

A Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families

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abstract Children and youth with special health care needs (CYSHCN) and their families continue to face challenges in accessing health care and other services in an integrated, family-centered, evidence-informed, culturally responsive system. More than 12 million, or almost 86%, of CYSHCN ages 1–17 years do not have access to a well-functioning system of services. Further, the inequities experienced by CYSHCN and their families, particularly those in under-resourced communities, highlight the critical need to address social determinants of health and our nation’s approach to delivering health care. To advance the system and prioritize well-being and optimal health for CYSHCN, the Health Resources and Services Administration’s Maternal and Child Health Bureau, with input from diverse stakeholders, developed a set of core principles and actionable strategies for the field. This article presents principles and strategies in the *Blueprint for Change: Guiding Principles for a System of Services for CYSHCN and Their Families (Blueprint for Change)*, which acknowledges the comprehensive needs of CYSHCN, a changing health care system, and the disparities experienced by many CYSHCN. Four critical areas drive the *Blueprint for Change*: health equity, family and child well-being and quality of life, access to services, and financing of services. Although discussed separately, these critical areas are inherently interconnected and intend to move the field forward at the community, state, and federal levels. Addressing these critical areas requires a concerted, holistic, and integrated approach that will help us achieve the goal that CYSHCN enjoy a full life from childhood through adulthood and thrive in a system that supports their families and their social, health, and emotional needs, ensuring their dignity, autonomy, independence, and active participation in their communities.

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All children deserve the opportunity to thrive and live meaningful lives, including almost 14 million children and youth with special health care needs (CYSHCN) in the United States.¹ Children are living longer with more chronic and complex conditions.² Service sectors that provide services to CYSHCN, for example, health, education, housing, transportation, etc. must adapt to the needs of this growing, diverse population throughout their life course. CYSHCN and their families have better outcomes when a system of services is comprehensive, coordinated, and family centered.³ Despite clinical innovations and significant changes in health care, such as the passage of the Affordable Care Act, 85% of CYSHCN still do not receive services via a well-functioning system (Table 1).¹

The COVID-19 pandemic highlighted the fragility of sectors serving CYSHCN and families, yet also demonstrated how quickly large health systems, public health agencies, and payment structures can pivot to meet the needs of children and families. Looking ahead, sectors serving CYSHCN and their families at the local, state, and federal levels can build on this experience and transform to improve health and well-being by embracing integrated and innovative health technologies.

To advance the system of services and improve well-being and optimal

health for CYSHCN, the Health Resources and Services Administration's Maternal and Child Health Bureau (MCHB) convened a group of diverse stakeholders to develop core principles and actionable recommendations for moving the field forward. The result of this work is the *Blueprint for Change: Guiding Principles for a System of Services that Meet the Needs of CYSHCN and their Families (Blueprint for Change)*.

This article presents the *Blueprint for Change*, which outlines principles and strategies to improve the lives of CYSHCN and their families. This agenda is a starting point for discussion across local, state, and federal entities that collectively can implement the principles and strategies outlined below. Further discussion about the epidemiology of the population, the history of services for CYSHCN, and specific areas of the *Blueprint for Change* can be found elsewhere in this supplement.

The Population: Children and Youth With Special Health Care Needs

MCHB defines CYSHCN as children and youth ages 0–21 years that “have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type or amount beyond that required by children generally.” These children and youth represent 19.4% of all children

within the United States¹ and include individuals with conditions such as asthma, cerebral palsy, and genetic disorders. A subset of this group are children with medical complexity, a fraction of the overall CYSHCN population that can require the most intensive services,⁴ including home nursing care, respite and palliative care.⁵ The MCHB definition of CYSHCN guides the work of state Children with Special Health Care Needs programs funded through the Title V Maternal and Child Health Services Block Grant,⁶ and has been adopted by some state Medicaid agencies.⁷ Further information about the characteristics of this population and the history of supporting CYSHCN can be found elsewhere in this supplement.^{8,9}

Although the vision of the *Blueprint for Change* is for broad use and adaptation across the larger population of CYSHCN, it is important to note the heterogeneous nature of CYSHCN and the complexities involved in developing policies and programs for a diverse population. There is currently no consensus on the definition of being “at increased risk.” However, the reality is that all children are at risk of developing a special health care need. The intended focus of this definition of CYSHCN is on the heightened health care and related needs of the child, youth, or family, not their differences. A well-functioning system of services for CYSHCN will not only benefit them and their families, but all children, youth, and families.

