Meeting Proceedings: Children and Youth with Special Health Care Needs (CYSHCN) Summit Series

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Executive Summary

Children and youth with special health care needs (CYSHCN) are a heterogeneous group with differing medical, developmental, and social needs. They often require care from multiple providers and coordination across a variety of service sectors, including health care, education, and social services. Despite advances in recent decades, many CYSHCN and their families, especially those impacted by poverty and discrimination, do not have the supports they need. In recent years, systems serving CYSHCN have experienced strains due to changing patterns of children and youth with complex medical and social needs, while factors like the increased use of Medicaid managed care arrangements and shifts in the health care workforce present new challenges and opportunities (Summit Series kick-off session).

Who are children and youth with special health care needs?

Children and youth with special health care needs are 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."

Source: Health Resources and Services Administration Blueprint; phone conversation with the Health Resources and Services Administration's Maternal and Child Health Bureau, September 28, 2020.◢

The Health Resources and Services Administration (HRSA) has historically played a key role in guiding federal and state policies to strengthen systems of care for CYSHCN. To advance its vision of CYSHCN and their families enjoying a full life and thriving in systems that are supportive of their social, health and emotional needs; and ensure dignity, autonomy and active participation of CYSHCN in their communities, HRSA (specifically, HRSA's Maternal and Child Health Bureau's Division of Services for Children with Special Health Needs) initiated a process to develop "A Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs and Families" (referred to as the "Blueprint").[1] The Blueprint is a roadmap to provide strategic direction for serving CYSHCN over the next 15 years, by outlining goals, objectives, and actionable steps to advance the field. Building upon foundational work conducted by HRSA and partners, HRSA began developing the Blueprint in 2019 through an extensive literature search and key informant interviews with a small group of CYSHCN, their families and experts in the field. HRSA then worked with a steering committee consisting of families, providers, state programs, and other stakeholders (Appendix B) to develop a draft Blueprint, which outlines recommendations for

What is the Health Resources and Services Administration's Blueprint?

The Blueprint outlines goals and objectives, action steps, and recommendations that can be implemented at the federal and state level, and by health systems, healthcare providers, payers, and advocacy organizations to achieve a strong system of care for children and youth with special health care needs. The goals and objectives in the Blueprint are organized around four key topic areas. Its aim is to guide recommendations for the field over the next 15 years. The Health Resources and Services Administration plans to finalize the Blueprint in summer 2021, with input from a steering committee, Summit Series participants, and a public request for information.◢

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[1] For more information on HRSA's Blueprint, see https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs.

improving systems of services across four topic areas: (1) health equity, (2) family and child well-being and quality of life, (3) access to services and supports, and (4) financing of services.

In 2020, HRSA convened stakeholders—families, providers, researchers, government staff, non-profit organization staff, and other individuals who work on behalf of CYSHCN and their families across the country for a CYSHCN Summit Series. The Summit Series consisted of five virtual sessions held between September 22 and October 29, 2020. These proceedings provide a summary of the key activities, discussions, and recommendations from the Summit Series.

The overarching goal of the Summit Series was for participants to build on the Blueprint by identifying actionable goals and objectives at the community, state, and federal levels to provide strategic guidance to the field over the next 15 years and improve systems of care for CYSHCN. Of the 185 Summit Series participants, over 70 participants offered recommendations in the four topic areas: (1) health equity, (2) family and child well-being and quality of life, (3) access to services and supports, and (4) financing of services.

Participants' recommendations included edits to the Blueprint, and suggestions for research, policy, and practice at the community, state, and federal levels. The recommendations were made in the context of the novel coronavirus pandemic and recent protests in response to ongoing racial injustice. Participants emphasized how the pandemic is exacerbating challenges that CYSHCN and their families face, and highlighted opportunities (such as the use of telehealth) that can address challenges. Participants also stressed the impact of racism on all topic areas addressed in the Blueprint.

Participants offered 14 broad recommendations that apply to more than one topic area, indicating that these recommendations may be of highest priority to participants and other stakeholders in the field of CYSHCN. Of the 14 recommendations, five apply to every topic area. In Table ES.1, we list these five recommendations and provide an example for each. The first recommendation pertains to updates that HRSA can make to the Blueprint across all topic areas, while the other four recommendations suggest strategies to address the goals and objectives of the Blueprint through research, measurement, partnership building, and engaging consumers.

Table ES.1. Participant recommendations that apply to all four topic areas

Participant recommendation	Example
Add missing concepts to the goals and objectives	Multiple participants recommended that the Blueprint goals and objectives should reflect that factors such as adverse childhood experiences, race and ethnicity, socioeconomic status, and geographic isolation in rural and frontier regions that can lead to health disparities.
Invest in research on various relevant issues	Multiple participants recommended increased investment in research on payment reform models and initiatives (such as alternative payment models and value-based contracting), the value of care coordination for CYSHCN and their families, the identification of CYSHCN in Medicaid datasets, and societal costs (such as lost wages for caregivers) for serving CYSHCN.
Advocate for and/or develop relevant measures	Multiple participants recommended developing and using health equity measures. This can be done by working with stakeholders developing the Medicaid Child Core Set measures and by developing a measurement framework to monitor social determinants of health and unequal treatment.

Table ES.1 (*continued*)

Participant recommendation	Example
Build or facilitate relevant stakeholder partnerships	Multiple participants recommended building and strengthening partnerships to better serve CYSHCN. A few participants recommended building coalitions with community organizations and leaders, such as cultural organizations, faith organizations, and community elders to increase trust between families and service providers. Other participants recommended that facilitating cross-agency partnerships, such as coalitions that include social services agencies, behavioral health agencies, care coordinators, palliative care providers, oral health providers and cultural organizations.
Empower and support CYSHCN and their families to be equal partners in achieving the goals and objectives	Multiple participants recommended that programs include CYSHCN and their families in work to address health inequity, noting that programs can encourage stakeholders to: • Partner with a diverse group of CYSHCN and families, including those who are low-income, from rural areas, and have limited education and health literacy; • Respect and elevate what CYSHCN and their families bring to partnerships via their lived experiences, their cultures, and their protective factors; and • Work with CYSHCN and their families to develop innovative engagement strategies that are tailored to specific cultural and community contexts.

Note: In describing how many participants made a particular recommendation during the Summit Series sessions, we use the word “multiple” to denote when a large number of participants (5 or more) made a recommendation and “few” to denote when 3 to 4 participants made a recommendation.

CYSHCN = children and youth with special health care needs; HRSA = Health Resources and Services Administration.

HRSA plans to use the information in these proceedings, as well as other feedback from a public request for information, to further develop and refine the Blueprint, finalizing it in summer 2021. The Blueprint can be used by stakeholders at the national, state, and community levels to guide the implementation of programs and policies to strengthen the system of services for CYSHCN and their families over the next 15 years.

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I. Introduction

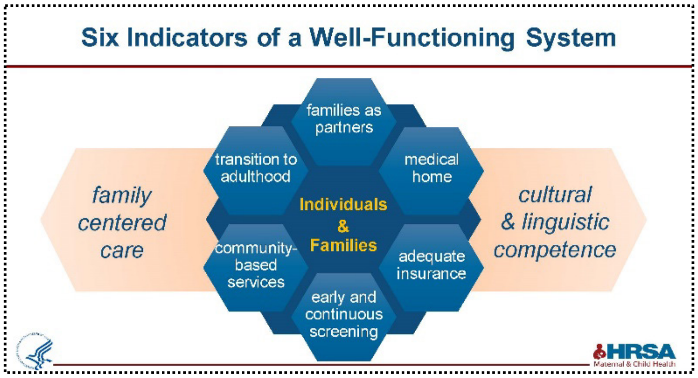
Children and youth with special health care needs (CYSHCN) are a heterogeneous group with differing medical, developmental, and social needs. They often require care from multiple providers and coordination across a variety of service sectors, including health care, education, and other social services. Despite advances in recent decades, many CYSHCN and their families, especially those impacted by poverty and discrimination, do not have the supports they need. Over 85% of CYSHCN do not receive services within a well-functioning system, as measured by the six core indicators (i.e., families as partners, receipt of care withing a medical home, access to adequate insurance, early and continuous screening, community-based services, and access to needed supports for transition to adulthood) (Figures I.1 and I.2). In recent years, systems serving CYSHCN have experienced strains due to changing patterns of children and youth with complex medical and social needs, while factors like the increased use of Medicaid managed care arrangements and shifts in the health care workforce present new challenges and opportunities (Summit Series kick-off session).

Who are children and youth with special health care needs?

Children and youth with special health care needs are 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."

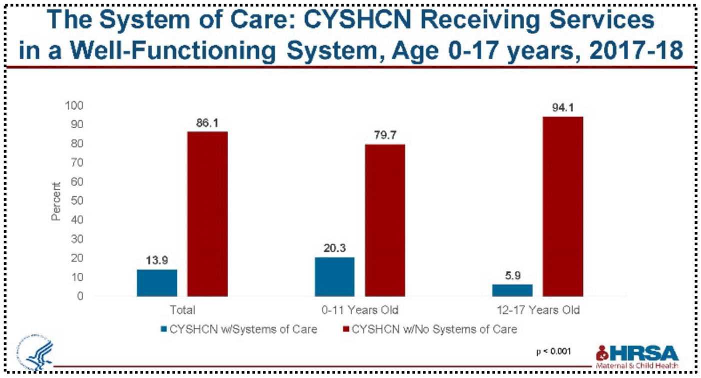
Source: Health Resources and Services Administration Blueprint; phone conversation with the Health Resources and Services Administration's Maternal and Child Health Bureau, September 28, 2020.◢

Figure I.1. Six Core Indicators of a Well-Functioning System for CYSHCN and their Families



Source: Summit Series kick-off session, September 22, 2020.

Figure I.2. Six Core Indicators of a Well-Functioning System for CYSHCN and their Families



Source: Summit Series kick-off session, September 22, 2020.

The Health Resources and Services Administration (HRSA) has historically played a key role in guiding federal and state policies to strengthen systems of care for CYSHCN. To advance its vision of CYSHCN and their families enjoying a full life and thriving in systems that are supportive of their social, health and emotional needs; and ensure dignity, autonomy and active participation of CYSHCN in their communities, HRSA (specifically, HRSA's Maternal and Child Health Bureau's Division of Services for Children with Special Health Needs) initiated a process to develop "A Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs and Families" (referred to as the "Blueprint"). The Blueprint is a roadmap to provide strategic direction for the field over the next 15 years.

The Blueprint builds upon foundational work conducted by HRSA and partners, including the development of the Six Core Indicators for CYSCHN and the Standards of Care for CYSHCN (Summit Series kick-off session). HRSA began developing the Blueprint in 2019 through an extensive literature search and key informant interviews with a small group of CYSHCN, their families and experts in the field. HRSA then worked with a steering committee consisting of families, providers, state programs, and other stakeholders (Appendix B) to develop a draft Blueprint, which outlines recommendations for improving systems of services across four topic areas: (1) health equity, (2) family and child well-being and quality of life, (3) access to services and supports, and (4) financing of services. These topic areas were selected based on discussions with key informants and steering committee members, and the review of literature, including "Health System Research Priorities for Children and Youth with Special Health Care Needs," by Coller et al. (2020). In 2020, HRSA convened stakeholders—families, providers, researchers, government staff, non-profit organization staff, and other individuals who work on behalf of CYSHCN and their families across the country for a CYSHCN Summit Series.

The overarching goal of the Summit Series was for participants to build on the Blueprint by identifying actionable goals and objectives at the community, state and federal levels to provide strategic guidance to the field over the next 15 years and improve systems of care for CYSHCN.[2] The Summit Series was composed of five sessions: a 2.5-hour kick-off meeting on September 22, 2020, and four 1.5-hour follow-up discussions on October 19, 20, 26, and 29, 2020. All sessions were conducted virtually using an online conference platform. Participants were invited to share comments and questions via email, the meeting platform's chat box, and verbally during the follow-up discussions.[3]

These proceedings provide a summary of the key activities, discussion, and recommendations from the Summit Series. In Chapter II, we present the four topic areas discussed during the Summit Series: (1) health equity, (2) family and child well-being and quality of life, (3) access to services and supports, and (4) financing of services. We also summarize participants' recommendations for the Blueprint in each of the topic areas. In Chapter III, we highlight participants' cross-cutting recommendations that apply to more than one topic area. These proceedings include five appendices: Appendix A provides the topic area definitions, goals, and objectives; Appendix B provides a list of CYSHCN Summit steering committee members; Appendix C includes lists of Summit Series participants; Appendix D includes the Summit Series session agendas; and Appendix E provides greater detail about each participant recommendation and whether it was made by one or multiple Summit participants.

