Ensuring a Place at the Table for Every Family

Comments of National PLACE & Family-Led Organizations on Revised MCH Block Grant to States Program: Guidance and Forms for the Title V Application/Annual Report

The National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE) is a national non-profit composed of over 40 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 revised Maternal and Child Health (MCH) Block Grant to States Program: Guidance and Forms for the Title V Application/Annual Report. National PLACE, as well as the other national, state, and local family organizations listed at the end of these comments, offer the following feedback and recommendations regarding the revised guidance and forms. The signatories serve as their state's Family to Family Heath 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 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. 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 the guidance that impact family and family organization engagement and influence, and the related issue of equity.

Overall Comments

Overall, National PLACE and the other family-led organization signatories to these comments support the revisions to the Title V Application/Annual Report Guidance and Forms. We are pleased at the inclusion of guidance in many sections regarding engagement of families and "consumers" (although we recommend use of a different term, such as constituents, as consumers implies a passive role which we know is not the intent). We appreciate that the Maternal and Child Health Bureau's (MCHB) investment in family-led organizations, the Family to Family Health Information Centers (F2Fs), are specifically identified as partners and stakeholders. We also strongly support the focus on health equity and social

determinants of health, to ensure that the voices of all families are heard and that the needs of all families and their children are met. However, we are concerned that, with all the references to family engagement at all levels, there is no performance measure focused on family satisfaction or family-professional partnership. Prior to the current MCH Block Grant Guidance, states reported on this measure at least for families of children with special health care needs. Now states do not have to report on this measure for any MCH population. *We urge MCHB to correct this immediately and add such a measure requiring states to measure effectiveness in engaging families at the individual level of care by reporting survey data from populations served through Block Grant funds*. Title V programs should work with family partners, especially F2FHICS, in designing and undertaking such surveys. In addition, in order to reach diverse families, surveys must be available in a variety of formats including translations, online, hard copy, telephone interviews and focus groups. Non-traditional outreach will assure input for culturally and linguistically diverse families. Potential sources/tools for data collection include:

- Questions from the Family Voices Family-Centered Care Assessment
- Questions from the National Survey on Children's Health
- Adapt the NCSEAM (National Center for Special Education Accountability and Monitoring) Early Intervention Family Outcomes survey
- Ensure consistent data elements across states for comparability

We also encourage MCHB to go even further in its guidance regarding partnering with families and with family-led organizations, including references in multiple sections regarding partnering with family-led organizations, not just individual families and "consumers," whose voices and experiences and recommendations are important, but who cannot come to the table with the wealth of knowledge, experience, and family stories that family-led organizations bring.

To ensure that diverse families who are representative of the population of women and children served by MCH 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 the National Center for Family Professional Partnerships, which is currently facilitating Serving on Groups Train-the-Trainer sessions for family-led organizations to turnkey to 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 and the other signatories to this letter - 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 the guidance must address the importance of meaningfully partnering with family-led organizations at all levels and stages*.

Specific Comments Related to Family/Family Organization Engagement and Equity

Guidance and Forms for the Title V Application/Annual Report

p. ii. Increased state flexibility to select national and state performance measures to meet their needs: *We recommend the addition of language requiring that such flexibility be exercised in collaboration with partners and stakeholders, including the diverse families and youth who are the intended beneficiaries of MCH services, and the family-led organizations whose purpose is to empower them at the individual, program, and systems level.*

p. iii. We appreciate and support the language indicating "*the updates to this edition also reflect a continued commitment to improving health care systems for the MCH population, particularly for CSHCN, and the leadership of families in being active partners engaged in Title V program planning and decision-making*." CSHCN have poorer health outcomes than children without, so this is an issue of equity. And families are leaders and active partners; this recognition is important.

I. Purpose of the MCH Program

B. "To reduce infant mortality and the incidence of preventable diseases and handicapping conditions among children…" *If this isn't a direct quote from the legislation, then handicapping conditions should be changed to disabilities; even if it is a direct quote from the legislation, there should be a footnote or [sic] or some other indication that MCHB is aware that this term is now perceived as disrespectful and is no longer in use among the disability community*.

