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THE MATERNAL & CHILD HEALTH MEASUREMENT RESEARCH NETWORK (MCH-MRN) YEAR 2 ANNUAL MEETING SUMMARY

Prepared by the Child and Adolescent Health Measurement Initiative for the Maternal and Child Health Measurement Research Network. This MCH-MRN is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) under grant UA6MC30375 (MCH-MRN).

CAHMI
The Child & Adolescent Health Measurement Initiative

Johns Hopkins Bloomberg School of Public Health | Population, Family and Reproductive Health

Coordinated by CAHMI
MCH-MRN
Maternal & Child Health Measurement Research Network

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Executive Summary

The Maternal and Child Health Measurement Research Network (MCH-MRN) is a multidisciplinary, collaborative network of experts who represent the MCH lifespan and who are active in the measurement of health and well-being of MCH populations. On August 1-2, 2018, the MCH-MRN Year 2 Annual Meeting took place in Washington, DC, convening a multidisciplinary and diverse group of MCH experts and stakeholders. The meeting objectives were to: 1) continue building a shared vision, framework, and strategic agenda for MCH measurement, 2) cultivate MCH-MRN strategic priorities and opportunities, and 3) advance Technical Working Groups (TWGs) in alignment with the MCH-MRN Strategic Agenda.

The TWGs are the MCH-MRN "operational arms" to advance the Strategic Agenda priorities and recommendations. In MCH-MRN Year 1 (2017-2018), the operating Technical Working Groups (TWGs) included: Positive Health, Family Health, Mental Health, Social Determinants of Health, and Cross-Cutting Methods to Optimize MCH Measures. During Year 2 (2018-2019) Technical Working Group (TWG) focus areas evolved to the following, which were the focus for the meeting:

1. ***Positive and Relational Health*** – active and ongoing TWG
2. ***Social Determinants of Health*** – active and ongoing TWG
3. ***Family Engagement*** – emerging active TWG, building upon Family Health TWG
4. ***Women's and Perinatal Health*** – emerging focus, TWG not yet fully defined
5. ***Value in Child Health*** – emerging focus, building upon work of the Mental Health TWG.

Meeting discussions identified opportunities with particular relevance to MCH measurement and with important implications for the work of the MCH-MRN. Participants called for efforts to:

- Define and advance measurement of positive and relational health, child and family well-being.
- Advance understanding of family engagement and how it can be measured.
- Emphasize measurement related to equity and social determinants of health as cross-cutting issues, across MCH populations, programs, clinical practice, administrative agency levels, etc.
- Address challenges in measurement of social determinants of health (SDOH) in MCH.
- Focus on measurement related to women's and perinatal health.
- Create new measures of value to guide effective value-based purchasing approaches in MCH.
- Integrate measurement of trauma informed care (TIC) into Positive and Relational Health TWG.
- Align across TWGs and topics to articulate measures and measurement strategies that support a holistic, ecological, and life course approach to improving MCH outcomes.

The MCH-MRN Strategic Agenda contains six high-level priorities and 15 recommendations to address these priorities in MCH measurement. In the Year 2 Annual Meeting, a set of high-level themes emerged, which reflect the priorities and recommendations of the Strategic Agenda.

- Develop measures to fill measurement gaps (e.g. positive health, family engagement, value).
- Improve access to, use, validation of and application of existing measures and data.
- Support continued sufficient public investment in MCH data collection and measurement.
- Coordinate with and build on past and existing measurement programs and initiatives.
- Strengthen partnerships and alignment among national organizations concerned with MCH.
- Assist in optimizing valid, feasible and actionable measurement in clinical practice.
- Improve communication with key stakeholders, including individuals and families; policy and public agency leaders; health care systems and providers; and researchers.
- Support community initiatives by optimizing use of existing data to create local area estimates, advance new measures, and promote community "data in action" capacity and skills.
- Support individual and family leadership, engagement, and advocacy with MCH data.

Introduction

The Maternal and Child Health Measurement Research Network (MCH-MRN) is a multidisciplinary, collaborative network of experts who represent the MCH lifespan and who are active in the measurement of health and well-being of MCH populations. The MCH-MRN is sponsored by the U.S. Health Resources and Services Administration (HRSA), Maternal and Child Health Bureau (MCHB) (UA6MC30375). The 2016-2019 cycle of the MCH-MRN is led by the Child and Adolescent Health Measurement Initiative (CAHMI).

On August 1-2, 2018, the MCH-MRN Year 2 Annual Meeting took place at the AcademyHealth offices in Washington, DC. The dinner meeting on August 1 and day-long meeting on August 2 was attended by a multidisciplinary and diverse group of MCH experts and stakeholders from around the country. (See Appendix 1 for the meeting agenda and Appendix 2 for a list of participants.) The MCH-MRN engages experts who represent the MCH lifespan and who are active in the measurement of health and well-being of MCH populations and the meeting participant group was a reflection of the overall Network membership, including key stakeholders and experts from the public and private sectors, from academic institutions and family self-advocacy organizations, and from public health and clinical practice.

The meeting objectives were to: 1) continue building a shared vision, framework, and strategic agenda for MCH measurement, 2) cultivate MCH-MRN strategic priorities and opportunities, and 3) advance Technical Working Groups (TWGs) in alignment with the MCH-MRN Strategic Agenda. The annual meeting is the primary mechanism used by the MCH-MRN to directly engage network leaders to define and advance a shared framework and agenda for MCH measurement, and increase collaboration among measurement related efforts across MCH populations, settings, topics, and purposes. The design of the meeting provided structured opportunities for participants to: refine MCH measurement priorities, discuss key opportunities related to emerging initiatives and innovations, and identify levers for change and improvement in MCH measurement. . (For a list of measurement initiatives and agency acronyms used in this document see Appendix 3.)

This document summarizes the high-level themes that emerged from the meeting and describes tangible next steps for the MCH-MRN based on the input of advisors and key partners attending the meeting

Part 1: Reflecting on MCH Measurement

On the afternoon of August 1, prior to the start of the full meeting, the CAHMI convened a small group of MCH-MRN Technical Working Group (TWG) leaders. This pre-meeting had two purposes: 1) to prepare for TWG breakout sessions on August 2, and 2) to increase cross-TWG engagement in relationship to key themes and priorities in the overall work of the MCH-MRN. The small, leadership group shared reflections on the history of and progress in MCH measurement over the past 25 years. The discussion foreshadowed and reinforced themes that emerged during the meeting. For example, the group talked about how our knowledge related to early childhood, healthy development, and positive and relational health often is not being put into action in the field of MCH in terms of either services or measurement. These leaders pointed out that social determinants of health (SDOH) and equity are widely discussed but comprehensively or consistently measured for children and their families. The role of partnerships with public and private sector organizations to advance measurement was emphasized. The small group discussion also pointed out the continuing importance of conducting and improving measurement to inform policy, programs, and clinical practice. This group also remarked on the need for continued efforts to measure family health and family engagement. The group further emphasized that measures are needed at different levels—for clinical practice with individual children and families, for risk

stratification and identifying levels of need within populations served, and at the community or population level, to understand overall system capacities and needs – and that these need to be aligned but at a level they can be effectively employed for their different purposes. Last but not least, these TWG leaders highlighted that opportunities exist for the MCH-MRN to act on what we know, measures that we have, and use data to guide action.

Following dinner, Dr. Christina Bethell made welcoming remarks and provided an overview of the meeting goals and agenda. Next, Dr. Anne Riley presented a summary of the work of the Family Health TWG and offered her reflections on some of the lessons learned. These remarks were grounded in her decades of research in the development of tools for measuring child and family health. She emphasized the importance of making sure that resources, expertise, and capacity match the challenge of developing measures. It often takes years, millions of dollars, many researchers, and engagement of practitioners and families to develop an individual or set of measures and ensure their use. For example, despite substantial federal investment and expert time in carrying out a rigorous process for measure development, measures of positive child and family health measurement may not yet be strongly represented. The Patient Reported Outcomes Measurement Information System (PROMIS ®) launched by the National Institutes of Health in 2004 invested hundreds of millions over more than a decade to develop and validate patient reported outcomes, including measures of health status that assess physical, mental, and social well–being from the patient perspective. Research was conducted to develop measures of "Family Relationships" that can be applied in research focused on determinants, outcomes, and the protective effects of children's subjective family relationship experiences. Dr. Riley also reflected on the importance of increasing use of existing measures and ensuring long range investment in research and development of measures.

