



Partners for Whole Child Preventive and Developmental Services:

A meeting to advance family-centered, whole child, integrated and equitable approaches to well-child care

April 7-8, 2020 Meeting Proceedings



Summary and next steps overview for a meeting held by the Child and Adolescent Health Measurement Initiative's Maternal and Child Health Measurement Research Network with support from both the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant UA6MC30375 (MCH-MRN) and by the Robert Wood Johnson Foundation under grant #7544

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Executive Summary

Introduction

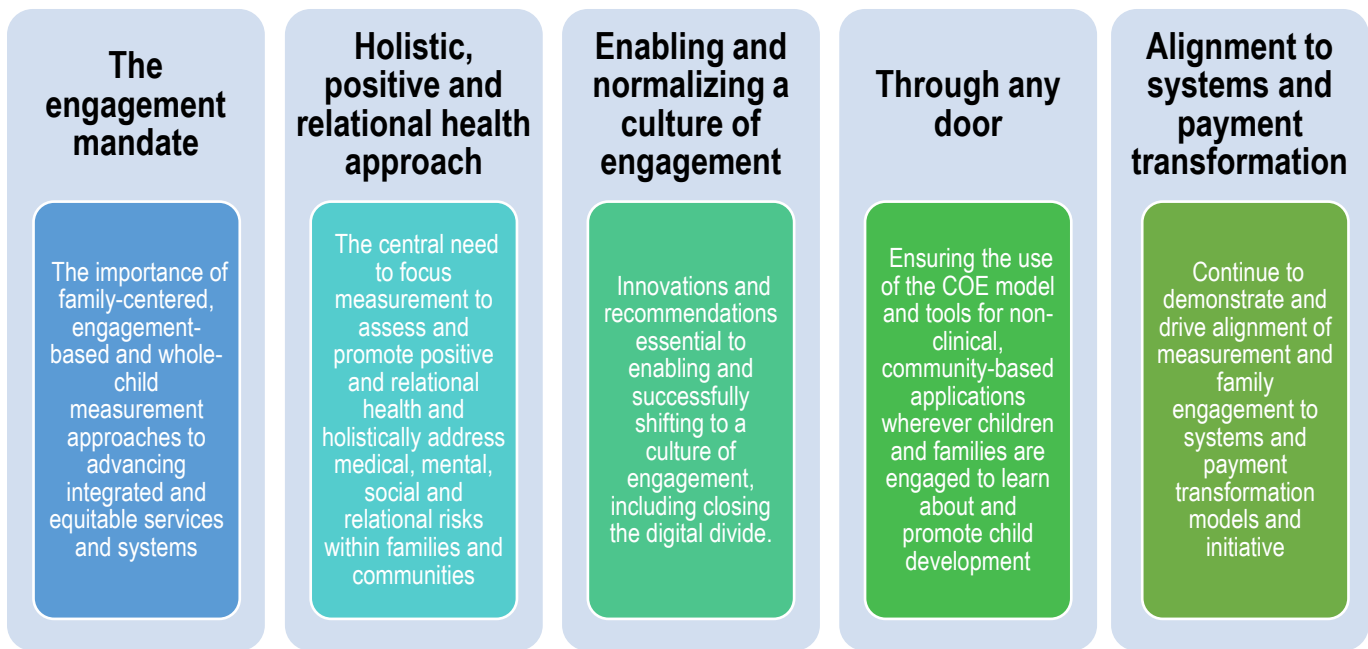
The Child and Adolescent Health Measurement Initiative (CAHMI) hosted an April 7-8, 2020 virtual meeting titled, “Partners for Whole Child Preventive and Developmental Services: A meeting to advance family-centered, data-driven approaches to improving well-child-care services.” This meeting focused on the translation of the CAHMI-led, HRSA funded Maternal and Child Health Measurement Research Network’s strategic measurement agenda for purposes of promoting the early and lifelong health of young children and families. The meeting also leveraged related research and policy work on measuring and promoting positive and relational health, advancing relationship-centered and healing encounters in pediatrics and evaluating and advancing payment and policy approaches to support a whole child, integrated and equitable approach to children’s health services. This related work was also led by the CAHMI and with support from the Robert Wood Johnson Foundation, David and Lucile Packard Foundation and the Children’s Hospital Association. As noted, the meeting built on MCH MRN strategic measurement agenda priorities to ensure whole child, engagement-based, integrated, actionable and flexible measures and data collection, use and reporting methods essential at both the individual and population levels for improving quality of early childhood health services through practice and policy. Due to the COVID-19 pandemic, this meeting shifted to a virtual meeting held on Zoom. This virtual meeting convened over 50 experts and stakeholders representing: MCHB and other federal agencies, the American Academy of Pediatrics, academic institutions, philanthropy, family self-advocacy organizations, public health and clinical practice and MCH-MRN project staff and consultants.

Purpose

The purpose of the meeting was to accelerate the development of a whole-child, engagement-based, actionable, integrated and modular (WE_AIM) measurement and data collection method that advances a guideline-based, personalized, and systems-oriented (GPS) approach to well-child-care services and early childhood development. Specifically, we anchored this goal to the CAHMI’s existing Cycle of Engagement model, a relationship-centered approach for whole child, equitable and integrated care, and corresponding tools, the Well-Visit Planner (WVP) and the Promoting Healthy Development Survey (PHDS). Detailed objectives of the meeting are included in the full proceedings.

Breakout and Full Group Dialogue: Common Emerging Themes

Three full group discussions were held, and six smaller groups engaged in two rounds of breakout discussions to consider, raise questions and issues and make recommendations on advancing a COE model and tools for transforming well-child services to improve early childhood development and child and family well-being. Pre-meeting materials and a pre-meeting input form laid the groundwork for these discussions. The feedback garnered from the pre-meeting input form highlighted essential qualities for well-child care that were discussed during the two-day meeting such as family engagement, family priority setting, actionable family data, and integration with community resources.



Full group feedback discussions during the meeting provided an opportunity to reflect on the insights and ideas generated within the breakout groups. See the Appendix for an overview of each breakout group. Perspectives, questions, issues and recommendations for advancing a COE model and tools that arose from both breakout and full group discussions are more thoroughly summarized in the full meeting proceedings report. Several key themes emerged across groups, which are included in the figure below.

Short Term Needs and Opportunities for the COE Models and Tools

Participants noted short term needs, such as expanding content and features of the COE tools, and opportunities for implementation. During the COVID-19 pandemic, participants found a huge opportunity for the COE model and tools to promote high-quality, relationship-centered well-child care conducted via telehealth or virtual visits.

Immediate Actions and the Next Steps

Below are immediate actions and next steps agreed upon to advance a relationship-centered approach for

1. **MCH MRN Agenda:** Integrate input, finalize and publish the 3.0 MCH MRN Strategic Agenda
2. **Virtual Care:** Partner to design and pilot a virtual well-child care model using the COE model and tools
3. **Link and Align:** Further link and align work to promote integrated, equitable care in collaboration with pediatric transformation, payment, systems change and policy reform models and initiatives
4. **Update and Improve:** Update COE tools to reflect updated Bright Futures Guidelines, promote a positive and relational construct of health and enable further customization and value
5. **Build Evidence and Inspire Research:** Build evidence for the COE model and tools, validate new whole child assessment metrics and advance a research network on community and family engagement

whole child, equitable and integrated well-child care.

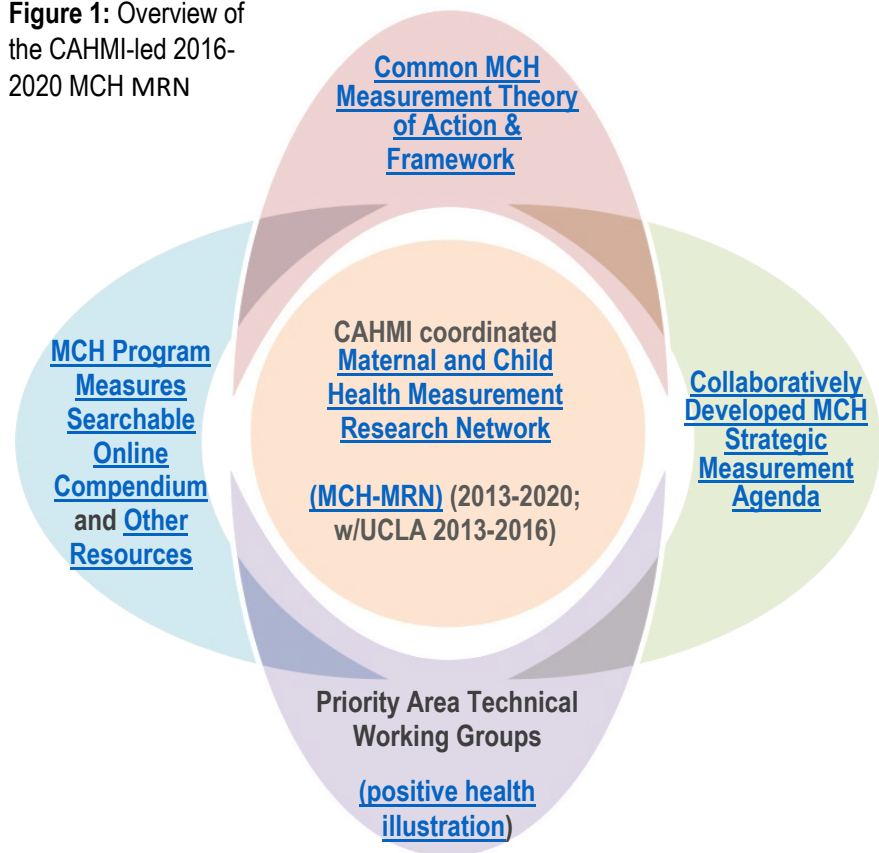
A. Meeting Overview and Pre-Meeting Input to Frame Discussions

1. Meeting background, approach and objectives

On April 7-8, 2020, the Child and Adolescent Health Measurement Initiative (CAHMI) hosted an online/virtual meeting titled “Partners for Whole Child Preventive and Developmental Services: A meeting to advance family-centered, whole child, integrated and equitable approaches well-child-care.” Initially planned as an in-person meeting, this virtual gathering brought together over 50 partners, experts and stakeholders sharing a commitment to advance a family-centered and engagement-based approach to measuring strengths, needs and the quality and outcomes of well-child care services and systems to promote early childhood development. See Appendix A for meeting background and a list of meeting participants and Appendix B for the meeting agenda and breakout team discussion questions. In summary, the meeting was conducted to:

1. **Further the key priorities set forth in the Maternal and Child Health Measurement Research Network’s strategic measurement agenda**, which was established under CAHMI leadership through the 2016-2020 HRSA supported Maternal and Child Health Measurement Research Network (MCH-MRN-see Figure 1); and

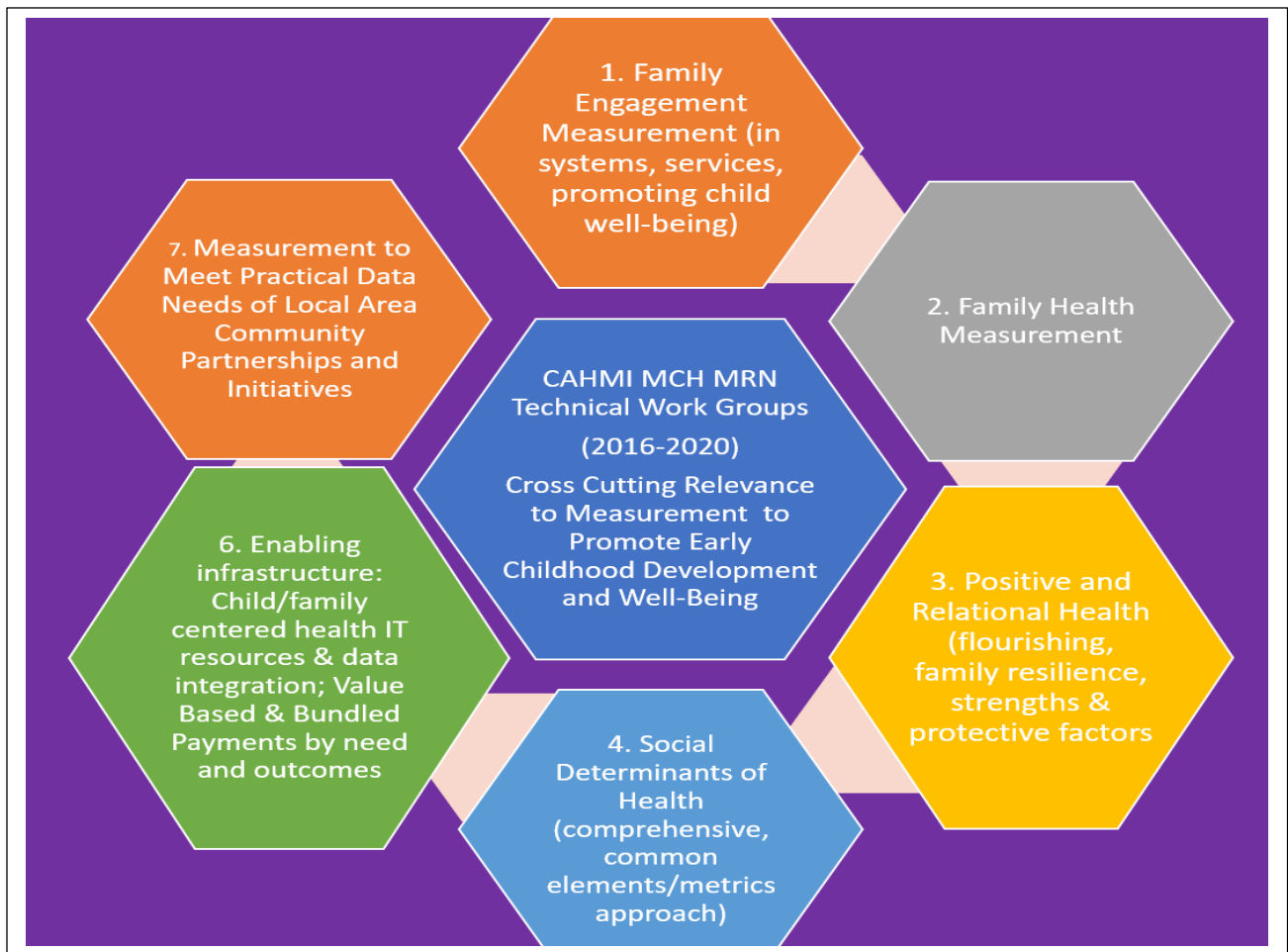
Figure 1: Overview of the CAHMI-led 2016-2020 MCH MRN



2. **Leverage the MCH MRN agenda recommendations** and the measurement research conducted through the 2016-2020 MCH MRN Technical Working Groups (TWGs- see Figure 2) and with support from HRSA’s Maternal and Child Health Bureau and other funding agencies--specifically the Robert Wood Johnson Foundation, the Lucile Packard Foundation for Children’s Health, The Casey Family Foundation, the David and Lucile Packard

Foundation and the Children’s Hospital Association. Each TWG conducted research and disseminated published papers or Issue Briefs relevant to promoting early childhood development in services and systems and emphasized the need for the full engagement of families in both measuring and improving services and systems outcomes.

Figure 2: 2016-2020 MCH MRN Technical Working Groups Advancing Measurement and Approaches Relevant to Measurement and Improvement in Services and Systems to Promote Early Childhood Development and Well-Being



The meeting built on MCH-MRN priorities to advancing whole child, engagement-based, integrated, actionable and flexible measures and data collection, use and reporting methods essential for:

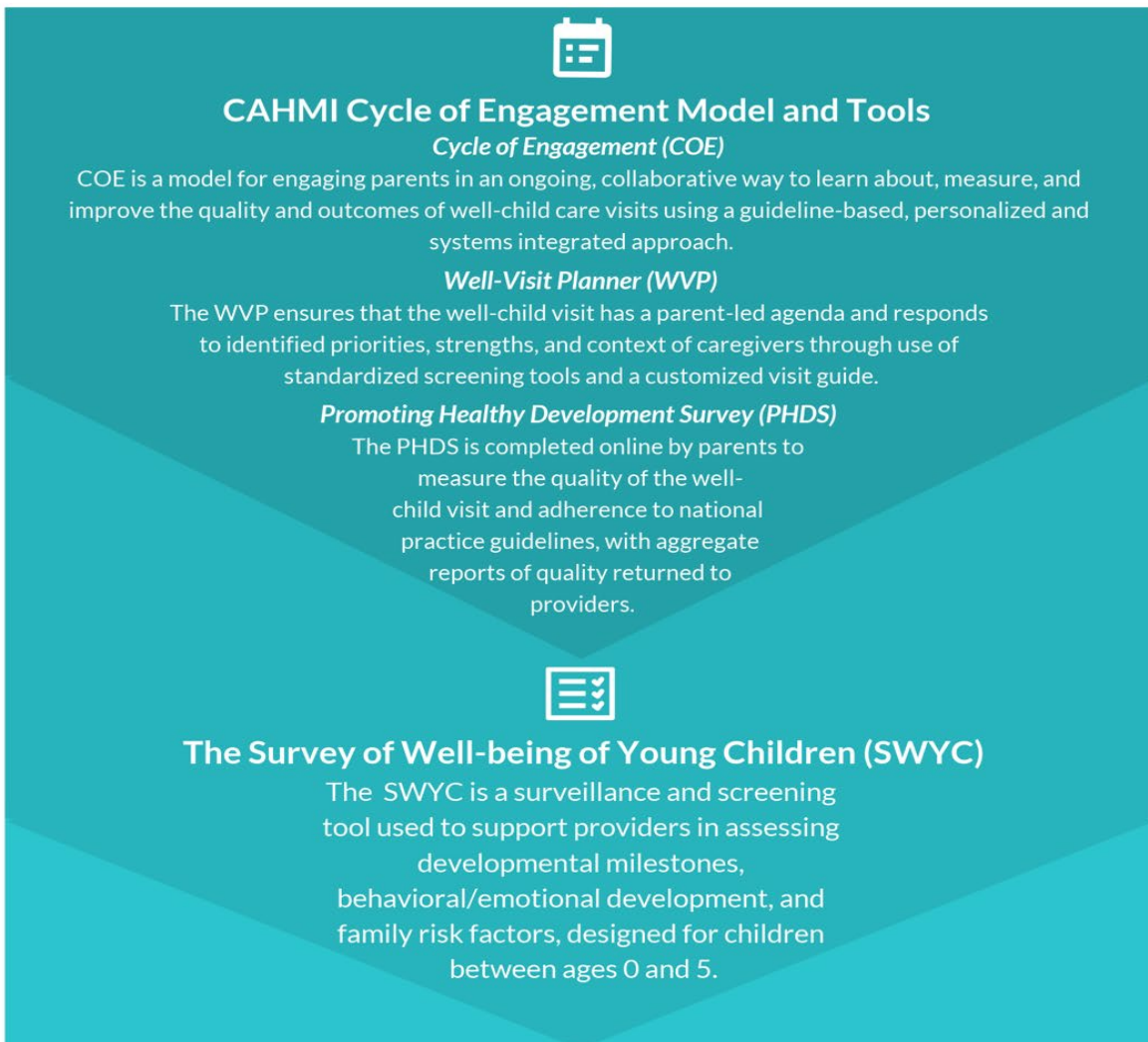
- a) authentically, concretely, and visibly engaging families in front end assessment of their strengths, context, needs and priorities to customize services that promote well-being for the whole child, family and community. This work includes ensuring focus on family engagement, social determinants, health equity and positive and relational child and family health.
- b) improving methods to assess the quality of early childhood health services and link quality/value findings to payment, certification continuing education and related levers for improving care.

c) integrating data to inform tailored services for children and families, including integration with electronic record platforms (leveraging IT to improve care); use of data to support tiered/bundled care payments).

d) ensuring population-based data at the local level to foster integrated and coordinated data and health improvement priorities at the practice, community and systems levels.

