



♥ Ensuring a Place at the Table for Every Family

National PLACE Comments in Response to RFI re: MCHB Strategic Plan

The National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE) is a national non-profit composed of 70 local, state, and national family-led organizations around the country. Our vision is that all families will be effective partners in improving services to and outcomes for our nation's children, especially those who face the greatest challenges. Our mission is to empower families and family-led organizations to advocate for enhanced, meaningful parent involvement and leadership in all policy decision-making that impacts services for children and families across education, health, and other systems.

We thank you for the opportunity to comment on the Maternal and Child Health Bureau (MCHB) Request for Information (RFI) on the Strategic Plan. National PLACE offers the following feedback and recommendations regarding the Strategic Plan. Many of our members serve as their state's Family to Family Health Information Center, Family Voices State Affiliate organization, Parent Training and Information Center or Community Parent Resource Center, Parent to Parent USA Affiliate, Federation of Families for Children's Mental Health Chapter, Family Empowerment Center, and/or Family Resource Center. Our comments are based on our extensive work with families of children and youth, including but not limited to children and youth with special healthcare needs (CYSHCN), as well as the experiences of our own staffs, most of whom are representatives of the women, children and families for whom the Title V program was created and who are its intended beneficiaries. Our comments are also based on our experience with multiple systems of care (education, health, mental health, early childhood, prevention, etc.) and best practices in serving and engaging families and youth, including families who have CYSHCN, families of color, immigrant and limited English proficient families, low-income families, and families in urban, rural, and suburban areas of the country including its territories. Many of us have longstanding partnerships with our State Title V agencies and/or the maternal and child health programs and services they fund. Given our vision and mission, our comments will focus primarily on those aspects of a Strategic Plan that would impact family and family organization engagement and influence, and the related issue of equity.

Introduction

To ensure that diverse families who are representative of the population of diverse children and families served by MCHB and MCH programs can effectively partner, adequate resources must be devoted to building their capacity to participate effectively and as truly equal partners with professionals – government agencies, service providers, and professional advocates – in individual service delivery, at the program level, and in systems change and improvement. There must be funded, multi-tiered opportunities for families to develop leadership knowledge and skills to more effectively represent diverse family voices in systems change across systems that

serve children and their families. The funding provided to family-led organizations to inform and support families must include funds to identify, train, and support diverse family leaders in systems change activities, as well as to provide professional development and support to government and private agencies and organizations that serve children and their families to enhance their family-centered services and supports, capacity to partner with families in systems-change and improvement efforts, and improve cultural competence/ reciprocity. We appreciate that the MCHB funds Leadership in Family Professional Partnerships, which continues to support family-led organizations to facilitate Serving on Groups trainings for diverse family leaders, and Leading by Convening sessions for state agencies and family-led organizations, to prepare conveners for a new cadre of trained parent leaders that is more representative of our nation's current MCH population. But this funding, and the funding provided by MCHB to F2Fs, must be supplemented in order to meet the current need.

Ensuring that family-run organizations are partners at all levels is critical to MCH success. An important part of effective systems is how successful they are in providing families with the tools they need, from information about child development to services for families needing help. But families are more than just consumers of services, they are leaders, too. Who is best to identify family needs, assess the effectiveness of services, or impact on policy development? Giving families a voice in decisions that affect them means more than asking parents for input on what they need or including them on advisory bodies. It means making sure that they have the knowledge and skills to influence policy decisions that impact on them and their children, and ensuring that diverse family voices are represented in policy development that affects children and their families. Providing an opportunity for families to attain these skills can best be accomplished by supporting family-run entities including but not limited to F2Fs to provide leadership training and support to existing and potential family leaders.

Both national and state government agencies too often fail to recognize the expertise that *family led organizations* bring to the policy and systems improvement table. Such organizations – the organizations who comprise National PLACE - are staffed by parents who have experienced the systems that need to be improved. We hear from thousands of families from a variety of backgrounds about what is and isn't working in those systems and can share those varied perspectives at systems improvement tables. We know a lot about what it takes to effectively engage and develop the capacity of families at all levels. We understand how systems work. We are aware of current research and evidence-based and informed strategies. Our primary commitment is to the families served by those systems, and to lifting up their voices to make change. *That is why MCHB's new Strategic Plan must explicitly address the importance of meaningfully partnering with family-led organizations at all levels and stages. Families and the family-led organizations that support them must be deeply and meaningfully involved in identifying barriers and underlying causes, developing and implementing solutions, and evaluating and improving impact, at all stages, phases, and levels. Families, including those representing the children who face the greatest barriers to high quality services and who have the poorest health and other outcomes, and the family-led organizations that support them, must be recognized and supported as integral partners and leaders in ensuring family/child well-being and quality of life.*

