

Request for Information: A Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs (CYSHCN) and Families

Goal: MCHB is seeking public input 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). Specifically, MCHB seeks responses to the “Questions to consider as you respond” section of this Request for Information (RFI).

Background: Children and youth with special health care needs and their families have better outcomes when systems of care are comprehensive, coordinated, and family-centered systems. Yet estimates from the 2017-2018 National Survey of Children’s Health (Survey) indicate 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.

In the fall of 2019, MCHB began working with a small group of CYSHCN experts and families to re-examine CYSHCN systems of care and to identify priorities and opportunities that can advance those systems and improve outcomes. The result is a draft Blueprint that can inform programs and policy at the community, state, and federal levels.

MCHB invites you to review the draft Blueprint below and provide input on how this work can be operationalized at the community, state and federal levels in four key areas:

- health equity
- access to services and supports
- family/child well-being and quality of life
- financing of services

Questions to consider as you respond:

1. Are there items that are missing from the draft goals and objectives?
2. What steps need to be taken to implement these goals at the community, state and federal levels?
3. How should families, providers and other key programs and systems be involved in the implementation of the goals and objectives outlined in the Blueprint?
4. What additional research, policy and programmatic work should be consulted and considered as the Blueprint is finalized?

Submitting Comments: Please submit comments via email to CYSHCN@hrsa.gov and reference “CYSHCN Blueprint RFI” in the subject line by Monday, November 30, 2020 by 11:59 p.m. Eastern Time. If you provide comments to more than one question, please identify the specific RFI question to which each comment is directed.

Information obtained as a result of this RFI may be considered by HRSA and HHS for program planning and program decision-making. Responses to this RFI may be made publicly available; therefore, respondents should not include any proprietary or confidential information.

HRSA will not respond to any individual comments, except to clarify written responses. Please note that HRSA also will not respond to questions about potential policy issues related to this RFI.

Special Note to Commenters: Whenever possible, respondents are asked to draw their responses from objective, empirical, and actionable evidence and to cite this evidence within their responses. This RFI is issued solely for information and planning purposes; it does not constitute a Request for Proposal, application, proposal abstract, or quotation. This RFI does not commit the Government to contract for any supplies or services or make a grant or cooperative agreement award. Further, HRSA is not seeking proposals through this RFI and will not accept unsolicited proposals. Responders are advised that the U.S. Government will not pay for any information or administrative costs incurred in response to this RFI; all costs associated with responding to this RFI will be solely at the interested party's expense. Not responding to this RFI does not preclude participation in any future procurement or program, if conducted. Submissions will not be returned.

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.

Achieving this vision requires coordination and collaboration across health care systems as well as other child and family-serving systems and programs. This Blueprint outlines specific goals and objectives in four key areas: health equity; family and child wellbeing and quality of life; access to supports and services; and financing of services; that could be implemented in partnership across leading stakeholder groups at the community, state, and federal levels.

The Blueprint is driven by several foundational factors:

1. To thrive in their communities, CYSHCN require more and different types of services than typically developing children and youth.
2. Current systems of services are not working well for many CYSHCN and their families, particularly CYSHCN and families impacted by poverty and discrimination
3. CYSHCN are more severely impacted by the effects of social determinants of health and inequities.
4. Racism is a social determinant of health that has a profound impact on the health status of children, adolescents, young adults and their families. ¹
5. Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society²

¹ Trent M, Dooley DG, Douge J, AAP SECTION ON ADOLESCENT HEALTH, AAP COUNCIL ON COMMUNITY PEDIATRICS, AAP COMMITTEE ON ADOLESCENCE. The Impact of Racism on Child and Adolescent Health. *Pediatrics* 2019; 144 (2): e20191765, 1.

² Individuals with Disabilities Education Act, 20 U.S.C. § 1400(c)(1).

1. Health Equity

For the purposes of this work, HRSA defines health equity as the absence of disparities or avoidable differences among socioeconomic and demographic groups or geographical areas in health status and health outcomes such as disease, disability, or mortality. The goals and objectives below also acknowledge that poverty and discrimination and their downstream consequences are barriers to health equity. ³

Goals:

- *All children have access to health care services that are appropriate to their needs, accessible, and free from discrimination.*
 - *Regardless of the circumstances in which they live, all CYSHCN have a fair and just opportunity to be as healthy as possible.*
 - *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.* ⁴
 - *CYSHCN are guaranteed the opportunity to thrive in school, society, as they become adults, and in the workforce, without discrimination.* ⁵
 - *All CYSHCN and their families receive care that is family-centered and culturally competent.*
 - *All CYSHCN, including those with chronic illness and disabilities, receive care that helps them achieve optimal health and functioning.*
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Objectives:

- Structural and systemic policies that further inequalities are replaced. Policies and programs recognize and address the barriers to health equity: poverty and discrimination and their downstream consequences.
- Interventions at the child/family level are undertaken to improve access to services, programs and supports that will increase the ability of children and families to thrive no matter their circumstance.
- Interventions are designed and implemented within a context of cultural humility and are considerate of the medical and environmental circumstances of the child.
- 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. ⁶
- Public health data systems support public health surveillance and services for all CYSHCN with emphasis on subgroups of CYSHCN that are most vulnerable.

