NEXT STEPS IN FAMILY-FOCUSED SCREENING TO ADDRESS SOCIAL DETERMINANTS OF HEALTH FOR YOUNG CHILDREN IN PEDIATRIC PRIMARY CARE.

During the 20th century, medical care evolved from a focus on infectious diseases and illnesses to a further emphasis upon the management of developmental and chronic health conditions. The patient-centered medical home, originating in pediatrics, reflected a response to providing such care management for those chronic conditions, one that extended beyond the medical practitioner as the sole agent in treating and managing health.¹

Currently, the health field, and particularly the field of children’s primary health care, is undergoing another transition—to focus on early and lifelong development of health and whole child well-being, which requires attention to social as well as medical determinants of health.² ³ ⁴ ⁵ ⁶ ⁷

Different bodies of research (Protective factors,⁸ Adverse childhood experiences, Resiliency,⁹ Epigenetics, Neurobiology, Toxic stress,¹⁰ and Social determinants of health—a “P.A.R.E.N.T.S. Science”¹¹) point to the critical need to address social determinants of health (SDOH); especially those that impact the safety, stability, and nurturing of children in the home environment, which science shows are most critical to optimize young children’s early and lifelong health and development.¹² ¹³ ¹⁴ ¹⁵ ¹⁶ ¹⁷ ¹⁸ ¹⁹ ²⁰ ²¹ ²² ²³ ²⁴ ²⁵


The 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 No. UA6MC30375 led by the Child and Adolescent Health Measurement Initiative. The information, content, and/or conclusions are those of the author and should not be construed as the official position or policy of, nor should any endorsements be inferred by HRSA, HHS, or the U.S. Government. To learn more, visit: http://childhealthdata.org/browse/mchmeasurement/MRN-project.
Healthy People 2020 and the Centers for Disease Control and Prevention emphasize the need to take a “life course” approach in primary care and public health, which requires attention to SDOH as key contextual factors that contribute to healthy development, health potential and lifelong well-being for children and families. A seminal article promoting value-based care and payment, *The Triple Aim: Care, Health, and Costs*, provided a new impetus to move beyond chronic health management to focus on whole-person, positive health development, with the role for health care practitioner champions to achieve transformation through five component actions: partnership with individuals and families, redesign of primary care, population health management, financial management, and macro system integration. The Medicare and Medicaid Services’ Center for Medicare and Medicaid Innovation (CMMI) was directed to promote innovation and diffusion that would achieve the “triple aim” of improved health quality, improved population health, and reduced per capita health care costs. The Affordable Care Act designated the national *Bright Futures* Guidelines as a standard for primary and preventive services in pediatrics, and the recently released 4th Edition of *Bright Futures* places greater emphasis on the role of well-child visits in identifying and responding to SDOH. Innovators in child health, through foundation support or support within their medical institutions, have developed broader and more ecological approaches to responding to young children in primary care—starting with screening that goes beyond specific child health risks and conditions to more fully engage families through supportive discussions and practice regarding factors influencing the whole well-being of children and families. The establishment of Patient Centered–Medical Homes in pediatrics has evolved as leaders in promoting primary care practice changes to advance health, based upon a whole-child and life course framework for thinking about healthy development. Despite innovations and growing commitment to this approach in the field, however, the emphasis in much of health care reform is still on immediate per capita health cost reductions through better managing chronic and high cost health conditions (although CMMI has begun to explore the implications to children). While there are many innovative and exemplary initiatives in children’s primary health care, particularly focused upon young children and their families, these have yet to be widely adopted. Many of the insights and successes from the innovative and exemplary practices remain within those practices. This is particularly true for the measurement of child health within a SDOH and life course framework—both for screening and attendant response within the primary care health practitioner’s office and for review of the status of child health on a population basis. Innovative programs and approaches to augment and extend primary health care practice are being selectively implemented across the country. For example, programs such as Child First, Help Me Grow, Healthy Steps for Young Children, Medical-Legal Partnership, MYCHILD, and Project DULCE have such purposes. These and other projects and programs use screening and surveillance tools to identify, for practitioner and community response, concerns beyond the specific assessment of the child’s physical, social, cognitive, and emotional development. Exemplary
practice tools have been developed, studied, and implemented to varying degrees, such as the Promoting Healthy Development Survey, A Safe Environment for Every Kid (SEEK) questionnaire, Survey of Well-being of Young Children (SWYC) WE CARE, and the Well Visit Planner. There have been multiple definitions of these SDOH, some focusing primarily upon material and environmental issues and others including ecological factors relating to family, social, environmental, or policy factors. Drawing substantially upon the initial definition and factors established by the World Health Organization, the definition used here is intentionally directed to young children—with recognition that the safety, stability, and nurturing in the family home environment is core to healthy development, along with community and macro level social and political issues typically discussed as SDOH. Our definition seeks to be comprehensive and inclusive of all factors that contribute to healthy child development which are not child-specific and biomedical in nature. These include measures related to what we categorize as four different domains.