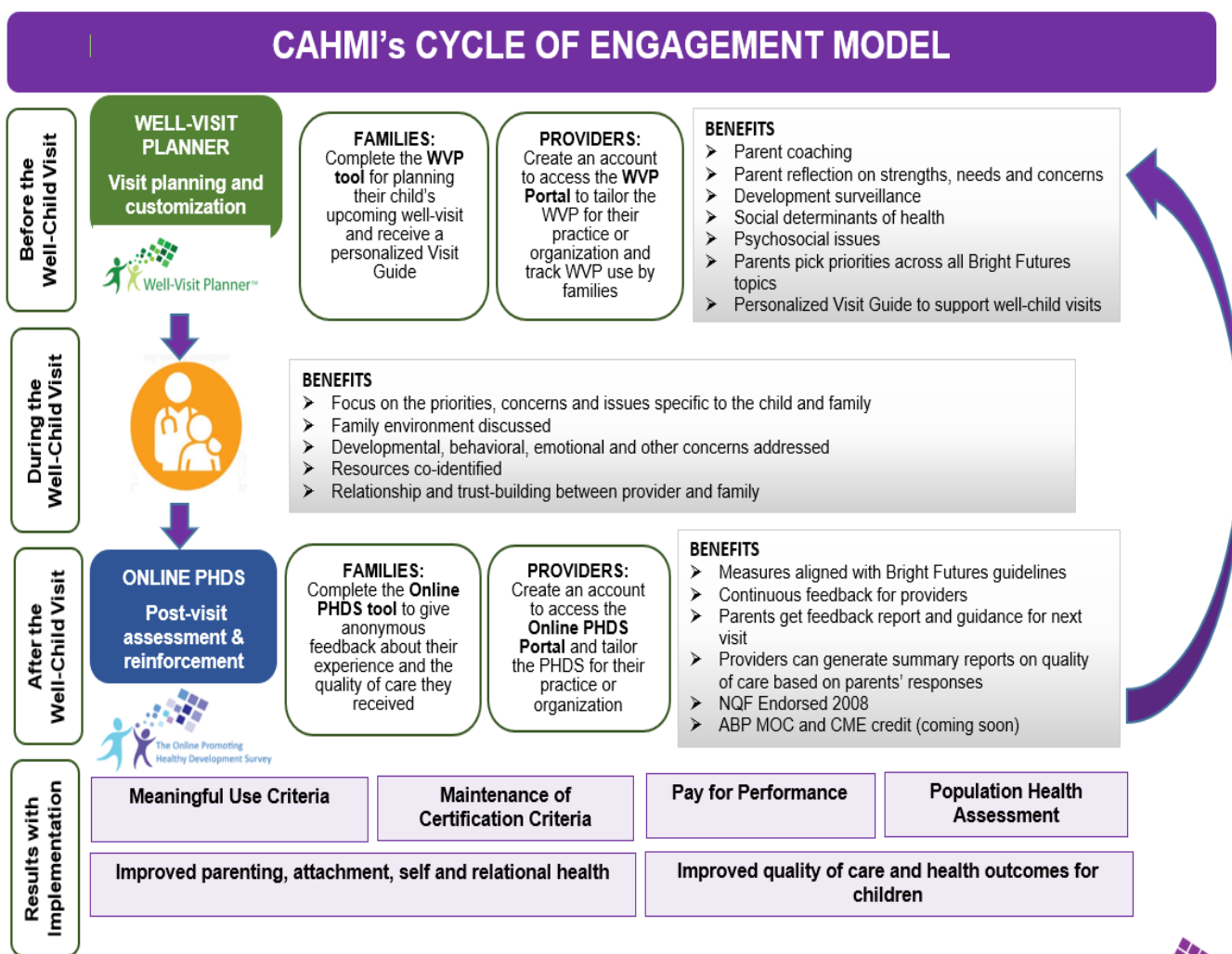
The previously validated Cycle of Engagement (COE) Model and Tools was used to focus a dialogue on operationalizing MCH MRN measurement recommendations as they relate to young children and their families. See Figures 3 and 4 for an overview of the COE model and tools, which represent a Bright Future Guidelines-based, personalized and systems-oriented approach to the provision of well-child care services.

Figure 3: Sketch of the Cycle of Engagement (COE) model and tools as visualized in the Help Me Grow led October, 2019 report: *Transforming the Pediatric Well-Child Visit through Technology* (Cornell, E, et al)



The COE model and tools have been developed throughout 1997-2020, validated for feasibility and impact in pediatric practices and have been piloted in community-based organizations, like Early Head Start and Help Me Grow. Figure 4 further illustrates the components and features of the COE model and tools, including the pre-visit, family completed Well Visit Planner (WVP) and post-visit family focused Promoting Healthy Development Survey.

Figure 4: Diagram illustrating the components and application of the Cycle of Engagement Model and Tools



These tools work together to enable an ongoing cycle of family engagement and have been shown to foster higher quality, relationship-centered and integrated services tailored to family-defined strengths, needs, priorities and experiences of care. In addition to dramatic improvements in developmental, psychosocial and family mental health screening, reductions in urgent care has also been demonstrated. Data captured are used to provide real-time child and family specific visits guides, practice level aggregate reports on quality of care and population-based reports to assess the strengths, needs, priorities across all families utilizing the Well Visit Planner. The COE model and tools

also ensure recommended screening occurs and inform practice and community-based interventions and referrals. See Appendix C for further detail on the history, milestones and key findings from the development and testing of the early childhood development and well-being focused Cycle of Engagement Model and Tools.

Specific objectives of the meeting included:

- 1. Align existing *Cycle of Engagement (COE) model and tools*:** Review and identify recommendations for shaping further development of the Well-Visit Planner (WVP) and Promoting Healthy Development Survey (PHDS) to enable efforts to advance a whole-child, engagement-based, actionable, integrated and modular measurement and data collection method that is aligned with *Bright Futures, 4th edition* and prominent frameworks for promoting early childhood development and well-being.
- 2. Further anchor to the pediatrics transformation movement:** Consider the potential value and role of the Cycle of Engagement model and WVP/PHDS tools in the context of pediatric transformation frameworks and efforts emphasizing changes to practice, metrics and payment approaches.
- 3. Identify requirements and design parameters for implementation:** To gather perspectives and recommendations for demonstrating value and scaling a model like the “Cycle of Engagement” model and its family-driven pre-visit planning (WVP) and post-visit quality assessment and reporting (PHDS) tools. Specifically, identify implementation and human-centered design-based testing options and recommendations to disseminate, maintain and support use of such a model for advancing a guideline-based, personalized and systems-oriented (GPS) model of well-child-care services. Includes identifying priority recommendations for policy and research to advance vision, assess innovations and continuously support improvement and learning.
- 4. Advance common measurement in the field:** Leverage dialogue to curate further recommendations for changes/additions to the National Survey of Children’s Health, National Health Interview Survey (etc.) and existing performance measures used in the field.

2. Results from Pre-Meeting Input on Strategies, Measurement Priorities and Considerations

Pre-Meeting Input Overview:

- **Family engagement is necessary for establishing priorities, needs, contexts and improving developmental and preventive services and outcomes.**
- **Pre-visit family engagement enables family-centered care.**

Before the meeting, participants were asked to complete a pre-meeting input form to assess the shared assumptions, beliefs and values held. Though the input form was sent out prior to the meeting, some participants shared their responses following the meeting. A total of 29 participants completed this form, and the shared assumptions, beliefs and values are summarized below. The feedback garnered from the pre-meeting input form highlighted values and desirable qualities for well-child care that

were discussed during the two-day meeting. Overall, participants

agreed that family engagement, family priority setting, actionable family data, and integration with community resources were all essential for high-quality well-child care. This guided discussion on how the COE model and tools help facilitate these essential attributes and thus may have value in improving the quality of family-centered, whole child, whole family, whole community, equitable and integrated well-child care.

Strategies to Improve Quality of Children’s Developmental and Preventive Services and Outcomes

When asked, in an open-ended manner, about the most important strategies for improving children’s developmental and preventive services and outcomes, the most common, unprompted responses (7 of 29) called for family engagement (including engaging families/meaningful engagement/whole family engagement). Further, all participants stated that there is explicit value in engaging families in pre-visit assessments in order to establish family’s priorities to focus the encounter on family needs, priorities, and contexts. Several participants stated pre-visit family engagement allows for family-centered care which facilitates stronger relationships between providers and parents/families. The overwhelming responses around the significance of family engagement serve as a mandate from the field to further relationship-centered approaches that center around family engagement and family-driven data. Interestingly, when asked to characterize current strategies to assess the quality and outcomes of well-child care services, all participants agreed that there are improvements that need to be made; however there was no consensus on which current strategies were most valuable in improving quality and outcomes of well-child care services. The majority of participants (18 of 19) also agreed that family-driven assessments of strengths, needs, risks, priorities and quality of services may potentially be used to catalyze innovative payment strategies (such as tiered and bundled payments, pay-for-performance, value-based purchasing), although 10 stated that there will be barriers to implementation.

Important Topics to Measure and Report in a Family-Centered Data-Driven Pre-Visit Planning Tool and Post-Visit Evaluation

Participants were also asked to share their perspectives on the topics most important to measure and report on in a family-centered data driven pre-visit child and family assessment and prioritization tool, like the WVP, and measurement topics important to address in a family-centered quality measurement tool, like the PHDS. Participants were asked to discern whether topics/measures should either definitely be included, made optional, or if they were unsure about their inclusion within each tool; there was also an option to provide comments on each topic/measure. Tables 1 and 2 below show which items the majority of participants responded should be “definitely included” or “made optional.” Participants were also able to state if they were “unsure” about topics/measures for inclusion within each tool; however, this option was rarely chosen and in no cases were the majority of participants unsure about the inclusion of a measure/topic. Common topics/measures that arose in the comments for definite inclusion in these tools were: strengths-based care highlighting positive childhood experiences, ensuring families feel comfortable to share their experiences, ensuring proper follow-up and referral processes, understanding context and community determinants of health, relationship-building and social ties/connections.

Table 1: Items and Measurement Topics for Consideration in the Family-Centered Pre-Visit Assessment Tool (Well Visit Planner)

Definitely Include

- Parent reflections of things they are enjoying about their child (as an open-ended prompt for parent)
- Parent report on something they look forward to doing/sharing with their child
- Parent report on recent changes/stressors in the home
- Screen for child developmental status
- Links to additional licensed parent assessment of child's development
- Screen for children with special health care needs and complexity
- Family health history
- Use of medication, vitamins and herbal supplement use
- Socioeconomic risks
- Tobacco, alcohol and substance use in the home
- Assessment of parent feeling safe at home
- Parent selection of priorities
- Protective family routines and habits
- Demographic and other stratifying information
- Parent report on risks to relational health
- Parent assessment of child's flourishing/positive health
- Parent's own well-being/positive health
- Parent assessment of parent-child connection
- Parent assessment of family resilience and health

Make Optional

- Assessment of fluoride in the water
- Assessment of lead exposure

Comments

- Strengths-based care with inclusion of positive childhood experiences
- Provider understanding of context and community determinants of health
- Social ties/connections for the family
- Building relationships between providers and families

Table 2: Items and Measurement Topics for Consideration in the Family-Centered Post-Visit Evaluation Tool (Promoting Healthy Development Survey)

Definitely Include
<ul style="list-style-type: none"> • Anticipatory guidance and parental education • Whether developmental surveillance took place • Whether parental concerns were addressed • Whether parent got needed information • If information received was easy to understand • Whether developmental screening took place as recommended • Whether risk for developmental, behavioral or social problems was assessed • Whether psychosocial risks and safety in family was assessed • Whether screening for guns in home/safety took place <ul style="list-style-type: none"> • Whether care was family-centered and culturally sensitive (experience of care standard item set) • Ratings of helpfulness and effect of care provided on confidence as a parent • Whether child/family had good access to care received needed care-coordination • Child health stratifiers: overall child health, CSHCN • Parent stress stratifier • Demographic stratifiers • Socioeconomic stratifiers
Definitely Include OR Make Optional*
<ul style="list-style-type: none"> • Whether screening for tobaccos use occurred • Family routines and habits tracking • Child developmental status stratifier • Parent health stratifier • Utilization stratifiers
Comments
<ul style="list-style-type: none"> • Relationship-building must be priority in care, in order for families to feel comfortable sharing experiences and contexts • Ensuring proper follow-up and referral sources

*Responses were split between “definitely include” or “make optional”, with neither receiving majority.

