

Progress, Persistence, and Hope: Building a System of Services for CYSHCN and Their Families

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Children and youth with special health care needs (CYSHCN) have long been a priority population for the federal Maternal and Child Health Bureau (MCHB). For more than a century, MCHB and its organizational predecessors have funded programmatic efforts to develop a community-based system of services to improve access and quality care for meeting the needs of children and families. MCHB's work has evolved to address system innovations and advances in clinical care while adapting to the changing legislative landscape. Despite improvement in some health-related outcomes, important gaps remain for ensuring the health and well-being of CYSHCN and their families. In particular, the stark racial inequities and longstanding challenges made more visible by the coronavirus disease 2019 (COVID-19) pandemic necessitate renewed efforts

by federal, state, and local governments, payers, and child- and family-serving organizations. Building on decades of experience and leadership, MCHB is releasing 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 historical leadership of MCHB in advancing a system of services for CYSHCN and introduces the *Blueprint for Change*, which focuses on 4 critical areas to ensure that CYSHCN thrive: health equity, family and child well-being and quality of life, access to services and supports, and financing of services.

The story of CYSHCN in the United States has been one of progress, persistence, and hopes still to be fulfilled. The MCHB, part of the Health Resources and Services

Administration, defines this population as "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally."¹ More than 14.1 million children in the United States meet this definition, comprising 19.4% of the population.² Compared to other children and youth, CYSHCN are more likely to live in poverty, live in families receiving public assistance, and be exposed to adverse childhood experiences (with more than one-third of families reporting divorce of a parent or guardian or having difficulty in covering basic expenses).³

The broad definition of CYSHCN results in a heterogeneous population with varying health

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statuses and needs. Diagnoses among CYSHCN range from allergies, asthma, and mental or behavioral health disorders to much less common, and even rare, conditions.² Recent focus has been placed on a specific subpopulation of CYSHCN: “children with medical complexity” (CMC). CMC are described as children with “substantial family-identified health care service needs,” the presence of “1 or more chronic clinical conditions ... that are severe and/or associated with medical fragility,” severe functional limitations that may require assistive technology, and “high projected utilization of health resources.”⁴ Estimates suggest the proportion of CMC ranges from 0.4% to 1.6% (320 000–1 200 000) of all children in the United States.^{5,6} CMC represent approximately 6% of children on Medicaid or the Children’s Health Insurance Program but account for almost 40% of pediatric health care costs.⁷ CYSHCN and their families often require services from various sectors across the life course, from health to education and beyond.

Although significant progress has been made in advancing the clinical care and system transformations necessary to improve outcomes for CYSHCN, much work still needs to be done to ensure that children and their families thrive in their communities. This article highlights MCHB’s historic leadership role in transforming the system that serves CYSHCN and their families, our current and ongoing progress, and how a new framework, *Blueprint for Change: Guiding Principles for a System of Services that Meet the Needs of CYSHCN and Their Families (Blueprint for Change)*, can advance the field.

THE EVOLVING WORK OF THE MATERNAL AND CHILD HEALTH BUREAU IN SUPPORTING CHILDREN AND YOUTH WITH SPECIAL HEALTH CARE NEEDS

From its earliest days, the job of the Children’s Bureau (the Bureau),

created in 1912 and the predecessor of the present MCHB, was to “investigate and report ... upon all matters pertaining to the welfare of children and child life among all classes of our people.”⁸ That early work included a survey of “provisions for crippled children” in 14 states, which influenced the Bureau’s recommendations to President Theodore Roosevelt’s Committee on Economic Security regarding the development of a program for such children in what would become the Social Security Act.⁹

The 1930 White House Conference on Child Health and Protection outlined a series of 5 rights for “the handicapped child” and endorsed a series of rights for all children in its report, the *Children’s Charter*. These rights included: “for every child health protection from birth through adolescence, including: periodical examinations and, where needed, care of specialists and hospital treatment”; “for every child who is blind, deaf, crippled, or otherwise physically handicapped, and for the child who is mentally handicapped, such measures as will early discover and diagnose his handicap, provide care and treatment, and so train him that he may become an asset to society rather than a liability”; and “for every child the right to grow up in a family with an adequate standard of living and the security of a stable income as the surest safeguard against social handicaps.”

