



## ♥ Ensuring a Place at the Table for Every Family

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 A Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs and Families (Blueprint). National PLACE offers the following feedback and recommendations regarding the Blueprint. 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 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 Blueprint that impact family and family organization engagement and influence, and the related issue of equity.

### **Overall Comments**

We understand that the National Survey of Children's Health showed that "86% of CYSHCN do not receive services in a well-functioning system as characterized by family-professional partnerships, access to a medical home, adequate financing, coordinated services, screening, and transition to adult services," and appreciate the efforts of the Maternal and Child Health Bureau (MCHB) to address this significant problem via the proposed Blueprint for Change.

Although we realize the importance of this future planning, we would also like to recognize the ongoing importance of the Maternal and Child Health Bureau's 6 Core Outcomes for Children and Youth with Special Healthcare Needs (CYSHCN) and continuing collaboration with Family Voices Affiliate Organizations and Family-to-Family Health Information Centers (F2Fs) 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), Parent-to-Parent programs, and Federation of Families for Children's Mental Health State Organizations and local chapters.

To ensure that diverse families who are representative of the population of CYSHCN and their families 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 Leadership in Family Professional Partnerships, which continue 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 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 Blueprint must explicitly address the importance of meaningfully partnering with family-led organizations at all levels and stages.*

## **Draft Blueprint**

**Vision:** Children and youth with special health care needs and their families enjoy a full life and thrive in systems that support their social, health, and emotional needs, and ensure dignity, autonomy and active participation in their community.

*We recommend that the Blueprint explicitly note that the Blueprint's goals and objectives are not intended to replace the six core outcomes for CYSHCN: 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, for our purposes the most important core outcome, family engagement at all levels.*

We support the 5 foundational factors included in the Blueprint, including the focus on CYSHCN and families impacted by poverty and discrimination, social determinants of health and inequities, and racism.

*We recommend that the Blueprint explicitly include a 6<sup>th</sup> foundation factor: Families of CYSHCN and youth with disabilities and SHCN 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.*

## **1. Health Equity**

We agree with the goals in this section of the Blueprint, including that all children have access to appropriate, accessible, and nondiscriminatory healthcare services, and a fair and just opportunity to be as healthy as possible; that regardless of race, ethnicity, socio-economic status, disability, religion, sexual orientation, gender or any other identity subject to discrimination, CYSHCN and families can access the care they need when, where and how they need it; that CYSHCN are guaranteed the opportunity to thrive without discrimination; that all CYSHCN and their families receive care that is family-centered and culturally-competent; and that all CYSHCN, including those with chronic illness and disabilities, receive care that helps them achieve optimal health and functioning.

*We recommend that Goal 4 be revised as follows: CYSHCN are guaranteed the opportunity to thrive in their communities, programs that serve all children and youth such as early childhood programs and schools, in the workforce, in housing, in civic engagement (including voting), and in our larger society, without discrimination. We recommend that Goal 5 include the right to care that is linguistically competent as well as culturally competent. We recommend adding the following goal: Families and YSHCN representing the CSHCN 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.*

We agree with the objectives identified in this section and make the following recommendations:

- Interventions are designed and implemented within a context of cultural humility and are considerate of the medical and environmental circumstances of the child. *We would add, “and their family” here.*
- Best practices are implemented to meet the needs of CYSHCN, including subgroups that are most vulnerable, e.g., CYSHCN in foster care, juvenile justice, children with medical complexities, children in urban and rural settings, children at higher risk of mental and behavioral health needs, etc. *We would revise “foster care” to “the child welfare system including but not limited to foster care,” as children who are involved in the child welfare system but who remain with their families are also more vulnerable populations. We would also specifically include children from immigrant families as a vulnerable subgroup.*
- All sectors actively coordinate: education; housing and community development; business; law enforcement and safety; built environment; government; community advocates; healthcare; nonprofits; and transportation to achieve and ensure *health equity for CYSHCN. We would add, “Family-led organizations are involved across sectors to help ensure coordination across silos.”*

## **2. Family/Child Well-being and Quality of Life**

National PLACE strongly supports shared decision-making, not just with families but with youth as well. *Thus, we recommend adding the use of supported decision-making to facilitate transition and protect the rights and dignity of youth and young adults with disabilities and special healthcare needs.*