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[2] For more information on HRSA's Blueprint, see https://mchb.hrsa.gov/maternal-child-health-topics/children-and-youth-special-health-needs.

[3] Participants were invited to email comments and questions to mchstrategy.hrsa@hrsa.gov or CYSHCN@hrsa.gov.

II. Summary and Recommendations from the Summit Series

During the kick-off session, Joan Scott, Director of the Division of Services for Children with Special Needs in HRSA's Maternal and Child Health Bureau (MCHB), set the stage by providing a definition of CYSHCN, and noted that approximately 1 in 5 U.S. families have a child with a special health care need. Ms. Scott introduced the Blueprint, and described the Summit Series' overarching goal of identifying actionable and objectives at the community, state and federal levels to provide strategic guidance to the field over the next 15 years and improve systems of care for CYSHCN. Ms. Scott recognized the summit planning committee and the Blueprint steering committee members, and welcomed Summit Series participants, noting that HRSA will rely upon their diverse expertise as providers; researchers; state, local and federal government agency staff; young adult leaders; and representatives from family, consumer, and non-profit organizations to inform the Blueprint.

How has coronavirus affected children and youth with special health care needs and their families?

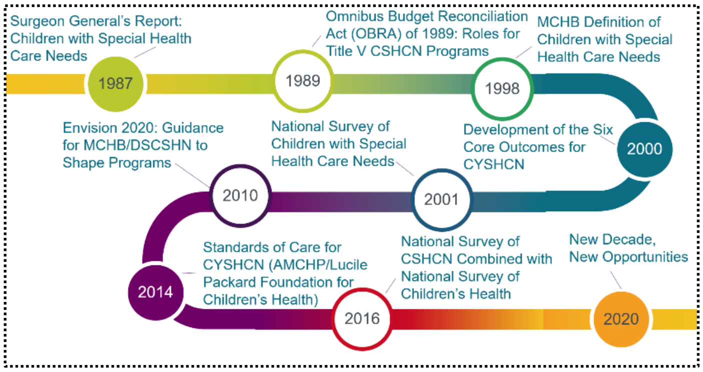
Effects of the coronavirus include the following:

- Exacerbated disparities
- Greater availability of telehealth services
- Greater need for trauma-informed care
- Demonstration of how fast systems of services can adapt

Source: Summit Series kick-off session, September 22, 2020.◢

Next, Dr. Michael Warren, Associate Administrator of MCHB, described MCHB's role within HRSA and articulated its mission "to improve the health and well-being of America's mothers, children and families" (Summit Series kick-off session). Dr. Warren discussed the six indicators of a well-functioning system (Figure I.1) and noted that the majority of CYSHCN do not receive services within a well-functioning system, with the lowest rates among adolescents and young adults (Figure I.2). Dr. Warren described sentinel events and key developments in improving systems of care for CYSHCN over time, starting with the 1987 Surgeon General's Report that advocated for policies to address families' financial and emotional support needs, and including initiatives led by MCHB and its partners (Figure II.1). While much progress has been made in creating better systems and supports for CYSHCN and their families, Dr. Warren highlighted current challenges, including demographic changes and social needs among CYSHCN, that strain systems. Dr. Warren presented a paradigm for improving maternal and child health –accelerate, upstream, together—and emphasized that CYSHCN and their families must be at the center of efforts to improve systems of care. Finally, Dr. Warren discussed the MCHB strategic planning process, introduced the Blueprint's framework, vision, assumptions, and four topic areas of focus (Table II.1).

Figure II.1. Key developments for improving systems of care for CYSHCN, 1987-2020



Source: Summit Series kick-off session, September 22, 2020.

Invited speakers Dr. Dennis Kuo (University of Buffalo Jacobs School of Medicine and Biomedical Sciences) and Ms. Shea Cleveland (Family Support Network of North Carolina) then discussed the impact of the novel coronavirus pandemic on CYSHCN and their families. Dr. Kuo and Ms. Cleveland highlighted how the pandemic has exacerbated long-standing inequities in access to health care, education, housing, transportation and food, and changed the ways in which CYSHCN receive services. These discussions provided important context for Summit Series participants to consider as they began to offer recommendations to further develop the Blueprint. During the remainder of the Summit Series kick-off session, HRSA and invited speakers elaborated on the importance of each of the four topic areas and highlighted each topic area's definition and set of goals and objectives. HRSA noted that the four topic areas, though discussed separately, are connected to each other and that participants' comments may apply to multiple topic areas.

What are social determinants of health?

Social determinants of health are conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.

Source: Summit Series kick-off session, September 22, 2020.◢

Table II.1. Blueprint framework, vision, assumptions, and topic areas

Blueprint
Framework
Articulation of a future system of care for children and families that effectively addresses their needs and the environments in which they live
Vision
CYSHCN and their families enjoy full lives and thrive in systems that: 1. Are supportive of their social, health, and emotional needs 2. Ensure dignity, autonomy, and active participation in their communities
Assumptions
1. CYSHCN require more different types of services than children generally. 2. Current systems of services do not work well for many CYSHCN and families, particularly those impacted by poverty and discrimination. 3. CYSHCN are more severely affected 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, and young adults and their families. 5. Disability is a natural part of the human experience and does not diminish the right of individuals to participate in, or contribute to, society.
Topic areas
1. Health equity 2. Family and child well-being and quality of life 3. Access to services and supports 4. Financing of services

Note: The four topic areas were identified by HRSA through interviews with experts in the field, an extensive literature search, discussions with the steering committee, and through HRSA's long history of driving improvements for CYSHCN and their families.

CYSHCN = children and youth with special health care needs; HRSA = Health Resources and Services Administration.

During each of the four follow-up discussion sessions, HRSA provided a brief review of the Summit Series purpose and the Blueprint. Next, invited speakers shared reflections about the topic area of focus. HRSA then divided participants into four breakout groups and facilitated small group discussions, inviting participants to respond to four discussion questions (see call-out box below). Each follow-up discussion session concluded with participants reconvening as a full group and sharing key points from their small group discussions. Participants' recommendations during both the kick-off session and follow-up discussions fell into four major categories: (1) suggested revisions to the topic area goals and objectives of the Blueprint, (2) recommendations for research and measurement, (3) policy recommendations, and (4) recommendations for practice, including workforce training and partnerships. In the remainder of this chapter, we describe the Summit Series key activities, discussion, and recommendations for each of the topic areas.

Follow-up discussion sessions: Questions about Health Resources and Services Administration's Blueprint topic areas

1. Are there missing items, concepts, or principles from these goals and objectives?
2. As we think about moving to action and developing strategies, what would this mean for your work? What additional research, policy, and programmatic work should we consider?
3. As we think about moving from goals and objectives, how can we think about implementation? Implementation at the community, state, and federal level?
4. What is the role of families, providers, and other programs and systems you interact with in making these goals and objectives achievable? ◢

A. Health equity

During the Summit Series kick-off session, HRSA defined 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" and noted that poverty and discrimination, and their related outcomes, contribute to health inequity. HRSA the outlined the specified six goals and six objectives in this topic area (Appendix A). Invited speaker Dr. Amy Houtrow (University of Pittsburgh) then described how social determinants of health (SDOH) can positively or negatively impact children's health and quality of life. She described poverty and discrimination as SDOH that are obstacles to CYSHCN and their families having a fair and just opportunity to be as healthy as possible, and she said that these factors must be addressed to achieve health equity. Dr. Houtrow also described disparities among subgroups in the CYSHCN population and areas for improvement. She cited data from the National Survey of Children's Health showing that CYSHCN in the U.S. are more likely to be poor and more likely to be Black than the overall child population, noting that the effects of racial discrimination can lead to increased risk for poor health among Black individuals and families (Figures II.2 and II.3).

What are adverse childhood experiences?

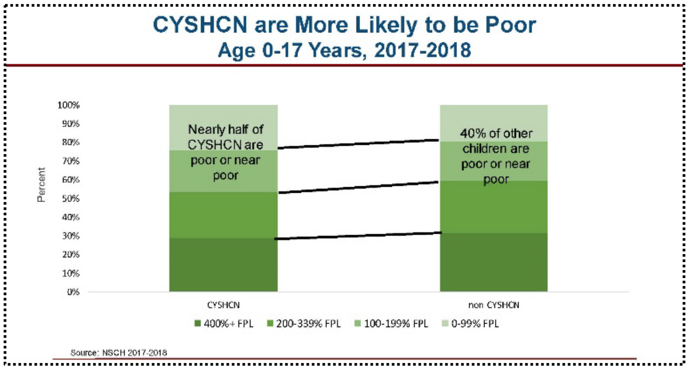
Adverse childhood experiences (ACEs) are events experienced during childhood that may be traumatic and impede children's feelings of safety and stability. Abuse, neglect, exposure to household violence, and having family members with mental health or substance use disorders are examples of ACEs. Exposure to ACEs increases the risk of chronic health conditions later in life. Preventing ACEs can improve health and social outcomes in adults and children.

Source: Centers for Disease Control and Prevention, 2020.◢

She said that more work needs to be done to address and eliminate racial discrimination. Dr. Houtrow also emphasized the difference between equality and equity, noting that equality focuses on implementing a "one size fits all" solution to address disparities, whereas equity focuses on making systems changes so that disparities do not exist.

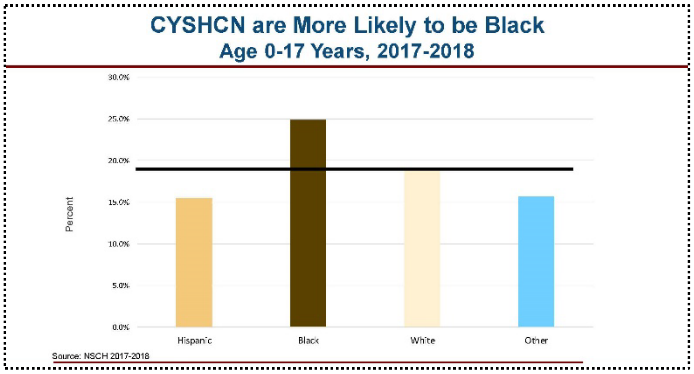
During the follow-up discussion session, invited speaker Dr. Deborah Allen (Los Angeles County Department of Public Health) discussed how racism impacts the care that CYSHCN and their families receive. She said that racism is infrequently discussed in work to serve CYSHCN and their families because it is difficult to tease racism apart from the social stigma and isolation that the CYSHCN population can experience as a whole. She said that the field of CYSHCN needs to grapple with racism in all its manifestations, including structural racism and interpersonal racism, and needs to stop conflating racism with cultural differences and simple miscommunication.

Figure II.2. CYSHCN are more likely to be poor, age 0-17 years, 2017-2018



Source: Summit Series kick-off session, September 22, 2020.

Figure II.3. Key developments for improving systems of care for CYSHCN, 1987-2020



Source: Summit Series kick-off session, September 22, 2020.

Next, invited speaker Alyssa Ware (Family Voices) discussed how racism prevents CYSHCN and their families from accessing services. She said that families of color often feel that their concerns are dismissed by providers, which prevents these families from being referred to needed services. She also noted that families may not be able to engage in conversations about health care needs because they are worried about police violence and other stressors related to racism. She recommended three solutions to address racism: (1) engage minority families "at the table" and compensate them for their time, (2) develop a workforce that looks like the individuals being served, and (3) ensure that reimbursement rates across Medicaid and private insurance are comparable in order to increase access to providers for low-income CYSHCN.

In Table II.2, we summarize participant recommendations made in response to the health equity presentations and discussions during the Summit Series, including recommendations from invited speakers related to health equity. The recommendations are grouped in four categories: (1) recommended revisions to the goals and objectives of the Blueprint, (2) recommendations for research and measurement, (3) policy recommendations, and (4) recommendations for practice, including those related to workforce, training, and partnerships. In Appendix E, Table E.1, we provide greater detail about each recommendation and whether it was made by one or multiple Summit participants.