Additional Note: Due to the need to host the meeting virtually, in-depth discussions on these specific topical updates to the COE tools did not occur as planned.

3. Meeting events and breakout groups

Due to the meeting’s transition to a virtual platform, the meeting agenda and structure was kept fluid to accommodate participants’ needs and ensure active participation. Table 3 details meeting events and a summary of each; for the full agenda of planned events, refer to Appendix A. Figure 5 provides an overview of breakout groups and key discussion topics. Input on specific content updates planned for each breakout group was limited by the virtual context and reduced total meeting time. However, this virtual meeting served to engage partners in higher-level dialogue about the needs and priorities related to measurement and engagement approaches, particularly to improve early childhood services and systems of care.

Figure 5: Overview of Meeting Events

Introductions

- Each member of the meeting introduced themselves and talked about their current efforts in the field as it related to measurement and engagement of families to advance early childhood development and well-being.

A Dedication to Paula Duncan (1947-2017)

- This meeting was dedicated to Paula Duncan who was central to the inspiration, development, testing and application of the COE model and tools, especially as it relates to assessing and promoting family and child strengths, resilience and flourishing. She was a driving force for this work and is dearly missed.

Cycle of Engagement Model and Tools Overview

- CAHMI Director Christina Bethell presented a holistic overview of the COE model and tools (WVP, PHDS and CPK). Additionally, Charlie Bruner of InCK Marks particularly spoke on the COE model, culture/practice transformation framework from InCK Marks and advancing child health.

Comparing ASQ, PEDs and SWYC

- Group facilitator and attendee Christopher Sheldrick of Boston University School of Public Health presented new findings from his recent paper which compares the ASQ, PEDs and SWYC screening tools in terms of identification of children with risks for development and social delays, and the need to frame both surveillance and screening as a relationship-centered and shared decision making process with families rather than a “screen and refer” endeavor.

The Cycle of Engagement Tools Amidst New Challenges, Crises and Opportunities

- Group facilitator and attendee David Bergman of Stanford University presented “Theory, logic and the case for a Cycle of Engagement Model,” speaking on bringing transformation to scale, overall implementation and the impact of COVID-19 on our efforts, including bringing COE tools to telehealth, the impact of the pandemic, and how to leverage tools.

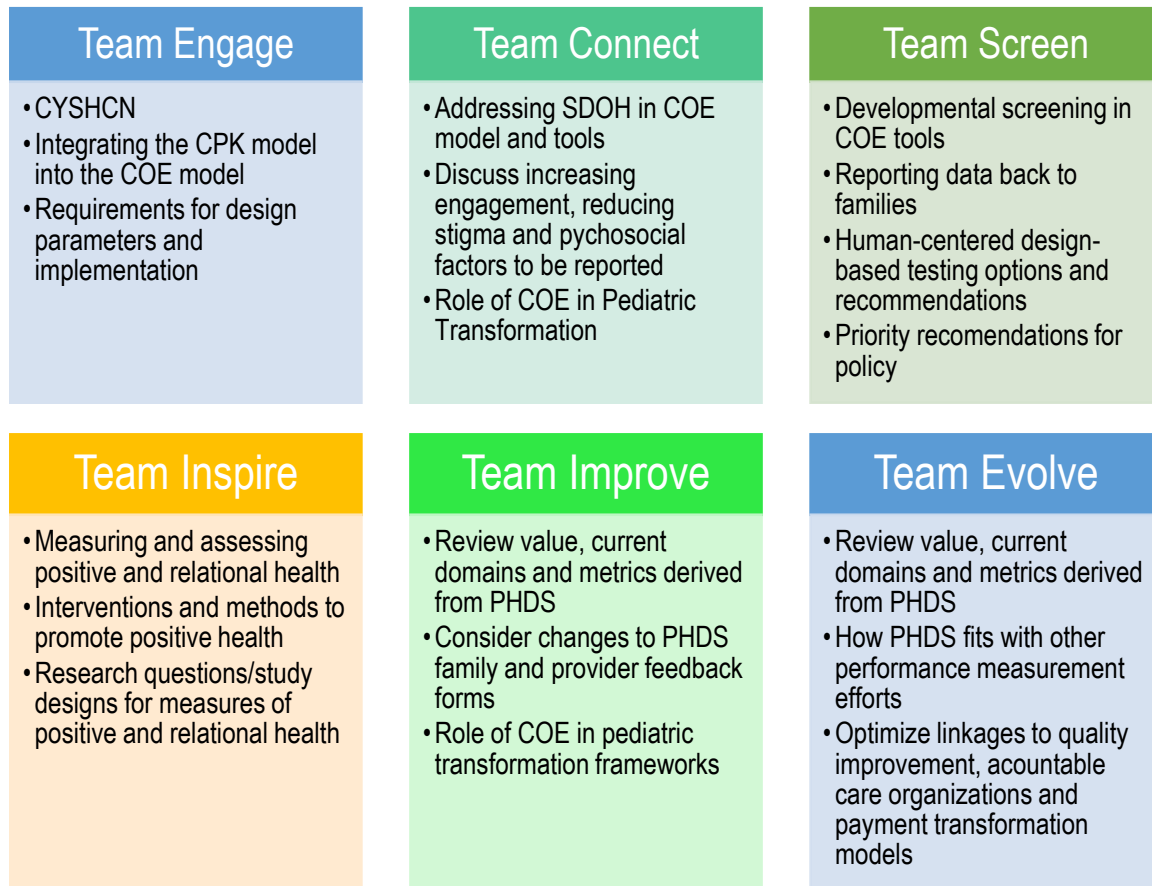
Promoting Pediatric Transformation

- Promoting pediatric transformation was a key theme throughout. Attendees summarized how the COE model and tools were developed to promote pediatric transformation and map to current models for pediatric transformation, each of which call for shifts in metrics and engagement of families in ways that are reflected in the COE model and tools.

The COE Complementing Existing Resources

- Additional conversations about how the COE model and tools can be complementary and help advance the work of already established resources, such as Help Me Grow, Healthy Start, Centering Parenting, and other parenting programs. The model and tools could complement community and home-based initiatives, such as Nurse-Family Practitioners and Project Dulce.

Figure 6: Overview of Breakout Groups and Key Discussion Guides



B. Common Themes Emerging from Meeting Deliberations

Key Takeaways and Group Consensus

Participants agreed that the COE model and tools provide a way to improve the overall quality of well-child care and promote healthy development, given **the relationship-centered, whole child approach to engaging families in care and the family-driven data** collected by the tools.

Common Themes Emerging:

1. The engagement mandate
2. Holistic, positive and relational approach
3. Enabling and normalizing a culture of engagement
4. Through any door
5. Alignment to systems and payment transformation

Over the course of the two-day meeting, participants joined together in discussions guided by the meeting objectives and specific questions for consideration (See Appendix B), with the overarching goal of advancing a relationship-centered approach for whole child, whole family, whole community, equitable and integrated well-child care. These took place in two small breakout groups and three full group feedback sessions. The first breakout group session focused on advancing the COE model and tools to optimize well-child care to improve early childhood development and child and family well-being as well as consideration of COE content areas for improving quality and outcomes, and the second breakout group session focused on opportunities, requirements and strategies to advance family engagement-based care planning and quality assessment to drive practice and systems change for larger pediatric transformation efforts (i.e. practice, metrics, payment). Five overarching themes arose regarding the consideration of approaches to advance a family-centered, engagement-based and whole child approach to measurement and improvement of well-child care services overall, and the Cycle of Engagement Model and Tools in particular. These themes are listed below and input provided is summarized.

1. *The engagement mandate: The importance of family-centered, engagement-based and whole-child measurement approaches to advancing integrated and equitable services and systems*

Having a family-centered, engagement-based and whole-child measurement approaches is paramount to a full understanding of a child's needs. Participants agreed that the COE model is unique in its centering of care around engaging families and promoting relationships, through family-driven data. Family engagement and building relationships between child, family, provider and care teams was prominent through all aspects of the meeting, including the pre-meeting input form, discussions and next steps of building evidence to advance the COE model.

The Engagement Mandate Overview:

- Relationships are at the center of meeting a child's health needs
- The "5 Rs" Implementation: Relate, Referral, Resources, Reinforce (screen) and Return

Regarding the 5 R's, 'relate' is first because, "We want to put that relationship and relating to the family and their concerns upfront."

***-Kay Johnson
Johnson Group Consulting, Inc.***

In order to advance family-centered, engagement-based and whole child measurement approaches, participants discussed ideal implementation and design, and almost all implementation strategies that emerged focused on family engagement. One such implementation method that emerged from discussions was termed the "5 Rs": Relate, Referral, Resources, Reinforce (screen), and Return. These "R's" refer to actions taken based on information provided by families through the COE tools.

Responses or information shared through either the WVP or PHDS should result in either a relationship being built (between provider and the family), a referral (to a community organization, another provider, etc.), a resource (parents/families are provided with appropriate resources), reinforcement (screening results are discussed with

families and reinforced) and a return (the data is owned by the family and nothing is being taken without benefit to the child/family). This method for implementation not only encourages family engagement and builds trust, but also allows for quality improvement efforts to explore which methods (such as referral, educational resource, conversation with provider) promote parent knowledge and skills. Additionally, participants noted that consistently engaging with families around all data collected helps families to feel at the center of care and as though any information shared with a provider benefits them.

Lastly, methods for supporting family completion of the tools also arose as necessary for successful implementation of the COE model and tools. Though the idea of having more accessible screening and pre-visit planning at the comfort of a parent's own time and not while physically in the clinic that focuses on family's needs, priorities, strengths, and contexts is key to reducing stigma, participants voiced concerns for providers attempting to implement tools to be completed pre- and post-visit, outside of the clinic setting. Several participants, including researchers and providers who implement pre-visit screening or planning, suggested that the addition of health coaches or parent advisors may be a tremendous asset to help implement the COE model and tools. These health coaches or parent advisors can then bridge the gap between the provider and the family and facilitate easeful introduction to family-driven tools and ensure families are engaged in their care.