We agree with the Goals in this section of the Blueprint, including that families have access to high-quality, cost-effective, community-based programs that support the psychosocial well-being of the primary caregiver and child and contribute to strengthening protective factors, building resilience and reducing family stress; care systems are integrated and prioritize quality of life and well-being for CYSHCN and families; health system metrics balance health care outcomes with priority outcomes as identified by families, with a focus on protective factors and family experience of care; and health systems have the capability to collect data on quality of life indicators, evaluate quality of life for all children including those with medical complexity and are tied to payment models that use quality of life outcomes. *We recommend adding “integrated, easy to access and use, and prioritize quality of life...” to the second goal. We would also add the following goal: Families and YSHCN including those representing the CSHCN 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, are integral partners and leaders in ensuring family/child well-being and quality of life.*

We agree with the objectives identified in this section and make the following recommendations:

- Shared decision-making between families and professionals considers clinical and Quality of Life outcomes. *We would revise this objective to include “families, including children/youth, and professionals...”*
- Workforce training for professionals serving CYSHCN and their families includes curricula that emphasizes child development, family/child well-being and quality of life. *We would add the following: Families of and YSHCN as well as the family-led organizations who serve them and build their capacity are compensated partners in professional development.*

As stated above, shared as well as supported decision-making must occur not only with families but also with youth as they reach transition age. Here again risk assessments must address the implicit bias that exists with consideration of race/ethnicity as well as disability. Pre-service training and professional development must include interaction with CYSHCN and their families, not just reading in a textbook.

### **3. Access to Services and Supports**

We agree with the Goals in this section of the Blueprint, including that CYSHCN and their families have timely access to the care they need, including physical, oral, and behavioral health care providers, adequate home and community-based supports, information and education (families need to know what is available and how to access), and coordinated care to support them; all services and supports, inclusive of health and other human service sectors, at the individual/family, community, and provider level are coordinated at a minimum, and ideally integrated at the systems level; CYSHCN and their families have access to high-quality, family-centered specialty and primary care and psychosocial support services in the communities where they live; telehealth is used a tool to connect families to specialists and other services to benefit the health of the child and support the family; CYSHCN and their families have access to the necessary medications, equipment, supplies, and technology they need; the workforce supporting CYSHCN and families are well-trained, culturally competent, accessible, and reflect the families they serve; services are easy to navigate by families and professionals; and systems share information and processes (eligibility, enrollment, outcomes, and referrals) across child and family serving systems.

*With regard to Goal 4, equity in access to equipment, connectivity, and understanding of how to use telehealth and telemedicine must be specifically addressed. We would add “linguistically appropriate” to culturally appropriate in Goal 6 and would specifically note in Goal 7 that families must have control over their family’s information and family-specific information is shared only with written family consent. We recommend adding the following goal: “Families and YSHCN including those representing the CSHCN 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, are integral partners and leaders in ensuring that CYSHCN and their families have access to needed care.”*

We agree with the objectives identified in this section and make the following recommendations:

*The objectives must specifically note that many families do not have access to technology or sufficient connectivity. 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. 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.*

#### **4. Financing of Services**

We agree with the Goals in this section of the Blueprint, including that health care for CYSHCN and families is financed and paid for in ways that support and maximize choice for the services they value; health insurance coverage for CYSHCN is accessible, affordable, comprehensive, and continuous to ensure access to high quality care; payment models and models of care delivery identify, assess, and address social determinants of health and their impact on quality of life outcomes for CYSHCN and families; and eligibility, enrollment, and referral processes for health care coverage, financial assistance programs, and other social services are streamlined across federal, state, and local agencies to benefit CYSHCN and families.

*We would add the following goal: Families and YSHCN including those representing the CSHCN 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, are integral partners and leaders in developing effective financing systems that meet CYSHCN and family needs.*

We agree with the objectives identified in this section and make the following recommendations:

*We would add the following objectives: Peer to peer supports are available and financed appropriately, and Services are sufficiently flexible to address the needs of CYSHCN and their families from the full array of racial, ethnic, language, socio-economic, and cultural backgrounds.*

#### **Conclusion**

In conclusion, we appreciate MCHB’s proposal for a [Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs and Families](#), including the focus throughout the Blueprint 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 YSHCN from diverse backgrounds as well as the

family-led organizations that support them as leaders and influencers at all levels and stages of improvement; specific inclusion of the six core outcomes for CYSHCN and their families; and inclusion of “linguistically appropriate” with “culturally appropriate” to ensure language access. In particular, we are significantly concerned that the Maternal and Child Health Bureau’s (MCHB) investment in family-led organizations, the Family to Family Health Information Centers (F2Fs), are not mentioned as key partners in achieving the Blueprint nor are any family-led organizations identified as partners and stakeholders. Family-led organizations bring the voices of many families and CYSHCN to the table, assist individual families to secure needed services and supports for their CYSHCN, and contribute to program and systems improvement. The Blueprint 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 implementing the Blueprint 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 Youth 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, implementing, evaluating, and improving the policies and practices that affect them.

Very truly yours,



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