Purpose

We understand that the strategic plan is intended to provide a roadmap to MCHB's future. We realize the importance of this future planning, but would also like to recognize the ongoing importance of the MCH 6 Core Outcomes and continuing collaboration with Family Voices Affiliate Organizations, Family-to-Family Health Information Centers, and other family organizations such as Parent Centers (Parent Training and Information Centers, which are usually statewide, and Community Parent Resource Centers, serving underserved communities), Federation of Families for Children's Mental Health State Organizations and Local Chapters, and Parent-to-Parent programs, among others. We note that two of the core outcomes, medical home and transition to adult systems of care, have been incorporated into expectations for all children, not just CYSHCN, which we applaud. We further believe that the remaining four outcomes are also relevant to all children and youth, not just CYSHCN. For example, all children need access to adequate public and private healthcare financing to meet their health needs. All children need access to early and continuous screening and ongoing monitoring. All children need access to community-based services that are easy to use. And all families should be seen as essential partners in decision-making at individual, program, and systems' levels. These six core outcomes are especially important not just to CYSHCN and their families, but also to the other children and families who face the greatest barriers to quality services and positive outcomes: children of color, immigrant children, low-income children, and children in families where English is not the first language.

We recommend that the Strategic Plan explicitly incorporate enhanced focus on the six core outcomes for CYSHCN and explicitly expand their coverage to all children and youth and their families: access to early and continuous screening to identify all special healthcare needs; access to a medical home that coordinates all needed care; community-based services that are easy to access and use; adequate public and private healthcare financing to pay for all needed care; services to support effective transition to adult systems of care; and family engagement at all levels.

Background

National PLACE members are intimately involved at local, state and national levels in addressing the needs of children and families across MCHB's 11 legislative authorities, from the Title V Maternal and Child Health State Block Grant (many of our members are funded in part through the Block Grant), to Community Integrated Service Systems, to Healthy Start, to disability-specific areas such as autism, sickle cell, deafness/hearing loss, and heritable disorders, to emergency medical services for children, to home visiting, to Family to Family Health Information Centers. Our experience across these legislative authorities and programs undergirds our recommendations for MCHB's new Strategic Plan. We strongly support maintaining the current focus on improving health outcomes and addressing/reducing/eliminating health disparities through access to quality services delivered by a skilled health workforce using innovative, high-value programs. We also strongly recommend including in that mission the focus on achieving this mission through strong, meaningful and impactful collaboration with families and youth representing our nation's full diversity and the family-led organizations who support, empower, and advocate with and on behalf of families and youth, such as our members.

National PLACE Responses to Questions for Public Comment

1. What do you see as core, critical activities of MCHB? What is most important to continue into the future? Are there things not being done that should be?

Core, critical activities for all children and youth and their families are the MCH 6 core outcomes which include access to early and continuous screening to identify all needed services, a culturally and linguistically competent medical home that coordinates all needed care, community-based services that are easy to find and easy to use, adequate public and private healthcare financing, services to support effective transition to adult systems of care, and family partnership and leadership at all levels.

We strongly recommend retention of the MCH 6 core outcomes in the Strategic Plan and their expansion to cover all children and youth and their families.

Other core activities include promoting engagement and leadership of people with lived experience and the organizations that support them and advocate with them and on their behalf at all stages and in all aspects of activities for which they are the intended beneficiaries; supporting technical assistance centers that can disseminate information on research-to-practice, evidence-based and evidence-informed practices, and resources to support implementation of effective practices; and promoting and supporting cultural and linguistic competence across all domains.

We strongly recommend increasing the focus on, and requirements for, family engagement and leadership across all of the MCH domains, building on the success of family engagement on issues impacting CYSHCN and their families.

2. MCHB has responsibility for a wide range of programs and initiatives. How could MCHB help its programs be more effective and successful? Do you see specific untapped opportunities related to one or more programs, populations, or areas of focus?

We see underserved populations as an untapped resource. Only by including the input of these stakeholders will the MCH programs be more effective and result in better outcomes.

We recommend adding the following goal: Families and youth representing the intended beneficiaries across all of the MCH domains who face the greatest barriers to high quality services and who have the poorest health and other outcomes, and the family-led organizations who support them, are integral partners and leaders in ensuring health equity.

3. Thinking about equity, how can MCHB support efforts to eliminate disparities and unequal treatment based on race, income, disability, sex, gender, and geography? How might MCHB guidance, funding opportunities, or partnerships play a role?