2. *Holistic, positive and relational health approach: The central need to focus measurement to assess and promote positive and relational health and holistically address medical, mental, social and relational risks within families and communities*

Holistic, Positive and Relational Health Approach Overview:

- **The WVP is a catalyst to form strong and trusting relationships**
- **Consider SDOH for more equitable and holistic well-child care**
- **Strengths-based care needs to address positives, not just risks**

Family engagement is mandated for high-quality, whole child, whole family, whole community, equitable well-child care services. Focusing on positive and relational health is important in engaging families in the front-end assessment of their strengths, contexts, needs and priorities in order to customize services to promote well-being for the whole-child, family and community. Participants agreed that the WVP can play a key role in voicing family's needs, while also being a catalyst to form strong and trusting relationships with providers and care teams, due to the

strengths-based, positive and relational approach of the COE model. Participants also noted that when families may have had previous negative and traumatic experiences with health care systems or in other areas of their lives, the COE can aid in establishing positive relationships with providers and care teams. They also agreed that, once this trusting relationship is established, families may be more honest in evaluating their experiences, such as in a survey like the PHDS, leading to improved quality of care.

While the COE model and tools address and consider social determinants of health (SDOH) as a key driver of health and well-being, further enhancements of SDOH content can help to provide more contextual and equitable well-child care and exemplify a holistic, positive and relational health approach. Now is a time where reducing overall disparities is more important than ever, especially as SDOH are not static and evolve over time. One participant discussed the success of 3 open-ended questions around SDOH previously used in primary care in New Mexico (dubbed the “New Mexico 3”) which asks has anything changed for the family, how did they handle it; in spite of it, what’s going well for the family. These three questions arose as an appropriate and respectful way to honor families, learn more about their context, and support relationships in a strengths-based manner, while approaching health from a holistic standpoint. Future iterations of the COE tools will include positive and relational health assessments to reinforce this approach of the COE model of care.

Lastly, in order to address holistically medical, social and relational risks in care, it was recommended that the relationship-centered encounter be further articulated and integrated into COE model and tools implementation resources. This may include, but is not limited to, professional development resources and COE implementation resources that focus on strengths-based and relationship-based care.

3. *Enabling and normalizing a culture of engagement: Innovations and recommendations essential to enabling and successfully shifting to a culture of engagement, including closing the digital divide.*

Enabling and Normalizing a Culture of Engagement Overview:

- ***Tools increase time available for engagement and increase provider/staff joy, but encounter time is currently limited***
- ***Medical training should include curriculum on relationship-centered care***
- ***Equitable language in measurement field is necessary.***

Participants emphasized that though the COE tools actively engage families in pre- and post-visit assessment, they do not replace face-to-face relationships; rather these relationships are promoted and facilitated through the COE model of care, which is built around a culture of engagement.

Specific benefits of this culture of engagement from the COE model and tools for both providers and families were discussed, including freeing up time for relationship-building between families and providers, addressing concerns of families and reducing burden of multiple

screening tools, all of which enable and normalize a culture of

engagement. These not only directly benefit families by centering care around their needs and priorities, but also allow providers to find joy in their work, which in turn can lead to improved quality of care. Participants also discussed how the COE model and tools can help organize the use of limited visit time around the family’s needs, contexts and priorities, which can allow providers to determine and allocate appropriate time for each visit and maximize

engagement. However, the issue of time constraints and demands in busy clinics was raised, and some stated that even with the support and context setting through the use of the COE model and tools, there may still not be sufficient time in the visit to follow all of the Bright Futures recommendations and address all of the family's priorities. This lack of time signals for the systems-wide need for increased average well-child visit time to prioritize family engagement.

Participants also called for the inclusion of relationship-centered care approaches in medical training, which would aid in shifting towards a culture of engagement. Specifically, in both meeting discussions and the pre-meeting input form, relationship-centered care approaches and mentoring in building relationships with patients were identified as fundamental to overall pediatric practice improvement. Participants felt that the use of the COE model and tools to engage families in a relationship-centered approach throughout medical training would be a start to achieving this.

When considering how to best enable a culture of engagement through measurement methods, health determinants such as race/ethnicity, income status, and education-level arose as influential in the use and success of family-centered assessment, such as the COE tools, and must be addressed. As such, addressing SDOH and equity in measurement is key for advancing engagement-based tools. For example, NIH PROMIS/ECHO measures are meant to increase engagement with parents and families across income status or race/ethnicity. However, other highly used measure sets (i.e. PCORI) must become aware of diversity and address equity, and future updates to the COE tools must pay attention to equitable language used elsewhere and draw from common measurement in the field.

Working with community members, families and stakeholders to implement the model and tools—in addition to providers—will make it easier to see the success of implementation strategies and should be a strategy employed in future learning collaboratives for COE model and tools implementation, within and outside of pediatric primary care. Participants agreed that it is important to have these voices heard in development and implementation processes in order to understand what is and is not working for them. Also important is the use of learning cycles (such as PDSA) into early implementation, with a focus on optimization of the model and tools and not necessarily precision in exact protocol or processes. With the acknowledgment that negative impact and consequences can arise, learning cycles allow for evaluation throughout implementation to improve and reduce harms for future use. Tailoring implementation to identified groups may lead to different results— however, this idea should be explored in future research.

4. *Through any door: Ensuring the use of the COE model and tools for non-clinical, community-based applications wherever children and families are engaged to learn about and promote child development*

Through Any Door Overview:

- **COE model and tools have use outside of pediatric primary care setting.**
- **Community-based organizations can benefit from using COE model and tools.**
- **Cross-sector collaboration promotes whole child, whole family, whole community care.**
- **Working with communities, families and stakeholders to customize implementing tools aids implementation.**

Discussions around the value of the COE model and tools beyond the medical model found that the WVP has value for families, even if not used for an actual well-visit. From prior research and use, the WVP has educational, engagement and empowerment value even for those who may not have a provider team. Additionally, the model and tools could provide support outside the medical model, i.e. supporting relationships and community needs, in educational or other early childhood care settings.

As the COE model and tools can be used by community-based organizations, not just by providers, cross-sector collaboration and integration can promote high-quality care that addresses the whole child, family and community.

Communities can also influence families to advocate for their

health. The COE model and tools enable discussions so that families will raise their needs, priorities and contexts with providers in such a way as to push the health care system and providers to work with community partners and external organizations. In this collaboration between child, family, provider and community, the COE model and tools can also advocate for relationship-based whole child, family, and community care. Participants discussed the example of the California's Office of the Surgeon General's implementation of ACEs screening throughout the state, expressing that if such screening were to occur in a COE model of care, with an integrated whole child/family/community focus, acceptability and capacity for follow-up would be much higher.

"Allowing [the COE tools and models] to support the relationships that families and communities need in an equitable way is really important"
-Tumaini Coker
University of Washington/Seattle Children's

In considering "through any door" approaches to scaling use of the COE model and tools, fostering positive relationships – with families and communities – was considered necessary to address equity. Participants voiced that the model and tools should think beyond individual relationships to promote relationships at the community-level, with a racial equity focus, as community-level determinants impact children. This is an opportunity for communities and care providers to come together, as parents often need support outside of the medical model.

5. Alignment to systems and payment transformation: Continue to demonstrate and drive alignment of measurement and family engagement to systems and payment transformation models and initiatives

Alignment to Systems and Payment Transformation Overview:

- **COE model and tools can help drive pediatric transformation and systems change.**
- **More research is needed to open the door for payment reform and approaches.**

Participants agreed that the COE model and tools are an apt vehicle for driving pediatric transformation given the data collected, as family-driven data on care needs could possibly support tiered/bundled payment approaches and family assessments of care could possibly support value-based payment models. However, further research on how the COE model and tools can open the door to payment reform is still required, and modeling after already established payment models may be key to addressing this barrier. Overall, furthering this model of care and its associated

tools can benefit pediatric transformation efforts, through supporting alternative payment approaches, such as tiered/bundled payments and value-based purchasing, improving quality of care, addressing the whole child and family in care, and bringing joy to providers and care teams. Additionally, uplifting the COE model and tools to integrate across systems and sectors as designed and intended, while difficult and requiring system-level change, is ideal for pediatric transformation and for the improvement of child development and well-being early and throughout the lifespan.

One of the main complexities involved with optimizing the family-centered data collected in order to best drive quality improvement and systems-level change was data integration. Participants discussed how EHR was the “elephant in the room,” bringing many levels of complexity and challenges for scaling and dissemination of the COE model and tools given the

multitude of systems used. Participants expressed that obtaining data from EHR systems is difficult and that many systems are not ready for integration. However, participants stressed that now may be a good time to advance integration as COVID-19 is bringing innovation to EHR systems with telehealth/virtual visits. Full integration likely will not be achieved until EHR companies are on board with revamping the system.

"The elephant in the room is compatibility with EHR and their portal systems...when we talk about going to scale, this has to be at the middle of the table"

-Marian Earls

University of North Carolina Medical School

C. Short Term Needs and Opportunities for the COE Model and Tools

Key Takeaways and Group Consensus

Participants noted that the COE model and tools are near final and needing minimal updates to align with Bright Futures, 4th edition and the Survey of Well-Being in Young Children. Additionally, in the time of COVID-19, the COE model and tools could ensure that care provided via telehealth and virtual visits are high-quality, focusing on the whole child, and continue to foster positive relationships.

Areas for Growth:

1. Expanded and flexible content and features
2. Virtual Care

1. *Expanded and flexible content and features: Priority content updates and customizable features for consideration when updating the Cycle of Engagement model and tools to ensure alignment to newest Bright Futures Guidelines and the science of child flourishing amid adversity*

Key Discussion Points:

- **COE tools require minimal updates for current guidelines alignment**
- **Screening must be done in an engagement-based, relationship-centered approach**
- **Using prior processes, apply updates to allow family input and expand accessibility in multiple languages**

Participants agreed that the COE model and tools are nearly ready-for-use in their current state (requiring minimal updates) and facilitate opportunities for families and providers to have conversations that would not have otherwise occurred and to have them in a strengths-based context. They also expressed ways that the COE model and tools could improve, such as ensuring screening questions are actionable (either by provider team/referral), ensuring engagement and trust building when obtaining family data and feedback, and creating whole person care approaches (as opposed to traditional sick/well approaches) to reinforce

well-being and positive health of children and families. Participants called for clarification and specific steps to foster relationships before, during, and after the encounter, through use of the model and/or tools. In line with these recommendations, participants discussed ways to clarify how to speak about and promote the Cycle of Engagement model and tools, referring to them as a relationship-centered model of care built on strengths, needs and contexts, as opposed to just screeners and tools. These suggestions were prominent throughout the pre-meeting survey and group discussions pointing to a common misconception that will be addressed in future education and dissemination on the COE model and tools.