Table II.2. Participant recommendations for health equity

Participant recommendation
Revisions to the goals and objectives of the Blueprint
1. Note the roles of adverse childhood experiences, race and ethnicity, socioeconomic status, and geographic isolation as factors affecting equity in the goals
2. Revise the goals and objectives to use child- and family-centric language
3. Elaborate on how service sectors can collaborate with each other in the objectives
4. Incorporate information on strategies organizations can implement to address bias and racism into the objectives
5. Continue to use the goals and objectives
Recommendations for research and measurement
1. Invest in research to better understand the underlying and structural causes of health inequities (such as racism), the impact of interpersonal racism on CYSHCN and their families, and approaches to address racism
2. Advocate for and/or develop measures for CYSHCN that are stratified by race, ethnicity and other factors to enable monitoring of health disparities
3. Require measurement of health disparities in grants and programs as a condition of funding
4. Promote data sharing across agencies and organizations to address health disparities
Policy recommendations
1. Encourage stakeholders to think about how to address the ways in which Medicaid exacerbates inequity
2. Streamline processes through which families of CYSHCN apply for services to shift the burden from families to systems
3. Help states collect and analyze data to identify disparities and factors that contribute to them
4. Develop a diverse workforce to serve CYSHCN and their families through targeted recruitment efforts and redesigned provider reimbursement structure
5. Create funding opportunities that enable researchers to access Medicaid data to study inequities in health care access
6. Address inequities in the child welfare system due to implicit bias, and focus on preventing child maltreatment
7. Standardize processes for developmental disability screening and referrals
Recommendations for practice
1. Include diverse families of CYSHCN in work to address health equity and empower them to be equal partners by providing information in multiple languages, compensating them for their time, and elevating the contributions they bring based on their lived experiences, their cultures, and their protective factors
2. Facilitate the building of coalitions with community organizations and leaders increase trust between families and service providers
3. Facilitate service provider training on racism and implicit bias
4. Partner with individuals who experience racism to create culturally responsive and culturally humble interventions and policy
5. Encourage service providers to share their personal experiences with their own special needs or the special needs of family and friends to foster trust

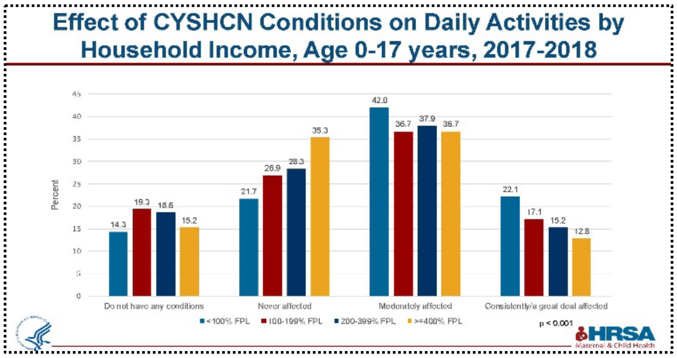
Notes: The table includes all participant recommendations made in response to the health equity presentations and discussions during the Summit Series kick-off session and follow-up discussion, regardless of whether participants' comments pertained to the topic area of focus.

CYSHCN = children and youth with special health care needs; HRSA = Health Resources and Services Administration; SDOH = social determinants of health; TA = technical assistance.

B. Family and child well-being and quality of life

During the Summit Series kick-off session, HRSA noted that focusing on family and 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 divisions affecting them and their children,” while recognizing that families may value functional outcomes, and physical, emotional, cognitive and social concerns as much as medical concerns. HRSA highlighted disparities in well-being and quality of life, noting that families with incomes below the federal poverty level were most likely to report that CYSHCN affected their household’s daily activities (Figure II.4). HRSA specified four goals and nine objectives in this topic area (Appendix A). Invited speaker Cara Coleman (Family Voices) then described the need to look holistically at CYSHCN and families, acknowledging that disability is only one factor among many that affects well-being and quality of life. She described two ways in which a more holistic approach can be taken: (1) use qualitative measures that assess the whole child and family and their dignity, autonomy, and independence—including measures of the overall life experiences of CYSHCN and their families, not simply their satisfaction with provider encounters; (2) develop the professional workforce so that it promotes and supports communication outside of health care and social service provider silos and also includes families as partners. Ms. Coleman emphasized the role that shared decision making can play in promoting and supporting communication and collaboration.

Figure II.4. Effect of CYSHCN conditions on daily activities by household income, age 0-17 years 2017-2018



Source: Summit Series kick-off session, September 22, 2020.

During the follow-up discussion session, invited speaker Dana Yarbrough (Center for Family Involvement) discussed the importance of measuring CYSHCN and family quality of life and encouraged participants to think about whose definition is being used (such as the child’s, the parent’s, the provider’s, or the payor’s definition) when discussing quality-of-life indicators.

Next, invited speaker Elizabeth Stout (Family Center) explained how shared decision making should consider quality-of-life outcomes and emphasized that providers serving CYSHCN and their families should ask about quality of life outside of the medical realm, as well as how taking quality of life into consideration can build closeness and compassion between providers and CYSHCN and their families.

In Table II.3, we summarize all participant recommendations made in response to the family and child well-being and quality-of-life presentations and discussions during the Summit Series, including recommendations from invited speakers related to family and child well-being and quality of life. The recommendations are grouped in four categories: (1) recommended revisions to the goals and objectives of the Blueprint, (2) recommendations for research and measurement, (3) policy recommendations, and (4) recommendations for practice, including those related to workforce, training, and partnerships. In Appendix E, Table E.2, we provide greater detail about each recommendation and whether it was made by one or multiple Summit participants.

Table II.3. Participant recommendations for family and child well-being and quality of life

Participant recommendation
Revisions to the goals and objectives of the Blueprint
1. Add missing concepts to the goals and objectives: (1) the need for CYSHCN and their families to be able to choose their providers and services, and (2) the link between QOL and timely identification of special needs
2. Revise the goals and objectives to use child- and family-centric language, such as removing the term “resiliency”
3. Include input from national workforce experts
4. Continue to use the goals and objectives
Recommendations for research and measurement
1. Identify and/or develop measures to assess child and family well-being and QOL from new perspectives, including measures that take into account the diversity of the CYSHCN population
2. Invest in more research on specific programs, such as the Pediatric Palliative Care Network
Policy recommendations
1. Use payment policies to compel systems to work across sectors and measure well-being and QOL
2. Sustain newly identified activities emerging from the novel coronavirus pandemic
3. Promote data sharing across providers
4. Establish checkpoints throughout childhood to enable identification of CYSHCN and connection to services
5. Conduct an awareness campaign to help families and providers learn about available resources
Recommendations for practice
1. Meaningfully include families in this work, including developing well-being and QOL measures, and compensate them for their time and efforts
2. Encourage Title V to (1) actively engage families and (2) expand improvements from the state level to the national level
3. Train the workforce on disability, well-being, and QOL
4. Identify the unique needs of each community
5. Build on existing constructs that outline disability as a natural human experience
6. Structure grant programs to require cross-sector partnerships

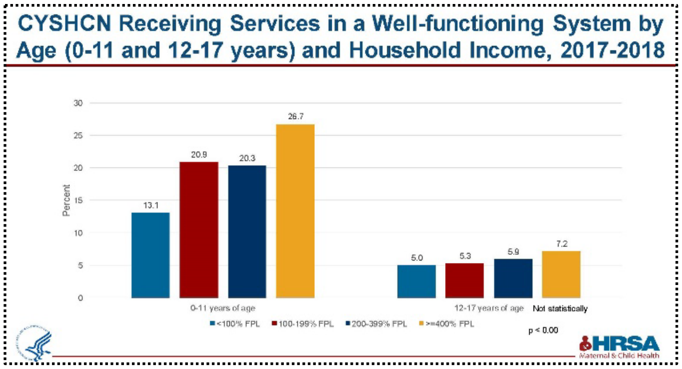
Notes: The table includes all participant recommendations made in response to the family and child well-being and quality-of-life presentations and discussions during the Summit Series kick-off session and follow-up discussion, regardless of whether participants’ comments pertained to the topic area of focus.

CHIP = Children's Health Insurance Program; CYSHCN = children and youth with special health care needs; HRSA = Health Resources and Services Administration; QOL= quality of life.

C. Access to services and supports

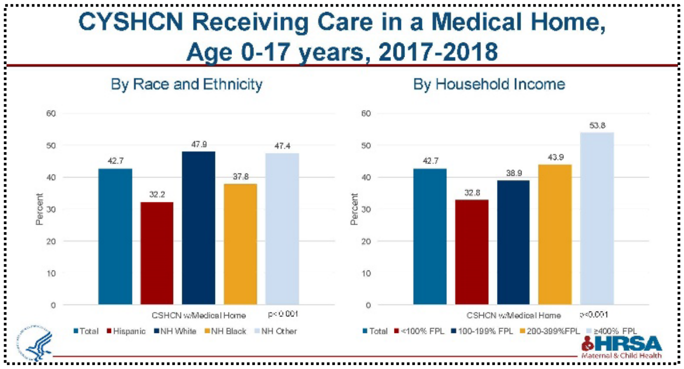
During the Summit Series kick-off session, HRSA defined access to services and supports broadly as including four components of health care access: coverage, services, timeliness, and workforce. HRSA described racial, ethnic and socioeconomic disparities in access to services and supports, noting that CYSHCN whose families have lower incomes are less likely to receive services in a well-functioning system (Figure II.5), and that CYSHCN who are Black and Hispanic, and whose families have lower incomes are less likely to receive care in a medical home (Figure II.6). HRSA specified seven goals and nine objectives in this topic area (Appendix A). Invited speaker Sharifa Peart (Georgia Department of Public Health) described how CYSHCN and their families need access to a range of services and supports to address their needs and how current systems of services are overwhelmingly complex and require CYSHCN and their families to invest large amounts of time and energy to access the services and supports they need. Ms. Peart then described six ways stakeholders can improve access to services and supports for CYSHCN and their families: (1) by collaborating with Title V to leverage what these programs have to offer for serving CYSHCN and their families; (2) by developing the workforce to address the growing provider shortage gap; (3) by creating opportunities for diverse groups of families to engage in quality improvement efforts for CYSHCN and their families; (4) by coordinating care across systems, particularly during the transition from pediatric to adult care; (5) by streamlining eligibility processes to take the burden off CYSHCN and their families as well as providers; and (6) by making investments and connections—in areas such as housing, transportation, and economic development—to support communities that are remote, rural, underserved, under-resourced, and underfunded.

Figure II.5. CYSHCN receiving services in a well-functioning system by age (0-11 and 12-17 years) and household income, 2017-2018



Source: Summit Series kick-off session, September 22, 2020.

Figure II.6. CYSHCN receiving care in a medical home, age 0-17 years, 2017-2018



Source: Summit Series kick-off session, September 22, 2020.

During the follow-up discussion session, invited speaker Elaine Gabovitch (Massachusetts Department of Health) described her own challenges accessing services and supports for her child, who has special needs, and noted that low-income and non-English speaking families face additional barriers accessing services. Ms. Gabovitch said that Title V can improve access to services and supports by building coalitions to develop upstream solutions, such as investing in workforce development, facilitating data sharing across systems, and fostering true family partnership and engagement. She noted that the COVID-

19 pandemic has shined a light on racial and economic disparities and placed additional burdens on families, but it has also spurred innovative partnerships and demonstrated the potential of telehealth to expand access to services and supports.

Next, invited speaker Dr. Rishi Agrawal (Lurie and La Rabida Children's Hospitals) spoke about the importance of broadly defining services and supports to include those that address social and economic factors, which have a larger impact on health outcomes than health care factors. He recommended the development of new measures and data sources to assess housing instability, food insecurity, discrimination, and caregiver support. He also recommended that public health stakeholders serve as conveners of CYSHCN and their families to help them build supportive social networks.

In Table II.4, we summarize all participant recommendations made in response to the access to services and supports presentations and discussions during the Summit Series, including recommendations from invited speakers related to access to services and supports. The recommendations are grouped in four categories: (1) recommended revisions to the goals and objectives of the Blueprint, (2) recommendations for research and measurement, (3) policy recommendations, and (4) recommendations for practice, including those related to workforce, training, and partnerships. In Appendix E, Table E.3, we provide greater detail about each recommendation and whether it was made by one or multiple Summit participants.

