

# Blueprint for Change: A National Framework for a System of Services for Children and Youth with Special Health Care Needs (CYSHCN)

## Blueprint Strategies: At-a-Glance Overview

### **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.*

**Health Equity Vision:** All CYSHCN have a fair and just opportunity to be as healthy as possible and thrive throughout their lives (e.g., from school to the workforce), without discrimination, 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 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.

**Family & Child Well-Being and Quality of Life Vision:** The service system prioritizes quality of life, well-being, and supports flourishing for CYSHCN and their families.

- *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.*
- 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, 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.
- 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.
- *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.*
- 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.

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**Access to Services Vision:** CYSHCN and their families have timely access to the integrated, 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.

- *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&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 (e.g., public health, hospital systems, provider groups, and so on) are available in communities where families live or via other service delivery technologies, e.g., 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 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.

**Financing of Services Vision:** Health care and other related services are accessible, affordable, comprehensive, and continuous; they prioritize the well-being of CYSHCN and families.

- *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.*
  - 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.
  - 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 strategies 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.
- 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.

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