Although not all of the proposed content updates specific to the COE tools on the meeting agenda were discussed, participants raised several necessary updates to the COE tools in order to reinforce prior research and add value for families and providers. The first updates discussed were to align the COE tools with Bright Futures, 4th edition guidelines, and align developmental screening questions with the non-proprietary, developmental screening tool, the Survey of Well-Being for Young Children (SWYC). However, given recent research findings in a recent paper presented during the meeting by Dr. Chris Sheldrick, participants determined that COE tool alignment with one particular developmental screening tool over another (i.e. the SWYC, Ages and Stages Questionnaire (ASQ), Parent Evaluation of Developmental Status (PEDS)) is not as important as ensuring that the developmental screening occurs in a relationship-centered approach with family engagement ¹. Without such an approach which supports families in taking necessary actions (i.e. educational discussion, referral) following screening, screening is not as effective in improving outcomes. Additional recommendations related to updating the tools included assessment of families' understanding of information given by their providers, allowing for more qualitative input from families in the form of pictures and voice recordings, and tailoring content for different communities to ensure cultural competency. While the current tools are available in both English and Spanish, participants stressed that development of the tools in multiple, additional languages would promote more equitable future application. Participants agreed that with these minimal updates, many clinicians and providers would be interested in implementing the model and tools in a collaborative learning network, where experiences and shared learning occurs.

"If you're going to use these screening tools effectively, how do you assess benefits, risks and costs [of follow up and referral]? ... that's where engagement with the family is essential."

-Chris Sheldrick

Boston University School of Public Health

While an objective was to discuss in-depth updates for consideration, discussions quickly moved towards current applications and opportunities for the model and tools, given the COVID-19 outbreak. Prior to and following the meeting, the CAHMI mapped content updates necessary for alignment of the COE model and tools with Bright Futures, 4th edition and the SWYC, which are a high priority, and has found necessary updates are minimal given the original conceptual development of the WVP and PHDS. Further consideration for the inclusion of additional screening tools and modules (i.e. positive childhood experiences, adverse childhood experiences and others) will follow the immediate update of the model and tools.

¹ Sheldrick RC, Marakovitz S, Garfinkel D, Carter AS, Perrin EC. Comparative Accuracy of Developmental Screening Questionnaires. JAMA Pediatr. 2020 Feb 17. PMID: 32065615.

2. Virtual Care: Application for virtual/telehealth well-child care services

Key Discussion Points:

- **The COVID-19 era presents a new way to utilize the COE models and tools**
- **Expansion to virtual and telehealth child well-care services and its benefits and challenges vs in-person care**
- **Family access to technology for telehealth**

This meeting was held virtually during the height of the COVID-19 pandemic in the United States, as telehealth and telemedicine services became more common and flexible throughout the nation. This era serves as an incredible opportunity to expand delivery of well-child care services to telehealth and telemedicine, and to explore how the COE model and tools can empower families and build relationships between providers and families virtually. The topic of integrating the COE model and tools into telehealth, especially in a time where families may not want to leave their homes out of safety concerns, came into focus for discussion frequently throughout the 2-day meeting.

Important related concerns arose on how to leverage the telehealth opportunity, determining periodicity for in-person and telehealth well-visits, equitable access by families, and the importance of in-person visits, particularly when considering payment options. Telehealth requires a level of trust between the provider and the patient, which adds complexity when delivering care particularly for families who have experienced racism and discrimination in the healthcare system in the past and who require more intentional relationship-building efforts. Additionally, a family's lack of certain technologies and lack of internet availability can diminish the effectiveness of a telehealth visit. The digital divide needs to be addressed as face-to-face interaction is still important. Further, in-person well visits with a pediatrician were considered a critical component of well-child care that needs to be preserved. It became clear that the COE model and tools must be leveraged in the current world situation in order to proceed with telehealth practices for the future. This era calls for a delineation of the COE model and tools for telehealth visits.

“What can we learn from the footprint of the WVP usage in this COVID-19 moment?”

-David Willis

Center for the Study of Social Policy (CSSP)

D. Immediate Actions and Next Steps

Key Takeaways and Group Consensus

There is much to be done to continue having relationships be the center of care and for the COE tools and models to be utilized. The following themes emerged when evaluating and determining immediate actions and next steps.

Next Steps:

1. Update and Publish 3.0 MCH-MRN Agenda
2. Test Application in Virtual Care
3. Link and Align with Pediatric Transformation Efforts (Policy and Payment)
4. Update and Improve the COE Tools
5. Build Evidence, Validate Whole Child Metrics and Inspire Community and Family Engagement Research

1. MCH MRN Agenda: Integrate input, finalize and publish the 3.0 MCH MRN Strategic Agenda

3.0 MCH-MRN Strategic Agenda is underway and influenced by participant response from this meeting.

The 3.0 MCH-MRN Strategic agenda builds upon previous agendas and continual environmental scans of federal programs' maternal and child health measures to prioritize and advance needed measurement research for the maternal and child health field. Following this meeting, the 3.0 MCH-MRN

Strategic Agenda will be informed by topics that emerged from this meeting, particularly around engaging families, improving quality of early childhood care and services assessments, integrating patient-centered/family-centered data to inform tailored services, and ensuring local-level population-based data.

2. Virtual Care: Partner to design and pilot a virtual well-child care model using the COE model and tools

With the current COVID-19 era, the possibilities of using the COE model and tools for telehealth and telemedicine must be explored. This is a time to leverage the moment, consider the future of what

Adjustments to the COE tools to complement virtual and hybrid care in the COVID-19 era needs to be explored.

well-child care may look like, and determine how the COE model and tools may need to be repurposed, depending on whether they are being utilized for an in-person visit or a virtual visit. With a 2.0 version on the horizon, quickly implementing a 1.5 version (updated to align with Bright Futures, 4th edition and the SWYC) and receiving feedback to ultimately influence 2.0 is needed. CAHMI plans to build upon these versions in the near future as well and improve their implementation design. Despite adjustments given the COVID-19 era, the relationship-centeredness of

the COE model and tools must continue to be specified and prioritized. In order to drive progress to improve and promote early childhood development and lifelong health, it must be made clear that the COE model relies on relationship-centered care with the focus on building trust between providers and families. Following the meeting, a webinar was held on May 14, 2020 in partnership with the Maryland Chapter of the AAP and LifeBridge Health titled, “The Future of Well-Child Care in a Post COVID-19 Era,” in which the COE model and tools were discussed as a vehicle for family engagement and relationship-building in in-person and telehealth visits. Providers and child health policy experts across the nation attended, with providers expressing interest in collaborating further to launch and test the COE model and tools. A recording of the webinar can be accessed [here](#).

3. Link and Align: Further link and align work to promote integrated, equitable care in collaboration with pediatric transformation, payment, systems change and policy reform models and initiatives

A relationship-centered model for well-child care is a tenet for pediatric transformation and family-driven assessment tools can drive alternative payment models.

Overwhelming support for the Cycle of Engagement model and tools as a relationship-centered approach to whole child, equitable and integrated well-child care emerged from the meeting. Participants expressed that a relationship-centered model for well-child care is a requirement for furthering pediatric transformation efforts, as it is a tenet of transformation. One participant stressed his hope for the collective group: to feel enlisted to demand this model of care in order to optimize value of well-child care to child, families and providers. Positive relationships between families and providers are key to the COE model and tools as well as pediatric practice transformation. Stronger, meaningful and positive relationships can aid in improving quality of care as providers are able to address family and child needs, through increased engagement, and families will feel more comfortable assessing their health care services and experiences honestly

Charles Bruner stressed his hope for the collective group “to feel enlisted to demand this model of care in order to optimize value of well-child care to child, families and providers”

-Charles Bruner

InCK Marks Resource Network Manager

4. Update and Improve: Update COE tools to reflect updated Bright Futures Guidelines, promote a positive and relational construct of health and enable further customization and value

In order to address the whole child, medical, social and relational health risks must be assessed in a positive, strengths-based manner.

Participants called for the need to update COE tools to reflect most recent Bright Futures Guidelines and offered support to assist in doing so in order to quickly make available these useful tools. While in-depth discussions around content updates were hindered by the virtual context of the meeting,

participants agreed on the need to promote a positive and relational construct of health through the family-driven assessment tools. Incorporation of measures to address social and relational determinants of health must be further explored. Further, addressing implementation barriers and cultural accessibility in coming research was also mentioned. Participants noted the importance of implementation design, particularly being adaptable to certain communities, and suggested human-centered study design to explore optimal implementation and dissemination. Additionally, as mentioned before, the tools can be developed in multiple languages to promote equity among populations.

5. **Build Evidence and Inspire Research:** Build evidence for the COE model and tools, validate new whole child assessment metrics and advance a research network on community and family engagement

In the interim months since this meeting was convened, many additional meetings among stakeholders for advancing the Cycle of Engagement model and tools for community and family engagement to promote child development and child and family wellbeing, either through whole child, equitable and

We are called and inspired to advance family-driven assessment metrics that promote whole child, equitable and integrated care.

integrated well-child care or in other early childhood services, have taken place or are being planned. This suggests that participants' excitement over the COE model and tools is ongoing and evidence must be built to further advance the model and tools. Efforts have also begun, with support from the Robert Wood Johnson Foundation, to build the evidence and learn from simultaneous implementations of the COE model and tools. By fall 2020, the CAHMI plans to release the "1.5 version" of the COE tools aligned with Bright Futures, 4th edition and the SWYC. To accompany this release, we are creating a Community and Family Engagement Research Network (C-FERN) in order to further articulate the landscape of engagement-based research for advancing whole child, whole family, whole community, integrated and equity focused approaches to promoting the early and lifelong health of children, families and communities. At this time, we are seeking partners to embark on an iterative research process with us, which includes cycles of learning, updating and implementing our COE model and tools (1.5 version and beyond), learning from real-time use and tailoring of the model and tools to specific contexts. Those interested in partnering with the CAHMI to either be a part of our C-FERN or our COE model and tools "launch and learn" can contact the CAHMI team at info@cahmi.org.

Our Sincere Gratitude

We appreciate and share our gratitude to all our participants for their time, insight, expertise and dedication to this work and for their flexibility to adapt to a virtual meeting.