The household’s **material well-being** (and financial ability to meet the child’s basic needs).

1. The parent or primary caregiver’s psychological and **personal well-being** (and therefore ability to be the child’s first nurse, teacher, and safety officer).

2. The parent, primary caregiver’s, and home’s **social well-being** (and ability to ensure a safe and nurturing environment for the child to explore the world through positive social relationships).

3. The parent and child’s **relationship well-being** (bonding, attachment and play and parental understanding and ability to provide the intimate, serve-and-return nurturing of the child).

These four SDOH domains are depicted in the graphic on the next page and all have an impact upon the child’s own well-being and healthy development—physical, cognitive, social, and emotional/behavioral.

Again, the P.A.R.E.N.T.S. Science points to these elements as contributing the largest share to healthy child development and as malleable and possible to proactively promote and address. While clinical care to treat bio-medical determinants of health plays a role in promoting healthy development, even when there are major bio-medical factors (particularly special needs requiring chronic care), clinical care alone cannot produce optimal outcomes without addressing these other SDOH. The What of Screening for Young Child Social Determinants of Health

Currently, there is much attention directed to screening for SDOH across the lifespan. Several reviews of existing screening tools have been conducted, with some formulating core sets of screening questions based upon their reviews. Many questions or series of questions around particular SDOH have been validated as part of research studies; others have been put into practice based upon this literature but not necessarily independently assessed for their reliability and validity in the context of broad-based screening. In our context, validity of questions is key and equally important to validity is whether asking SDOH questions fosters critical educational, support and problem-solving discussions with parents and families.
One of the first steps the MCH-MRN TWG took was to identify and categorize existing screening tools and questions, using the four domains described above (material well-being, psychological well-being, social well-being, and relationship well-being). Although this effort was far from exhaustive, both the published and the grey literature (particularly tools developed by exemplary primary child health programs) were examined.

This compilation (conducted by Bruner for review by the TWG) yielded a broad set of questions. Many were validated in some form as part of research projects, with some designed as sets of questions to be comprehensive in their approach and others focusing upon a specific domain or element within that domain. Several syntheses also provided sets of recommended screening questions for use, either for preventive pediatric practice or for broader use across the age range. While these syntheses generally covered more than one of the domains, however, none covered all four and most covered questions related to only some aspects of that domain.

Further, while validity has been determined for specific screening questions or sets of questions, there was limited information regarding the interactions across and multi-collinearity among different questions. Since the goal of this screening is not to determine a health condition or specific need for a referral, but to open a discussion to determine needs and provide education and support, our focus was on content and construct validity of items and not their predictive power for a specific condition or risk factor requiring referral or medical treatment.

Currently, exemplary programs and practices are continuing to modify their tools and seeking a firmer body of evidence that using these tools has value for primary care goals to promote healthy
development and child well-being. The MCH-MRN TWG determined that the field could benefit from additional development, action research, and testing of a screening tool covering all four domains of social determinants of health as they relate to young children and their families.

Through a modified Delphi process, the TWG developed a screening tool composed of 18 questions, designed for use in the first years of life. This report makes this tool available for testing and further analysis of its properties and utility; but the MCH-MRN TWG and its sponsor MCHB/HRSA are not endorsing it, per se. The TWG sees this as a further step to advance development of such screening tools, coupled with the follow-up practice that makes use of them. Practices which have developed their own tools should continue to use what works for them, although they may want to review and adapt what they do. Practices should not initiate screening without a commitment to discussing responses from families and providing education and problem solving with parents on needed follow-up resources and supports. A screen is just that, and its utility rests as much on how it is used.