³<https://www.hrsa.gov/about/organization/bureaus/ohe/index.html#:~:text=The%20Office%20of%20Health%20Equity,their%20highest%20level%20of%20health>

⁴ National Academies of Sciences, Engineering, and Medicine 2019. *Vibrant and Healthy Kids: Aligning Science, Practice, and Policy to Advance Health Equity*. Washington, D.C.: The National Academies Press.

⁵ National Academies of Sciences, Engineering, and Medicine 2018. *Opportunities for Improving Programs and Services for Children with Disabilities*. Washington, DC: The National Academies Press.

⁶ Ibid.

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

Historically, health systems focused on health outcomes and did not account for broader metrics of well-being and quality of life. A focus on family/child well-being and quality of life acknowledges the importance of achieving dignity, autonomy, independence, and the need for families to be active participants and drivers of decisions affecting them and their children. This focus also recognizes that functional outcomes, as well as and physical, emotional, cognitive and social concerns are as important as traditional medical concerns. Underlying all these goals and objectives is the concept of shared decision-making: CYSHCN and families are partners within care systems and family engagement is supported and measured at all levels of health care, including direct patient care, organizational design and governance, and program and policy.

Goals:

- *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.*⁷
 - *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.*
 - *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.*
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Objectives:

- Interventions and policies support families and communities that help CYSHCN to have improved quality of life and protective factors e.g., supportive and stable relationships, positive parenting practices, healthy family dynamics.^{8, 9}
- Interventions and policies are implemented to promote and support resilience and enhanced self-management capacities for CYSHCN and their families.
- Shared decision-making between families and professionals considers clinical and Quality of Life outcomes.
- CYSHCN, families, and service providers/professionals have information and tools (e.g., care maps, guides supporting family/professional conversations, information on

⁷ Ibid.

⁸ Child Trends 2018: *A State Multi-Sector Framework for Supporting Children and Youth with Special Health Care Needs*. Lucile Packard Foundation for Children's Health.

⁹ Mattson G, Kuo DZ, AAP COMMITTEE ON PSYCHOSOCIAL ASPECTS OF CHILD AND FAMILY HEALTH, AAP COUNCIL ON CHILDREN WITH DISABILITIES. Psychosocial Factors in Children and Youth With Special Health Care Needs and Their Families. *Pediatrics*. 2019;143(1):e20183171

patients' and families' past and current social circumstances and experiences) to practice family-centered, trauma-informed care, and to voice informed opinions and preferences regarding decisions about care and self-care/management.¹⁰

- Health systems metrics include measures of child and family well-being, resiliency, and quality of life.^{11,12}
 - Standards for data collection that improve reliability and usability of Quality of Life measures are developed and implemented.
 - The impacts of social determinants of health including systemic racism on child/family quality of life and well-being are identified and assessed.
 - Risk assessments for CYSHCN consider family/child well-being and quality of life.
 - Workforce training for professionals serving CYSHCN and their families includes curricula that emphasizes child development, family/child well-being and quality of life.
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3. Access to Services and Supports

Access to services and supports is defined broadly. This focus area include components of access to health care: coverage, services, timeliness, and workforce.¹³ In addition, it includes other social and educational services that are necessary for CYSHCN and families to have full, thriving lives. An ideal structure of services and supports is one that is integrated at the systems level. The delivery, payment, and administration of services are aligned 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.¹⁴

Goals

- *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.*¹⁵

¹⁰ National Academies of Sciences, Engineering, and Medicine 2018. *Opportunities for Improving Programs and Services for Children with Disabilities*. Washington, DC: The National Academies Press.

¹¹ Simon TD. The Future of Measuring Health Outcomes for Children With Medical Complexity. *Pediatrics*. 2018;142(3):e20181925

¹² Barnert ES, Collier RJ, Nelson BB, et al. A Healthy Life for a Child With Medical Complexity: 10 Domains for Conceptualizing Health. *Pediatrics*. 2018;142(3):e20180779

¹³ <https://www.ahrq.gov/research/findings/nhadr/chartbooks/access/elements.html>

¹⁴ Report to Congress on Medicaid and CHIP: June 2020. Medicaid and CHIP Payment and Access Commission (MACPAC). p.3

¹⁵ Child Trends 2018: *A State Multi-Sector Framework for Supporting Children and Youth with Special Health Care Needs*. Lucile Packard Foundation for Children's Health.