Needed Services and Supports

CYSHCN and their families may need to access a range of public and private services and supports at various points across their life course, including specialized therapies, such as speech and language, or physical or

TABLE 1 Well-Functioning System of Services for CYSHCN Systems of Services

Families of CYSHCN are partners in decision making at all levels
CYSHCN receive coordinated, ongoing, comprehensive care within a medical home
Families of CYSHCN have adequate private and/or public insurance
Children are screened early and continuously for special health care needs
Services for CYSHCN are organized so families can use them easily and are satisfied with the services they receive
Youth with special health care needs receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence

Adapted from Perrin JM, Romm D, Bloom SR, et al. A family-centered, community-based system of services for children and youth with special health care needs. *Arch Pediatr Adolesc Med.* 2007;161(10):933–935.

occupational therapies; psychological, educational, or vocational counseling; home nursing care; school-based health services; and education for families about their child's care.³ The workforce providing these services and supports includes health care and public health professionals, education and social services providers, home and community-based providers, such as therapists and nursing aides, community health workers, and family members.¹⁰

Multiple services, sectors, and providers create a complex and complicated network for families to manage. Navigating fragmented sectors, from health to education, is costly, time consuming, frustrating, and exhausting for families, particularly those from underserved communities.⁵ The lack of integration across the system creates additional barriers for families in accessing and enrolling in services, understanding what is available to them, and meeting their child's needs.¹¹ System fragmentation increases the inequities experienced by CYSHCN and their families.¹² Navigating a poorly coordinated system is harder for those families who struggle with poverty, lack of food, housing, and/or transportation, and racism. For CYSHCN who have more complex needs, family members frequently are called on to serve as caregivers and care coordinators.⁵

The *Blueprint for Change* acknowledges the critical role of families in achieving its stated vision. Although the *Blueprint for Change* addresses system-level principles, the work and overall conceptualization and implementation centers on meeting the needs of children and families and requires partnering with families in implementing needed changes.

Barriers to a Well-functioning System

Structural racism¹³ and ableism¹⁴ in public policies and institutional practices limit access to health care and education. Sectors, policies, and the workforce can perpetuate inequities and presume "ablebodiedness,"¹⁴ which impedes progress in improving outcomes for CYSHCN and their families. Additionally, social, environmental, and political factors influence health and well-being. There are social and environmental conditions where people are born, live, learn, work, play, worship, and age, or social determinants of health, that influence many aspects of health, functioning, and quality of life.¹⁵ CYSHCN, especially those with increased medical complexity, have elevated social needs and risks; as a result, they often need additional nonclinical supports to thrive, such as supportive housing, food assistance, and special education. With increasing medical complexity come additional social and other supportive needs, which sometimes go unmet.¹⁶

The COVID-19 pandemic further exposed the fragility of service sectors and highlighted numerous disparities in accessing care, resulting in additional inequities.¹⁷ Throughout the pandemic, children and adults of color and those with disabilities experienced greater mortality and morbidity from COVID-19. Multisystem Inflammatory Syndrome, a rare but severe complication of SARS-CoV-2 in children and adolescents, disproportionately affects black, Hispanic or Latino, and Asian or Pacific Islander persons.¹⁸ These inequities informed the *Blueprint for Change*, and the identification of the following 4 critical areas: health equity, family and child well-being and quality of life,

access to services, and financing of services.