The remaining sections of this report speak to such use and how to further develop effective ways for practices to identify and respond to SDOH.

The composite screening tool covers the four domains, drawing as much as possible on validated screening questions and existing tools in practice and an additional crosswalk between the screening questions in the tool and the different questions presented in Bright Futures Guidelines.

Details about the tool and its development can be found in the Appendices. Appendix A provides the developed 18-item SDOH screening tool for early childhood (in two iterations). Appendix B shows existing screening tools and questions used by the MCH-MRN TWG in their review. Appendix C contains a crosswalk between the developed screening tool and Bright Futures Guidelines.

The Why and How of Screening for Social Determinants of Health among Young Children and Families

A screening tool is just that – a tool that can be appropriately and effectively or ineffectively and inappropriately used. The MCH-MRN TWG recognizes that the “why” and “how” are as essential as the “what” in screening for and responding to social determinants of health. Screening for social determinants of health is part of a process of engaging parents (or other primary caregivers) with young children and not an end in itself. A screen only identifies potential concerns and cannot be used to either direct or exclude a course of action, but rather to identifying topics for the practitioner and practice to follow-up with more extensive discussion. Similarly, the context in which screening is conducted may enhance or hinder the practitioner and caregiver relationship.

In terms of the “why,” it is essential that any screening or surveillance for SDOH results in a response within the practice itself that is helpful to and supportive of the family and the practice. In terms of “how,” it is essential that the screening is conducted in ways that engage and contribute to relationship.
development with the family and the young child and lead to positive results.

**Why screen?**

Simply put, any screening for social determinants represents the start of a process to help and support the child and family in the child’s healthy development. However extensive, a screen is not a definitive assessment of the complex array of factors that can impact child development, but it can be used to initiate a conversation and discussion that can help the family better respond to the child. This is true for any screen, whether for hearing, developmental status, or SDOH. Particularly with very young children (birth to three), the health practitioner often is the family’s first and most frequent point of contact with an outside professional who can initiate meaningful responses to both the child’s presenting health conditions and the family’s conditions and circumstances that impact the child’s healthy development.

While it does not take a medical degree for a practitioner to sense that a mother bringing her infant into a well-child visit is stressed, not picking up on her child’s cues for attention, and, from her and the child’s appearance, struggling to make ends meet, a screen can be more precise in identifying the range of circumstances families face that can jeopardize their well-being and their child’s healthy development – and what particular ways to best engage that family around them. The value of a screening tool for SDOH is that it can better identify families who can benefit from attention to their home circumstances and help the practitioner initiate a discussion with and exploration of family concerns. Research shows practitioners often miss the most at risk children and families when they rely only on their observations.

This means that the primary child health practitioner and the practice itself must be committed to and capable of making use of the screen. This involves training and ongoing continuous reflection and improvement with the practitioner and practice. Not every practice is ready today to implement such screening.

### How to screen and respond?

One of the dictums in the helping professions is “do no harm.” Asking parents to respond to sensitive questions about themselves, without providing the opportunity to discuss them, can produce anxiety, shame, or the reliving of negative experiences (one of the reasons the TWG selected not to include questions regarding ACEs). Not asking about these topics that clearly impact health can also result in similar anxiety, shame and negative experiences.

The MCH-MRN TWG determined that any screening tool used should be clear that responses on any individual questions or the whole screen should be voluntary. Moreover, screens should be done in a manner that validates and affirms the parent or caregiver, not interpreting any responses, but asking parents/families how the issue asked about impact them, providing education and discussing resources and needs. Recognition and discussion of a challenging situation or condition by the primary health practitioner (and the overall practice), even when the practitioner or practice may not be able to offer a specific referral or direct action to address that specific condition, can have a positive impact on the patient-provider relationship and the development of trust. They also can serve to motivate practitioners to seek and advocate for availability of resources for families that they did not previously know were present. In addition, many families will know of resources available to them but they
did not consider accessing. Such discussions are core to effective use of a screening tool, the development of trust, and what can be a helpful response in its own right. Because the MCH-MRN TWG recognized that some of the questions in the screening tool are sensitive and could be viewed as intrusive or distressing, the TWG sought to use wording and an array of questions that are positively as well as negatively framed. The TWG also emphasized that the dangers of being intrusive rest much more with how the screening tool is introduced to families and how results are used or not used, than the battery of questions it asks.