III. Guiding Principles for the Development of the MCH Block Grant Application/Annual Report

p. 1. "These principles are: 1) delivery of Title V services within a public health service model; 2) data-driven programming and performance accountability; and 3) family/consumer partnership. These principles have contributed to the MCH Block Grant Program's success in operationalizing the legislative requirements and in delivering public health services and systems of care that address the needs of the MCH population." *We would recommend "that address the diverse needs of MCH populations."*

p. 4. "(1) Mobilize partners, including families and consumers, at the federal, state and community levels in promoting shared vision for leveraging resources, integrating and improving MCH systems of care, promoting quality public health services and developing supportive policies." *We would recommend*

replacing "families and consumers" with "families, consumers/constituents, and family- and consumer/constituent-led organizations."

p. 5. Cross Cutting and Systems Building Needs: We support including both family/consumer partnership (although would prefer the word constituent in the place of consumer as consumer is passive) and social determinants of health as possible State Performance Measures in this category.

p. 7-8. Family Consumer Partnership.

"Traditionally, state Title V programs have engaged families in a variety of program activities. Specific examples include:
(1) Paid Program Staff;
(2) Advisory Committees/Task Forces;
(3) Agency Decision-Making and Policy Development;
(4) Program Outreach;
(5) Training; and
(6) Peer Support."

We recommend revising this to include "contracting with family-led organizations such as Family to Family Health Information Centers to partner with State Title V programs to provide services, participate on and/or identify and support diverse family and youth leaders to participate on advisory committees/task forces, assist in decision-making and policy development, facilitate parent and professional training, and provide peer support."

"For purposes of the MCH Block Grant Program, family/consumer partnership is defined as, "the intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level." *We recommend the addition of language indicating that "families must be representative of the population(s) served." We further recommend not using the word "consumer," which is passive and doesn't reflect their active role in decision-making, partnering at all levels, etc.*

We appreciate that the guidance indicates that "This edition of the Application/Annual Report Guidance provides added emphasis on the need for a state to demonstrate the value of family/consumer partnerships in improving health outcomes across all sectors of the MCH population," and in particular its emphasis that "a state should: (1) Assure families and consumers are key partners in health care decision-making at all levels in the system of services, especially those who are vulnerable and medically underserved; (2) Ensure the provision of training, both in orientation and ongoing professional development, for staff, family leaders, volunteers, contractors and subcontractors in the area of cultural and linguistic competence; and (3) Collaborate with community leaders/groups and families of every background in needs/assets assessments, program planning, service delivery and valuation/monitoring/quality improvement activities." We strongly endorse the language, "families of every background," and the requirement to ensure cultural and linguistic competence training for all.

We recommend adding to (2), "and engage family leaders and family-led organizations to provide professional development for MCH Title V staff and MCH Title V-funded programs at all levels." Families and family-led organization staff should not only be participants in training as learners but also trainers and facilitators of parent and professional development.

p. 9 Use of Allotment Funds: "The second is a MCH Technical Assistance Partners Meeting, which aims to: 1) update State MCH and CSHCN Directors on relevant legislation and MCHB initiatives; 2) convene

leaders, disseminate best practices and share innovations in the field of MCH; and 3) provide opportunities for information exchange, networking, and collaboration among states and with MCHB ". *We would recommend adding to 2), "including family and family organization leaders," who would both benefit from attendance and be a value-add to other attendees.*

p. 12 Logic Model. "Consistent with the block grant concept, the state has flexibility in the types of programs and activities that it implements to address the unique needs of their individual MCH populations. As depicted by the process flow diagram in Figure 4, a state's priority needs should "drive" the development of a five-year program plan that is responsive to the needs identified and is performance driven." *We recommend the addition of language indicating that "Stakeholders, including families and family-led organizations representing the diversity of the state/territory, should be involved at every step of the process described below."*

p. 15 Executive Summary. "(2) A high level overview of the working framework used by the state or jurisdiction in carrying out needs assessment, program planning and performance reporting." *We recommend adding, "including the engagement of families and family-led organizations representing the diversity of the state/territory."*

p. 17 Needs Assessment Update. "a. A brief description of the state's ongoing needs assessment activities (e.g., MCH data collection and analyses, program evaluation, key informant interviews, customer satisfaction surveys, advisory councils, and other approaches for soliciting consumer feedback and conducting ongoing performance monitoring and assessment) and the extent to which families, consumers and other stakeholders were engaged in the process." *We recommend that "Information from Family to Family Health Information Centers and other family-led organizations who serve many families in the state should also be included to the extent relevant as part of ongoing needs assessment."*