APPROACH

In early 2019, MCHB began revisiting national frameworks to improve the health and well-being of CYSHCN and their families. The *Blueprint for Change* builds on foundational work conducted by MCHB and partners, including the 6 core indicators of a system of services³ and the National Standards for Systems of Care for CYSHCN.¹⁹ The *Blueprint for Change* was informed by input from key informant interviews, including grantees, researchers, and families, who confirmed the need to review existing frameworks and develop a renewed charge to the field. They also identified 4 critical areas that must be addressed to improve the system for CYSHCN and their families. In fall 2019, a steering committee of 9 national experts met monthly to discuss a draft *Blueprint for Change*. It was shared broadly through a variety of mechanisms, including a public request for information (RFI) in fall 2020 and a virtual CYSHCN Summit on September 22, 2020, which facilitated conversations with families and experts in the field.

The virtual CYSHCN Summit drew more than 160 stakeholders representing families, youth, federal and state governments, health care professionals, health insurers, foundations, and advocates. Following the Summit, 4 follow-up listening sessions in each critical area engaged an average of 80 participants. The comments and feedback from the Summit and subsequent listening sessions informed the final version of the *Blueprint for Change* presented in this article.

THE BLUEPRINT FOR CHANGE

The *Blueprint for Change* is intended to inform research, programs, and policy at the community, state, and national levels over the coming decade (Fig 1).

BLUEPRINT FOR CHANGE'S OVERALL VISION

Children and youth with special health care needs enjoy a full life, from childhood through adulthood, and thrive in a system that supports their social, health, and emotional needs, ensuring dignity, autonomy, independence, and active participation in their communities.

Below are the assumptions underlying the *Blueprint for Change's* principles and strategies:

- Disability is a natural part of the human experience and in no way

diminishes the right of individuals to participate in or contribute to society.²⁰

- Racism is a social risk factor that has a profound impact on the health status of children, adolescents, young adults, and their families.²¹
- CYSHCN require more and different types of services than those for typically developing children and youth, yet the current system is not ensuring access to these services, particularly for CYSHCN impacted by poverty and discrimination.
- CYSHCN are more severely impacted by the adverse effects of social determinants of health and inequities.²

The Blueprint for Change is organized in 4 critical areas: health

equity, family and child well-being and quality of life, access to services, and financing of services. In each critical area, a definition, overall vision, key principles, and actionable strategies are presented. Success in achieving the vision and implementing the principles in the *Blueprint for Change* is dependent on progress in all 4 areas, from upstream system transformation to downstream programmatic change.

CRITICAL AREA 1: HEALTH EQUITY

Healthy People 2030 defines health equity as “the attainment of the highest level of health for all people. Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.”²² Addressing poverty, damaging living conditions, and access to health and social services will mitigate adverse health effects. In addition to physical health, health²³ includes mental and behavioral health. The principles and strategies below acknowledge that poverty, discrimination, and their downstream consequences cause health inequities.²⁴

Vision: All CYSHCN have a fair and just opportunity to be as healthy as possible and thrive throughout their lives (eg, from school to the workforce), without discrimination,¹¹ and regardless of the circumstances in which they were born or live.

Principle 1: Structural and systemic causal barriers to health equity are eliminated, including discrimination, poverty, and other social risk factors.

1a. Service sectors and policy makers recognize and address the fundamental causes of health disparities. Federal, state, and local policies and laws that