Table II.4. Participant recommendations for access to services and supports

Participant recommendation
Revisions to the goals and objectives of the Blueprint
1. Incorporate out-of-state care considerations into the goals and objectives
2. Add schools as a critical point of identification and coordination of services in the goals and objectives
Recommendations for research and measurement
1. Invest in research on (1) the value of early screening and intervention, (2) the impact of Medicaid managed care on CYSHCN, and (3) the impact of telehealth services
2. Develop family-centered measures, such as measures assessing family functioning and caregiver depression
Policy recommendations
1. Promote the use of telehealth and address its challenges
2. Expand the ways in which stakeholders identify and track CYSHCN, including developing a consensus definition of CYSHCN
3. Promote data sharing across organizations and sectors, including Medicaid agencies, education departments, Title V, and Medicaid managed care
4. Support PCPs in their work with CYSHCN through education, opportunities to obtain certification for psychiatry services, and higher reimbursement rates
5. Address SDOH-related barriers to accessing services and supports
6. Expand existing HRSA adolescent health programs to include CYSHCN
7. Facilitate collaboration between Title V and Medicaid
8. Consider access challenges in rural and frontier regions
Recommendations for practice
1. Invest in family engagement strategies and foster connections among families of CYSHCN
2. Facilitate cross-agency partnerships
3. Facilitate opportunities for CYSHCN and their families to connect with service providers in unique settings
4. Develop a diverse workforce to serve CYSHCN and their families
5. Ensure that the workforce includes community health workers
6. Promote interdisciplinary care teams to increase access to services and better support CYSHCN
7. Invest in case management to help CYSHCN and their families receive necessary services and supports

Table II.4 (*continued*)

Participant recommendation
8. Streamline service and support enrollment processes
9. Simplify navigation of community- and home-based services and supports
10. Educate families and providers on SSI

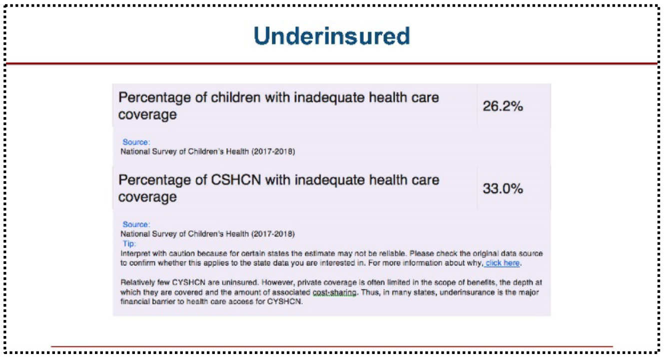
Notes: The table includes all participant recommendations made in response to the access to services and supports presentations and discussions during the Summit Series kick-off session and follow-up discussion, regardless of whether participants' comments pertained to the topic area of focus.

CMS = Centers for Medicare & Medicaid Services; CYSHCN = children and youth with special health care needs; HRSA = Health Resources and Services Administration; PCP = primary care provider; SDOH = social determinants of health; SSI = Supplemental Security Income; TA = technical assistance.

D. Financing of services

During the Summit Series kick-off session, HRSA defined financing of services broadly as including financing, payment models and insurance, and encompassing models that aim to improve a range of outcomes valued by families, provider, payors, and other stakeholders. HRSA specified four goals and eleven objectives in this topic area (Appendix A). Invited speaker Dr. Jeff Schiff (AcademyHealth) described how financing services is part of the larger goal of improving the quality of life for CYSHCN and their families, and noted that CYSHCN are more likely to have inadequate insurance than children overall (Figure II.7). Dr. Schiff stated that there is much work to do to improve the financing system and that thinking about it can be overwhelming. He emphasized the need to practice "radical incrementalism"— making small, strategic shifts in the system rather than creating a new system from scratch. Dr. Schiff then described ways to improve the financing system: (1) by forming coalitions with policymakers, with CYSHCN and their families playing a central role in the coalitions; (2) by sharing quantitative and qualitative data to prove the value of making changes to the financing system; and (3) by developing skills for policy implementation, including promoting collaboration between Medicaid agencies and Title V. He noted that payors share the goal of improving care and want to collaborate with other stakeholders to improve the financing system. He concluded by describing financing system opportunities stemming from the novel coronavirus pandemic and social justice challenges, including opportunities to increase the breadth and depth of telehealth and care coordination, share records better, expand the treatment community, screen for and address social drivers of health, and link measurement of care processes to outcomes.

Figure II.7. Underinsurance among children and CSHCN, 2017-2018



Underinsured

Percentage of children with inadequate health care coverage	26.2%

Source:
National Survey of Children's Health (2017-2018)

Percentage of CSHCN with inadequate health care coverage	33.0%

Source:
National Survey of Children's Health (2017-2018)
Tip:
Interpret with caution because for certain states the estimate may not be reliable. Please check the original data source to confirm whether this applies to the state data you are interested in. For more information about why, click here.

Relatively few CYSHCN are uninsured. However, private coverage is often limited in the scope of benefits, the depth at which they are covered and the amount of associated cost-sharing. Thus, in many states, underinsurance is the major financial barrier to health care access for CYSHCN.

Source: Summit Series kick-off session, September 22, 2020.

During the follow-up discussion session, invited speaker Karen Van Landeghem (National Academy for State Health Policy) specified three actions stakeholders can take to improve financing of services for CYSHCN: (1) develop greater shared understanding among families, providers, and payors on insurance coverage and provider reimbursement around what services should be covered, (2) implement financing reforms that create systemic change through innovative models like integrated care delivery and value-based payment, and (3) leverage states' current movement toward focusing on children and adults with special health care needs.

Next, invited speaker Dr. Ben Hoffman (Oregon Health & Science University) described how health inequities result from misalignment between the services that are reimbursable by payors and the services that are valued by patients and from lower reimbursement rates in Medicaid compared to Medicare and private insurance. To address this issue, he recommended implementing alternative payment mechanisms and shifting resources from health care into SDOH supports like housing and employment assistance for caregivers.

Last, invited speaker Meg Comeau (Boston University) described how financing is a foundation for the other three topic areas in the Blueprint: poverty is a factor that leads to health inequities, financial hardship affects CYSHCN and family quality of life, and inadequate financing limits CYSHCN and family access to services and supports. She said that, even though the novel coronavirus negatively impacts state and federal budgets, new opportunities for financing reform have emerged and that Title V can play a role building and strengthening partnerships with stakeholders to implement financing reform.

In Table II.5, we summarize all participant recommendations made in response to the financing of services presentations and discussions during the Summit Series, including recommendations from invited speakers related to financing. The recommendations are grouped in four categories: (1) recommended revisions to the goals and objectives of the Blueprint, (2) recommendations for research and measurement, (3) policy recommendations, and (4) recommendations for practice, including those related to workforce, training, and partnerships. In Appendix E, Table E.4, we provide greater detail about each recommendation and whether it was made by one or multiple Summit participants.

Table II.5. Participant recommendations for financing of services

Participant recommendation
Revisions to the goals and objectives of the Blueprint
1. Identify stakeholders to lead the work to achieve the goals and objectives
2. Note available federal funding opportunities for behavioral health services in the goals and objectives
Recommendations for research and measurement
1. Invest in research on (1) approaches to payment reform, (2) care coordination, (3) the identification of CYSHCN in Medicaid datasets, and (4) societal costs for serving CYSHCN
2. Use health and QOL measures to assess CYSHCN services and incentivize improvement
3. Collect data on CYSHCN subpopulations
Policy recommendations
1. Encourage payors to finance services and supports that promote holistic health for CYSHCN and families
2. Develop and/or support innovative funding structures
3. Advocate for Medicaid-Medicare parity
4. Create an insurance assistance program and address challenges CYSHCN and their families face with insurance network requirements and continuity
5. Aim for strategic, incremental change
6. Identify ways to integrate specialty care into medical homes

Table II.5 (*continued*)

Participant recommendation
Recommendations for practice
1. Improve care coordination for CYSCHN
2. Build and facilitate trusting partnerships to support comprehensive care
3. Create opportunities for CYSHCN and their families to be equal partners in this work
4. Develop definitions, talking points, and tools to support stakeholders in this work

Notes: The table includes all participant recommendations made in response to the financing of services presentations and discussions during the Summit Series kick-off session and follow-up discussion, regardless of whether participants' comments pertained to the topic area of focus.

CMC = children with medical complexity; CMS = Centers for Medicare & Medicaid Services; CYSHCN = children and youth with special health care needs; ED = emergency department; HRSA = Health Resources and Services Administration; PCP = primary care provider; QOL = quality of life.

III. Cross-Cutting Considerations to Guide Strategic Programming

The four topic areas, though discussed separately during the Summit Series, are connected to each other. Thus, several participant recommendations, from a broad perspective, apply to multiple topic areas. In this chapter, we highlight participants' cross-cutting recommendations. We then conclude by outlining potential next steps for the field in advancing and improving systems of services for CYSHCN and their families.

A. Cross-cutting recommendations

Participants offered 14 recommendations to HRSA that apply to more than one topic area, indicating that these recommendations may be of highest priority to participants and other stakeholders in the field of CYSHCN. Of the 14 recommendations, five apply to every topic area: (1) add missing concepts to the goals and objectives, (2) invest in research on various relevant issues, (3) advocate for and/or develop relevant measures, (4) build or facilitate relevant stakeholder partnerships, and (5) empower and support CYSHCN and their families to be equal partners in achieving the goals and objectives (Table III.1). The first recommendation pertains to updates that HRSA can make to the Blueprint across all topic areas, while the other recommendations suggest strategies to address the goals and objectives of the Blueprint through research, measurement, partnership building, and engaging consumers.

Table III.1. Cross-cutting participant recommendations

	Topic area			
Participant recommendation at a broad level[a]	Health equity	Family and child well-being and quality of life	Access to services and supports	Financing of services
1. Add missing concepts to the goals and objectives	X	X	X	X
2. Invest in research on various relevant issues	X	X	X	X
3. Advocate for and/or develop relevant measures	X	X	X	X
4. Build or facilitate relevant stakeholder partnerships	X	X	X	X
5. Empower and support CYSHCN and their families to be equal partners in achieving the goals and objectives	X	X	X	X
6. Promote data sharing across providers, organizations, and sectors	X	X	X	
7. Train the workforce	X	X	X	
8. Promote the use of telehealth		X	X	X
9. Revise the goals and objectives to use child- and family-centric language	X	X		
10. Continue to use the goals and objectives	X	X		
11. Develop a diverse workforce	X		X	
12. Streamline and simplify systems of services	X		X	
13. Incorporate payment policies and reforms into strategy development		X		X
14. Encourage stakeholders to think about how to address the ways in which Medicaid exacerbates inequity	X			X

[a] Detailed information on participant recommendations is in Chapter II and Appendix E.

CYSHCN = children and youth with special health care needs.

B. Next steps

HRSA plans to use the information in these proceedings, as well as other sources of information, to further develop and refine the Blueprint, finalizing it in summer 2021. HRSA will then use the Blueprint to develop a strategy for serving CYSHCN and their families over the next 15 years. In addition, stakeholders in the field of CYSHCN may use the information in these proceedings, the Blueprint, and HRSA's 15-year strategy to guide their work in advancing and improving systems of services for CYSHCN and their families.

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Appendix A:

Topic Area Definitions, Goals, and Objectives

Table A.1. Health equity definition, goals, and objectives

Health equity

Definition

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.

Goals

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

Objectives

1. Structural and systemic policies that further inequalities are dismantled and replaced. Policies and programs recognize and address the barriers to health equity: poverty and discrimination and their downstream consequences.
2. Interventions at the child/family level are undertaken to improve access to services, programs, and support that will increase the ability of children and families to thrive no matter their circumstance.
3. Interventions are designed and implemented within a context of cultural humility and are considerate of the medical and environmental circumstances of the child.
4. 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.
5. Public health data systems support public health surveillance and services for all CYSHCN with emphasis on subgroups of CYSHCN that are most vulnerable.
6. All sectors actively coordinate: education; housing and community development; business; law enforcement and safety; built environment; government; community advocates; health care; nonprofits; transportation to achieve and ensure health equity for CYSHCN.

CYSHCN = children and youth with special health care needs.