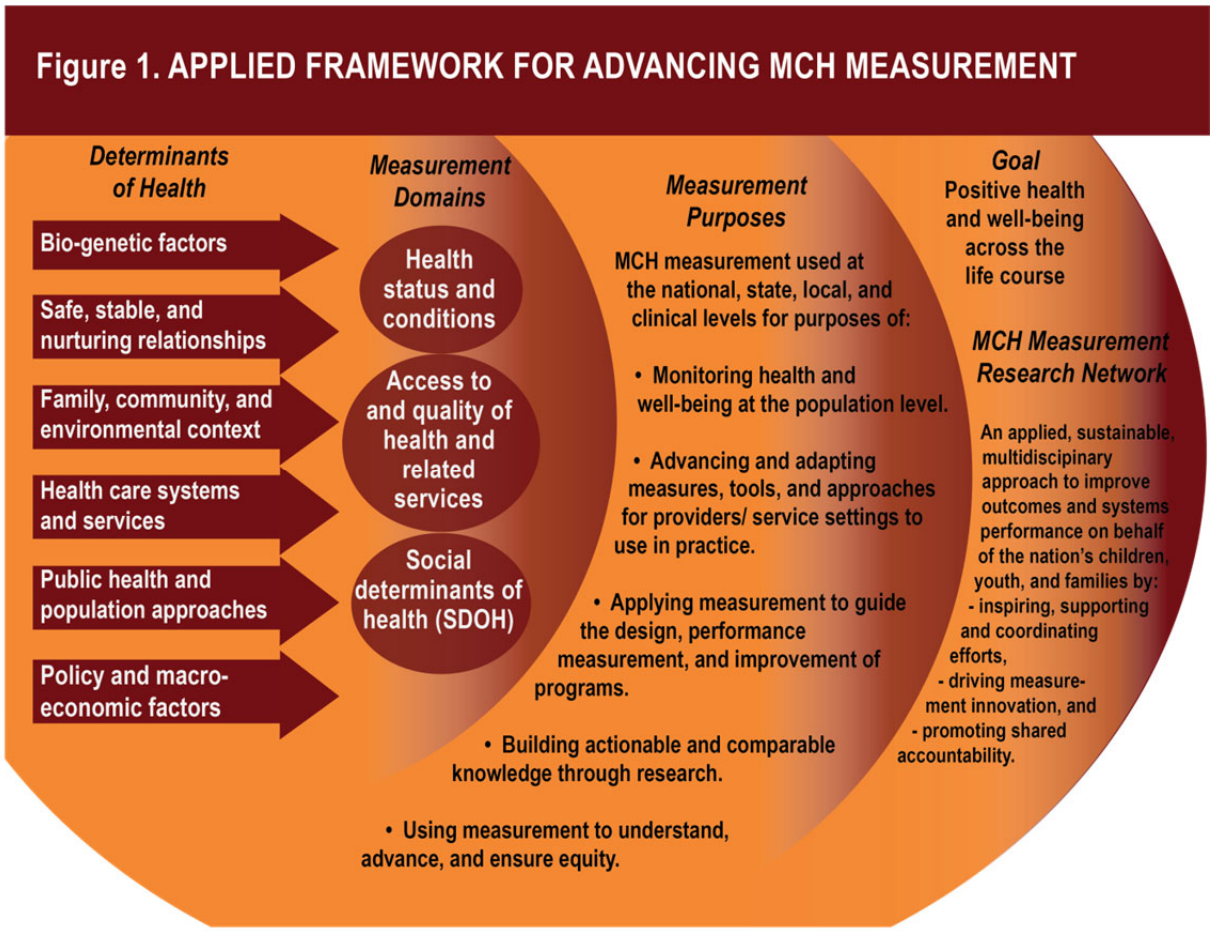
Part 2. Overview of the MCH-MRN

The CAHMI kicked off day two of the MCH-MRN Year 2 Annual Meeting by providing background context on the MRN's past and current work. The CAHMI staff and consultants described the purpose, goals, design, and approach for the MCH-MRN. The applied framework for the MCH-MRN shown in Figure 1 highlights the goal of measurement, measurement purposes, key measurement domains, and key determinants of health.

The purpose of the Maternal and Child Health-Measurement Research Network (MCH-MRN) is to provide a sustainable, multidisciplinary platform to: inspire, support, coordinate, and advance efforts related to MCH measurement; promote measurement innovation and shared accountability; and improve outcomes and systems performance on behalf of the nation's children, youth, and families.

From Fall 2016 to Summer 2019, the MCH-MRN aspires to establish and maintain the following.

- **A common, recognizable framework,** which creates a shared vision for the landscape of MCH measures needed for monitoring, accountability, research, evaluation, improvement and public education.
- **A strategic agenda embraced by MCH stakeholders,** which leverages existing opportunities and addresses key gaps to ensure effective MCH measurement, and guides the development and harmonization of measures across programs and initiatives where doing so adds value.
- **An applied network,** which provides the platform and opportunities for interdisciplinary experts who represent the MCH lifespan to connect and develop innovative, funded MCH measurement initiatives.
- **Actionable resources**, which support MCH stakeholders in their knowledge and use of MCH measures in priority areas, and application of measures into a variety of practices, policies, and processes.