The 1930 conference findings influenced the CYSHCN provisions (including the authorization of grants-in-aid to states) in Title V of the Social Security Act (Title V), enacted in 1935.^{10,11} Title V authorized appropriations to states for, among other purposes: “enabling each State to extend and improve (especially in rural areas and in areas suffering from severe economic distress), as far as practicable under the conditions in such State, services

for locating crippled children and for providing medical, surgical, corrective, and other services and care, and facilities for diagnosis, hospitalization, and aftercare, for children who are crippled or who are suffering from conditions which lead to crippling.”¹²

In the ensuing years, Bureau investments supported efforts to improve access to and quality of care for children with acute and chronic health conditions. In the 1960s, interest by the Kennedy administration and Congress resulted in amendments to Title V and additional funding for “mentally retarded” children.¹³ Later, the “Children and Youth” projects increased the availability of clinical resources (facilities, providers, support services, and so on) to accompany payment for medical services offered under the newly created Medicaid program.^{10,14}

In 1981, Title V was converted into the Maternal and Child Health Services Block Grant (block grant). The special emphasis on CYSHCN persisted, but in 1985, language in the Omnibus Budget Reconciliation Act (OBRA) changed the terminology from “crippled children” to “children with special health care needs.”¹⁵ OBRA 1989 amended the Social Security Act and mandated that state Title V programs spend at least 30% of their federal block grant funds on services for CYSHCN and to “facilitate the development of community-based systems of services for such children and their families.”¹⁷ Historically, states used their block grant funds to provide direct services to CYSHCN. This legislative change allowed states to implement efforts to improve the system of services for CYSHCN. In recent years, states have shifted from providing direct, clinical services (to relatively small numbers of CYSHCN) to population health approaches, maximizing the

reach and impact of block grant funds to address the health and well-being of all CYSHCN in a state. These approaches work at the policy level or across multiple service sectors and may address social or environmental factors that impact health equity.¹⁸

A hallmark of the Bureau's work through the block grant and its other investments for CYSHCN is partnering with families, health professionals, and state MCH leadership to transform and advance a system of services for CYSHCN. The flexibility provided by the block grant allows states to tailor their approaches to meet state- and community-specific needs. This strategy yields substantial variability in services offered to CYSHCN and their families, and system development across states and jurisdictions.¹⁹ MCHB's efforts to ensure a robust and impactful system of services for CYSHCN have extended, and must continue to extend, beyond efforts financed by the block grant to leverage other national leadership opportunities and partnerships with government and private sector entities. These partnerships will remain essential to optimally serve CYSHCN and achieve the principles set forth in the *Blueprint for Change*.

Bureau programs for children and families have evolved along with advanced understanding of disease detection, treatment, prevention, and family needs. For example, as the science of newborn screening evolved in the latter half of the 20th century, the Bureau established programs to expand state-based screening programs and access to specialty genetic services. Hearing screening technology developed in the late 1980s and early 1990s allowed for the development of state systems for universal early hearing detection and intervention.²⁰ During initial discussions around health reform in

the 1990s, the Bureau facilitated conversations on financing of care for CYSHCN, care coordination, and family-centered care. The increasing incidence of autism and tools to support early diagnosis led to legislation authorizing the Bureau to create programs that expand access and training of professionals to diagnose and treat autism spectrum disorder.

The 1982 Surgeon General's workshop "Children with Handicaps and Their Families" and the subsequent Surgeon General's report on children with special health care needs influenced the development of family-centered care approaches and a community-based system of care.²¹ After the Surgeon General's report and passage of OBRA 1989, MCHB and its partners developed and disseminated a definition of CYSHCN. To implement and monitor progress toward achieving the system of services for CYSHCN required by OBRA 1989, MCHB and its partners subsequently established the 6 core indicators of a well-functioning system of services.²² These 6 indicators (Fig 1) would serve as the sentinel measures for CYSHCN programming for the next 2 decades. In 2001, MCHB worked with the Centers for Disease Control and Prevention to field the National Survey of Children with Special Health Care Needs, which provided national- and state-level estimates of CYSHCN for the first time, as well as performance on the 6 core indicators.² In 2002 and 2011, MCHB partnered with families

and other stakeholders to develop comprehensive 10 year strategic plans to implement the 6 core indicators and coordinate a system of services for CYSHCN. It was incumbent on MCHB to translate how these changes could influence and effect the MCH public health workforce and the populations they serve.