p. 19 Needs Assessment Process Description. "(ii) Level and extent of stakeholder involvement, including families and consumers." *We recommend revision to "including families, consumers/constituents, and family and constituent-led organizations."*

p. 20 MCH Population Health Status. "At a minimum, the discussion should include the major health issues reflected in the state's priority needs relative to the MCH population as a whole or specific sub-populations when stratified by age, income, geography, frontier/rural/urban status, or other relevant characteristics." *We recommend explicitly including race, ethnicity, immigrant status, language, socio-economic status, etc. as these are key areas of health disparities.*

p. 21 Agency Capacity. "The state should also describe the extent to which the Title V program collaborates with other state agencies, health services entities and private organizations to support health services delivery at the community level." *We recommend specifically including "including family and consumer/constituent-led organizations."*

p. 21 MCH Workforce Capacity. "(iii) Number of parent and family members, including CSHCN and their families, who are on the state's Title V program staff and a brief description of their roles (e.g., paid consultant or volunteer)." *We recommend additional language, "or number of parent and family members, including CSHCN and their families, who work for a family organization contracted by the state's Title V program and a brief description of their roles." (States who contract with a family-led organization should get as much - or more - credit as states who hire parents directly).*

p. 22 Partnerships, Coordination and Collaboration. (a) Other MCHB investments (e.g., State System Development Initiative (SSDI) Grants, Family-to-Family Health Information Centers…" We appreciate the specific reference to F2Fs, which is another MCHB investment in the states and DC.

p. 24 Identifying Priority Needs. "Specifically, this discussion should include:
(i) Methodologies used to rank the broad set of identified needs and the state's process for selecting its final seven to ten priorities;
(ii) Emerging issues or other frequently cited needs that were not included in the final list of priority needs and a rationale for why they were not selected."

We recommend adding the following: "including the extent to which diverse stakeholders, including families and consumers/constituents, and family and consumer/constituent-led organizations, were meaningfully involved in ranking the broad set of identified needs and selecting the state's final priorities."

p. 27 Five Year State Action Plan. "a. Priority Needs – Title V legislation directs states to conduct a state-wide MCH Needs Assessment every 5 years to identify the need for preventive and primary care services for pregnant women, mothers, infants, children, and CSHCN. From this assessment, states select seven to ten priorities for focused programmatic efforts over the five-year reporting cycle." *We recommend adding the following: "in collaboration with stakeholders including families, consumers/constituents, and family- and consumer/constituent-led organizations."*

p. 29 State Title V Program Purpose and Design. "Most relevant to this discussion is the Title V program's demonstrated leadership in such areas as:
(i) Serving as a convener, collaborator and partner in addressing MCH issues."

We recommend adding, "including by convening diverse stakeholders such as families, consumer/ constituents, and family- and consumer/constituent-led organizations."

p. 30 MCH Workforce Development: *We recommend revising (c) as follows: "Innovations in staffing structures and workforce financing including funded partnerships with family and consumer/constituent-led organizations with the capacity to contribute to the MCH workforce vision."* Family leaders and family-led organizations can be – and are – part of the MCH workforce!

p. 30 Family Community Partnerships: *We recommend the following revision: "Descriptions of partnership activities with families, consumers/ constituents, and/or family- and consumer/constituent-led organizations, may include, but are not limited to, the following areas:"*

p. 31 Family Community Partnerships: We particularly value and appreciate the following language in the guidance: "Specific details on the roles and responsibilities of families and consumers, at the direct care, organizational and governance, and policymaking levels, should be presented in each of the MCH domain-specific discussions in the State Action Plan. The state should highlight the outcomes and impacts of their family/consumer partnerships on Title V program policies and activities in the overarching discussion. Specific impacts of family/consumer partnership on each of the five MCH populations and on the Title V program's crosscutting and systems building activities should be included in the appropriate MCH domain narrative discussion." *We would suggest "families, consumers/constituents, and family- and consumer/constituent-led organizations."*

p. 35 Public Input. We strongly support the language in this section, "The state should clearly identify specific activities for engaging families and other stakeholders prior to, during and after the Application process. Such activities may include:
(1) Public Hearings;
(2) Advisory Council Review;
(3) Web Posting;

(4) Social Media;
(5) Public Notices;
(6) Other Use of Media; and
(7) Outreach to Specific Stakeholders (e.g., MCH Training Grantees)." *We would revise this section to read "MCH Training Grantees, Family to Family Health Information Centers, organizations providing services to the most underserved populations such as FQHCs, immigrant-serving organizations, and community-based agencies, etc.).*

We would also suggest listing as a strategy "Partnering with/engaging a family-led organization such as your F2F to assist you to solicit comments and recommendations from families and youth."