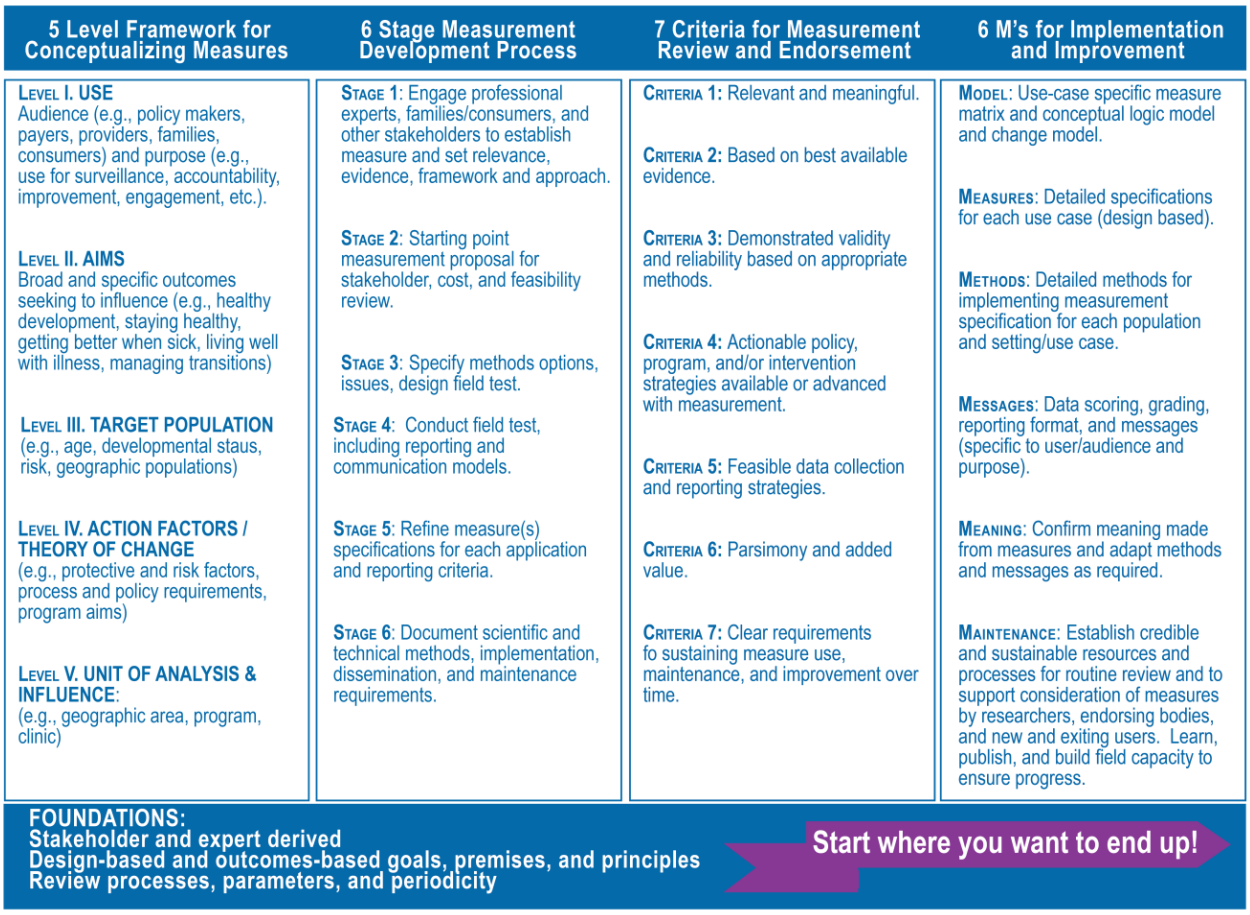


The meeting overview described the MCH-MRN Strategic Agenda. The Strategic Agenda: aims to: improve MCH measurement and its application toward better health and well-being for MCH populations; is based on identified gaps and opportunities; makes recommendations for action to fill gaps and optimize opportunities; sets short-term, actionable priorities; promotes the development, harmonization, and alignment of measures; and guides translation into policy, programs, and practice. The strategic agenda of an organization is the set of issues that guide resource allocation. Strategic agendas are typically built through group action, generally by using communications, issue development, and consensus building. Champions, entrepreneurs, and opinion leaders play a key role. The process for developing the Strategic Agenda for MCH measurement used these approaches. The Year 2 Annual Meeting continued to collect perspectives and opinions from key stakeholders to further inform the MCH-MRN Strategic Agenda. The themes of the meeting in relationship to the priorities and recommendations of the Strategic Agenda are discussed further below in Parts 5 and 6.

As shown in Figure 2, the overarching paradigm and theoretical approach rests on specific *measurement for action* frameworks that the CAHMI has developed and refined over many years. While each framework offers in itself a strong vision and set of guiding principles, taken together they create a wide, deep, and comprehensive approach to measure development at each stage of the process, specifically measure: selection, development, review, and implementation. The CAHMI *5 Level Framework for Conceptualizing Measures* provides a basis and rationale for identifying which measures or sets of

measures should be examined and why. The *Six-Stage Measurement Development Process* articulates a comprehensive set of procedures that are required to build, test and validate new measures. The *Seven ("7-C's") Criteria for Measurement Review and Endorsement* guide the developer through a review process to ensure that a measure meets standards for scientific soundness, will produce actionable data, is feasible, and will add value. The *Six ("6-M's") Framework for Measurement Implementation and Improvement* offers benchmarks for how a measure will be used in the real world and what is needed to ensure its value to users. These frameworks were described and referenced throughout the meeting as guides to action.

Figure 2. CAHMI Four Part Model of Measurement for Action



Source: Bethell, C. Overview of the CAHMI Measurement Framework and Development Process. 2014.

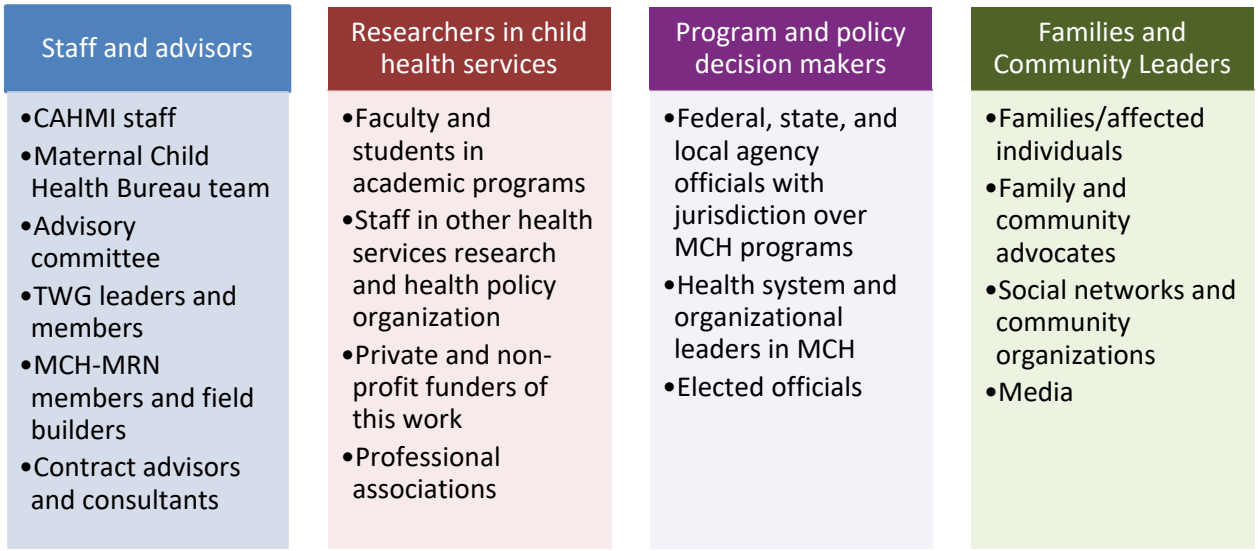
The overview portion of the meeting also discussed MCH-MRN key activities and achievements to date. These include the following.

- Strategically identified and engaged a multi-disciplinary network of MCH experts and stakeholders.
- Engaged stakeholders in an environmental scan (n=388).
- Reviewed and compared 20 MCH measurement frameworks and models related to child health and well-being.
- Analyzed 11 national programs and initiatives to identify measurement assets, gaps, and opportunities and created profiles to assist users for these program measures.

- Developed MCH-MRN Strategic Agenda with six priority areas.
- Designed and fostered development of technical working groups (TWGs) to advance measurement in gap areas.
- Convened annual in-person meetings of key advisors and stakeholders.
- Developed MCH-MRN online portal and interactive MCH measures compendium (>800 measures).
- Developed an open-source question set on social determinants of health for screening young children in pediatric primary care.
- Convened a summit to build the field of positive health.
- Prepared and disseminated articles, briefs, fact sheets, and other related publications (>15 completed in 2017-18).

The overview portion of the meeting continued in a lunchtime discussion of the communication and dissemination goals of the MCH-MRN. These are part of a communications plan developed by the CAHMI in partnership with AcademyHealth. The first of these goals, consistent with design of the Network, is to create and nurture stakeholder relationships with a wide variety of diverse, interdisciplinary professionals in order to support sustainable efforts to advance a common strategic agenda to advance MCH measurement. The second is to increase awareness, understanding of, and support for a common, recognizable national research agenda and measurement framework among target audiences. The third communication and dissemination goal is to engage, empower, and incentivize MCH stakeholders to disseminate and use MCH-MRN tools and evidence to improve outcomes and systems performance on behalf of the nation's children, you and families., Finally, the fourth goal is to improve the quality and efficiency of the CAHMI team's communications and dissemination efforts with MCH stakeholders to achieve the aims of the MCH-MRN. Figure 3 shows key audiences and influencers for MCH-MRN network development, communication, and dissemination.

Figure 3. Key Audiences and Influencers for the MCH-MRN



Part 3: Refining Shared Vision and Opportunities for MCH Measurement

The MCH-MRN's Technical Working Groups (TWGs) are its "operational arms" to put the Strategic Agenda priorities and recommendations into action. A TWG under the MCH-MRN is a group of individuals who come together for the explicit purpose of addressing an MCH measurement gap or opportunity area identified in the agenda. Individuals engaged in TWG efforts include MCH researchers, advocates, practitioners, program specialists, policymakers, and more. At a minimum, the TWGs apply for funding to support their work, publish on priority topics, and make program/policy recommendations to the Strategic Agenda. To achieve their aims, the TWGs are provided with resources and support by the CAHMI, who assist TWG leaders with group start-up and provide a TWG Toolkit and resources to help the TWGs get started and stay focused.

MCH-MRN TWGs are not permanent entities and, as such, are evolving as leadership, gaps, and opportunities in MCH measurement evolve. In MCH-MRN Year 1 (2017-2018), the operating TWGS included: Positive Health TWG, : Family Health TWG, Mental Health TWG, Social Determinants of Health TWG and Cross-Cutting Methods to Optimize MCH Measures TWG. During Year 2 (2018-2019) TWG focus areas evolved to the following, which were the focus for the meeting:

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These are illustrated in Figure 4, which shows the TWGs for 2018-19 project year.

Small, break-out groups related to each of these five topics met together in the morning and afternoon of the MCH-MRN annual meeting. Attendees were assigned based on their interests, expertise, and organizational focus. Each small group included a balance of public/private, academic/practice, family/professional, and policy/program perspectives. Highlights of key themes emerged from these small group discussions regarding leadership, initiatives, and programs that create opportunities for change in MCH measurement.