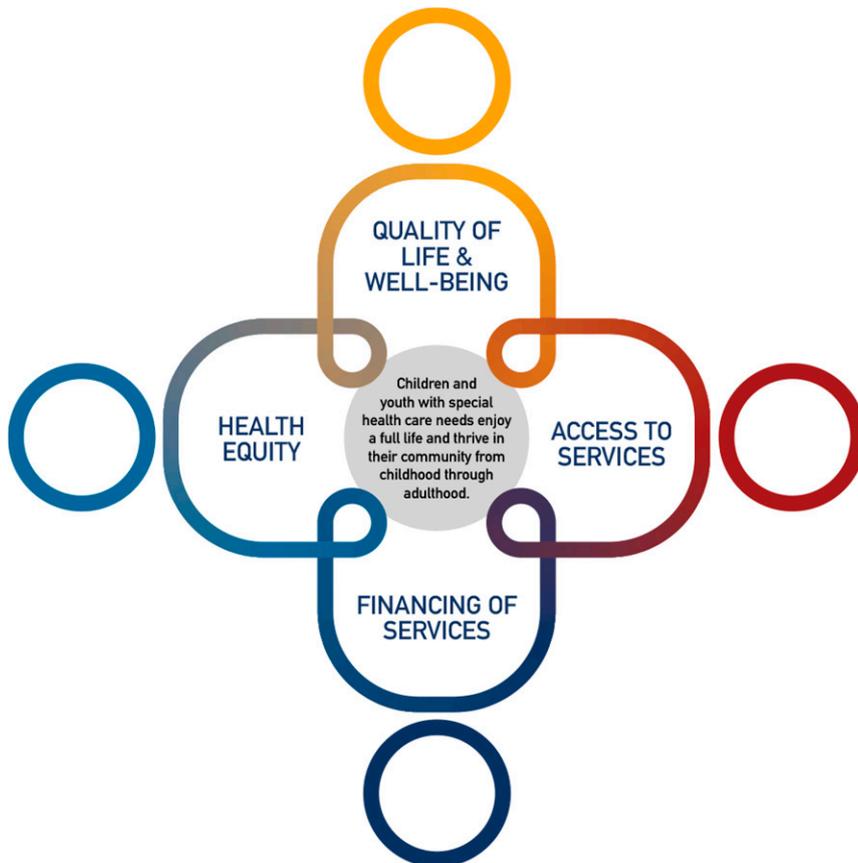


FIGURE 1
Blueprint for Change.

systematize oppression are dismantled and replaced with equitable policies and laws.

- 1b. All sectors that serve CYSHCN, including but not limited to health care, public health, education, housing, nutrition, and income supports, collaborate with each other and policy makers to ensure that policies are coordinated, effective, and developed equitably to address the root causes of health disparities.
- 1c. Surveillance systems identify, track, and cross-share data on social risk factors, including discrimination, that impact health outcomes and their consequences across the life course.

Principle 2: Sectors, systems, and programs that fund, deliver, and monitor services and supports for CYSHCN are designed and implemented to reduce health disparities and improve health outcomes for all CYSHCN.

- 2a. Entities that serve CYSHCN and their families coordinate policies, practices, and procedures across sectors to mitigate the health effects of societal oppression.
- 2b. Entities that serve CYSHCN and their families have a diverse and appropriately compensated workforce trained in evidence-informed, equitable, and culturally responsive delivery of services and supports.
- 2c. Entities that serve CYSHCN and their families develop and implement performance and outcomes measures, ensuring system accountability for equitable, high quality services for CYSHCN.
- 2d. Children and youth who are at risk of a special health care need are defined, identified, and supported by the entities designed to serve them to optimize their health outcomes.

CRITICAL AREA 2: FAMILY AND CHILD WELL-BEING AND QUALITY OF LIFE

Traditionally, health care does not include a proactive focus on patient and family well-being and quality of life. Yet, studies have shown that parents and families of CYSHCN often experience disruptions to family life, social isolation, and chronic stress, and have significant and diverse psychosocial support needs. Data reveal that “CYSHCN and their families are at risk for adverse outcomes in economic, academic, and social-emotional domains, in addition to physical health. Moreover, racial and ethnic disparities in access to opportunities and supports exacerbate the inequities that CYSHCN and their families experience.”²⁵ Historically, the health system focused on measuring health outcomes, not necessarily metrics meaningful to families. These metrics should be developed in partnership with families and can include the well-being and quality of life of the child from birth through adulthood, well-being of the family unit, and the ability to achieve dignity, autonomy, and independence.