Appendix of Supporting Documents

p. 5 Government Performance and Results Act (GPRA). "GPRA is intended to "...improve federal program effectiveness and public accountability by promoting a new focus on results, service quality, and ***customer satisfaction."*** GPRA requires each federal agency to develop comprehensive strategic plans, annual performance plans with measurable goals and objectives, and annual reports on actual performance compared to performance goals." It is important to stress here the need for Title V programs to have meaningful tools and strategies to gauge "customer satisfaction." *Given this intention, we are very concerned that there is no measure of family satisfaction, family-professional partnership, etc. and strongly recommend including such a measure.*

p. 7 Appendix B: Family Consumer Partnership Continuum. *This continuum is a valuable tool; a missing component is the recognition that family-led organizations such as F2Fs are essential partners to engage diverse families at all levels of engagement and across the continuum of engagement.* Family-led organizations bring the knowledge of the experiences of many families to the table; they also are more likely to have the trust of other families and thus are better able to develop their self-advocacy and leadership skills

p. 11 Needs Assessment – Background and Conceptual Framework. "The Needs Assessment is a collaborative process that should include the HRSA/MCHB, the state Department of Health, families, practitioners, the community, and other agencies and organizations within each state and jurisdiction that have an interest in the wellbeing of the MCH population. *We recommend language recognizing that, "For children with special healthcare needs and their families, Family to Family Health Information Centers as well as other family-led organizations such as Parent to Parent programs, parent centers, Federation of Families for Children's Mental Health chapters, etc., are essential partners in identifying needs."*

p. 11 We strongly appreciate and value the expectation that "states will have ongoing communication with stakeholders and partners throughout the Needs Assessment process and continue to engage with such partners during the interim reporting years."

p. 12 State Title V MCH Program Needs Assessment, Planning, Implementation and Monitoring Process. We support inclusion of the circle of the improvement process, noting that improving outcomes starts with strengthening partnerships and engaging stakeholders.

1. Engage Stakeholders. "…The starting point for the Needs Assessment process is to **engage stakeholders**. Engaging stakeholders and strengthening partnerships is a continuous and on-going activity. The state needs strong partnerships with its stakeholders throughout the Needs Assessment process. Effective coalitions can help the state to realistically assess needs and identify desired outcomes and mandates, assess strengths and examine capacity, select priorities, seek resources, set performance

objectives, develop an action plan, allocate resources, and monitor progress for impact on targeted outcomes." *We strongly support this statement and would only add that engaged stakeholders must include families and youth who are representative of the impacted MCH populations.*

p. 13. 2. Assess Needs and Identify Desired Outcomes and Mandates**.** *In this section, we would recommend adding: "Family-led organizations such as F2Fs are essential partners in the needs assessment process. As advocates for families, and organizations that hear the stories of thousands of families each year, family-led organizations have access to critical information that must be considered as part of the needs assessment process."*

p. 13. 3. Examine strengths and capacity. *When identifying the state's current resources, activities and services, including information about the resources, activities and services of other MCH investments such as F2Fs will help flesh out a deeper understanding of the state's strengths and capacity*.

p. 13. 4. Select priorities. We appreciate that the guidance includes the opinions of stakeholders as important in selecting priorities. *It is critical that the opinions of diverse stakeholders, including families and youth representing the full diversity of the state (within the broad context of culture as defined by the National Center for Cultural Competence), and families and youth who have the worst health outcomes, be solicited, heard, and used to identify priorities.*

p. 14. 6. Develop an action plan. *Diverse stakeholders including those representing the most underserved families and youth as well as family-led organizations should be meaningfully involved in the development of the State Action Plan.*

p. 15. 9. Report back to stakeholders. *We strongly support this requirement: "This final step assures accountability to the stakeholders and partners who have worked with the MCH staff throughout the Needs Assessment process. It also assures the continued involvement of all stakeholders and partners in the ongoing Needs Assessment processes."*