During the morning breakout sessions, topical groups focused on "learning edges" — meaning the edge of the topic where they need to apply their competence and experience to improve, to go beyond where things stand today. During these discussions, participants shared what is being learned in the field and what challenges and opportunities they see. Small groups also identified key initiatives and programs that provide opportunities for alignment, might help to accelerate progress, and/or create emerging challenges.

Figure 4. MCH-MRN Technical Working Groups (TWGs) Project Year 2018-19

Positive and Relational Health TWG

What are major learning edges related to this topic?

- ✓ Better understanding about positive health, particularly through work on terminology, frameworks, communication, and partnerships. Emphasizing that positive health is not the absence of illness and distinguishing protective factors, positive childhood experiences, and positive health outcomes among well-being measurement concepts.
- ✓ Need to sort out and align different terminology and frameworks used in different disciplines that overlap, but never collaborate (e.g., is it social emotional/mental/relational health? well-being?).
- ✓ Opportunities to rapidly and accurately identify more and better measures for positive and relational health and disseminate them for broad use in data collection and research activities (i.e., beginning to overcome the overwhelming dominance of negative measures, such as diseases and/or risks like Adverse Childhood Experiences- ACEs).
- ✓ Design and conduct of research projects to confirm how positive and negative health operate on a dual continuum and promotion of positive childhood experiences differs from eliminating adverse experiences, etc.
- ✓ Need for evolving strategies to enable national and state level survey data (e.g., NSCH, BRFSS) to be used to generate evidence that links positive experiences and relationships to positive health/resilience and how this interacts with disease and risks like ACEs.
- ✓ Growing interest among community-based, local, and state initiatives in use of measures and assessment tools to monitor population health and well-being, SDOH, and gaps in services.
- ✓ Need to integrate measures of the impact and assessing fidelity of trauma-informed care (TIC) as part of the broader aim to promote positive and relational health and advance measures that can be used in a standard way in the field.

What programs and initiatives create opportunities for change?

- Adoption and infusion of positive measures into state and federal programs (e.g., BRFSS w/ optional modules for positive health behaviors and experiences, Title V state optional performance measures, measures of well-child visit quality, and value based purchasing metrics).
- Emerging CMS initiatives and models (e.g. CMMI's new Integrated Care for Kids program) provide opportunities for new and better measurement.
- Continued national, state, and local attention to early childhood, including coordinated system design, home visiting, early care and education, primary care, social/emotional/mental health, and other initiatives that explicitly seek to promote positive and relational health for young children.
- More tools available in clinical and public health practice for assessment and family/youth engagement to foster a focus on positive and relational health.
- Philanthropic initiatives related to prenatal to age three period or early childhood birth to 5/6 years, both individual and collaborative efforts engaging foundations of all sizes.
- Focus on TIC, with SAMHSA's and other national players' leading efforts to define, characterize, and measure efforts to promote positive and relational health as a key strategy to prevent, mitigate the effects of and heal from trauma and toxic stress associated with disruptions in safe, stable, nurturing relationships and environments for children and youth.

- Recognizing that children who experience trauma may not require interventions that focus specifically or exclusively on dealing with the traumatic incident and may benefit from care and support that strengthens protective factors.
- HOPE—Health Outcomes of Positive Experiences—framework that studies and promotes positive child and family well-being (Sege and Brown, 2017) and the New Science of Thriving and We Are the Medicine Frameworks associated with the CAHMI/AcademyHealth National Agenda to Promote Child and Family Well-Being.
- More publications related to understanding science of flourishing and positive health, along with specifics on HOPE, ACEs, resilience, and so forth.

Social Determinants of Health TWG

What are major learning edges related to this topic?

- ✓ Opportunities to integrate a focus on children, youth and families into the otherwise widespread emphasis on SDOH; we need to add perspectives on SDOH for children and how they may be distinct, overlapping and/or similar to SDOH for adults only.
- ✓ More discussion of equity and unequal treatment in health care (e.g., what constitutes quality and equity in prenatal care, pediatric care, women's preventive care) How do we use measurement to understand and advance equity in care?
- ✓ The epidemiology of children's lives is changing in terms of SDOH, health conditions, social connections, family/neighborhood environments, and socio-political context. How can we measure these changes and their impact?
- ✓ Need to expand understanding of the impact of parent health and behavior on child health and well-being.
- ✓ Opportunities to use two-generation strategies to shift SDOH from negative to positive.
- ✓ Growing understanding of the impact of social determinants on children's health and well-being in short term and throughout their life course.
- ✓ Need to balance measurement of risk, preventive, and promotive factors. Currently, there is more emphasis on measuring risks and unmet needs than on measuring strengths and opportunities to build resilience.
- ✓ Use of measurement to making the case that SDOH of children and families matters in the long term to health and well-being. Need to better describe value of interventions early in life. Longitudinal data can help build such a case.

What programs and initiatives create opportunities for change?

- National discussion and initiatives related to SDOH and measurement of SDOH, in both public and private sectors.
- Emerging knowledge and data related to SDOH and equity issues available to inform policy, program, and practice.
- Primary care providers are encouraged by professional associations and others to use SDOH and related screening tools.
- National surveys (e.g., Census, NSCH, BRFSS) and other measurement efforts (e.g., County Health Rankings) provide information on SDOH, much of which is underutilized.
- Common SDOH measures are now included in some large electronic health record/electronic medical record (EHR/EMR) systems (e.g. the Survey of Well-Being for Young Children).

However, this inclusion fails to engage families prior to encounters and does not lead to more efficient use of encounters to tailor to family needs.

- High profile media coverage related to SDOH and health equity, particularly on MCH topics such as maternal mortality, infant mortality, child poverty, ACEs, etc.
- Many initiatives in local communities focused on changing SDOH for whole population, for families, and for children.
- Growing recognition that "place matters" and responses to SDOHs also require community-building efforts and broadly available social supports.

Family Engagement TWG

What are major learning edges related to this topic?

- ✓ Recognition of family engagement as an ethical imperative rather than something nice to do.
- ✓ Identification of what "family engagement" means in across service settings, how to define and operationalize the term family engagement in systems and in individual care.
- ✓ Identification of means and approaches to finance family engagement.
- ✓ Focus on measuring how pediatric primary care providers (e.g., pediatricians, family physicians, nurse practitioners) engage families in direct care, decisions, and leadership roles.
- ✓ Focus on measuring how leaders in public health and Medicaid departments, hospitals and health care settings engage families in policy development and decisions and leadership roles.
- ✓ Paradigm shift in thinking about family engagement. Family engagement is both more and less then researchers often expect or state, in that the impact may be most immediate in terms of attitudes and perceptions, and less in terms of what is actually done.
- ✓ Need to balance focus and measures for families in general and families with CSHCN more specifically.
- ✓ Opportunity to develop a more comprehensive national group of family leaders, beyond CSHCN.
- ✓ Need to advance and translate knowledge from diverse disciplines into policy, public programs, and clinical practice. Many people getting on the band wagon; however, they don't agree on what "engagement" means, much less how to do it well, much less how to measure it.
- ✓ Need to recognize cultural and linguistic variations in how families are engaged, combined with recognition of the universal need of children for safe, stable, and nurturing home environments.

What programs and initiatives create opportunities for change?

- Measurement of family health and family functioning advanced in a purposeful manner by MCH-MRN leveraging work done for the Family Health TWG and reformatted Family Engagement TWG (family health concepts largely represented now in the Positive and Relational Health and SDOH and other TWGs.)
- Family Voices has offered leadership, including their work on developing the Framework for Assessing Family Engagement in Systems-level programs, policies, and practices (supported by the Lucile Packard Foundation for Children's Health) and the current development of Family Engagement in Systems Assessment Tool and Toolkit (FESAT) (supported by the Lucile Packard Foundation for Children's in consultation with CAHMI).

- Family engagement in systems and individual-level services is a topic in health care, social services, Head Start, home visiting, early childhood mental health, education, and other family services, with similarities in principles across diverse systems.
- Movements and initiatives for children and adults in patient-centered medical home and patient-centered outcomes research.
- Measurement included in HEDIS, Centers for Medicare and Medicaid Services core child health measures, and other child health quality measurement sets, particularly in CAHPS survey in a language understandable to families.
- Title V requires family engagement in the needs assessment and block grant planning but currently has no measures to monitor it.
- Early efforts to build capacity into electronic health records/electronic medical records (EHR/EMR).