Recognizing the importance of child and family well-being also acknowledges the need for CYSHCN and their families to be active partners within care sectors. The system needs to incorporate shared decision making at all levels of health care, including direct patient care, organizational design and governance, and programs and policies.²⁶

Vision: The service system prioritizes quality of life, well-being, and supports flourishing for CYSHCN and their families.²⁷

Principle 1: Families, regardless of circumstance, can access high-quality, affordable, community-

based services that support the medical, behavioral, social, and emotional well-being of the child or youth and whole family.¹¹

- 1a: Families of CYSHCN are equal partners in developing services and supports designed for their benefit.
- 1b: Service sectors promote and support flourishing, enhanced self-management,²⁸ and peer-to-peer social connections and support for CYSHCN and their families, including but not limited to a sense of self-worth, purpose, and fulfillment; engagement; and positive, stable, and supportive relationships.²⁹
- 1c: Training programs for professionals serving CYSHCN and their families emphasize child and life course development, and family and child well-being and quality of life.
- 1d: Service providers and professionals have the tools and training they need to practice culturally responsive, family-centered, trauma-informed care for CYSHCN and their families.¹¹

Principle 2: Health systems place value on the measurement and use of both child and family well-being and quality-of-life outcomes and health outcomes.^{30,31}

- 2a: Health systems collect data on child and family well-being and quality of life, including but not limited to protective factors, social connection, family stress, and stability.
- 2b: Data collection standards are in place to improve the reliability and usability of quality-of-life and well-being measures.
- 2c: Risk and eligibility assessments for CYSHCN include family and child well-being and quality-of-life measures.
- 2d: Shared plans of care include medical, social, functional, and financial goals; and are jointly

developed and implemented with CYSHCN and their families.
2e: Health systems evaluate and link payment models to quality of life for all children and youth.

CRITICAL AREA 3: ACCESS TO SERVICES

Access to services and supports is defined broadly and includes the 4 components of access to health care: coverage; services; timeliness; and a capable, qualified, and culturally competent workforce.³² This concept includes all social services necessary for CYSHCN and families to have full, thriving lives, including but not limited to education, early intervention, child welfare, foster care, health, and community-based supports. This critical area recognizes the educational system as an entry point and major deliverer of services for children and families. The ideal system is integrated across all sectors and anticipates families' needs. It aligns the delivery, payment, and administration of services with the goals of improving care, eliminating incentives for cost shifting, and reducing spending that may arise from duplication of services or poor care coordination.³³

Vision: CYSHCN and their families have timely access to the integrated,^{25,11} easy-to-navigate, high-quality health care and supports they need, including but not limited to physical, oral, and behavioral health providers; home and community-based supports; and care coordination throughout the life course.²⁹

Principle 1: All services and supports at the individual, family, community, and provider levels are easy for families and professionals to navigate when, where, and how they need them.

- 1a: CYSHCN and their families receive services that anticipate their needs and provide service options and guidance and includes a roadmap to care.
- 1b: CYSHCN and their families receive the appropriate accommodations* and technologies they need to access services and supports.
- 1c: Population health approaches are implemented to ensure equitable access to services and supports.†
- 1d: Public health programs connect and collaborate with stakeholders in the private sector to invest in and advance the system for CYSHCN and families.
- 1e: Essential providers (eg, public health, hospital systems, provider groups, and so on) are available in communities where families live or via other service delivery technologies, eg, telehealth.
- 1f: Services sectors support care models through regionalized specialty services, palliative care, and other approaches that serve the needs of children with medical complexity and their families.

Principle 2: The workforce is trained to meet the needs of CYSHCN and their families, reflects the families

*For the purposes of this document, appropriate accommodations services or technology include any aids and services necessary to ensure effective communication with individuals who have disabilities that inhibit the ability to communicate. Some examples include, but are not limited to, sign language interpreters, braille materials, communication boards, and real-time captioning.

†A population health strategy for CYSHCN intends to improve the health and well-being of an entire group or subgroup. These strategies occur at the policy or systems level and are measurable over time. They are designed to improve health equity and often focus on social and environmental factors.

- and communities they serve, and is culturally responsive.
- 2a: Training programs promote and incentivize opportunities for individuals, particularly those from underrepresented populations and/or with relevant lived experiences, to participate meaningfully in the development, implementation, and monitoring of services, policy, and research.
- 2b: Innovative and alternative training programs explore opportunities to ensure a diverse and inclusive workforce.

Principle 3: Service sectors increase the ability of CYSHCN and their families to access services by addressing administrative and other processes that hinder access.

