

Introducing the Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs

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Over the past 2 years, families have felt the weight of the pandemic, natural disasters, social and economic unrest, and the traumatic toll these crises have on their children. Families with children and youth with special health care needs (CYSHCN) often experienced this trauma more acutely in their ability (or inability) to access needed health care and supportive services. The stark reality of their experiences of care and differences in health and wellbeing as a result of race, income, and disability have come into greater focus. We present this supplement, a *Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs*, as a national agenda and framework to advance the system that serves this population to improve their lives and wellbeing.

Families of CYSHCN tell us that the current system of services is not

working for their children. There are vast inequities experienced by families in accessing and paying for services and support to care for their children; the system is not responsive to their needs or values.¹ If the system is not working for CYSHCN, it is likely not working for children generally, any of whom could have a special health care need at some point in childhood.² We have opportunities to take advantage of rapid changes in the health care landscape, including advances in technology and new mechanisms to finance care to advance the existing system and address equity through a fresh new lens.

Over the last several decades, the Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB) has served as the locus of responsibility and leadership at the national level for

CYSHCN and their families. Although progress has been made, many gaps remain. Through MCHB's partnership with families and family-led organizations, MCHB has and continues to identify emerging issues, support the development of best practices, and invest in system change efforts. MCHB continues to serve as a federal voice urging the inclusion of self-advocates and families to be represented and heard at all levels of care.

This supplement represents more than 2 years of work led by the MCHB in partnership with families, health care professionals, public health leaders, and more about how to implement and achieve a strengthened system of services, the *Blueprint for Change*. The 7 articles that compose the supplement present data on the population, the history of MCHB's work and commitment to the

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population, principles and strategies to achieve the *Blueprint for Change*, and detailed discussions of 4 critical areas identified in the *Blueprint for Change*: health equity, family and child wellbeing and quality of life, access to services, and financing of services.

Using the most recent data from the National Survey of Children's Health, Ghandour et al³ present a profile of a diverse population of CYSHCN facing ongoing challenges receiving services in a well-functioning system. Warren et al⁴ tell the story of the public health role, particularly at the federal level, in building systems that support CYSHCN, and emphasizes the need to address social determinants of health. McLellan et al⁵ present the *Blueprint for Change*, which includes the rationale, guiding assumptions, principles, and strategies to achieve the stated vision.

The 4 critical area articles center around the issues families consider most important to strengthen the system of services: equity, quality of life, access to services, and financing. The authors, composed of self-advocates, family members, health care professionals, and other stakeholders, present data, discussions, innovations, and recommendations in the 4 areas. Houtrow et al⁶ present a vision of health equity that seeks to address the upstream and downstream factors that inhibit CYSHCN from a fair and just opportunity to be healthy. Coleman et al⁷ discuss the need for systems to acknowledge and measure outcomes that are meaningful to children and their families. Kuo et al⁸ argue for an adaptive, responsive system built around the needs of children and families, not just a diagnosis or treatment protocol. Finally, Schiff et al⁹ discuss the need for a service

system to support and finance improvements to ensure access, equity, and system integration, and ease the financial burden on families.

The editors of this supplement are exceptionally grateful for the many contributors who devoted time in a period of uncertainty to articulate a fresh vision about building a system in which CYSHCN enjoy a full life, from childhood through adulthood, and thrive in systems that support their families, their social, health, and emotional needs and ensure dignity, autonomy, independence, and active participation in their community. In presenting this supplement, the editors and authors fully recognize that the hard work will come in the months and years ahead; yet urgent change is needed. Progress requires the collective leadership, partnership, will, opportunity, and persistence of all stakeholders to achieve the Blueprint's vision and improve the lives and wellbeing of CYSHCN and their families.

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