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Partners for Whole Child Preventive and Developmental Services:

A meeting to advance data-driven family-centered approaches to improving well-child-care services

April 7th | 11:00am – 1:30pm ET;
2:00-4:30 ET

April 8th | 11:00am – 1:00pm ET

Zoom Video Conference Lines: <https://zoom.us/j/7696705683>

Meeting ID: 769 670 5683

Call-In Numbers: +1 312 626 6799 | +1 301 715 8592 | +1 253 215 8782

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Meeting Background, Agenda, Breakout Teams and Participant List Partners for whole child preventive and developmental services

A meeting to advance data-driven family-centered approaches to improving well-child-care services

April 7th | 11:00am – 1:30pm ET; 2:00-4:30 ET **Zoom Video Conference Lines**
April 8th | 11:00am – 1:00pm ET **Zoom Video Conference Lines**

Background: This meeting builds on the strategic measurement agenda established through the HRSA supported Maternal and Child Health Measurement Research Network (MCH-MRN) and leverages the leadership and related research and policy work of the *Child & Adolescent Health Measurement Initiative* (CAHMI) conducted more recently through support from the Robert Wood Johnson Foundation, David and Lucile Packard Foundation and the Children’s Hospital Association. In its national strategic measurement agenda, MCH-MRN identified as a priority the advancement of whole child, engagement based, integrated, actionable and flexible measures and data collection, use and reporting methods that are essential to:

- (1) authentically, concretely and visibly **engage families in front end assessment** of their strengths, context, needs and priorities in order to customize services to promote well-being for the whole child, family and community. This includes ensuring focus on family engagement, social determinants, positive and relational child and family health.
- (2) **improve methods to assess the quality** of early childhood health services and link quality/value findings to payment, certification and continuing education and related levers for improving care.
- (3) **integrate data to inform tailored services** for children and families, including integration with electronic record platforms (leveraging IT to improve care); use data to support tiered/bundled care payments.
- (4) **ensure population-based data** at the local level to foster integrated and coordinated data and health improvement priorities at the practice, community and systems level.

Meeting Overview: In this meeting will build off prior work to take stock of and recommend updates to CAHMI’s existing *Cycle of Engagement* model and tools, including the *Well-Visit Planner* (WVP) and the *Promoting Healthy Development Survey* (PHDS). Fully aligned with MCH-MRN priorities, these tools are explicitly based on national *Bright Futures* guidelines and integrate a prior version of the *Survey of Well-Being of Young Children’s* developmental milestones section. See Figures 1 and 2. Meeting results will also inform similar efforts in the field and advance a common approach where needed. In this meeting we will also translate recommendations for consideration in future updates to the *National Survey of Children’s Health* (NSCH), *National Health Interview Survey* (NHIS) (etc.) as well as to enhance performance measurement systems (e.g. HEDIS, CMS) as it relates to early childhood development and child and family well-being. Enriched connections among us is a priority.

¹This project is led by the Child and Adolescent Health Measurement Initiative (CAHMI) through grants from the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (UA6MC30375) and the Robert Wood Johnson Foundation (#75448).

Meeting Purpose:

To accelerate the development and implementation of a whole-child, engagement-based, actionable, integrated and modular (**WE_AIM**) measurement and data collection method that advances a guideline-based, personalized and systems-oriented (**GPS**) approach to well-child-care services and early childhood development.

Meeting Approach: Meeting Approach: The CAHMI's *Cycle of Engagement* and online Well Visit Planner and online Promoting Healthy Development Surveys (PHDS) resources will be used as an anchor to focus meeting deliberations. Six smaller groups will engage in 3 rounds of breakout discussions to consider, raise questions and issues and make recommendations, followed by four full group discussions. 3.5 hours of discussion, 1 hour of group presentation, 1/2 hour welcome and introductions. Breakout teams are: 1: Team Engage; 2. Team Connect; 3: Team Screen; 4. Team Inspire; 5. Team Improve; 6. Team Evolve. You will stay with the same team through the duration of the meeting unless you request to move to another team.

Meeting Objectives:

- **Improve existing measurement models and tools (anchor to CAHMI's Cycle of Engagement-COE)**
 - *Advance a whole-child, engagement-based, actionable, integrated and modular measurement and data collection method*
 - *Aligned with Bright Futures, 4th edition.*
- **Further anchor to the pediatrics transformation movement:**
 - *Consider value of COE-like model and WVP/PHDS engagement, assessment and quality measurement tools for pediatric transformation practice, metric and payment approaches*
- **Identify requirements and design parameters for implementation:**
 - *Data reporting, linkages and use*
 - *Priorities for "building the evidence" while continuing to solidify and develop the model/tools*
 - *Iterative strategies to disseminate, maintain and support use in a "launch and learn" model*
- **Advance common measurement in the field:**
 - *Create further recommendations for national surveys (NSCH, NHIS) and performance measures (HEDIS, CMS)*
 - *Advance an interoperable core assessment and quality measurement set of metrics while enabling variation in their application and refinement*

Figure 1: High level summary of the Cycle of Engagement and Survey of Well-Being for Young Children as visualized in the Help Me Grow led report on innovations with potential to strengthen the well child visit (October 2019)* *Strengthening Children’s Social-Emotional Well-Being and Ensuring a Parent-Led Agenda: Transforming the Pediatric Well-Child Visit through Technology (Cornell, E, et al. Help Me Grow, Oct. 2019)

behavioral/emotional development, and family risk factors, designed for children between ages 0 and 5.



Welch Emotional Connection Screener (WECS)

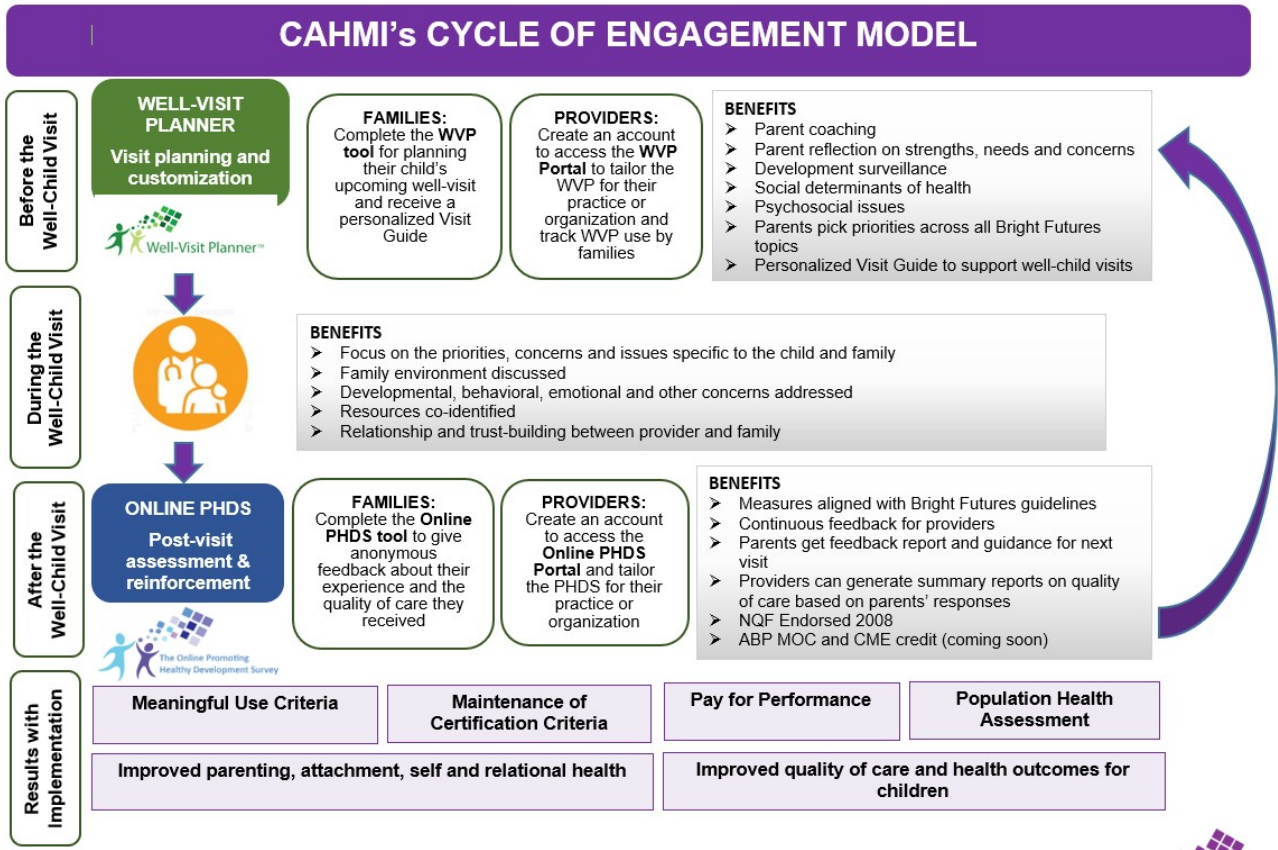
WECS evaluates parent-child interactions such as attraction, vocal communication, facial expressiveness, and sensitivity to assess emotional connection and offers the opportunity for a provider to identify and intervene with respect to relational health using a brief assessment.



FINDconnect

FINDconnect is a family-centered and customizable platform that automates identifying family needs, matching to resources, developing action plans, enabling case management, and facilitating analytics. This allows organizations to maintain and track the impact of social determinants on patient health and the usage of community resources.