- *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.*^{16,17}
 - *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 reflects the families they serve.*
 - *Services are easy to navigate by families and professionals.*
 - *Systems share information and processes (eligibility, enrollment, outcomes, and referrals) across child and family serving systems.*
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Objectives:

- Eligibility for services and programs is streamlined across systems.
- CYSHCN and their families receive services in a proactive manner that provide guidance and a roadmap to care.
- Essential service system providers (public health, hospital systems, provider groups, etc.) are physically available in communities where families live.
- Information technology and virtual communication, including telehealth and other evolving care solutions, are used to facilitate access and address gaps in care for CYSHCN, including access to specialized health-related services coordination across health care providers.
- Information technology and virtual communication, including telehealth and other evolving care solutions, are accessible to families through modalities that are readily available and easy to use.
- Service delivery methods, such as telehealth are assessed for impact on child/family quality of life.
- Systems of care that provide regionalized specialty services and build capacity for serving children with medical complexity at the community level are developed and supported.
- Population health efforts for CYSHCN, including subgroups, are implemented to support and enable equitable access to services and policies at all levels for CYSHCN and families.¹⁸

¹⁶ Abdi, F. et al. *Children with special health care needs face challenges accessing information, support, and services*. Child Trends: February 2020.

¹⁷ National Academies of Sciences, Engineering, and Medicine 2018. *Opportunities for Improving Programs and Services for Children with Disabilities*. Washington, DC: The National Academies Press.

¹⁸ A population health strategy for Children and Youth with Special Health Care Needs (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.

- Public health programs leverage opportunities to connect to the private sector and policymakers who want to invest in and advance systems for CYSHCN and families.
 - Opportunities and incentives are increased for individuals, particularly underrepresented populations, to enter training programs serving CYSHCN, by increasing outreach and access to education and training to individuals with special health care needs, families and community members of diverse backgrounds
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4. Financing of Services¹⁹

Financing of services includes financing, payment models and insurance. This focus area includes goals and strategies for financing of services that improve quality, provide return on investment, and recognize and value outcomes meaningful to different stakeholders including families, providers, and payors.²⁰ While the following goals and objectives focus on health care services, CYSHCN may require an array of services and supports, funded through a variety of entities including public (Medicaid, CHIP) and private insurance, employer-based insurance, and additional social and educational services.

Goals:

- *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.*^{21,22}
- *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*
- *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.*

Objectives:

- Service systems adopt a comprehensive, inclusive definition of CYSHCN.²³
- Service systems establish identification processes for improved care coordination, monitoring, and early identification of health issues.²⁴
- Service systems consider a standard of medical necessity that takes into account a child's health and development.

¹⁹ For the purposes of this Blueprint, services are broadly defined and identified by families and CYSHCN as necessary to thrive. These include but are not limited to health care, community based services and supports, and social services.

²⁰ Coller, RJ, Berry JG, Kuo DZ et al. Health System Research Priorities for Children and Youth with Special Health Care Needs. Pediatrics: 2020: 145 (3): e20190673

²¹ National Committee for Quality Assurance. 2013 Special Needs Plans Structure & Process Measures

²² Standards for Systems of Care for CYSHCN, Version 2.0. July 2017. Association of Maternal and Child Health Programs.

²³ CYSHCN are 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.

²⁴ Mann, C. et al. *Keeping Medicaid's Promise: Strengthening Access to Services for Children with Special Healthcare Needs*. Manatt Health: October 2019.

- Service systems support team-based and enhanced primary care to support CYSHCN.
 - Care coordination²⁵ is adequately financed to meet the varying levels of service needs of the child and family and is assessed through measures including family experience, integration across medical, social, behavioral sectors, and quality of life for CYSHCN and families.²⁶
 - Information technology and virtual communication, including telehealth and other evolving care solutions identified by families and CYSHCN are adequately financed.
 - Service systems identify and assess financial burden on families of CYSHCN and consider eliminating or reducing cost-sharing payments for medically necessary services, supplies and equipment.
 - Integrated care across service sectors is adequately financed, monitored, and evaluated.
 - Health systems use payment models that are linked with quality of life indicators and measure the impact of services on outcomes including child and family wellbeing and resiliency.
 - Financing mechanisms support quality care through innovative approaches (e.g. paying families to deliver care).
 - Investments in health services and care delivery are balanced to encompass services that address negative consequences of social determinants of health and build resiliency.
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²⁵ For the purposes of this Blueprint, care coordination “generally involves an interdisciplinary approach to ensuring access to health care and social support services, in which a care coordinator manages and monitors an individual’s needs, goals, and preferences based on a comprehensive plan.” Sara S. Bachman, Meg Comeau, and Katharyn M. Jankov, “The Care Coordination Conundrum and Children and Youth with Special Health Care Needs,” The Catalyst Center, November 2015.

²⁶ Sara S. Bachman, Meg Comeau, and Katharyn M. Jankov, “The Care Coordination Conundrum and Children and Youth with Special Health Care Needs,” The Catalyst Center, November 2015.