Table A.2. Family and child well-being and quality of life definition, goals, and objectives

Family and child well-being and quality of life

Definition

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. It also recognizes that functional outcomes, as well as physical, emotional, cognitive and social concerns are as important as medical concerns.

Goals

1. 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.
2. Care systems are integrated and prioritize quality of life and well-being for CYSHCN and families.
3. 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.
4. 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; payment and are tied to payment models that use quality-of-life outcomes.

Objectives

1. Interventions and policies are implemented to support protective, improved quality-of-life factors for CYSHCN and families, e.g., supportive and stable relationships, positive parenting practices, healthy family dynamics.
2. Interventions and policies are implemented to promote and support resilience and enhanced self-management capacities for CYSHCN and their families.
3. Shared decision making between families and professionals consider clinical and quality-of-life outcomes.
4. CYSHCN, families, and service providers/professionals have information and tools (e.g., care maps, guides supporting family/professional conversations, information on 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.
5. Health systems metrics include measures of child and family well-being, resiliency, and quality of life
6. Standards for data collection that improve reliability and usability of quality-of-life measures are developed and implemented.
7. The impacts of social determinants of health including systemic racism on child/family quality of life and well-being are identified and assessed.
8. Risk assessments for CYSHCN consider family/child well-being and quality of life.
9. Workforce training for professionals serving CYSHCN and their families include curriculum that emphasizes child development, family/child well-being and quality of life.

CYSHCN = children and youth with special health care needs.

Table A.3. Access to services and supports definition, goals, and objectives

Access to services and supports

Definition

Includes the four components of access to health care: coverage, services, timeliness, and workforce, as well as all other social and educational services that are necessary for CYSHCN and families to have full, thriving lives. The ideal system for these systems and supports is an integrated one: approach that is intended to align 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.

Goals

1. 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.
2. All services and supports, inclusive of health and other human service sectors, at the individual/family, community, and systems level are coordinated and ideally integrated.
3. 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 as a tool to connect families to specialists and other services to benefit the health of the child and support the family.
4. CYSHCN and their families have access to the necessary medications, equipment, supplies, and technology they need.
5. The workforce supporting CYSHCN and families are well-trained, culturally competent, accessible, and reflects the families they serve.
6. Services are easy to navigate by family and professionals.
7. Systems share information and processes (eligibility, enrollment, outcomes, and referral) across child and family serving systems.

Objectives

1. Eligibility for services and programs is streamlined across systems.
2. CYSHCN and their families receive services in a proactive manner that provide guidance and a roadmap to care.
3. Essential service system providers (public health, hospital systems, provider groups, etc.) are physically available in communities where families live.
4. 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, and are accessible to families through the modalities that are readily available and easy to use.
5. Service delivery methods, such as telehealth, are assessed for impact on child/family quality of life.
6. 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.
7. 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.
8. 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.
9. Opportunities and incentives are increased for individuals, particularly underrepresented populations, to enter training programs serving CYSHCN, with outreach to individuals with special health care needs and families and community members of diverse backgrounds who are interested in pursuing a career as a health care professional or related field to ensure access to necessary education and training.

CYSHCN = children and youth with special health care needs.

Table A.4. Financing of services definition, goals, and objectives

Financing of services

Definition

Includes financing, payment models and insurance and is intended to address both financing models that improve quality, provide return on investment, and recognize and value outcomes meaningful to different stakeholders including families, providers, and payors.

Goals

1. Health care for CYSHCN and families is financed and paid for in ways that support and maximize choice for the services they value.
2. Health insurance coverage for CYSHCN is accessible, affordable, comprehensive, and continuous to ensure access to high quality care.
3. Payment models and models of care delivery identify and assess social determinants of health and their impact on quality-of-life outcomes for CYSHCN and families and identify mechanism and supports to address them.
4. 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

1. Service systems adopt a comprehensive, inclusive definition of CYSHCN.
2. Service systems establish identification processes for improved care coordination, monitoring, and early identification of health issues.
3. Service systems consider a standard of medical necessity that takes into account a child’s health and development.
4. Service systems support team-based and enhanced primary care to support CYSHCN.
5. Care coordination is adequately financed to meet the varying levels of services needs of the child and family and are assessed through outcomes measures including family experience, integration across medical, social, behavioral sectors, and quality of life for CYSHCN and families.
6. Information technology and virtual communication, including telehealth and other evolving care solutions identified by families and CYSHCN are adequately financed.
7. 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.
8. Integrated care across service sectors is adequately financed, monitored, and evaluated.
9. 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 well-being and resiliency.
10. Financing mechanisms support quality care through innovative approaches (e.g. paying families to deliver care).
11. Investments in health services and care delivery are balanced to encompass services that address negative consequences of social determinants of health and build resiliency.

CYSHCN = children and youth with special health care needs.

Appendix B:

CYSHCN Summit Steering Committee

Table B.1. CYSHCN Summit Steering committee

Name	Agency
Cathy Caldwell	Alabama Department of Rehabilitation Services
Cara Coleman	Family Voices
Rachel Hutson	Not reported in Summit Series registration
Dennis Kuo	University of Buffalo, Jacobs School of Medicine and Biomedical Sciences
Jennifer Kyle	UnitedHealthcare
Rylin Rodgers	Association of University Centers on Disabilities
Ed Schor	Not reported in Summit Series registration
Sharifa Peart	Georgia Department of Public Health
Debra Waldron	American Academy of Pediatrics

Appendix C:

Summit Series Participants

Table C.1. CYSHCN Summit Series participants

Name	Agency
HRSA speakers	
Michael Warren, M.D., M.P.H., F.A.A.P.	HRSA, MCHB
Treeby Williamson Brown, M.A.	HRSA, MCHB
Joan Scott, M.S., CGC®	HRSA, MCHB
Mia Morrison, M.P.H.	HRSA, MCHB
Invited speakers	
Allysa Ware	Family Voices
Amy Houtrow*, M.D., Ph.D., M.P.H.	University of Pittsburgh
Ben Hoffman, M.D.	Oregon Health & Science University
Cara Coleman*, J.D., M.P.H.	Family Voices
Dana Yarbrough	Virginia Commonwealth University, Partnership for People with Disabilities
Deborah Allen	Los Angeles County Department of Public Health
Dennis Kuo*, M.D., M.H.S.	University of Buffalo, Jacobs School of Medicine and Biomedical Sciences
Elizabeth Stout	Michigan Children's Special Health Care Services
Elaine Gabovitch	Massachusetts Department of Public Health
Jeff Schiff*, J.D., M.B.A.	AcademyHealth
Karen Van Landeghem	The National Academy for State Health Policy
Meg Comeau	Boston University
Rishi Agrawal	Lurie and La Rabida Children's Hospitals, Chicago
Sharifa Peart*, M.P.H.	Georgia Department of Public Health
Shea Cleveland*	Family Support Network of North Carolina, Family Resource Center South Atlantic
Participants	
Aimee Ossman	Children's Hospital Association
Alex Kemper	Nationwide Children's Hospital
Alison Martin	Oregon Health & Science University, Oregon Center for Children and Youth with Special Health Needs
Amy Zapata	Louisiana Department of Health
Angela Lello	Autism Speaks
Anna Christensen	Mathematica
Anna Wiencrot	Not reported in Summit Series registration
Beverley Francis-Gibson	Not reported in Summit Series registration
Bonnie Strickland	Not reported in Summit Series registration
Britta Seifert	Mathematica
Caitlyn Newhard	Mathematica
Candida Bush	Not reported in Summit Series registration
Carolyn Langer	Not reported in Summit Series registration
Cathy Caldwell	Alabama Department of Rehabilitation Services
Charlene Shelton R.N., M.P.A., Ph.D.	CYSHCNet National Research Network, University of Colorado
Charles Smith	Oregon Health & Science University, Oregon Family-to- Family Health Information Center
Christie Mackie	Not reported in Summit Series registration
Christina Boothby	American Academy of Pediatrics
Christopher Blackmon	HRSA, Office of Epidemiology and Research
Christopher Stille	University of Colorado

Table C.1 (*continued*)

Name	Agency
Christy Bethell	Not reported in Summit Series registration
Christy Kavulic	Not reported in Summit Series registration
Cindy Mann	Not reported in Summit Series registration
Colleen Morris	Not reported in Summit Series registration
Colleen Sonosky	Department of Health Care Finance, District of Columbia
Danielle Laraque-Arena	New York Academy of Medicine
Dawn Bailey	Arizona Department of Health, Maternal and Child Health/Title V Program
Dawn Levinson	Not reported in Summit Series registration
Deb Wagler	HRSA, MCHB
Debbie Badawi	University of Maryland School of Medicine
Debi Sarkar	HRSA, MCHB
Deborah Garneau	Rhode Island Department of Health
Debra Waldron	American Academy of Pediatrics
Denise Dougherty	AcademyHealth
Dorothy Cilenti	University of North Carolina
Ed Schor	Not reported in Summit Series registration
Elaine Chhean	National Governor’s Association
Ellen Pliska	Association of State and Territorial Health Officials
Ellen Volpe	HRSA, MCHB, Division of State and Community Health
Ellen-Marie Whelan	Not reported in Summit Series registration
Emily Robinson	West Virginia Statewide Independent Living Council and Youth as Self-Advocates
Enrique Martinez-Vidal	Association for Community-Affiliated Plans
Eric Levey	Health Services for Children with Special Needs, Inc.
Erin Paton	Not reported in Summit Series registration
Georgina Peacock	Centers for Disease Control and Prevention, Division of Human Development and Disability
Gerri Mattson	Not reported in Summit Series registration
Gil Liu	Not reported in Summit Series registration
Hakim Fobia	HRSA, MCHB
Hannah Kotz	HRSA
Heather Smith	Kansas Department of Health and Environment
Hoangmai Pham	Institute for Exceptional Care
Holly Henry	Lucile Packard Foundation for Children’s Health
James Perrin	MassGeneral Hospital for Children, Harvard Medical School
Jamin Johnson	Wyoming Department of Health
Jane Perkins	National Health Law Program
Janet DesGeorges	Hands & Voices
Jay Berry	Boston Children’s Hospital, Harvard Medical School
Jean Willard	University of Iowa Child Health Specialty Clinics
Jeanette NuMan	Sickle Cell Foundation of Georgia, Inc.
Jed Miller	Maryland Department of Health
Jeffrey Brosco	University of Miami Department of Pediatrics
Jennifer Fiedelhotz	HRSA, MCHB
Jennifer Johnson	HHS, ACL, AoD
Jennifer Kyle	UnitedHealthcare
Jennifer Lail	Jennifer Lail, LLC
Jessica Teel	HRSA, MCHB
Jill Bohnenkamp	National Center for School Mental Health

Table C.1 (*continued*)

Name	Agency
Johanna Bergan	Youth MOVE National
John Richards	Georgetown University/National Center for Education in Maternal and Child Health
Judith Palfrey	Boston Children’s Hospital
Julia Bascom	Autistic Self Advocacy Network
Kara Ayers	Cincinnati Children’s Hospital Medical Center
Karen Thompson	ASK Resource Center, Inc.
Karen VanLandeghem	National Academy for State Health Policy
Karl White	Utah State University
Kasey Farrell	Not reported in Summit Series registration
Kate Bradford	Not reported in Summit Series registration
Kate Honsberger	National Academy for State Health Policy
Kate Taft	Association of Maternal & Child Health Programs
Katherine Beckmann	David and Lucile Packard Foundation
Katherine McLaughlin	Not reported in Summit Series registration
Kathleen Noonan	Camden Coalition
Kelly Buckland	National Council on Independent Living
Khanh Nguyen	National Conference of State Legislatures
Kim Morriosn	HRSA, MCHB, DSCSHN
Krista Scott	Robert Wood Johnson Foundation
Laura Kavanagh	HRSA, MCHB
Lauren Ramos	HRSA, MCHB
Lauren Tobias	Not reported in Summit Series registration
Leticia Manning	HRSA, MCHB, DSCSHN
Lily Brown	Parent to Parent USA
Lis Harkins	Not reported in Summit Series registration
Lisa Simpson	HRSA, MCHB
Lolita McLean	Not reported in Summit Series registration
Lynda Gargan	National Federation of Families
Lynn Davidson	Not reported in Summit Series registration
Mabatemije Otubu	HRSA, MCHB, DSCSHN, Genetic Service Branch
Maia Banks	HRSA
Manda Hall	Texas Department of State Health Services
Marco Beltran	ACF, Office of Head Start
Marcus Allen	Virginia Department of Health
Maria Paz Carolos	Not reported in Summit Series registration
Mary Emanuele	Not reported in Summit Series registration
Mary Kay Kenney	HRSA, MCHB
Megumi Okumura	University of California, San Francisco
Meredith Pyle	Not reported in Summit Series registration
Michael Kogan	HRSA, MCHB
Michael Sauter	HRSA, MCHB
Michele Lawler	HRSA, MCHB
Michelle Koplitz	HRSA, MCHB, DSCSHN
Mirean Coleman	National Association of Social Workers
Miya Asato	Children’s Hospital
Monique Fountain Hanna	HRSA, MCHB, DVHECS
Mynti Hossain	Mathematica
Natasha Bonhomme	Not reported in Summit Series registration