We strongly agree with eliminating disparities, but addressing social determinants of health must occur for this to be implemented. This is not achievable solely by MCHB or even by HRSA, but requires strong collaboration and partnership with all federal, state and local agencies including

housing, labor, community development, juvenile justice and prisons, education, early childhood programs, child welfare, and many more. In addition to issues of racism, anti-immigrant bias, the implications of poverty, and denial of language access, all of which contribute to poor health outcomes, the strategic plan must address other impacted subgroups such as populations who are involved with juvenile justice, homelessness, the child welfare system including but not limited to foster care, etc. And the voices of the parents of the children facing this discrimination, bias, and poor quality services must be lifted up and listened to in identifying the problems, the barriers to accessing quality services and outcomes, and the solutions, including being part of implementation and evaluation of quality improvement efforts.

We recommend ensuring that regardless of race, ethnicity, socio-economic status, disability, religion, sexual orientation, gender or any other identity subject to discrimination, infants, toddlers, children and youth, including CYSHCN, and families can access the care, services and support they need when, where, and how they need it not only across MCH domains but also across all agencies and areas. All MCH constituencies must receive care that is family-centered, culturally and linguistically competent, and explicitly anti-racist.

4. Thinking about trends in emerging science, public health, health care, workforce, and technology, what do you see as key opportunities for MCHB?

Emerging science includes to broaden the use of telehealth. COVID-19 has accelerated the use of telehealth, which should continue. In addition, Health Information Technology and the use of Electronic Health Records will improve care coordination, reduce duplicative services, and reduce medical errors. However, many families do not have access to technology or sufficient connectivity. Some live in rural areas. Even with technology, there must be access to interpreters for ASL or languages other than English. In addition, some families may need accommodations such as large print, speech-to-text, contrast for low vision, etc. Other families may need training and support around use of technology for telehealth/telemedicine.

We recommend that equity in access to equipment, connectivity, and understanding of how to use telehealth and telemedicine must be addressed. Cultural and linguistic competence is especially critical when services are delivered remotely; virtual communication provides many more opportunities for misunderstanding, challenges to developing trusting relationships, and barriers to follow-up. These must be explicitly considered and families and youth from diverse cultural, racial, language, socio-economic, and other backgrounds and the family-led organizations that support and empower them must be included in planning, implementing, evaluating, and improving telehealth and telemedicine services.

Another emerging area is the important value-add of involving the voices of lived experience in decision-making at all levels from the beginning throughout the process of continuous quality improvement. Federal, state and local agencies must build into their plans and their budgets programmatic and financial support for diverse families and youth and family-led, family-serving organizations to be a key component of the public health workforce. Research in several areas, from support for families of CYSHCN to enrolling and maintaining enrollment in Medicaid to helping families who have lost custody of their children due to child abuse or neglect regain and maintain custody, has demonstrated that families of children with and without

SHCN are more successful when they receive support from peers with lived experience. Our workforce, our funding, and our programs must reflect this research. A trained parent with lived experience, supported by a parent-led organization, has a greater positive impact on their peers than a nurse or social worker. Why then is this not THE model that is sweeping the nation?

Peer to peer supports must be available and financed appropriately, and such peer-to-peer services must be sufficiently flexible to address the needs of children and their families from the full array of racial, ethnic, language, socio-economic, and cultural backgrounds. We recommend that MCHB's strategic plan explicitly include this as a major goal with specific, measurable objectives, activities and timelines aimed at bringing these models to scale.

Conclusion

In conclusion, we welcome MCHB's plans to develop a new strategic plan and urge a stronger focus in the plan on health equity and social determinants of health and elimination of racism and other discrimination. Our most significant recommendations for revision include a greater focus on the role of families and youth from diverse backgrounds as well as the family-led organizations that support them as leaders and influencers at all levels and stages of improvement; strengthening of peer supports and recognition of the effectiveness and efficiency of family-led organizations run and staffed by people with lived experience; and specific inclusion of the six core outcomes, not only for CYSHCN and their families but for all infants, toddlers, children, and youth and their families. Family-led organizations bring the voices of many families and youth to the table, assist individual families to secure needed services and supports for their children, and contribute to program and systems improvement. The strategic plan must reflect this key role to ensure that the voices of all families are heard and that the needs of all families and their children are met.

We also respectfully request that, as MCHB moves forward in developing and implementing the new strategic plan once approved, you meet with diverse parents/families and family organizations including in particular national organizations such as National PLACE, Family Voices, Parent to Parent USA, and the Federation of Families for Children's Mental Health, among others; representative family-led organizations at the state and local level; and youth and young adults with disabilities and their national leadership organizations such as the Autistic Self Advocacy Network, Youth MOVE, and Youth As Self Advocates, as well as youth without disabilities, among others. Families and family organizations as well as youth/young adult leadership organizations should be recognized as key stakeholders in maternal and child health and should be explicitly included in developing, implementing, evaluating, and improving the policies and practices that affect them.

Very truly yours,



Diana Autin, Executive Director

National Center for Parent Leadership, Advocacy, and Community Empowerment

National PLACE

dautin@parentsatthetable.org

www.parentsatthetable.org