- 3a: Eligibility criteria and enrollment processes for services and supports are linked and streamlined across programs.
- 3b: Legal and other barriers are eliminated to increase efficient data sharing and information across systems.
- 3c: Information technology, including virtual communication and data interoperability across service sectors, offer solutions to help decrease health disparities and improve access to preventive, chronic or routine care.

CRITICAL AREA 4: FINANCING OF SERVICES

Addressing health equity, well-being, quality of life, and access to care requires an adequately financed system of services.‡ This includes both the overall systems of financing, including insurance design

‡For the purposes of this Blueprint for Change, services are broadly defined and identified by families and CYSHCN as needed to thrive. They include, but are not limited to, health care, community-based services and supports, and social services.

and organization of programs, as well as specific models and mechanisms for payment and eligibility. It supports models that improve quality and value, and recognize outcomes meaningful to stakeholders, including families, providers, and payers.³⁴ Although the following principles and strategies focus on health care and related services, including care coordination, which is necessary in a system that is not fully integrated, CYSHCN also may require an array of additional social services and educational supports.

Vision: Health care and other related services are accessible, affordable, comprehensive, and continuous; they prioritize the well-being of CYSHCN and families.^{19,35}

Principle 1: Health care and other related services for CYSHCN and families are financed and paid for in ways that support and maximize an individual's values and choice in meeting needs.^{19,36}

- 1a: CYSHCN and their families have the information they need to make fully informed choices about health care and other related services.
- 1b: All health care services meeting a broad standard of medical necessity are adequately funded for all CYSHCN.
- 1c: Care coordination and care integration across sectors are considered medically necessary and adequately funded to manage varying service needs as defined by the family. These needs can be monitored through measures of family experience and integration across medical, social, and behavioral sectors, and quality of life.³⁷
- 1d. Financing mechanisms support innovative approaches to delivering quality care—for example, by paying families for

the medical services they provide.

Principle 2: Health and social service sector investments address social determinants of health to increase family well-being and flourishing.

- 2a: Health care financing systems adopt a standard of medical necessity that considers the health consequences of racial inequity and social risks or /determinants.
- 2b: Health care financing systems adequately support health care providers that offer CYSHCN and their families screening, referrals, follow-ups, and care for social risks.
- 2c: Health care financing systems and health delivery financing models assess the impact of their interventions on quality of life for CYSHCN and their families.
- 2d: Health care financing systems and health care delivery financing models invest in strategies to mitigate implicit bias and structural racism to address racial and ethnic health disparities.

Principle 3: Payers and service sectors adopt value-based payment strategies³⁸ that support families, advance equity, and incorporate continuous quality improvement by enhancing team-based integrated care.

- 3a: Service sectors adopt a comprehensive, inclusive definition of CYSHCN, including children and youth at risk of a special health need.
- 3b: Service sectors, including payers, identify and assess family financial hardship and eliminate or reduce cost-sharing payments for medically necessary services, supplies, and equipment.

- 3c: Care integration across service sectors is adequately financed.
- 3d: Information technology and virtual communication solutions, including telehealth and other evolving care options are adequately financed across the life course.³⁹
- 3e: Financial incentives are structured to promote enhanced primary care provider teams, communities (community-based organizations), and others in direct support of CYSHCN and their families.

LIMITATIONS

Every effort was made to incorporate stakeholder feedback in the *Blueprint for Change*; however, despite broad outreach, some perspectives may have been underrepresented at the Summit and the subsequent request for information responses. There also were limitations on participant engagement and interaction because the CYSHCN Summit was conducted virtually. Finally, the *Blueprint for Change* is not a formal consensus document, but rather a guide for the diverse community of stakeholders that serve and represent CYSHCN and their families.

CONCLUSIONS

The *Blueprint for Change* is intended to be a dynamic and visionary agenda that can guide public and private stakeholders at the community, state, and federal level. Although implementation of each aspirational principle may take a decade or more, the time for action is now. Efforts are underway to incorporate this work into MCHB investments, with the expectation that all who support CYSHCN and their families will embrace the *Blueprint for Change* and join us to help children and their families thrive.

ABBREVIATIONS

CYSHCN: children and youth with special health care needs

MCHB: Maternal and Child Health Bureau

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