Appendix E. Performance Measure Framework (Note "Measure" is misspelled.)

p. 17 Overview of the Framework. *We support the addition of foregone health care as a measure*. Foregone health care is a critical measure for underserved populations.

p. 19 Cross Cutting/Systems Building: As noted earlier, *we support including both family/consumer partnership (although would prefer the word constituent in the place of consumer as consumer is passive) and social determinants of health as possible State Performance Measures in this category.*

p. 25 Evidence-based or informed strategies: We strongly appreciate this guidance that "States should work closely with family/community partnerships as they revise/develop the ESMs for their selected NPMs," as well as the definition, "family/consumer partnership is defined as: "The intentional practice of working with families for the ultimate goal of positive outcomes in all areas through the life course. Family engagement reflects a belief in the value of the family leadership at all levels from an individual, community and policy level." *However, we would not use the term "consumer," or would pair it with "constituent," and would add family- and consumer/constituent-led organizations.*

p. 99 Definitions: In the definition of "life course theory," the word should be "stated," not "state."

p. 103 Definition of CoIIN: *CoIINs should ALWAYS include representatives of the targeted population/people with lived experience relevant to the focus of the CoIIN, as well as family-led*

organizations who provide support to such representatives of the targeted population. "Nothing about us, without us!"

p. 104 Definition of Learning Collaborative: *Learning collaboratives should include representatives of the targeted population from the beginning and as both learners and teachers.*

p. 105 Definition of Cultural Competence: *This definition would benefit from a broader description of the types of characteristics that are part of culture, including but not limited to race, ethnicity, religion, immigrant status, LGBTQ, rural, urban, low-income, single parent family, disability, etc.*

p. 105 Definition of Culturally Sensitive: *Cultural reciprocity, which recognizes the essential value of relationships when working with people from different cultural backgrounds from one's own, is a concept that should be defined here.*

p. 105 Definition of Family Consumer Partnership: *Reference to family and consumer/constituent-led organizations should also be included.*

Conclusion

In conclusion, we thank the Maternal and Child Health Bureau for the opportunity to provide these comments on the proposed Block Grant Guidance and Forms. We also respectfully request that, as MCHB moves forward in implementing the revised guidance once finally 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 Kids As Self Advocates, 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 policies 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

On behalf of the following local, state and national family-led organizations:

National PLACE Members

AFCAMP (Hartford, CT)
Arkansas Waiver Association
ASK Resource Center (Iowa)
Association for Special Children and Families (NW New Jersey)
Connecticut Parent Advocacy Center (Connecticut)
Exceptional Children's Assistance Center (North Carolina)
FACT Oregon (Oregon)

Family Connection of South Carolina
Family Matters PTI (Illinois)
Family Network on Disabilities (Florida)
Family Resource Center on Disabilities (Chicago Metro Area, Illinois)
Family Soup (California)
Family Voices of California
Family Voices of New Jersey
Family Voices of Wisconsin
Federation for Children with Special Needs (Massachusetts)
FIRST Parent Center (North Carolina)
Formed Families Forward (Virginia)
INCLUDEnyc (New York City)
Long Island Advocacy Center (Long Island, New York)
Louisiana PTI
Matrix Parents (California)
National Federation of Families for Children's Mental Health (National)
Open Doors for Multicultural Families (Washington)
Parent Educational Advocacy Training Center (Virginia)
Parents Helping Parents (San Jose, California)
Parent Network of Western NY (Buffalo)
Parents Place of Maryland
Parents Reaching Out (New Mexico)
Parent to Parent of Georgia (Georgia)
Parent to Parent USA (National)
PEAK Parent Center (Colorado)
PEAL Parent Center (Pennsylvania)
PEATC (Virginia)
Rhode Island Parent Information Network
Rowell Family Empowerment (California)
SPAN (New Jersey)
Starbridge (New York State)
Support for Families (San Francisco, California)
Washington PAVE
West Virginia Parent Training & Information
Wisconsin FACETS

Other Family Organizations

Family to Family of Ohio
Family Voices of Colorado
Idaho Parents Unlimited
Utah Family Voices