Table C.1 (*continued*)

Name	Agency
Neal Halfon	Not reported in Summit Series registration
Nora Wells	Family Voices
Pamella Vodicka	HRSA, MCHB, Division of Child, Adolescent and Family Health
Patience White	Got Transition
Paul Shattuck	Mathematica
Rachel Hutson	Not reported in Summit Series registration
Rebecca Seltzer	Johns Hopkins University
Reem Ghandour	HRSA, MCHB, Office of Epidemiology and Research
Renee Turchi	Not reported in Summit Series registration
Richard Antonelli	Boston Children's Hospital
Robert Karch	Florida Department of Health
Robin Harwood	Not reported in Summit Series registration
Rylin Rodgers	Association of University Centers on Disabilities
Sadeeka Scott	HHS, Boston Public Health Commission
Sandra Battiste	HRSA, MCHB
Sara Kinsman	HRSA, MCHB
Sarah McLellan	HRSA, MCHB
Shirley Johnson	SPAN Parent Advocacy Network
Shirley Payne	Not reported in Summit Series registration
Soohyun Kim	HRSA
Stephen Fitton	Fitton Consulting
Susan Chacon	New Mexico Department of Health
Susan Colburn	Children's Rehabilitation Service, Alabama Department of Rehabilitation Services
Suzanne Swan	New York State Department of Health
Suzette Oyeku	Children's Hospital at Montefiore, Albert Einstein College of Medicine
Sydney Rice	University of Arizona
Tarra Thomas	Montana Parent Partner Program
Tawny Holmes Hlibok	National Association of the Deaf
Teresa Marks	Not reported in Summit Series registration
Teresa Nguyen, M.P.H.	Not reported in Summit Series registration
Thomas Scholz	University of Iowa
Valeria Tarantino	HRSA
Yasmin Mazloomdoost	HRSA, MCHB, DSCSHN
Yetta Myrick	Not reported in Summit Series registration

Notes: This participant list is based on the "Attendee List" tab in the CYSHCN Summit Series portal and includes only information entered by attendees in the portal. Asterisk denotes kick-off session speakers.

ACF = Administration for Children and Families; ACL = Administration for Community Living; AoD = Administration on Disabilities; DSCSHN = Division of Services for Children with Special Health Needs; DVHECS = Division of Home Visiting and Early Childhood Systems; HHS = U.S. Department of Health and Human Services; HRSA = Health Resources and Services Administration; MCHB = Maternal and Child Health Bureau.

Appendix D:

Summit Series Session Agendas

Table D.1. CYSHCN Summit Series agenda for kick-off session

	TIME
SETTING THE STAGE	**2:00 PM**
Joan A. Scott, MS, CGC Director, Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration	
THE ROLE OF MCHB IN UNDERSTANDING AND BUILDING THE SYSTEM OF CARE FOR CYSHCN	**2:10 PM**
Michael D. Warren, MD, MPH, FAAP Associate Administrator Maternal and Child Health Bureau Health Resources and Services Administration	
IMPACT OF COVID-19 PUBLIC HEALTH EMERGENCY ON CYSHCN, FAMILIES, AND SYSTEMS OF SERVICES	**2:25 PM**
Dennis Z. Kuo, MD, MHS Associate Professor and Division Chief General Pediatrics University of Buffalo Jacobs School of Medicine and Biomedical Sciences **Shea Cleveland** Program Coordinator Family Support Network of North Carolina	
OVERVIEW OF KEY TOPIC AREA DISCUSSIONS	**2:45 PM**
Treeby Williamson Brown, MA Chief, Integrated Services Brand Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration **Key Topic Areas:** • Health Equity • Family/Child Well-being and Quality of Life • Access to Services and Supports • Financing of Services	
TOPIC AREA 1: HEALTH EQUITY	**2:55 PM**
Amy Houtrow, MD, PhD, MPH Professor of Physical Medicine and Rehabilitation and Pediatrics University of Pittsburgh	

Table D.1 (*continued*)

	TIME
HEALTH EQUITY: DISCUSSION/Q+A	**3:10 PM**
Treeby Williamson Brown, MA Chief, Integrated Services Brand Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration **Mia Morrison, MPH** Senior Public Health Analyst Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration	
TOPIC AREA 2: FAMILY/CHILD WELL BEING AND QUALITY OF LIFE	**3:15 PM**
Cara L. Coleman, JD, MPH Program Manager Family Voices	
FAMILY/CHILD WELL BEING AND QUALITY OF LIFE: DISCUSSION/Q+A	**3:30 PM**
Treeby Williamson Brown, MA Chief, Integrated Services Brand Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration **Mia Morrison, MPH** Senior Public Health Analyst Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration	
BREAK	**3:35 PM**
TOPIC AREA 3: ACCESS TO SERVICES AND SUPPORTS	**3:40 PM**
Sharifa Peart, MPH Children and Youth with Special Health Care Needs Program Director Georgia Department of Public Health	
ACCESS TO SERVICES AND SUPPORTS: DISCUSSION/Q+A	**3:55 PM**
Treeby Williamson Brown, MA Chief, Integrated Services Brand Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration **Mia Morrison, MPH** Senior Public Health Analyst Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration	

Table D.1 (*continued*)

	TIME
TOPIC AREA 4: FINANCING OF SERVICES	**4:00 PM**
Jeff Schiff, MD, MBA Senior Scholar Academy Health	
FINANCING OF SERVICES: DISCUSSION/Q+A	**4:15 PM**
Treeby Williamson Brown, MA Chief, Integrated Services Brand Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration **Mia Morrison, MPH** Senior Public Health Analyst Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration	
WRAP-UP AND CHARGE TO GROUP	**4:20 PM**
Treeby Williamson Brown, MA Chief, Integrated Services Brand Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration **Joan A. Scott, MS, CGC** Director, Division of Services for Children with Special Health Needs Maternal and Child Health Bureau Health Resources and Services Administration	
ADJOURN	**4:30 PM**

Table D.2. CYSHCN Summit Series agenda for follow-up discussions

Agenda	Time
Introduction and Instructions for Discussion	10 minutes
Reflections on Focus Area from Invited Discussants	15 minutes
Small Group Discussion Break Outs	55 minutes
Large Group Reconvening	5 minutes
Next Steps	5 minutes

Appendix E:

Participant Recommendations and Descriptions

Table E.1. Participant recommendations for health equity

Participant recommendation	Description
Revisions to the goals and objectives of the Blueprint	
1. Note the roles of ACEs, race and ethnicity, socioeconomic status, and geographic isolation as factors affecting equity in the goals	Multiple participants recommended that the goals should reflect that ACEs, race and ethnicity, socioeconomic status, and geographic isolation in rural and frontier regions are factors that can lead to inequity. One participant recommended that HRSA consider focusing the goals and objectives on race and ethnicity, noting that the Blueprint may complement Healthy People 2030, which does not focus on racial differences.
2. Revise the goals and objectives to use child- and family-centric language	Two participants recommended that the Blueprint use language that communicates that CYSHCN and their families are partners in this work, with power and responsibility to address health equity, rather than just recipients of care and services.
3. Elaborate on how service sectors can collaborate with each other in the objectives	Two participants recommended that the goals elaborate on opportunities for cross-sector collaboration, particularly for the business service sector and for stakeholders in various sectors that prevent and respond to ACEs—such as child welfare and Medicaid agencies. One participant added that it is important to describe the economic impacts of health disparities and engage the business sector in conversations about health equity.
4. Incorporate information on strategies organizations can implement to address bias and racism into the objectives	One participant recommended that strategies such as implicit bias training be added to the objectives to elaborate on how organizations can address bias and racism.
5. Continue to use the goals and objectives	One participant noted that the goals resonated with them.
Recommendations for research and measurement	
1. Invest in research to better understand the underlying and structural causes of health inequities (such as racism), the impact of interpersonal racism on CYSHCN and their families, and approaches to address racism	Multiple participants recommended additional investment in research on health inequity. Specifically, participants stated that research is needed on the underlying and structural causes of health inequity (including racism), the impact of health inequity on caregivers, the impact of interpersonal racism on CYSHCN and their families, the testing of approaches to address racism, and detailed findings from National Survey of Children's Health data. One participant added that a more detailed research framework is necessary to help improve understanding of the underlying causes of health inequity, rather than the currently used framework, which is reductionist. Participants said that systems and states can use the research to inform policy changes.
2. Advocate for and/or develop measures for CYSHCN that are stratified by race, ethnicity and other factors to enable monitoring of health disparities	Multiple participants stated a need for measures for CYSHCN that are stratified by race, ethnicity, and other factors. Participants recommended that the Medicaid Child Core Set measures include a measurement framework to monitor SDOH and unequal treatment. Two participants noted that this recommendation includes work to standardize data collection.
3. Require measurement of health disparities in grants and programs as a condition of funding	One participant recommended that programs require measurement of health disparities as a condition for funding.
4. Promote data sharing across agencies and organizations to address health disparities	One participant recommended promoting data sharing across agencies and organizations, as the lack of data sharing is a barrier to addressing health disparities.

Table E.1 (*continued*)

Participant recommendation	Description
Policy recommendations	
1. Encourage stakeholders to think about how to address the ways in which Medicaid exacerbates inequity	Multiple participants recommended encouraging stakeholders to think about how to address the ways in which Medicaid exacerbates inequity, racism, and discrimination.
2. Streamline processes through which families of CYSHCN apply for services to shift the burden from families to systems	A few participants recommended streamlining how CYSHCN and their families apply for services to shift burden from families to systems. Participants suggested a single point-of-entry application that identifies families for several health and social needs at once.
3. Help states collect and analyze data to identify disparities and factors that contribute to them	A few participants recommended support for states to collect and analyze data to identify systems, structures, and policies that perpetuate disparities. This support can include guidance on data collection and analysis techniques, such as oversampling racial and ethnic minority groups and stratifying data by region, to obtain more accurate information on disparities. It can also include technical assistance.
4. Develop a diverse workforce to serve CYSHCN and their families through targeted recruitment efforts and redesigned provide reimbursement structure	A few participants recommended targeted recruitment efforts to ensure that providers serving CYSCHN and their families are from diverse communities. One participant added that one way to support this work is by redesigning the provider reimbursement structure to compensate providers for mentoring other providers.
5. Create funding opportunities that enable researchers to use Medicaid data study inequities in health care access	Two participants noted that the cost of accessing Medicaid data prevents health services researchers from conducting research on inequities in health care access. These participants recommended non-federal funding opportunities, such as funding through AcademyHealth, to enable researchers to access Medicaid data.
6. Address inequities in the child welfare system due to implicit bias, and focus on preventing child maltreatment	Two participants recommended working with the child welfare system to address implicit bias and build supports that focus on child maltreatment prevention. One participant emphasized standardizing processes for child welfare referrals; the other noted that collaborative work can be done across health departments, social service agencies, and community organizations to build supports to prevent child maltreatment, rather than relying on punitive approaches to child maltreatment that disproportionately affect vulnerable communities.
7. Standardize processes for developmental disability screening and referrals	One participant recommended promoting universal screening for developmental disabilities and a comprehensive system to track screening, referrals, and service access., to address implicit bias and discrimination,
Recommendations for practice	
1. Include diverse families of CYSHCN in work to address health equity and empower them to be equal partners by providing information in multiple languages, compensating them for their time, and elevating the contributions they bring based on their lived experiences, their cultures, and their protective factors	Multiple participants recommended including CYSHCN and their families in work to address health inequity, encouraging stakeholders to: • Partner with a diverse group of CYSHCN and families, including those who are low-income, from rural areas, and have limited education and health literacy • Provide CYSHCN and their families with resources and information in multiple languages so that they can be seen as equal partners alongside providers and government staff (who are sometimes seen as being the most powerful partners) • Respect and elevate what CYSHCN and their families bring to partnerships via their lived experiences, their cultures, and their protective factors

