements often are included in goal and vision statements of exemplary practices, as well as in aspirations for the field of practice overall. In pediatrics, they are represented in the principles for a medical home and in the well-child visit standards established within *Bright Futures*. They have been articulated, in various ways, in systems reform efforts in child welfare, juvenile justice, special education, child mental health, early childhood education, disability services, and welfare reform/child poverty reduction.<sup>47</sup>

Lisbeth Schorr’s seminal publication, *Within Our Reach*,<sup>48</sup> described these as “attributes of effective practice,” drawing from the study of a diverse set of exemplary programs that showed strong evidence of success working with children that other systems had failed. These attributes, rather than the specific programmatic interventions, protocols, or location or professional affiliation of the organization, represented the basis for their success. While some of the exemplary programs Schorr studied have been identified as “research-based” or “evidenced-based” program models (usually because they have incorporated research models that involve a strong counterfactual), it is more the quality of their staffing and commitment to such principles than the specific model itself which produced their results.

They also are more than a set of buzzwords; they have a very substantial research and scientific base.<sup>49</sup> The focus upon program evaluation and research and the emphasis upon measuring program efficacy in terms of discrete outcomes often fail to capture the impact such attributes produce. Where they have been examined in their own right – as qualities of practice – there is a strong research base for their importance to achieving success.

Measuring them in practice is key for developing monitoring and performance accountability systems that assign a value to them (and a value-based payment appropriate to that value). Measuring also is key for quality improvement and for embedding them within the organization’s own operation and culture of practice. Charts and case records should reflect family voice and measures of satisfaction; training and selection processes for new staff should demonstrate attention to such attributes; office configuration and setting should be welcoming and supportive; and active solicitation of and response to feedback and ideas from parents should be evident in written records. All these have and can be measured, although most of the literature and research is found in the family support and not the health care field.<sup>50</sup>

## Measuring Parent/Caregiver Engagement and Contribution

Parents have the most intimate and deep knowledge of who their child is, what the child can and likes to do, and how the child feels and relates. Gathering information and therefore metrics from the parent about the child and the child’s relationship with the world represents a critical part of screening, assessment, and response. Moreover, gathering and using this information is part product and part process. If done in a manner that engages parents, where they see the information they provide as

relevant to the practice's response to their child and to their own continued nurturing of that child, that information will be more completely provided and will help build a relationship of trust between practitioner and parent. The more this trust is established, the more the parent will share intimate information and be receptive to changing views and actions, including how to nurture and protect the child.

Like a practitioner's own surveillance, screening, or any diagnostic tests of the young child, the parent's view of the child only provides one perspective. The practitioner's medical expertise is critical for some diagnoses and the treatment and response they require. The practitioner office's knowledge of overall healthy child development can convey more extensive collective knowledge and insight from the science and research on development than some parents are able to access and assemble themselves. When presented in ways that build upon what parents themselves express as hopes and concerns for their child, most parents are eager for such information and anticipatory guidance.

Gathering information from parents as part of the process of engagement and relationship development is iterative. It works best when integrated into an ongoing structure for interaction and response. It also works best when parents feel control over the information they provide.

At the practice level, gathering information from parents is possible through employing parent surveys or questionnaires. In face-to-face interactions with the child health practitioner or other staff, motivational interviewing or appreciative inquiry represent tools and strategies for engaging and securing information from parents. Outreach to and provision of both information about children's development before and between well-child and other health visits also can foster greater communication and trust, as well as providing pertinent information for the parent's own use.

Research has shown that parents are most likely to be complete and forthcoming in the information they provide when they recognize providing it will help them and their child and will only be shared as far as they wish it to be shared. When parents can complete a survey in private, receive feedback from their responses even before it is shared with others, and are offered guidance on how the information relates to them and their child, parents who often rightfully fear sharing intimate details about their lives are more likely to open up than even when asked to provide information through skilled and empathetic motivational interviewing.

CAHMI has led in the field in developing both initial parent-administered and parent-preparation tools for well-child visits (the Well-Visit Planner) and a Cycle-of-Engagement process that supports continuous engagement of families in their children's health and development.<sup>51</sup> The former supports the parent in being an active participant in well-child visits, equipped to raise questions and concerns. The latter ensures continued feedback from parents and creates part of a performance accountability and improvement system for practices.

CAHMI also has developed and validated the Promoting Healthy Development Survey (PHDS)<sup>52 53</sup> as a tool for evaluating the performance of practices in providing family-centered anticipatory guidance, parent education, and coaching. These are vital elements of pediatric primary care practice; however, parents generally report that they did not experience discussion of screening, receive guidance, or feel their preferences were considered in the processes.<sup>54</sup> The PHDS and similar tools can measure parent experience and have been used as one measurement approach for child health practice transformation.<sup>55</sup>

The Consumer Assessment of Healthcare Providers and Systems (CAHPS) tools tailored for child health and also for children with special health care needs also have been used to assess family satisfaction and are part of several standard measurement sets, including those for Medicaid and CHIP.<sup>56 57 58</sup> Refining CAHPS for transformed child health care and assuring it is culturally and linguistically competent are important future activities.

These measurement processes also may reflect or be related to parent-child interventions embedded in pediatric primary care practice. A meta-analysis of primary care-based interventions to support parenting found statistically significant positive effects on parent-child interactions and activities that stimulate cognitive development.<sup>59</sup> Outcomes were in three domains: language, social-emotional, and cognitive development. The outcome measures and standardized assessment tools used in such studies may yield information that can guide overall measurement related to pediatric primary care for young children.

In this respect, there are tools and strategies now available to practices (although only beginning versions of what might be developed) which can employ technology to gather and use such information most effectively and relationally. Integrated into the practice's overall operations, "high tech" activities can support and enhance "high touch" ones, although they cannot be a substitute for them.



Gathering information from parents about their child represents part product and part process. The "how" is every bit as essential as the "what."

## Conclusion

As stated in the forward, there are two adages about metrics that are particularly appropriate to supporting child health care transformation for young children to be more preventive, promotional, and relational – "You measure what you treasure" and "What gets measured gets done." We know that children's healthy development in the earliest years is dependent upon secure attachment and bonding through a safe, stable, and nurturing home environment. Our task is to include, and often lead, with that in our measures of children's health and child health care practice.

There is another adage about metrics that also deserves attention, "garbage in ... garbage out." We are not going to get the information we need unless those providing that information are informed, see its relevance, and are eager to provide it – and the people receiving that information value it and know how to make use of it.

In overly simple but still relevant terms, improving young children's healthy development requires nurturing and fostering resilience. At least proximate measures for these must be part of a child health care system of metrics and measures. They are measurable, if we truly treasure them and want actions taken that support their "getting done."

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