The Bureau's work over the past century has also evolved in the context of a changing legislative landscape related to the protection and coverage of people with disabilities, including CYSHCN. As an example, the Tax Equity and Fiscal Responsibility Act of 1982 included the "Katie Beckett Provision," which made it easier for families of CYSHCN to qualify for Medicaid coverage of home-based care.²³ Additionally, the Family Opportunity Act of 2005 established Family-to-Family Health Information Centers, now located in every state, the District of Columbia, 5 territories, and 3 tribal organizations. These family-run centers provide information, training, technical assistance, and peer support to families of CYSHCN to help them make informed decisions about their children's health and participate in system-building activities within their communities and states.¹⁶ The Patient Protection and Affordable Care Act (ACA) of 2010 codified important health insurance coverage provisions and protections for CYSHCN, including the prohibition of "preexisting conditions," removal of lifetime benefit caps, expansion of

1. Families of CYSHCN are partners in decision making at all levels
2. CYSHCN receive coordinated, ongoing, comprehensive care within a medical home
3. Families of CYSHCN have adequate private and/or public insurance
4. Children are screened early and continuously for special health care needs
5. Services for CYSHCN are organized so families can use them easily and are satisfied with the services they receive
6. 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

FIGURE 1. Six Core Indicators of a Well-Function System of Services for CYSHCN.

Medicaid coverage and allowing children to remain covered under their parents' insurance until age 26, and prohibition of cost-sharing for preventive services.²⁴ After passage of the ACA, MCHB invested in a number of programs to support families, providers, and states in understanding and implementing the act. Although the ACA had a positive impact on many families with CYSHCN, the act was not a panacea and did not fully address adequate coverage or underinsurance.²⁵ MCHB continues to fund research and other investments to identify, measure, and fill the gaps and reduce financial hardships and burden for families.

Today, in addition to the Block Grant, MCHB funds a variety of programs aimed at improving outcomes for CYSHCN and families. Current efforts include identifying emerging issues, measuring CYSHCN needs and outcomes, optimizing service delivery, supporting public health infrastructure, providing technical assistance, supporting family leadership, and engaging in policy development or assurance. After decades of working to build the system of services, the Bureau has learned, through both successes and challenges, a number of key lessons: (1) we must engage families meaningfully through all steps of the process; (2) to strengthen the system of services for CYSHCN, we must be able to define and measure the population and components of the system; (3) we must continually assess and evaluate the Bureau's research and programmatic resources to address ongoing and emerging issues that impact CYSHCN and the services they receive; (4) we must always approach this work through a lens of equity; and (5) MCHB has a unique and enduring role as the only federal agency with

a statutory responsibility to support systems of care for CYSHCN.

DESPITE PROGRESS, CHALLENGES PERSIST: THE NEED FOR A BLUEPRINT FOR CHANGE

Although efforts to improve care and functional health outcomes over the years have benefitted CYSHCN and their families, much work remains. Families of CYSHCN have reported favorably on some of the 6 core outcomes for CYSHCN, including easy-to-access services and shared decision-making. However, less than one-half of families with CYSHCN report receiving care that meets medical home criteria.² Similarly, only 1 in 5 families report receiving needed supports for a successful health care transition to adulthood, and only 1 in 6 CYSHCN are served in well-functioning system of care.² Further, the lack of integrated care contributes to families of CYSHCN having to provide care coordination and informal family caregiving. Households that forego employment due to caregiving for CYSHCN lose as much as \$18 000 in earnings per year, and nationally, family caregivers provide approximately 1.5 billion hours of care to CYSHCN annually.^{26,27}

Among CYSHCN, disparities exist by race and language status in measures of care quality, such as medical home, access to easy-to-use services, and family partnership in decision-making.²⁸⁻³⁰ Black and Hispanic children also experience higher rates of certain diagnoses (eg, asthma, cerebral palsy, HIV/AIDS, depression, and so on) than do white children; lower rates of other diagnoses (eg, ADHD); and decreased rates of survival for acute leukemia, Down syndrome, Type 1 diabetes, and traumatic brain injury.³¹ The impact and intersection of racism and

discrimination cannot be overlooked in any conversation on child health, particularly for CYSHCN.³² CYSHCN are more susceptible to experiencing racism and discrimination compared to children of similar age, race, and sex who do not have a special health care need.³³