The MCH-MRN TWG also recognizes that, while one key reason for employing the tool is to identify specific families who might benefit from further discussion and potential intervention, no family is without some stress or challenge as a result of its role in parenting and that some universal information can be provided to all parents, regardless of the responses to the screen. In particular, the American Academy of Pediatrics “Bright Futures: Guidelines for Health Supervision of Infants, Children, and Adolescents,” calls for providing information at each well-child visit about developmental expectations and ways parents can promote child health, both in the visit itself and as hand-out information with the completion of the screening tool.

The MCH-MRN TWG further recognizes that the screening tool, while it should be completed at least in the practice office at the time of a well-child visit, also could be completed prior to the visit, ideally as part of a resource such as the Well-Visit Planner, which can lead to a more interactive and family-centered visit. Specifically, the validated Well-Visit Planner equips families with questions to raise with their practices during the well-child visit and enables them to follow-up on items they themselves identify that can be concerns. This tool will be updated to enrich existing SDOH content based on the findings of the MCH-MRN SDOH TWG. The more any SDOH screening tool can be used by the family as well as the practice for identifying, discussing, and responding to concerns, the more useful it will be.

For a substantial proportion of families (an estimated 10 to 30 percent overall, and half or more in certain poor and isolated communities), the TWG emphasizes that follow-up involves more than anticipatory guidance provided by the practitioner in the well-child visit. While in some cases, pediatric practices can provide interventions, response to most SDOH will require a referral and follow-up.

Effective follow-up entails a “warm handoff” from the health practitioner to a care coordinator, social worker, family advocate, resource navigator, or other individual – either within the office or practice or through an outside resource (such as the care coordinators provided by Help Me Grow). Again, the screening tool is simply a starting point for referral and further discussion with a care coordinator; often, such a discussion results in uncovering family goals, ideas, or positive actions that are not evident from or directly tied to the survey responses. When additional services are needed, families generally benefit from the support care coordination can provide when navigating multiple systems of care.

The MCH-MRN TWG recognizes that different practices and practitioners have different capacities, as well as different inclinations, for responding to SDOH. While all practices can be supportive of and attentive to family as well as child-specific concerns, some practices may not have the skills to use a comprehensive
screening tool or the capacity to make effective community referrals. The level of social risk in the population served by a practice may also be a factor. Such practices may seek to limit the questions they are about SDOH to those they feel they can provide a helpful response.

The MCH-MRN TWG emphasizes, however, that more important than capacity is practitioner and practice interest in working with and supporting families in terms of the SDOH. The “why” of the screening tool is to better engage families in their role in the healthy development of their children. While most primary child health practitioners went into their professions because of their desire to do that, not all practitioners or practices are comfortable or inclined to place a major emphasis on SDOH. At this point in the evolution of primary child health care practice, the use of separate screening tools for SDOH is not at the point of being a required standard of care, but rather an opportunity for diffusion to additional practices and continuous learning and improvement in use.

Finally, the MCH-MRN TWG recognizes that addressing SDOH involves more than individually-focused responses to young children and families. Issues of poverty, discrimination, employment, housing, neighborhood safety and support, and developmental services and activities (including child care) require public responses and policies that ensure any and all families have the opportunities and resources within their communities to support their children’s healthy development. These go beyond direct service responses to individual young children and families. Child health programs and practices can be part of the voice for such policies, and public health activities often can help create new public resources needed to address SDOH on a population level. At the same time, however, through the primary care they provide, child health practitioners have the opportunity, if not to always address larger social issues and determinants of health, at least to improve the ability of the families they serve to navigate service systems and try to meet their and their children needs. While not a part of the screen itself, practitioners, particularly through their on-the-ground experience and their credibility within their communities, can contribute to identifying and advocating for policy responses needed to address SDOH.

Next Steps in the Use and Development of a Comprehensive SDOH Screening Tool

While the screening tool provided in Appendix A could be used as a freestanding screen (and could be billed as such, particularly as part of an initial well-child visit), it is only part of the information practices should gather to inform the well-child visit. Practices will want other contact and background information about the family as well as the child, as well as parental assessments of the child’s current development and health status and any health concerns.