Women's and Perinatal Health TOPIC

What are major learning edges related to this topic?

- ✓ Topic of longstanding interest, but gaining renewed interest through issues such as SDOH, equity, maternal mortality, and preconception health.
- ✓ Collection and use of SDOH data related to women's health, as well as measuring impact of interventions designed to reduce negative SDOH.
- ✓ Need to do more in terms of measuring quality and unequal treatment. Emerging questions such as: How do we partner with those most affected to ensure equity? How do we engage providers in non-judgmental, quality improvement processes to reduce bias and unequal treatment? (For example studies showing worse outcomes for those served by NICUs with concentration of poor and African-American populations.)
- ✓ Need to focus on quality in perinatal health. Some measures exist and need to be used. Others may need further development (e.g., unequal treatment, role of fathers in perinatal health). Some measures (e.g., prenatal care) may need to be restored to widespread use.
- ✓ Medicaid finances half of births; however, related data (e.g., service utilization, demographic factors, and outcomes) are not routinely collected by the Centers for Medicare and Medicaid Services, prepared with consistent methodologies, or used by most states.
- ✓ The focus on women leads to less discussion of families and/or fathers in MCH.
- ✓ Need to explain conceptual connections across the life course, explaining to stakeholders the meaning and importance of measures and how they might relate to the problems they wish to address (e.g. school readiness is affected by prenatal care quality; housing and food adequacy are related to birth outcomes).
- ✓ Emerging interest on measures of "agency" at the individual and community levels (e.g., impact of internalized and/or institutionalized racism, social isolation, ACEs).
- ✓ Conceptualizing how SDOH impact the health and well-being of women before, during, and beyond pregnancy as well as any children they may choose to have.
- ✓ Need for increased funding and capacity to conduct research and advance measurement in this area.
- ✓ Need to better use existing measures and identify gaps, with new measure development to follow.

What programs and initiatives create opportunities for change?

- Vital statistics in form of birth and death records continue to be a major repository of information, which are even more useful when linked to Medicaid or other administrative data.
- Measures and measurement sets have been created (e.g., life course, preconception health). Opportunities exist to increase their utility and application.
- Infant Mortality Collaborative Improvement and Innovation Network (IM CoIIN) efforts in states.
- Major national initiatives; however, much this work is being done by volunteers through private organizations (e.g., March of Dimes Prematurity Campaign and Collaborative).
- National Committee for Vital Health Statistics working to improve measurement.
- Various initiatives not specific to MCH but focused on health and measurement, such as Robert Wood Johnson Foundation culture of health, 500 cities project, and County Health rankings.
- Perinatal Quality Collaboratives available in increasing number of states with additional federal and state funding.
- National/societal, media, and policymaker focus on maternal mortality, perinatal depression, etc.
- Women's reproductive health is a highly charged political issue. This may create opportunities for new emphasis on improved measurement.
- Medicaid starting to use their data with an eye towards population health, but such data are often not available to public health agencies.
- Major focus on home visiting programs through federal and state funding; however, programs often give little attention to health of women beyond pregnancy (e.g., postpartum and interconception periods).
- Increased focus on fathers and fatherhood, particularly through local initiatives such as federally funded Healthy Start.

Value in Child Health Topic

What are major learning edges related to this topic?

- ✓ Measuring value for children's health care is an aspirational goal so products for this TWG need to be realistic and provide "next steps" short-term benefit to the field.
- ✓ Efforts should reflect the Heckman approach: define value as avoiding the cost of various types of failures to prevent avoidable developmental delays, health problems early and across life. There is a need to define where value is created, to look explicitly beyond costs to the health system and define in the context of lifelong health and well-being, with human and fiscal costs across service systems.
- ✓ Need for increased understanding of how measuring value for children is not completely different than for adults. Opportunity is to show alignment – reducing waste is same, also show where are they different and show the return on investment. MCH leaders need to get into the conversation, not just proclaim the exceptionalism of children.
- ✓ Focus on more than short term results for adult chronic disease reduction. A broader focus on improving outcomes, reducing costs, and increasing productivity across the life span.

- ✓ With focus on purchasing outcomes, the child health conversation is better framed. Not just about saving money. For example, we are not currently paying for the type of services that promote optimal child health and development. Focus more on proximate outcomes and measures (e.g., bonding, self-regulation) that are associated with distal outcomes desired (e.g., school readiness, reduced chronic disease in adulthood), . For young children, this includes family relationships and social context not just the child.

What programs and initiatives create opportunities for change?

- Value-based purchasing is a national discussion underway in context of Medicaid, private payers, state government spending, and health system design. The new CMMI Integrated Care for Kids (InCK) initiative may be a vehicle for developing and testing new measures of value.
- Value-based purchasing should not be defined as "cost-containment purchasing" and should reflect increased payments for higher value primary and preventive health services, which entail greater attention to identifying and responding to SDOHs
- CAHMI, AcademyHealth, and Children's Hospital Association project regarding value-based purchasing for children and advocate for redefining value in ways consistent with what this TWG recommends. Any follow up efforts from that project may provide leverage.

Part 4: Key Priorities and Action to Leverage Change

As discussed above, small, break-out groups related to five topics met together in the morning and afternoon of the MCH-MRN annual meeting. Continuing discussions from the morning, each breakout group in the afternoon was asked to identify key priorities and potential actions to leverage change. Unlike the morning discussion which used a broader lens on opportunities, groups were asked to focus more in the afternoon on what their TWG or the MCH-MRN might do. The following themes emerged from these small group discussions regarding priorities and action steps.

Positive and Relational Health TWG

What are the short-term high priority actions and opportunities related to this topic?

- Advance concepts and measures related to positive childhood experiences and their impact on development and outcomes (parallel to ACEs). This should result in increased measurement of positive childhood experiences as well as positive health outcomes in national surveys (e.g., BRFSS, NSCH), programs, and practice settings.
- Develop better conceptualizations and definitions that support measurement of positive health, especially for early childhood, youth report, families, and women's health.
- Accelerate communication and coordination of efforts as possible to leverage the work of the MCH MRN, CAHMI overall, NIH ECHO and PROMIS efforts, IHI efforts, those of RWJF and Doris Duke Foundation and the like. Obtain research support to examine existing data to report on results, communicate findings, explore effective messaging and improve measurements.
- Focus on deliberate coordination and/or pruning of potentially redundant efforts (without undermining benefits of "a thousand flowers blooming" in this relatively new area of measurement. Good measurement in action work requires a long term commitment with

consistent expertise and can be very expensive and complex (e.g. NIH PROMIS, CMS/AHRQ Pediatric Quality Measures Program - PQMP). If coordinated well, consolidation or pruning could create room for each partner to advance other measurement gaps other than new measures design (e.g. advancing measures to data collection and research; advancing data collection and research into communication for policy and practice improvements, etc.)

- Publish on validity of all existing and emerging tools that have value for specific goals for improving child, youth and family health, especially those used in any existing or emerging population surveillance/monitoring systems or that are being standardized for use in clinical practice or community needs assessments, etc.
- Develop open source measures/assessment tools through collaboration with stakeholder groups such as schools and community based-organizations.
- Conduct studies that provide new evidence on how building positive relationships decreases risk for poor outcomes.
- Include more parent and community voices in the processes for measure selection.
- Disseminate information and provide technical assistance regarding available data and measures.
- Develop open source measurement and assessment tools through collaboration with stakeholder groups (e.g., schools, communities, health care practices).
- Study questions such as: what are the best measures of positive health, how does measurement impact health (measurement as an intervention), and how do families perceive measurement of positive health?

What are the potential next steps?