The COVID-19 pandemic presented numerous challenges for CYSHCN. Children with underlying medical conditions had a higher rate of hospitalization for COVID-19, with Black and Hispanic CYSHCN having the highest rates.³⁴ Three-quarters of all childhood deaths due to COVID-19 were among children with at least 1 underlying medical condition.³⁵ A few months after the start of the pandemic, a survey of parents found that among children with special education needs, 40% reported receiving no support for their child, and few parents reported that their child received all of the services they needed. Additionally, compared to parents of other children, parents of children with special education needs were more likely to report that their child was engaged in "little to no remote learning" and more likely to report concerns about their child's mental health.³⁶ The COVID-19 pandemic demonstrated the unique considerations needed for CYSHCN, including ensuring continuity of special education services delivered in school or community settings in the face of stay-at-home orders and planning for safe delivery of in-home health services in the setting of a respiratory virus pandemic.³⁷

The persistence of suboptimal health outcomes and disparities in access and quality care for CYSHCN, heightened by the COVID-19 pandemic, requires revisiting MCHB's strategic efforts to provide national leadership to improve the health and well-being of CYSHCN and their families. The *Blueprint for*

Change includes 4 critical areas of focus: health equity, family and child well-being and quality of life, access to services and supports, and financing of services. As described in *Blueprint for Change*, the principles and strategies were developed after extensive stakeholder engagement. It envisions that “CYSHCN enjoy a full life, from childhood through adulthood, and thrive in a system that supports their social, health, and emotional needs, [and] ensures dignity, autonomy, independence and active participation in their community.”³⁸

The *Blueprint for Change* aligns with MCHB’s recently released strategic plan, which focuses on 4 strategic goals: access, equity, workforce and capacity, and impact.³⁹ Specific objectives within the plan include family and consumer leadership, a system of care, team-based and coordinated approaches to care, health equity, and state or local capacity building. Collectively, the *Blueprint for Change* and MCHB’s strategic plan can position the field to move forward, overcome persistent challenges, and achieve the vision set forth in both agendas.

LOOKING AHEAD: OPPORTUNITIES TO ACCELERATE IMPROVEMENTS IN THE HEALTH AND WELL-BEING OF CYSHCN

The release of the *Blueprint for Change* builds on MCHB’s legacy of providing national guidance and leadership to benefit CYSHCN and their families. It comes at a time of rapid transformation in our health care system, a national reckoning on racism and discrimination, and in the midst of a global pandemic that has exposed and exacerbated the vulnerabilities faced by many families. This confluence of events presents key opportunities for transformative leadership to advance a system serving CYSHCN and their families.

MCHB will continue its historic leadership in monitoring, identifying, and assessing needs through the National Survey of Children’s Health and elevating the importance of family and stakeholder partnerships. The Title V MCH block grant can be a mechanism to advance the *Blueprint for Change* and support state Title V programs in modeling leadership for CYSHCN in a system of services through policy, practice, and measurement. MCHB will continue to support innovations in system- and practice-level research and implementation; promote workforce development and coordinating and integration of data across agencies, organizations, and data sets; and work to remove barriers to equitable health care and services to ensure the optimal health and well-being of all CYSHCN.

Ongoing system transformation will require leadership and partnerships across agencies at the federal, state, and local levels, and between families, health care professionals, policy makers, and public health practitioners. MCHB can build on its strong partnerships with key federal agencies such as the Centers for Disease Control and Prevention, Centers for Medicare and Medicaid Services, National Institutes of Health, Department of Education and others to bring attention to and collectively advance the *Blueprint for Change*. Strong partnerships with state Title V programs, academic centers, provider organizations and families will generate momentum to further accelerate improvements in the health and well-being of CYSHCN.

Below are key recommendations that build on the principles in each of the 4 critical areas outlined in the *Blueprint for Change*: health equity, child/family well-being and quality of life, access to services and supports, and financing of services.

Health Equity

- Build equity: Eliminate systemic barriers, including racism and bias, and ensure equal access to health. The White House has instructed federal agencies to do so⁴⁰; state and local governments, health care systems and payers, and child- and family-serving organizations should adopt similar approaches to eliminate systemic causes of inequity so as to advance health promotion, health status, and health outcomes for CYSHCN.
- Disaggregate data: The Biden-Harris Administration has tasked federal agencies with expanding efforts to disaggregate data, which will include data related to CYSHCN.⁴⁰ State and local governments, health care systems and payers, and child- and family-serving organizations should also collect data in a way that can be disaggregated, thus ensuring equity in health status and health outcomes across a variety of domains: race, ethnicity, gender, disability, geography, insurance type, and so on.