Table E.1 (*continued*)

Participant recommendation	Description
1. Include diverse families of CYSHCN in work to address health equity and empower them to be equal partners by providing information in multiple languages, compensating them for their time, and elevating the contributions they bring based on their lived experiences, their cultures, and their protective factors (*continued*)	• Ensure that CYSHCN and their families are not punished or reported for communicating their viewpoints and needs. For example, families may be hesitant to disclose needs for safe housing because they are worried about child protective services taking their children away. • Use participatory needs assessments to engage and learn from CYSHCN and their families that belong to minority communities • Empower CYSHCN and their families to serve as cultural brokers in communities, particularly immigrant and refugee communities, to provide peer support and to build trusting relationships with systems partners • Use the *Family Engagement in Systems Toolkit* to drive improvements in family engagement at the systems level • Work with CYSHCN and their families to develop innovative engagement strategies that are tailored to specific cultural and community contexts • Compensate families for their time so low-income families can participate • Communicate to CYSHCN and families that true partnership can be messy and require creativity and time
2. Facilitate the building of coalitions with community organizations and leaders increase trust between families and service providers	A few participants recommended that agencies and providers build coalitions with community organizations and leaders, such as cultural organizations, faith organizations, and community elders. These coalitions can increase trust between families and service providers.
3. Facilitate service provider training on racism and implicit bias	A few participants recommended facilitating health equity-focused training and professional development opportunities for service providers on topics such as cultural humility and how racism can prevent families from seeking services and supports they need.
4. Partner with individuals who experience racism to create culturally responsive and culturally humble interventions and policy	One participant recommended that ensure that individuals who experience racism are included in this work in order to develop a stronger understanding of how systems (including Title V and health care settings) are founded on the basis of white privilege and to create culturally responsive and culturally humble interventions and policy.
5. Encourage service providers to share their personal experiences with their own special needs or the special needs of family and friends to foster trust	One participant recommended that service providers share their personal experiences with their own special needs or the special needs of family and friends, as this would build trusting relationships with CYSHCN and their families.

Notes: In describing how many participants made a particular recommendation during the Summit Series sessions, we use the word “multiple” to denote when a large number of participants (5 or more) made a recommendation and “few” to denote when 3 to 4 participants made a recommendation.

The table includes all participant recommendations made in response to the health equity presentations and discussions during the Summit Series kick-off session and follow-up discussion, regardless of whether participants’ comments pertained to the topic area of focus.

ACE = adverse childhood experiences; CYSHCN = children and youth with special health care needs; HRSA = Health Resources and Services Administration; SDOH = social determinants of health; TA = technical assistance.

Table E.2. Participant recommendations for family and child well-being and quality of life

Participant recommendation	Description
Revisions to the goals and objectives of the Blueprint	
1. Add missing concepts to the goals and objectives: (1) the need for CYSHCN and their families to be able to choose their providers and services, and (2) the link between QOL and timely identification of special needs	Multiple participants recommended adding missing concepts to the goals and objectives. First, a few participants recommended that HRSA communicate the importance of CYSHCN and their families being able to choose their providers and services. Second, two participants recommended that the Blueprint communicate the relationship between identification of special health care needs and child and family QOL, noting that QOL is negatively affected if a child does not have a diagnosis and well-defined plan of care.
2. Revise the goals and objectives to use child- and family-centric language, such as removing the term "resiliency"	A few participants recommended that the Blueprint use language that communicates that CYSHCN and their families are at the center of this work. Participants noted that the current language is written from the systems' perspective. For example, two participants recommended that HRSA remove the term "resiliency," because this term can imply that CYSHCN and their families have to brace themselves to work in challenging systems of services—negating the responsibility that stakeholders have to create systems of services that work efficiently for CYSHCN and their families.
3. Include input from national workforce experts	Two participants recommended that HRSA have national experts on workforce development review the goals and objectives to provide suggestions for actionable strategies.
4. Continue to use the goals and objectives	Two participants expressed agreement with the goals and objectives; one said that they appreciated that the concept of equity was included, and the other said that the goals resonated with them.
Recommendations for research and measurement	
1. Identify and/or develop measures to assess child and family well-being and QOL from new perspectives, including measures that take into account the diversity of the CYSHCN population	Multiple participants noted the importance of recognizing and addressing that some existing well-being and QOL measures are not ideal. Participants stated that some existing measures define QOL from ableist, Western medicine, and system perspectives, and they felt that measures should instead consider factors important to families and factors outside the medical realm. Two participants also noted that some existing measures do not take into account the diversity of the CYSHCN population, both in terms demographic characteristics and diagnoses, and recommended stratifying data to understand QOL by race, ethnicity, gender, diagnosis, age, and geography. In addition, multiple participants discussed the need to identify and/or develop measures. Participants recommended developing a research agenda to identify the best well-being and QOL measures to use. Participants also recommended resources to use in this work: • National Core Indicators measures • The Child and Adolescent Health Measurement Initiative's Compendium of Maternal and Child Health Measures • National Spina Bifida Patient Registry, which is piloting a QOL measure • Centers for Disease Control and Prevention cooperative agreement to identify measures for Emergency Department Information Exchange • State Medicaid metrics • Social service sector measures, including those used in education, psychology, sociology, and social work • Joining Together to Create a Bold Vision for Next Generation Family Engagement: Engaging Families to Transform Education

Table E.2 (*continued*)

Participant recommendation	Description
1. Identify and/or develop measures to assess child and family well-being and QOL from new perspectives, including measures that take into account the diversity of the CYSHCN population (*continued*)	- Family Engagement in Systems Toolkit - HRSA's previous work with Family-to-Family Health Information Centers, parent training information centers, and family-led organizations A few participants said that HRSA should focus on better identifying the CYSHCN population (that is, the denominator) and existing inequities before considering measures to use.
2. Invest in more research on specific programs, such as the Pediatric Palliative Care Network	One participant recommended investing in more research on families served by the Pediatric Palliative Care Network.
Policy recommendations	
1. Use payment policies to compel systems to work across sectors and measure well-being and QOL	Multiple participants recommended using payment policies (such as financial incentives for providers and value-based care models) to compel systems to work across sectors and measure well-being and QOL. One participant noted that payment policies are particularly necessary to operationalize the objectives around interventions and policies to support protective, improved quality-of-life factors and resilience as well as enhanced self-management capacities for CYSHCN and families. One participant provided the example of Oregon's Medicaid and CHIP metrics that are tied with a financing strategy.
2. Sustain newly identified activities emerging from the novel coronavirus pandemic	A few participants recommended sustaining new activities that are emerging in response to challenges stemming from the novel coronavirus pandemic into strategy development—such as providers using new processes in referral systems, increased use of telehealth services, and insurance plans and families engaging in more collaboration to meet needs.
3. Promote data sharing across providers	Two participants recommended that HRSA help states, including state Medicaid agencies, by creating and sharing a legal framework outlining what types of data can and cannot be shared across a child's service providers, by sharing best practices from states, by offering states technical assistance, and by facilitating partnerships between states and attorney generals.
4. Establish checkpoints throughout childhood to enable identification of CYSHCN and connection to services	One participant recommended establishing more checkpoints at which children are screened for special needs, so that CYSHCN and their families do not fall through the cracks. For example, CYSHCN who are not identified as infants may not be engaged with again until kindergarten, creating missed opportunities for early intervention. The participant noted that registries can be used for tracking CYSHCN throughout childhood.
5. Conduct an awareness campaign to help families and providers learn about available resources	One participant recommended raising awareness among families and providers who are not familiar with available resources across service sectors.
Recommendations for practice	
1. Meaningfully include families in this work, including developing well-being and QOL measures, and compensate them for their time and efforts	Multiple participants recommended meaningfully including families in this work, such as including them in developing well-being and QOL measures. Participants also emphasized that families be compensated for their time and efforts and not treated like volunteers.

Table E.2 (*continued*)

Participant recommendation	Description
2. Encourage Title V to (1) actively engage families and (2) expand improvements from the state level to the national level	A few participants recommended that HRSA address well-being through state Title V. First, participants recommended that Title V develop family leaders who can sit on boards and committees and encourage systems of services to focus on well-being and QOL. Participants recommended that HRSA use toolkits, such as the *Family Engagement in Systems Toolkit*, in Title V grant reviews to assess whether states are actively promoting family voices. Of note, one participant said that not all families want to be in leadership roles and that stakeholders should work with these families to find other ways for them to actively engage with systems. Second, one participant said that HRSA should work with Title V to get them to expand their focus, as states are missing an opportunity to make improvements at the national level.
3. Train the workforce on disability, well-being, and QOL	A few participants recommended that stakeholders work to ensure that training on these topics is provided to the workforce, as the workforce directly and indirectly communicates messages to families about these topics. Two participants added that families, particularly those with lived experience serving CYSHCN, should be part of the workforce and involved in delivering training.
4. Identify the unique needs of each community	One participant recommended considering each community's unique needs and how promoting well-being and QOL will be different in, for example, rural communities versus urban communities.
5. Build on existing constructs that outline disability as a natural human experience	One participant recommended using the deaf community's model of positive construct that outlines disability as a natural human experience to develop actionable strategies.
6. Structure grant programs to require cross-sector partnerships	One participant recommended that grant programs require partnerships across service sectors. The participant said that grantees should be assessed on their performance by reviewers with perspectives from various service sectors.

Notes: In describing how many participants made a particular recommendation during the Summit Series sessions, we use the word "multiple" to denote when a large number of participants (5 or more) made a recommendation and "few" to denote when 3 to 4 participants made a recommendation.

The table includes all participant recommendations made in response to the family and child well-being and quality-of-life presentations and discussions during the Summit Series kick-off session and follow-up discussion, regardless of whether participants' comments pertained to the topic area of focus.

CHIP = Children's Health Insurance Program; CYSHCN = children and youth with special health care needs; HRSA = Health Resources and Services Administration; QOL= quality of life.

Table E.3. Participant recommendations for access to services and supports

Participant recommendation	Description
Revisions to the goals and objectives of the Blueprint	
1. Incorporate out-of-state care considerations into the goals and objectives	One participant recommended that the goals and objectives address financial and logistical considerations for accessing out-of-state care, such as ensuring Medicaid providers are registered in multiple states.
2. Add schools as a critical point of identification and coordination of services in the goals and objectives	One participant recommended that the goals and objectives include schools as a critical point of identification and coordination of services.
Recommendations for research and measurement	
1. Invest in research on (1) the value of early screening and intervention, (2) the impact of Medicaid managed care on CYSHCN, and (3) the impact of telehealth services	A few participants recommended investing in research. One participant said that more research is needed to understand the return on investment for early screening and intervention, as many states do not add new conditions to newborn diagnostic screenings because they do not have a system in place to provide services to CYSHCN and their families if certain needs are identified. Another participant said more research is needed to understand how Medicaid managed care impacts access to care and quality of care for CYSHCN, given that a large proportion of CYSHCN have transitioned into Medicaid managed care. A third participant recommended qualitative and survey research to evaluate the impact of telehealth services on access to care and health outcomes, and to understand family experiences using telehealth services.
2. Develop family-centered measures, such as measures assessing family functioning and caregiver depression	One participant recommended developing outcome measures that are meaningful to families, such as measures assessing family functioning and caregiver depression.
Policy recommendations	
1. Promote the use of telehealth and address its challenges	Multiple participants recommended that stakeholders promote the continued use of telehealth and simultaneously address its challenges. For example, participants noted the challenge some families in rural areas face in accessing telehealth services is due to Internet bandwidth issues. In addition, participants discussed the need for payment mechanisms and policy changes to sustain telehealth services beyond the pandemic, as well as to determine which services are appropriate for telehealth and how they would fit into the broader model of CYSHCN services and supports.
2. Expand the ways in which stakeholders identify and track CYSHCN, including developing a consensus definition of CYSHCN	Multiple participants recommended expanding CYSHCN identification and tracking efforts. Participants recommended expanding identification methods to include a consensus definition of CYSHCN, especially children “at risk” for special health care needs, universal early intervention, and tools like predictive analytics. They recommended expanding tracking efforts to include the development of registries and a checkpoint between newborn screening and daycare entry.
3. Promote data sharing across organizations and sectors, including Medicaid agencies, education departments, Title V, and Medicaid managed care	Multiple participants recommended that HRSA promote data sharing among partners and between systems of services. Participants noted that HRSA should develop a legal framework outlining guidelines for data sharing between state Medicaid agencies and education departments and that Medicaid data should be linked to Title V data. One participant recommended collecting data on CYSHCN’s social and medical complexity, and sharing that with Medicaid managed care plans so they can provide targeted services and care coordination.