1. Continue writing and publishing documents that set forth a positive and relationship health measurement framework, define common ground, and create a platform to advance measurement of positive and relational health. For example, topics might include: theory (why flourishing matters), data (epidemiology of flourishing), validation reports (e.g., on tools or measures), summaries of conceptual meetings, and other work. Prepare this with a user-centered design mindset (e.g. see the CAHMI 4 part measurement framework).
2. Promote use of the revised MCH-MRN interactive measure compendium, which includes emphasis on positive health. Update the MCH MRN measures compendium for additional measures that may be appropriate for inclusion.
3. Engage in national movement and conversation regarding TIC to address ACEs in the context of broader goals to advance well-being and positive and relational health. Ensure approaches to measurement anchor to assessing impact of TIC and focus on the healing and engagement-based approaches essential to preventing and mitigating effects of childhood trauma and adversity. Also advance the priority to assess impact of TIC in terms of reducing symptoms of trauma and creating positive health like engagement in life, hope and meaning in life, etc.)
4. Coordinate with the NIH ECHO/PROMIS program's focus on positive health for children under age 5. The NIH Project ECHO (Environmental influences of Child Outcomes) is a collaborative model of medical education and care management that empowers clinicians everywhere to provide better care to more people, right where they live.
5. Advance a common set of definitions to guide measurement in this area. Examine language used by different disciplines and types of programs related to positive and relational health, well-being and flourishing, social/emotional/mental health, trauma and resilience.

Social Determinants of Health TWG

What are the short-term high priority actions and opportunities related to this topic?

- Advance SDOH screening tool through next stages of piloting and dissemination.
- Design and conduct longitudinal study, with key steps to include: consider design and purpose, write proposal to private foundations for feasibility study, write proposal to federal agencies such as NICHD-NIH, MCHB-HRSA, DOE, ACF, etc. Alternatively use existing survey data for longitudinal studies (e.g., Statewide Longitudinal Education Data System - SLEDS).
- Improve data collection on equity, by promoting approaches such as: use of linked data sets, use of control group studies, increased application of standardized approaches, and focus on measuring what matters.
- Design and conduct a project to increase access to SDOH-related Census data by local community leaders and initiatives.
- Conduct / prepare case study narratives about SDOH measurement, to include: reporting on what communities are leaders in SDOH measurement (e.g., Milwaukee, Philadelphia, select California counties) and selecting sites that exemplify alignment and harmonization, shared accountability, and collective impact.
- Apply SDOH framework for population measurement.
- Develop and disseminate what works lists, tools, best practices, local examples, etc.

What are the potential next steps?

1. Advance the SDOH screening tool for use by primary care providers serving families with young children, with key steps to include: disseminating consensus statement that includes open-source tool, encouraging pilot/beta testing sites, and identifying resources for an optimization (not validation) study.
2. Apply SDOH framework for population measurement approach, applying user-centered design, aligned with purpose and population. Two main components include: dissemination of the perinatal SDOH/equity measurement framework and indicator set developed for the HRSA Infant Mortality CoIIN, and development of a framework and indicator set for the early childhood population.
3. Design and conduct a project to increase access to Census data (at state, county, city and neighborhood/census tract/sip code level) by local community leaders and initiatives, with key steps to include: identifying indicators, create extracted database from Census, develop web-based resources, prepare a technical assistance toolkit on using the American Community Survey for monitoring SDOH at the local level, and disseminate resources to stimulate data use.

Family Engagement TWG

What are the short-term high priority actions and opportunities related to this topic?

- Clarify definitions and meaning of family engagement and family centered care across different systems and context.
- Develop and use measures, measurement tools, and information collected.
- Use available data from national surveys (e.g., National Survey of Children's Health), EHR/EMR, and other sources.

- Develop and apply definitions of family health and family engagement for use in MCH data collection (e.g., national surveys, performance measures).
- Add family engagement measure(s) to Title V performance measurement set.
- Encourage studies of family engagement relationships to child and family health.
- Support family leadership in measure development, research, and other activities related to family engagement.

What are the potential next steps?

1. Continue to gather, review, and analyze existing research on family engagement in clinical care and system initiatives.
2. Through Family Voices leadership, complete development of the family engagement systems tool (FESAT), with key steps to include: conceptualization, development of items, piloting tool, validation of tool, and other relevant measurement research steps based on the CAHMI frameworks.
3. Disseminate completed FESAT tool and tookit to state Title V MCH Programs, state Medicaid agencies, hospitals, health systems, and families.
4. Develop application for research support (e.g., R40 MCH research program).
5. Share existing resources via Internet.

Women's and Perinatal Health Topic

What are the short-term high priority actions and opportunities related to this topic?

- Refine concepts and develop measures related to personal "agency" and "social connectedness" among US women of childbearing age and reproductive health.
- Encourage more systematic collection and use of Medicaid data, including birth-related and women's health services utilization and outcomes.
- Use longitudinal data from national surveys to understand women's health and well-being across the life course.
- Engage in and connect with National Committee for Vital and Health Statistics health data framework and process.
- Develop training and technical assistance tools to build capacity for analysis, distribution, and turning data into action, particularly at the local level.
- Develop new and improved partnerships across an array of stakeholders.
- Increase knowledge of how health care quality and value-based purchasing affect women's and perinatal health.
- Increase use of data regarding positive reproductive outcomes.
- Use data and measurement for community engagement and mobilization, including data on health quality, social determinants, and perinatal outcomes.
- Share examples of successful local efforts to improve women's and perinatal health.
- Develop measurement approaches for monitoring the impact of federal, state, and local paid and unpaid family leave.

What are the potential next steps?

1. Increase and expand stakeholder partnerships, including: partnerships with national initiatives that collect self-reported well-being among women of childbearing age, and engagement of women and families in development, identification, and use of measures.

2. Expand knowledge and effective application of health care quality and value-based approaches, including: dissemination of information regarding health care quality and value in communities, working with Perinatal Quality Collaboratives, and conduct of studies to learn about what women and families and communities prioritize in terms of health and well-being.
3. Expand knowledge and effective application of life course theory and epigenetics. This would begin with review of MCH Measurement Compendium (and other sources such as CDC and County Health rankings) to: identify existing measures regarding how changes in adult population and society affect children, identify gaps, and encourage new measure development.

Value in Child Health Topic

What are the short-term high priority actions and opportunities related to this topic?
What are the potential next steps?

- Use a pragmatic approach and build on existing efforts related to value-based purchasing (e.g., Medicaid) to introduce a new model for thinking about value in MCH for use in value based purchasing initiatives.
- This topic is new to the MCH-MRN. Key next steps will include continued discussion to identify opportunities related to measurement and to develop an MCH-MRN TWG charter if appropriate.

Part IV: Considerations for the MCH-MRN: Emerging Themes and Opportunities in MCH Measurement

In full group and small group discussions throughout the meeting, participants identified emerging themes and opportunities related to MCH measurement. Some of these are directly linked to the MCH-MRN Strategic Agenda, its framework and priorities. Others are emerging in the field of MCH as health care, health policy and programs, and child/family health and well-being are changing, with implications for measurement. The following were identified by meeting participants as emerging themes and opportunities with particular relevance to MCH measurement and with important implications for the work of the MCH-MRN. Participants called for MCH-MRN, its TWGs, and its members to:

1. Continue to improve the definition and measurement of child **well-being, positive and relational health**. Accelerating adoption of positive measures is one key step. Using existing information (e.g., national survey data) to increase understanding of the importance of relational health to positive health and lifelong well-being is another. Articulating the science and epidemiology of positive health and flourishing is essential. Advancing knowledge of positive health and the value of measuring it from a policy, program, and practice perspective is a key next step.
2. Advance understanding of **family engagement** and how it can be measured. While family engagement is a central MCH value, it remains an insufficiently used and measured in clinical practice. The field is ready to move beyond defining and/or measuring family as a concept. Developing, testing, and using of a family engagement tool for use in health care systems is a high priority.