Family and Child Well-Being and Quality of Life

- Measure quality of life: As payers embrace value-based reimbursement models, it will be important to measure family and child well-being and quality of life, and incorporate such metrics into reimbursement models. In the quality improvement world, the mantra is “what gets measured gets improved.” In this case, perhaps what gets *paid for* will get improved, and linking to value from the perspective of the patient and family may drive system improvement.
- Assess family caregiver well-being: Family caregivers of CYSHCN

are more likely to describe their own health as “fair or poor” and report detrimental impacts on their emotional, social, and financial well-being. Most assessments of caregiver health and well-being describe outcomes for adults caring for their parents. Surveying entities should develop and include robust measures of the physical, social, and emotional well-being of family caregivers to drive public health and social service programming and policy.

Access to Services and Supports

- Support innovative health delivery approaches: Continue telehealth flexibilities made available during the COVID-19 pandemic, but recognize that telehealth is not a panacea. Telehealth can reduce barriers, such as transportation and child care, and increase flexibility for parents and providers. For some CYSHCN, however, telehealth is not a viable replacement for in-person services.⁴¹ Additionally, for many families, access to broadband services should be expanded to reduce disparities and improve the health and well-being of CYSHCN, particularly those in rural and tribal areas.
- Integrate care across the system: CYSHCN and their families experience the system in simultaneous and interconnected ways. Integrated care requires increased interagency collaborations and increased coordination of funding across organizational entities at the federal, state, and local levels. Child- and family-serving sectors can measure family experiences of care integration using tools such as the Pediatric Integrated Care Survey and use the results to inform system development and refinement.⁴² Ensuring that services

and supports continue seamlessly throughout the life course requires longitudinal data collection from birth through adulthood to assess biologic, environmental, psychosocial, health care, and other variables.

- Train a diverse workforce ready to meet the unique needs of CYSHCN: Identify and train health care and public health professionals who mirror the populations they serve, and equip the public health workforce to prepare for and address the needs of CYSHCN in emergency planning efforts. Planning typically has focused on more acute, life-threatening care needs. The COVID-19 pandemic showed that additional unique considerations for CYSHCN include ensuring continuity of special education services delivered in school or community settings in the face of stay-at-home orders and planning for safe delivery of in-home health services in the setting of a respiratory virus pandemic.³⁶

Financing of Services

- Adequately finance high-quality, accessible, and equitable care delivery models: Such models could include paying for innovative encounter types (including those not occurring face-to-face), effective care coordination, and incentivizing care within the patient- or family-centered medical home.⁴³ They also could include prioritizing financing of screening for social determinants of health and integrating services and data across the system, including hospitals, home health, long-term care, public health, education, and social services, to reduce health inequities for CYSHCN and their families.

- Recognize and reimburse the experience and expertise of family caregivers: Existing Medicaid authorities allow for such coverage, and some states exercised these options during the COVID-19 pandemic when stay-at-home orders created barriers for CYSHCN to receive services from other in-home providers.⁴⁴
- Consider the uniqueness of the CYSHCN population in value-based payment designs: The low prevalence of many conditions and the relatively high cost of care for CYSHCN necessitates alternative approaches that differ from other pediatric or adult population models. Also needed are funding models for supporting system changes that assist youth with special health care needs, regardless of age, race or ethnicity, insurance status, or level of disability, in moving into adult system of services, including health care.

CONCLUSIONS

The health and well-being of CYSHCN and families has improved over the last century, but great opportunities exist to improve outcomes and focus on eliminating inequities. Longstanding disparities, many exacerbated by the pandemic, underscore the urgency of transforming the system that serves this population. MCHB's *Blueprint for Change* provides not only a roadmap for improvement, with a focus on health equity, family and child well-being and quality of life, access to services and supports, and financing of services but also demonstrates our commitment to lead this effort. MCHB will continue to build on its rich history and legacy of shepherding programmatic and legislative changes to improve the health and well-being of CYSHCN and their families.

ABBREVIATIONS

ACA: Patient Protection and Affordable Care Act
ADHD: attention deficit hyperactivity disorder
CMC: children with medical complexity
COVID-19: coronavirus disease 2019
CYSHCN: children and youth with special health care needs
MCH: maternal and child health
MCHB: Maternal and Child Health Bureau
OBRA: Omnibus Budget Reconciliation Act

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