Ensuring a Place at the Table for Every Family

**Comments of National PLACE on Proposed Changes to F2F Reporting**

**Introduction**

The National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE) is pleased to provide our comments and recommendations on the US Department of Health and Human Services (HHS) Maternal and Child Health Bureau’s proposed changes to the reporting requirements for Family to Family Health Information Centers (F2Fs) (Maternal and Child Health Bureau (MCHB) Performance Measures for Discretionary Grant Information System (DGIS), OMB No. 0915-0298—Revision).

National PLACE is a coalition of 70 national, state, and local parent-led, family-serving non-profits who are committed to enhancing the voice and impact of diverse families and family-led organizations at decision-making tables at the individual, program, and systems levels. Our members include federally-funded Parent Centers (US Department of Education), Family to Family Health Information Centers (US DHHS HRSA Maternal and Child Health Bureau), and Statewide Family Networks (US DHHS SAMHSA), as well as National Federation of Families (for Children's Mental Health) and Parent to Parent USA affiliates, among others.

National PLACE supports the comments of Family Voices, home to the TA center for the F2Fs, Leadership in Family Professional Partnerships. National PLACE member SPAN Parent Advocacy Network is a partner with Family Voices in this project, and many National PLACE members are also the Family Voices Affiliate Organization for their state or territory.

Our comments pertain exclusively to the F2F-1 Performance Measure, as this is the only component of DGIS that applies exclusively to the F2Fs who are part of our membership. While we appreciate efforts to reduce the reporting burden of F2Fs, particularly given their low funding amounts, we also believe that it is critical to have data that demonstrates the full reach, scope, and impact of individual F2Fs and the F2F network.

In particular, we are concerned that the proposed changes seem to be taking us farther away from a commitment to the six core outcomes for Children and Youth with Special Health Care Needs (CYSHCN) and their families: early and continuous screening to identify any special needs; access to a medical home to coordinate all needed services; access to community-based services that are easy to use; adequate public and private healthcare financing to pay for all needed care; effective services for the transition to adult healthcare; and partnerships with families at all levels. This step is consistent with earlier actions that also seem to signal an abandonment of the six core outcomes. For example, questions related to the six core outcomes were formerly contained in the national survey of CYSHCN; when that survey was ended, a few of the questions were added to the National Survey of Children’s Health, but the data is not as rich as the data from the previous CYSHCN survey. In the recent draft of the *Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs and Families*, the six core outcomes were not even mentioned as being critical to the blueprint, although they have been “guiding principles” for services to CYSHCN for many years. The current proposed changes in DGIS propose eliminating the collection of any data from the F2Fs about the six core outcomes and the extent to which families are contacting F2Fs with questions and concerns about each of them. This is of great concern to us, especially since there is data on the critical nature of these core outcomes to the lives of CYSHCN and families. It is also of concern because MCHB has not asked the field – families (parents and youth/young adults) or professionals – about our perspective on the continuing value of the six core outcomes as an organizing framework for MCH services to CYSHCN and their families.

We strongly agree with Family Voices’ statement that, whether or not MCHB moves ahead with the plan to eliminate all data collection questions related to the six core outcomes, Family Voices recommends that an additional question be added to monitor the emerging issues for CYSHCN. Suggested wording: What other emerging issues, or issues not included here, are important to families you have supported?

We also strongly agree with the concern of Family Voices regarding the removal of the details “family centered, comprehensive, and coordinated system,” replaced with “a system of care” in the benchmark data sources. As noted in their comments, “We have seen clearly over the years that some of the biggest challenges families and youth have are around receiving coordinated, comprehensive care that takes into consideration unique family situations. This change reflects changes made between Healthy People 2020 and Healthy People 2030, which in turn reflect changes made to the National Survey of Children’s Health. To fully account for these changes, we suggest the possibility of listing additional benchmarks here, such as MICH=19, which focuses on medical home."

In terms of the new questions that are proposed to be added, we join with Family Voices in expecting that the vast majority of F2Fs will report that 100% of their calls involve “assisting families in making informed choices” and “providing information on resources available to CYSHCN.” These are at the heart of what F2Fs do across systems. Given that reality, it is unclear exactly what purpose these questions would serve.

**Conclusion**

As noted by Family Voices in their comments, “in the past, when MCHB was planning to make revisions to the data collection requirements, they consulted with F2Fs and with Family Voices as the TA provider to the F2Fs early and throughout the process. This ensured that the voices of those directly providing the services and implementing the data collection and reporting were able to share our insights, experiences, and expertise at the beginning and throughout the process. That did not happen here, and we believe that the draft revised form would likely have been stronger if it had. MCHB states its belief that individuals who are impacted by its work must be involved in helping to shape that work, which did not happen here. In addition, the process for securing the actual proposed language was burdensome and not timely; despite repeated requests to the entity named in the Federal Register as the person to contact, some F2Fs who requested the draft document received no response, even to this day, the day the comments are due. That does not speak to a true interest in hearing the perspectives of MCHB’s investment in family engagement for CYSHCN, the F2Fs.”

Thank you for your anticipated serious consideration of our comments and recommendations. We look forward to continued collaboration with MCHB to enhance services to, and outcomes for, CYSHCN and their families. Please contact National PLACE’s Executive Director, Diana Autin, at dautin@parentsatthetable.org to discuss our comments and recommendations in greater detail.