3. Emphasize measurement related to **equity and social determinants of health** as cross-cutting issues, across MCH populations, programs, clinical practice, administrative agency levels, and so forth. Having better measures of discrimination and racism is one aspect of this work. Another is to have valid approaches for measuring unequal treatment and bias in clinical practice and service delivery systems.
4. Address the challenges in measurement of **social determinants of health** (**SDOH**) in MCH at the clinical, program, and population levels. For young children, SDOH includes family relationships and social context that surround the child. The SDOH TWG has developed a consensus statement regarding a screening in practice but next steps call for pilot testing and optimization studies. Improving measurement related to equity is one key element. Advancing knowledge of neighborhood level risks and social determinants, particularly using Census and other data is another next step.
5. Focus on **women's and perinatal health** topics. Building upon the work of National Preconception Health and Health Care Initiative is one priority, focusing on the health of women before, during, and beyond pregnancy. Increasing measurement of SDOH and their relationship to the health of women throughout the life course is part of this work. Advancing this work at a time when reproductive health is a highly charged political issue may be both a challenge and an opportunity.
6. Advance understanding about **value and value based purchasing in child health,** particularly using measurement to understand better the value of investments and interventions and the potential application of measurement in value-based purchasing. Using a value focus creates an opportunity and may be a cross-cutting topic across TWGs. Getting into the conversation about value-based purchasing is a priority, using payment, performance, evaluative, and other approaches. Measuring value for children is not completely different than for adults, ; but the benefits from improving value affect trajectories over a much longer period and have much greater overall impacts across physical, cognitive, social, and emotional/behavioral health. Showing alignment and distinctions is central to this work.
7. Understand, measure, and guide delivery of TIC as a part of the work of the Positive and Relational Health TWG. A nationwide conversation and many initiatives are underway related to Adverse Childhood Events (ACEs) and TIC, and measurement should be part of the development of new clinical services, programs, and policies. Moreover, we must keep sight of the fact that many young children have risks which do not fall into the category of trauma but could and should be identified and addressed early.
8. Apply **holistic, ecological, and life course approaches** in MCH measurement. Whether as part of defining health, of setting a measurement framework, or of understanding the value of action (vs. inaction) these were key concepts throughout the day and across topical discussions.

Part V: Considerations for the MCH-MRN: Working Together to Advance Strategic Agenda

As discussed above, the MCH-MRN Strategic Agenda presents six high-level priorities for MCH measurement, and 15 recommendations to address these priorities. These were generated from the CAHMI's key informant interviews, environmental scans, solicitation of input from MRN members, and ongoing identification of opportunities to leverage existing research, practice, and policy efforts.

Table 1. High Level Priorities and Recommendations for Action

Priority 1: Fill key conceptual gaps, especially in topic areas such as: positive health, well-being, socio-emotional functioning, family/relationship factors, perinatal health, early and middle childhood, and social determinants of health.

Priority 2: Increase the use and application of under-utilized measures at the national, state, and local levels.

Priority 3: Address barriers to equity analysis through the collection and use of key person-reported and demographic data.

Priority 4: Improve data availability and translation at the local level.

Priority 5: Promote alignment across programs and practices to enable shared accountability for health and well-being outcomes.

Priority 6: Address gaps in measure specification and validity.

Throughout the Year 2 annual meeting, rich and complex discussions focused on how to advance work in the field of MCH measurement and the priorities identified in the Strategic Agenda. These conversations flagged important considerations for the work of individual Network members, TWGs, and the MCH-MRN as a whole. Many discussion points related to filling gaps and increasing use or application of measures, as discussed in Priorities 1 and 2. The topic of equity, as defined in Priority 3, was threaded across topics and throughout the day of small and larger group discussions. In particular, engagement of women and families in the measurement process (e.g., measure development, data collection, and data use) was seen as essential to advancing equity and MCH measurement. Related to Priority 4—improving data availability at the local level—the meeting participants discussed the importance of supporting local community initiatives related to health and well-being, as well as supporting emerging leadership and advocacy. This was part of most small group topical discussions. Promoting alignment, as described in Priority 5, was discussed particularly in the context of national organizations, systems, and clinical practice. The following ten high-level themes emerged from these conversations and reflect multiple elements of the MCH-MRN Strategic Agenda.

1. **Develop and advance measures to fill gaps**. Many of the gaps identified in the Strategic Agenda were discussed throughout the meeting, including: 1) positive and relational health and well-being, 2) perinatal health and services, 3) SDOH, 4) equity, and 5) family/family engagement. Some new, related topics emerged such as TIC and value-based approaches. In addition, concerns were raised about losing hard-won and/or longstanding measures (e.g., prenatal care).
2. **Improve use and application of existing measures and data**. Optimizing use of Census and national survey data were discussed. Advancing collections of measures (e.g., SDOH, perinatal,

early childhood, and positive health) is another way to promote their use. At the macro level, many participants discussed the importance of measurement in context, used to drive clinical, program, and policy decisions. As stated by one participant: One major opportunity for MCH-MRN is to function at a meta-level, to take work that has been done and advance it in the field, to leverage opportunity

3. **Support continued sufficient public investment in data collection.** This was particularly identified as an essential part of maintaining national surveys and vital statistics. Participants also discussed the importance of augmented investment in data collection in some key areas (e.g., equity, Medicaid). Most groups discussed the importance of collecting longitudinal data.

4. **Leverage programs and initiatives underway**. Many mentioned were those led by philanthropy (e.g., Robert Wood Johnson Foundation "Culture of Health," Institute for Healthcare Improvement "100 Million Lives," Pritzker Children's Initiative, David and Lucile Packard Foundation philanthropic collaboration on "Big Bets" in early childhood). Linking to, informing, and building upon small topical "movements" in MCH (ACEs, TIC, maternal morbidity and mortality, early childhood initiatives, family engagement) are natural opportunities for leverage.

5. **Strengthen partnerships and alignment among national organizations concerned with MCH measurement** (e.g., American Academy of Pediatrics, American Public Health Association, Association of Maternal and Child Health Programs, Association of State and Territorial Health Officials, CityMatCH, Institute for Healthcare Improvement, National Association of City and County Health Officials, National Institute for Children's Health Quality). While many leaders in MCH measurement work in academic institutions and many work in government, others are members of national MCH, public health, and health care quality organizations. Engagement with and collaboration among such national organizations can help to inform, guide, and accelerate the MCH-MRN Strategic Agenda.

6. **Assist in optimizing measurement in clinical practice** by promoting measurement use, integration, harmonization, and prioritization, as well as by leveraging electronic records capacity and emphasizing quality and performance. Advancing the capacity to measure family engagement in clinical settings was also discussed. Aiming for meaningful measures and streamlining (or pruning), rather than adding more data collection burden was widely discussed. Too many measures have been developed and too few measures are in active use. Federal leadership has led to stronger measures; however, providers and health systems do not routine use what is available. Opportunities exist to improve measurement in clinical settings by enabling more and more effective use of existing measures, integrating fields into the electronic record to receive family/youth reported data and include assessments essential for MCH and that drive priorities and improvements in quality and performance. Identification and dissemination of key MCH measures into practice is a central role for MCH-MRN. Development and dissemination of tools, structures, and approaches that yield manageable measurement approaches and useful information are essential. Partnerships with professional organizations, major health systems, Medicaid, and other payers can support this work.

7. **Improve communication with key stakeholders**, including individual women, youth, and families; policy and public agency leaders; health care systems and providers; and researchers in an array of organizations and institutions. The MCH-MRN can help with communication and coordination of efforts to leverage efforts underway and work being done. This might be done by: making data more available, creating data and measurement tools, routine communication for MRN members, dissemination of MCH measurement publications, presentations, and use of

traditional or social media. Designing messages based on existing data and knowledge is an important element of this work.

8. **Support local community efforts to improve child and family health and well-being** by enhancing measures, data capacity, tools, other resources, and communication strategies. Promoting varied approaches for using data at local level to inform and "tell the story" was discussed across groups. Participants called for creation of tools and infrastructure such as a guide to help local leaders: use census data, augment with other data, use these data to tell the story, create geo-maps, and add information about cost, benefit, and value of intervention. Development and dissemination of technical assistance tools, as well as building a database from Census data, was recommended. This is especially important for directing appropriate attention to smaller geographic areas (census tract or zip code levels) and the needs for community-building and population health approaches as well as individual service provision approaches.

9. **Support individual and family leadership, engagement, and advocacy with MCH data to improve services for themselves and others**. Patient and family engagement in health care and other services is a stated priority in MCH. Families and youth can be leaders in the development, implementation and improvement of programs, policies and services such as the emerging Family Voices FESAT measure and leveraging and/or improving other relevant measures. Using measurement and research strategies (e.g., qualitative studies, photo voice) to advance understanding of people's lived experiences, particularly among traditionally underserved populations is one step. Some called for building upon the power of data derived from personal experience. Reaching untapped knowledge from women, families, and communities was seen by many as a priority. As described by one participant, we must: "advance equity in partnership with those affected by inequity."