Table E.3 (*continued*)

Participant recommendation	Description
4. Support PCPs in their work with CYSHCN through education, opportunities to obtain certification for psychiatry services, and higher reimbursement rates	A few participants recommended helping pediatricians and pediatric nurse practitioners obtain training and certification to offer psychiatry services, offering medical professionals education on how to meaningfully engage with CYSHCN and their families, and addressing issues (such as low reimbursement rates for PCPs) that lead PCPs to refer work with CYSHCN and families to specialists.
5. Address SDOH-related barriers to accessing services and supports	A few participants recommended working to address access barriers related to housing and transportation, and develop plans to better serve CYSHCN who live in communities that are remote, rural, underserved, under-resourced, and underfunded.
6. Expand existing HRSA adolescent health programs to include CYSHCN	One participant recommended expanding and modifying existing adolescent health programs to allow CYSHCN to participate. The participant said this has already been done in programs in the education system.
7. Facilitate collaboration between Title V and Medicaid	One participant recommended that HRSA facilitate collaboration between Title V and Medicaid programs within states by working with CMS to educate Medicaid directors about Title V and by aligning care coordination services in Title V and Medicaid managed care plans.
8. Consider access challenges in rural and frontier regions	One participant noted that that CYSHCN in rural and frontier areas may not have access to care within their communities, and encouraged the development of strategies to address access challenges in these areas.
Recommendations for practice	
1. Invest in family engagement strategies and foster connections among families of CYSHCN	Multiple participants recommended investing in family engagement strategies to both partner with families to improve access to services and supports and to foster connections among families. Participants suggested convening parent leaders for conferences, implementing a certification process for family and peer navigators, supporting family-to-family health information centers in connecting families to resources, and bringing families together to help build social networks. A few of these participants emphasized engaging diverse families, including marginalized families and those from rural and frontier regions, to identify opportunities to improve access and reduce duplication of services.
2. Facilitate cross-agency partnerships	Multiple participants recommended facilitating cross-agency partnerships to prevent agencies from working in silos and encourage agencies to combine resources and align efforts. These participants discussed how funding constraints and day-to-day pressures can prevent staff from coming up with innovative ways to work with other agencies. One participant recommended building coalitions that include social services agencies, behavioral health agencies, care coordinators, palliative care providers, oral health providers and cultural organizations.
3. Facilitate opportunities for CYSHCN and their families to connect with service providers in unique settings	A few participants recommended facilitating opportunities for CYSHCN and their families to connect with service providers outside of typical service settings. For example, participants said that CYSHCN may benefit from connecting with health care providers at schools and churches in addition to health care settings. One participant noted that making services available in these settings reduces the stigma associated with seeking help.
4. Develop a diverse workforce to serve CYSHCN and their families	A few participants recommended strategic efforts to encourage and support young adults from diverse backgrounds to enter medical professions, noting that these young adults may face barriers to enter the workforce due to inequitable education systems.

Table E.3 (*continued*)

Participant recommendation	Description
5. Ensure that the workforce includes community health workers	A few participants noted the importance of including community health workers in the workforce, as they are key to building trusting relationships with families and working with families to manage complex systems of services, including services to address SDOH.
6. Promote interdisciplinary care teams to increase access to services and better support CYSHCN	Two participants recommended promoting interdisciplinary care teams, noting that interdisciplinary teams can increase access to diverse services, establish trauma prevention initiatives, and provide individualized support.
7. Invest in case management to help CYSHCN and their families receive necessary services and supports	One participant recommended that investing in more case management, as case managers play an important role in ensuring that CYSHCN and their families receive necessary services and supports.
8. Streamline service and support enrollment processes	One participant recommended investing in streamlining processes that CYSHCN and their families, as well as providers, go through to connect to services and supports, focusing on reducing burden for families and providers.
9. Simplify navigation of community- and home-based services and supports	One participant recommended making non-health care services and supports easier to navigate, as they believe these services and supports are more complicated.
10. Educate families and providers on SSI	One participant recommended offering training and TA to providers and families on SSI.

Notes: In describing how many participants made a particular recommendation during the Summit Series sessions, we use the word “multiple” to denote when a large number of participants (5 or more) made a recommendation and “few” to denote when 3 to 4 participants made a recommendation.

The table includes all participant recommendations made in response to the access to services and supports presentations and discussions during the Summit Series kick-off session and follow-up discussion, regardless of whether participants’ comments pertained to the topic area of focus.

CMS = Centers for Medicare & Medicaid Services; CYSHCN = children and youth with special health care needs; HRSA = Health Resources and Services Administration; PCP = primary care provider; SDOH = social determinants of health; SSI = Supplemental Security Income; TA = technical assistance.

Table E.4. Participant recommendations for financing of services

Participant recommendation	Description
Revisions to the goals and objectives of the Blueprint	
1. Identify stakeholders to lead the work to achieve the goals and objectives	One participant recommended that HRSA note in the Blueprint the specific stakeholders who should lead the work to achieve the goals and objectives. The participant said that HRSA should consider focusing on the goals and objectives that it can lead.
2. Note available federal funding opportunities for behavioral health services in the goals and objectives	One participant recommended that the Blueprint describe the array of federal funding sources for behavioral health services for CYSHCN and their families in the goals and objectives.
Recommendations for research and measurement	
1. Invest in research on (1) approaches to payment reform, (2) care coordination, (3) the identification of CYSHCN in Medicaid datasets, and (4) societal costs for serving CYSHCN	Multiple participants recommended investing in research on payment reform models and initiatives (such as alternative payment models and value-based contracting), the value of care coordination for CYSHCN and their families, the identification of CYSHCN in Medicaid datasets, and societal costs (such as lost wages for caregivers) for serving CYSHCN. One participant noted that it may take time to see desired outcomes when evaluating payment reform models. Another participant suggested that Title V funding could support work with Medicaid datasets. One participant noted that both quantitative and qualitative data demonstrating value of services for CYSHCN are important.
2. Use health and QOL measures to assess CYSHCN services and incentivize improvement	A few participants recommended tying CYSHCN services to health measures and quality-of-life measures in order to demonstrate the value of these services and incentivize improvement. Participants noted that measures should assess processes and outcomes that families deem high priority.
3. Collect data on CYSHCN subpopulations	One participant recommended collecting data on CYSHCN subpopulations (such as children with sickle cell disease) that are not represented in the Medicaid Child Core Set and other large reporting efforts.
Policy recommendations	
1. Encourage payors to finance services and supports that promote holistic health for CYSHCN and families	Multiple participants recommended encouraging payors to cover particular services and supports to promote holistic health for CYSHCN and their families, including respite care, home attendant care, compensation for families for caregiving labor, long-term services and supports, telehealth services, and financial assistance. This requires building shared understanding among families, providers, and payors about which services are valuable to CYSHCN. Of note, one participant recommended focusing on financing system redesign and quality, rather than insurance coverage.

Table E.4 (*continued*)

Participant recommendation	Description
2. Develop and/or support innovative funding structures	Multiple participants recommended developing and supporting innovative funding structures and payment arrangements, including: • Models that sustain telehealth services that are now available because of the novel coronavirus; • Payment arrangements that pay for both the work needed to improve processes and outcomes, as well as the result (that is, the improved process or outcome); • Funding structures that are flexible across the social drivers and health (such as allowing a community to use funding to improve housing that leads to better health, rather than using funding to buy a new MRI machine); • Funding structures that financially incentivize providers to work with children with complex needs; and • Funding structures that eliminate wage caps and similar limiting requirements in respite care benefit programs.
3. Advocate for Medicaid-Medicare parity	A few participants recommended advocacy to increase Medicaid reimbursement rates so they are comparable to Medicare and commercial insurance rates. Participants said that the current reimbursement disparity is discriminatory against low-income CYSHCN and families and people of color. Participants noted that higher reimbursement rates could prompt providers to accept more Medicaid patients and expand the CYSHCN provider workforce.
4. Create an insurance assistance program and address challenges CYSHCN and their families face with insurance network requirements and continuity	A few participants recommended creating an insurance assistance program for CYSHCN and their families that is similar to the State Health Insurance Assistance Program for Medicare beneficiaries; they also recommended that HRSA address challenges CYSHCN and families face when ED visits involve multiple in-network and out-of-network providers and when their payors change as a result of company buyouts and contract changes.
5. Aim for strategic, incremental change	Two participants recommended aiming for strategic, incremental change as the most effective strategy to improve systems. One participant noted that the Advancing Care for Exceptional Kids Act is a good example to follow.
6. Identify ways to integrate specialty care into medical homes	One participant recommended identifying ways to integrate specialty care into medical homes, as many CYSHCN (especially CMC) spend more time with specialists than PCPs.
Recommendations for practice	
1. Improve care coordination for CYSCHN	Multiple participants recommended improving care coordination for CYSHCN by: • Helping state Medicaid agencies leverage contracts with managed care organizations to ensure quality; • Funding broader wraparound care coordination to address challenges related to the novel coronavirus pandemic (such as school closures and service disruptions); • Increasing the focus on addressing behavioral health through care coordination; • Advocating for hospital care coordination practices that focus on supporting CYSHCN’s longer-term needs for life at home rather than just discharge planning; • Expanding the definition of care coordinators to include unlicensed individuals who are savvy at navigating the health care system; • Partnering with high quality clinical partners who support care coordination; and • Including patient navigators in medical practices.

Table E.4 (*continued*)

Participant recommendation	Description
1. Improve care coordination for CYSCHN (*continued*)	Of note, one participant recommended focusing on simplifying processes (such as pre-authorization processes) in systems of services so that care coordination is not needed. The participant believes that too much attention is given to improving care coordination, rather than addressing larger inefficiencies within the health care system that create the need for care coordination.
2. Build and facilitate trusting partnerships to support comprehensive care	Multiple participants recommended building partnerships with a variety of stakeholders, including Federal Reserve Banks, CMS, Medicaid managed care organizations, the private sector, and community social service agencies. Participants said that this will foster collaboration, help streamline stakeholder efforts, help identify and fund services that overlap between health and social drivers, and foster the development of innovative models and policies for CYSHCN and their families.
3. Create opportunities for CYSHCN and their families to be equal partners in this work	A few participants recommended engaging CYSHCN and their families as partners in making financing decisions to ensure that payment reforms address family needs. Participants suggested that HRSA fund learning collaboratives for families, payors, and providers to work together to identify financing reform models and activities. Participants said that providers should be able to earn continuing education credits for their participation in learning collaboratives. Participants also suggested that HRSA encourage medical professional groups and family advocacy groups to collaborate and pool their resources together to ensure that CYSHCN and families are equal partners in this work.
4. Develop definitions, talking points, and tools to support stakeholders in this work	Two participants noted that stakeholders use different definitions for CYSHCN and recommended developing a consensus definition for CYSHCN (including a definition of “at risk” populations). Another participant recommended that HRSA develop talking points on financing services for CYSHCN and a map of the insurance landscape for CYSHCN by state that notes key agencies and their responsibilities. Participants noted that this could foster collaboration among agencies and bolster advocacy efforts.

Notes: In describing how many participants made a particular recommendation during the Summit Series sessions, we use the word “multiple” to denote when a large number of participants (5 or more) made a recommendation and “few” to denote when 3 to 4 participants made a recommendation.

The table includes all participant recommendations made in response to the financing of services presentations and discussions during the Summit Series kick-off session and follow-up discussion, regardless of whether participants’ comments pertained to the topic area of focus.

CMC = children with medical complexity; CMS = Centers for Medicare & Medicaid Services; CYSHCN = children and youth with special health care needs; ED = emergency department; HRSA = Health Resources and Services Administration; PCP = primary care provider; QOL = quality of life.

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