For example, the Bright Futures Guidelines have tools to support such efforts, as does the Well-Visit Planner, which is based on these guidelines and developed in collaboration with its developers. There are a variety of develop-mental screening tools (including the PEDS, the Ages and Stages and Ages and Stages Social-Emotional tools) for screening for developmental issues that can be easily linked into the Well-Visit Planner or otherwise use in conjunction with a SDOH screening tool. Analysis shows that the majority of children identified as being at risk for development, behavioral and social
delays do in fact experience social risks. This screening tool itself should not be considered as a finished product, and practices which currently are doing screening using other tools reflecting some SDOH or which have developed their own should continue to use what works for them, although they want to consider adding or modifying select questions into their screen to at least try them out (which could be conducted under a PDSA improvement model). The MCH-MRN TWG recognizes that the ability to get to this point in developing its screening tool was dependent upon the initiative and innovations that practices and initiatives took to develop their own approaches in this area. In addition to testing the screening tool itself, practices should monitor the communication strategies that are employed when discussing the screen with families and coach staff and providers in optimizing patient engagement during difficult conversations.

At the same time, the MCH-MRN TWG believes that the field would benefit from an open-source, core set of screening questions that incorporates validated questions, builds upon the experiences of practitioners to date, and uses the research base regarding SDOH. This will require additional testing and refinement of this screening tool, including testing with practices which have a strong inclination to use such a screen and can offer additional responses through a “warm handoff” to follow-up even beyond the well-child visit.

Beyond the testing phase, more research will afford the opportunity to understand the validity and reliability of these questions used together for relationship-centered screening. While most of the individual questions in the screen have been validated for some purposes—and the TWG sought to keep the tool of a manageable length—there are many properties of the tool as a whole that require additional field testing for value and statistical properties, which only application on a broad and representative set of young children and their families can provide. This testing may result in item reduction and further streamlining of the questions, without loss of its impact in both identifying family concerns and determining education and follow up steps that may require a warm handoff for further in-depth discussion and support for families. Some questions may be reasons in themselves to provide that handoff, while in other instances it may be the combination of responses that call for other referrals and follow-up action.

For example and as illustration:

If the screen indicated tobacco use in the home, some anticipatory guidance is warranted – to inform parents that, even if an adult continues to smoke, it is important and possible for the child to be protected from second-hand smoke (in the air, by not smoking in the house or car) and third-hand smoke (on clothing and couches) and this is particularly important for infants and young children because of the development of their respiratory and immune systems. In addition, referral and support for smoking cessation interventions may be warranted.

With positive results on the two-item depression screen, a discussion of stress and social support may be warranted in the pediatric primary care practice. In addition, connecting the parent to follow-up diagnostic assessment for depression or other mental health concerns, perhaps with the support of care coordinators, is important.

In instances of housing or food insecurity, responses may require knowledge of specific community resources. Most practices
can at least have a list to share of locations for the Supplemental Nutrition for Women, Infants, and Children (WIC) Program, Supplemental Nutrition Assistance Program (SNAP), and food banks in the community.

At the same time, virtually all families can benefit from some anticipatory guidance and information about nutrition and exercise for their infants and toddlers (e.g., 5-2-1-almost none), both to inform and to reinforce behaviors and actions.

Given the current state of innovation and diffusion around screening for SDOH, the MCH-MRN TWG strongly recommends further work to advance a comprehensive screening tool for use and adaptation in the field – starting with testing of the tool provided here and with an eye toward its refinement, along with guidelines for its use, for children birth to five.

The MCH-MRN TWG further recommends that support be provided for this work in informing further iterations of both the Bright Futures Guidelines screening recommendations and the related Well-Visit Planner family completed pre-visit planning tool.

Appendices

- **Appendix A** includes two iterations of an 18 item social determinants screening tool for use with children birth to five. The first is a simplified set of 18 declarative statements to which the parent can respond yes, sometimes, or no – and has been adapted from the second iteration that more directly uses questions in the exact form they have been validated (often in research studies and for discrete purposes).

- **Appendix B** provides the review and presentation of existing screening questions and tools for social determinants of health, developed by Charles Bruner for review by the TWG.

- **Appendix C** provides the cross-walk, developed by Charles Bruner for review by the TWG, of the screening questions from Appendix A with the Bright Futures (4th Edition) “Guidelines for Health Supervision” questions related to providing anticipatory guidance for four different well-child visit (prenatal, newborn, year 2, and year 4).
References