Table 2. Examples of Proposed Action by Meeting Theme

Meeting Themes	Examples of Action
Develop and advance measures to fill gaps.	• Continue focus on key topics identified in the MCH-MRN Strategic Agenda such as positive and relational health, SDOH, and perinatal health. • Enhance work to reduce gaps in measurement of family engagement and TIC; both linked to TWG areas. • Advance a common set of definitions to guide measurement in positive and relational health. • Use a pragmatic approach to build on existing efforts related to value-based purchasing.
Improve use and application of existing measures and data.	• Optimize use of data from national surveys, clinical practice, and emerging measure sets (e.g., PROMIS, PQMC). • Focus on narrowing and guiding measurement efforts.
Support continued sufficient public investment in MCH measurement.	• Make the case for continuing and improving key national surveys. • Support and sustain important longstanding measures (e.g., developmental screening, prenatal care).
Leverage programs and initiatives underway.	• Continue to identify and connect with state and local measurement projects related to key TWG topics. • Engage and partner with leaders from federal and philanthropic initiatives related to measuring health and well-being.
Strengthen partnerships and alignment among national organizations.	• Deepen partnerships with public health organizations such as Association of Maternal and Child Health Programs, CityMatCH, and Association of State and Territorial Health Officials to advance Strategic Agenda. • Continue to provide conceptual connections and promote alignment among federal agencies' measurement initiatives.
Assist in optimizing measurement in clinical practice.	• Advance use of CMS Medicaid/CHIP child health measures among practices, health plans, and states • Promote use and refinement of open-source screening tools for the social determinants of health, as developed by the CAHMI TWG • Increase use of PROMIS framework and instruments. • Accelerate adoption of practice tools such as the Well-Visit Planner. • Promote use of SDOH screening in practice. • Work with Perinatal Quality Collaboratives.
Improve communication with key stakeholders.	• Strengthen partnerships among national organizations concerned with MCH measurement. • Increase participation of women, youth, and families in measure development.
Support local initiatives with measurement tools and strategies.	• Develop a toolkit to encourage use of Census data by local initiatives. Further develop neighborhood-level analyses (census tract and zip code level) and how they can inform population-level actions, including being included in community benefit assessments. • Involve community leaders in designing data use strategies and analyses.
Support individual and family leadership, engagement, and advocacy.	• Use measurement to advance understanding of people's lived experiences, particularly among traditionally underserved populations. • Develop tools and strategies to measure family engagement. • Partner with national initiatives that collect self-reported well-being among women of childbearing age. • Encourage use of data to guide changes in programs and policies.

Appendices

Appendix 1. MCH-MRN Annual Meeting Agenda

August 1- 2, 2018

AcademyHealth Offices
Washington, DC

Wednesday, August 1

3:00 – 5:00 pm **Pre-meeting for TWG leaders**

6:00 – 8:00 PM **Welcome Dinner**

Welcome and Introductions

- Christina D. Bethell, PhD, MPH, MBA – Director, The Child and Adolescent Health Measurement Initiative and MCH-MRN, Johns Hopkins University Bloomberg School of Public Health

Family Health Measurement

- Anne W. Riley, PhD – Professor, Department of Population, Family and Reproductive Health, Johns Hopkins University Bloomberg School of Public Health

Thursday, August 2

8:00 – 8:30 AM **Breakfast**

8:30 – 8:45 AM **Agenda Review and Federal Welcome**

- Christina D. Bethell, PhD, MPH, MBA – Director, CAHMI and MCH MRN
- Michael D. Kogan, PhD – Director, Office of Epidemiology and Research, Maternal and Child Health Bureau, Health Resources and Services Administration

8:45 – 9:45 AM **Overview and Discussion of MCH-MRN Goals, Design, Strategic Measurement Agenda, and Engagement Approach**

9:45 – 10:45 AM **Breakout Session: Engaging in Shared Vision and Strategies**

10:45 – 11:00 AM **Break**

11:00 AM – Noon **Full Group Discussion: Optimizing Opportunities and Priorities**

12:00 – 1:00 PM **Lunch**

1:00 – 1:15 PM **Measurement Compendium Update and Dissemination**

1:15 – 2:30 PM **Breakout Session: Planning for Action**

2:30 – 2:45 PM **Break**

2:30 – 3:00 PM **Full Group Sharing and Discussion: Key Action to Leverage Change**

3:00 – 3:45 PM **Full Group Discussion: Putting Strategic Agenda into Action**

3:45 – 4:00 PM **Next steps**

4:00 PM **Adjourn**

Appendix 2. Participant List for 2018 MCH-MRN Annual Meeting

Richard Antonelli
Medical Director of Integrated Care
Boston Children's Hospital

Evva Assing-Murray
Health Scientist
MCHB-HRSA-HHS

Romey Azuine
Director, Division of Research, Office of Epidemiology and Research
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Courtney Blackwell
Research Assistant Professor
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Mary Blake
Public Health Advisor,
CMHS-SAMHSA-HHS

Stephen Blumberg
Director, Division of Health Interview Statistics
NCHS-CDC-HHS

Claire Brindis
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University of California San Francisco

Charlie Bruner
Senior Fellow
Center for the Study of Social Policy and RISE Institute

Cheryl Clark
Associate Director, Epidemiolgy & Evaluation
Association of Maternal & Child Health Programs

Nathaniel Counts
Senior Policy Director
Mental Health America

Jill Denson
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Health Scientist
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CityMatCH

Stephanie Guinosso
Senior Research Associate
ETR Associates

Clarissa Hoover
Project Director
Family Voices

Laura Howell
Project Manager
Institute for Healthcare Improvement

Lawrence Kleinman
Professor of Pediatrics and Director, Center for Child Health and Policy
Case Western Reserve University

Michael Kogan
Director, Office of Epidemiology and Research
MCHB-HRSA-HHS

Milton Kotelchuck
Professor of Pediatrics
MGH/Harvard Medical School

Jasmine LaCoursiere
Assistant Clinical Director, Nurture Science Program
Columbia University Medical Center

Jeffrey Linkenbach
Director & Chief Research Scientist
The Montana Institute

Marianne McPherson
Senior Director
100 Million Healthier Lives
Institute for Healthcare Improvement

Christopher Millman
MD/MPH Student
Tufts University

Kamila Mistry
Director, Division of Priority Populations Research
AHRQ-HHS

Kristin Moore
Senior Scholar and Past President
Child Trends

Colleen Murphy
Early Childhood Program Director
National Institute for Children's Health Quality

Anne Riley
Professor
Johns Hopkins Bloomberg School of Public Health

Alexandra Rothenburger
Manager, Strategic Policy and Analytics
Children's Hospital Association

Robert Sege
Professor of Pediatrics and Medicine
Tufts University

Chris Sheldrick
Associate Professor
Boston University School of Public Health

Stephanie Sundborg
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Kay Johnson
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Research Assistant
CAHMI

Rabia Syed
Student Research Assistant
CAHMI

Beth Johnson
Director
Academy Health

Appendix 3. Acronyms used throughout this document

Federal Agencies and Programs

ACF – Administration for Children and Families-HHS

AHRQ – Agency for Healthcare Research and Quality-HHS

CDC – Centers for Disease Control and Prevention-HHS

CHIP – Children's Health Insurance Program

CMHS – Center for Mental Health Services-SAMHSA-HHS

CMMI – Center for Medicare and Medicaid Innovation-CMS-HHS

CMS – Centers for Medicare and Medicaid Services-HHS

DOE – US Department of Education

HHS – US Department of Health and Human Services

HRSA – Health Resources and Services Administration-HHS

MCHB – Maternal and Child Health Bureau-HRSA-HHS

MIECHV – Maternal, Infant, and Early Childhood Home Visiting program

NCHS – National Center for Health Statistics-CDC-HHS

NICHD – Eunice Kennedy Shriver National Institute of Child Health and Human Development-NIH-HHS

NIH - National Institutes of Health-HHS

SAMHSA – Substance Abuse and Mental Health Services Administration-HHS

Measurement Initiatives, Surveys, and Terms

To learn more about MCH measurement initiatives, visit http://action.cahmi.org/browse/mchmeasurement/

BRFSS – Behavioral Risk Factor Surveillance System

CAHMI – Child and Adolescent Measurement Initiative

CAHPS® - Consumer Assessment of Healthcare Providers and Systems

MIECHV – Maternal, Infant, and Early Childhood Home Visiting program

NSCH – National Survey of Children's Health

PRAMS – Pregnancy Risk Assessment Monitoring System

PROMIS® – Patient Reported Outcomes Measurement System

PQPM - Pediatric Quality Measures Program

Title V MCH – Title V Maternal and Child Health Services Block Grant program, including performance measures

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