Figure 2: Visual depiction of the Cycle of Engagement Model (note: it is feasible to translate this model for use in virtual well visit encounters as we build telehealth capacities during this coronavirus pandemic)



Meeting Agenda

Partners for whole child preventive and developmental services

A meeting to advance data-driven family-centered approaches to improving well-child-care services

April 7th | 11:00am – 1:30pm ET; 2:00-4:30 ET **Zoom Video Conference Lines**
April 8th | 11:00am – 1:00pm ET **Zoom Video Conference Lines**

Day 1: April 7, 2020: COLLECTIVE REVIEW AND CONTENT AND APPLICATION RECOMMENDATIONS

- 11:00 – 11:25am ET **Welcome and Overview**
- Welcome from meeting hosts and Zoom Instructions
 - Meeting overview, objectives and agenda
- 11:25– 11:40am ET **Introductions/comments from funders and development and testing partners**
- 11:40 – 12:00pm ET **Introductions by Team—everyone!**
(Six Teams: 1. Team Engage; 2. Team Connect; 3. Team Screen; 4. Team Inspire; 5. Team Improve; Team Evolve). See participant list for your team assignment.
- 12:00-12:10pm ET **Vision for Bright Futures implementation and perspectives on meeting objectives----** American Academy of Pediatrics
- 12:10– 12:45pm ET **Theory, logic and the case for a *Cycle of Engagement* model and toolkit** to advance a whole-child, engagement-based actionable, integrated and modular measurement and data collection approach in well-child-care-services
- Christina Bethell, Christopher Sheldrick, David Bergman
- 12:45 – 1:30pm ET **Breakout #1 (6 teams):** Perspectives, questions and recommendations on advancing a COE model and tools to optimize and transform well-child-care services to improve early childhood development and child and family well-being
- 1:30 – 2:00pm ET **BREAK/LUNCH**
- 2:00 – 2:30pm ET **Full Group Discussion and Reflection** (Host: David Bergman)
- 2:30 – 3:00pm ET **Breakout #2-Part 1:** In depth consideration in key content areas and optimizing value for improving quality and outcomes
1. Team Engage: Making the model work for Children with Special Health Care Needs

2. Team Connect: Social Determinants of Health
3. Team Screen: Developmental Screening and Risks
4. Team Inspire: Positive and Relational Child and Family Health:
5. Team Improve: PHDS Quality Tool: Group 1
6. Team Evolve: PHDS Quality Tool: Group 2

- 3:00 – 3:30pm ET **Full Group Discussion and Reflection** (Host: Christopher Sheldrick)
- 3:30 – 4:00pm ET **Breakout #2-Part 2:** In depth consideration of key content areas and optimizing value for improving quality and outcomes (continued)
Return to Breakout Teams
- 4:00 – 4:25pm ET **Full Group Discussion and Reflection** (Host: Christina Bethell)
- 4:25-4:30pm ET **Closing and reminders about tomorrow’s session and sending your input notes**

Day 2: April 8, 2020: Connecting the Dots: Short and Long-Term Action Plans

- 11:00 – 11:30am ET **Group Discussion and Reflection and Preparation for Final Breakout Group**
- 11:30 – Noon ET **Breakout 3#:** Opportunities, requirements and strategies to advance family engagement-based care planning and quality assessment to drive practice and systems change
 - Return to Breakout Teams
- Noon – 12:30 ET **Full Group Discussion and Reflection** (Host: David Bergman)
- 12:30 – 1:00pm ET **Wrap Up:** Round Robin of Key Takeaways and Next Steps
Christina Bethell and Christopher Sheldrick



Breakout Team Discussions Overview

Partners for Whole Child Preventive and Developmental Services:

A meeting to advance data-driven family-centered approaches to improving well-child-care services

Included below are brief descriptions for the three breakout group sessions that will be held during the meeting. Please see the participant list for your breakout team assignment. Note that you will meet with the same group for each breakout session, and your focus topic will adjust throughout the meeting.

April 7th | 11:00am – 1:30pm ET;
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April 8th | 11:00am – 1:00pm ET

Call-In Numbers: +1 312 626 6799 | +1 301 715 8592 | +1 253 215 8782

Breakout #1: Perspectives, questions and recommendations on advancing a COE model and tools to optimize and transform well-child-care services to improve early childhood development and child and family well-being

Each team will consider and share perspectives on the concept, claims/theory of action, potential value and application of the Cycle of Engagement (COE) model and tools -- the Well-Visit Planner (WVP) and Promoting Healthy Development Survey (PHDS). Each team will specifically reflect on the potential value of the COE model for their own work and goals of pediatric transformation set forth across numerous organizations. We wish to understand your perspective on the importance of resources to engage families in pre-visit assessments, education and priority setting and post-visit experience/quality of care may support families to drive improvements in services. Finally, would like you to take time to review the one page at-a-glance summaries of current content and considerations for modifications to the WVP and PHDS. In doing so, simply consider if there are key domains or topics you think are missing and list these in the feedback form. In breakout #2 you will have an hour to dive further into the content and recommendations for modifications. Please review all materials in the Overview and Agenda Packet and Background Materials for Review Packet shared prior to the meeting in preparation for this discussion. Also see "Cross-cutting questions for consideration" at the end of this document since we are eager to get feedback on each of these throughout the course of the meeting.

Breakout #2 (Broken into two 30-minute sections with a 30-minute full group discussion in between): In-depth consideration of key content areas and optimizing value for improving quality and outcomes

Group 1: Team Engage: Making the COE work for CYSHCN: Children and youth with special health care needs require extra consideration to optimize the value of the COE to meet their often-unmet needs for developmental and preventive services. Team Engage will consider how the COE model and tools are or can be further optimized for CYSHCN, their families, and providers, including a review of the content and reporting specifically for CYSHCN. Team Engage will also consider how the CAHMI developed, CYSHCN-specific CARE_PATH for Kids (CPK) (shared care planning tool for families) should integrate into the broader COE model and how a family-driven model of use could be defined and implemented.

Group 2: Team Connect: Social Determinants of Health: Promoting early and lifelong development of health and whole child well-being requires attention to social as well as medical and relational determinants of

health. Team Connect will discuss appropriate measures and methods for assessing and addressing child and family social determinants of health in the context of the COE model, so that families are engaged to reflect on their context, stigma is reduced, and psychosocial factors easily reported on and often prioritized can be discussed. Specific recommendations for content refinements to the WVP and PHDS will be made along with recommendations for family and provider feedback on results and supports needed to address needs.

Group 3: Team Screen: Developmental Screening and Risks: Screening for developmental growth and risks are a core component of well child visits and engaging the family in self-assessment and reflection using standardized instruments is a recommended an effective way of doing so. Success requires that clinical structures meaningfully engage families about and follow-up on findings, each of which are assessed in the PHDS. Team Screen will consider the importance of developmental surveillance and screening and other risks and how this fits into a comprehensive and integrated assessment approach. Team Screen will make specific content edits, additions and other changes to the WVP and PHDS as well as how information collected can and should be reported back to families and to providers either in a feedback report or through integration of family reported information in the electronic health record (EHR). Fit with other approaches to screening will be considered to enable flexibility of the COE model and tools with existing and emerging approaches.

Group 4: Team Inspire: Positive and Relational Child and Family Health: When children are very young, optimal development requires safe, stable and nurturing homes and other environments, and as children grow, their health continues to be dependent on their family's physical, emotional, material and social circumstances. Strengthening family relationships, positive health and well-being is essential for ensuring health and well-being across the lifespan. Additionally, research and evidence continue to show that the absence of negative experiences/factors/health do not ensure the presence of well-being or supportive or protective conditions; alternatively, there can be positive assets and flourishing in the face of adversity. Team Inspire will discuss research around and measures for assessing and addressing positive and relational health in the context of the COE model for both the child and family in ways that promote parent-child connection, child and family flourishing, and resilience. This team will consider and make specific recommendations for content (and use of data) that should be considered for the WVP and/or PHDS and how this information should be reported back to families as well as to providers via feedback reports and/or EHR integration. As possible, the team will identify interventions and methods for use during well child care encounters to promote positive and relational child and family health.

Group 5: Team Improve: Provider Quality Improvement and Family Education Focused Utilization of the PHDS: The PHDS is a parent-completed online tool that assesses whether young children are receiving nationally recommended preventive and developmental services and promotes continuous engagement of families to measure and improve the quality of care. Team Improve will review the value, current domains and metrics derived from the current PHDS as well as the family and provider feedback reports, considering changes or additions. Team Improve will consider how the PHDS fits with other quality improvement efforts for providers as well as mechanisms for supplying educational resources for families.

Group 6: Team Evolve: Policy and Research Focused Design and Utilization of the PHDS: The PHDS is a parent-completed online tool that assesses whether young children are receiving nationally recommended preventive and developmental services and promotes continuous engagement of families to measure and improve the quality of care. Team Evolve will review the value, current domains and metrics derived from the current PHDS as well as the family and provider feedback reports, considering changes or additions. Additions specific to assess experience with use of the Well Visit Planner is important to address. Team Evolve will consider how the PHDS fits with other efforts to assess quality and value of well child-care services and how to optimize linkages to quality improvement, accountable care organizations, and payment transformation

models.

Breakout #3: Opportunities, requirements and strategies to advance family engagement-based care planning and quality assessment to drive practice and systems change

Group 1: Team Engage: Identify requirements and design parameters for implementation: Team Engage will consider perspectives and recommendations for demonstrating value and scaling a model like the “Cycle of Engagement” (COE) model and its family-driven pre-visit planning (WVP) and post-visit quality assessment and reporting (PHDS) tools in both in-person and virtual well-child visits.

Group 2: Team Connect AND Group 5: Team Improve: Further anchor to the pediatrics transformation movement: Teams Connect and Improve will consider the potential value and role of the Cycle of Engagement model and WVP/PHDS tools in the context of pediatric transformation frameworks and efforts emphasizing changes to practice, metrics and payment approaches.

Group 3: Team Screen: Identify implementation and testing options: Team Screen will identify specific implementation and human-centered design-based testing options and recommendations to disseminate, maintain and support use of such a model for advancing a guideline-based, personalized and systems-oriented (GPS) model of well-child-care services. Identify priority recommendations for policy and research to advance vision, assess innovations, and continuously support improvement and learning.

Group 4: Team Inspire: Build the Evidence: Team Inspire will consider how this work can be built upon to grow the evidence of the COE model overall and the positive and relational child and family health metrics in particular. The team will work to identify specific research questions and study designs that are important to consider in building the evidence for the COE and its application to improve child development and family health. Consider if there are different standards for validation required when considering measurement context and application (i.e. clinical care vs. national survey vs. research)?

Group 6: Team Evolve: Advance common measurement in the field: Team evolve will leverage dialogue to curate further recommendations for changes/additions to the National Survey of Children’s Health, National Health Interview Survey, among others, and existing performance measures used in the field. Goal is to align measures across levels (national, state, plan, practice, community) and enable epidemiologic monitoring and research critical to assessing progress in engaging and meeting the needs and priorities of children, youth and families.

Partners for Whole Child Preventive and Developmental Services:

A meeting to advance data-driven family-centered approaches to improving well-child-care services

April 7th | 11:00am – 1:30pm ET;
2:00-4:30 ET
April 8th | 11:00am – 1:00pm ET

Zoom Video Conference Lines: <https://zoom.us/j/7696705683>
Meeting ID: 769 670 5683
Call-In Numbers: 1 312 626 6799 | 1 301 715 8592 | 1 253 215 8782

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CAHMI: Child & Adolescent Health Measurement Initiative

COE: Cycle of Engagement

CPK: Care-Path for Kids

DRC: Data Resource Center

MCHB: Maternal and Child Health Bureau

MCH-MRN: Maternal & Child Health Measurement Research Network

NSCH: National Survey of Children's Health

PHDS: Promoting Healthy Development Survey

WVP: Well-Visit Planner