



600 13TH ST., NW, SUITE 500  
WASHINGTON, DC 20005  
p | 202-753-5500  
f | 202-347-5147

16011 COLLEGE BLVD., SUITE 250  
LENEXA, KS 66219  
p | 913-262-1436  
f | 913-262-1575

[WWW.CHILDRENSHOSPITALS.ORG](http://WWW.CHILDRENSHOSPITALS.ORG)

November 30, 2020

TO: [CYSHCN@hrsa.gov](mailto:CYSHCN@hrsa.gov)  
FROM: Children's Hospital Association  
RE: CYSHCNs Blueprint RFI

Thank you for the opportunity to provide input on “A Blueprint for Change: Guiding Principles for Advancing the System of Services for Children and Youth with Special Health Care Needs and Families.” We commend the Maternal and Child Health Bureau (MCHB) for developing the Blueprint and for considering broad stakeholder feedback on how best to provide a strong system of care for Children and Youth with Special Health Care Needs (CYSHCNs) and their families. To improve care and costs, it will require us all working together to share best practices and reforms that allow children timely access to needed care and to achieve their full potential.

Children's hospitals care for many children with special health care needs, with more than 50% of our patients having complex medical needs. As you know, many CYSHCNs are enrolled in Medicaid and rely on the program for access to services and supports not available through private insurance. On average, over half of the patients in children's hospitals rely on Medicaid for their health coverage. Several children's hospitals have medical home programs focused on children with chronic and/or complex conditions and strive to improve care through delivery system reforms. Additional support for these efforts, which have been shown to improve quality, and family experience is critical to sustaining and spreading better systems of care across the country.

The Blueprint highlights key areas of focus for this population of children, their families and the providers who care for them. We welcome the opportunity to be part of these discussions and offer some high-level comments drawing from children's hospitals' experiences across the country.

### **1. Are there items that are missing from the draft goals and objectives?**

We recommend a larger focus on national data, particularly for CYSHCNs enrolled in Medicaid. To make real improvements in care and costs across systems, we need comprehensive, standardized national data that encompasses the entire continuum of care for this population of children. This data is critical to all other efforts, including our ability to drive quality improvement and develop appropriate payment models for CYSHCNs. The implementation of the Advancing Care for Exceptional Kids Act of 2019 can be a step toward better access to national data with emphasis on children with complex medical conditions, the most vulnerable subset of CYSHCN, if the national definition of eligible children is consistently applied across states.

The Blueprint appropriately highlights the need to get children care as close to their homes and communities as possible, but does not sufficiently acknowledge the reality of the regional nature of care for children, particularly for children with chronic or specialized health care needs. Children's hospitals anchor these regional systems of care for children and are relied upon for resources as we look to improve access to out-of-state care and ensure proper support closer to home. We request that the Blueprint acknowledge the regional nature of pediatric care, particularly as it relates to children needing specialized services, the challenges related to accessing care outside a child's home state, which are many, and how the system can be improved to address these challenges.

Innovations in use of telehealth have been a promising practice for many points of access, like care across state lines, but cannot address significant gaps that remain when specialty care is needed in person and when comprehensive services are required (e.g., home health and DME providers). There could be other promising practices, like ECHO programs that create a virtual learning community with primary care providers and content experts with the goal of democratizing specialty care and increasing access to these needed services.

Under the health equity goal, we recommend including improved access to technology that supports provider communication, such as telehealth and communication devices for hearing impairment and language services, and improved functioning and health monitoring. Telehealth has proved invaluable during the pandemic to connect children and families to care, but more needs to be done to ensure families have equitable access to care moving forward.

The financing goals and objectives, specifically sustainability, are critical to our ability to achieve a seamless, comprehensive and well-functioning system of care. Currently, there are many challenges with ensuring access to the myriad of services due to low payment and current payment mechanisms that do not align payment with outcomes. We also are concerned that new genetic treatments and high-cost biologics, though therapeutically promising, will add exponentially to the cost of care. These costs often drive the high costs of care for this population of children. We will need to determine ways to manage these costs more effectively while also ensuring quality of care is not reduced.

We also recommend additional focus on behavioral health. Many children with special health care needs have co-occurring mental, emotional and behavioral health needs. This affects their care and how the system is organized around them. Currently, the system is not organized in a way that supports these needs for children. These needs are only expected to increase in the COVID-19 environment with many schools and other social opportunities restricted and reductions in in-person care.

## **2. What steps need to be taken to implement these goals at the community, state and federal levels?**

We appreciate your efforts to outline key goals and objectives. High level and visionary goals are important, but we also need concrete specific plans and actions. We hope the next step in the process is to break down these goals to identify concrete steps we all can take to improve the system of care for CYSHCNs.

A core theme of the Blueprint is “coordination and collaboration across health care systems as well as other child and family-serving systems and programs.” To achieve this at the state and local level, it is imperative that there is that same level of integration across programs and agencies at the federal level. We recommend exploring how the federal government can better leverage current resources and opportunities across agencies (e.g., HRSA and CMS), aligning initiatives and resources to better support this work.

## **3. How should families, providers and other key programs and systems be involved in the implementation of the goals and objectives in the Blueprint?**

It's critical for families to be at the center of care in addition to being partners in shared decision-making. They are also the essential partners as we explore how best to design systems of care for their children—they know what works, what does not and have ideas on how to address existing challenges. Pediatric providers playing a key role for this population of children should be included as well. Children's hospitals are critical to the provision of specialized care for children and support the broader infrastructure. State Medicaid programs, Title V and

CYSHCNs directors and others at the state and local level who provide support for children are also necessary partners. It will take all these stakeholders working together to improve the system of care for CYSHCNs.

**4. What additional research, policy and programmatic work should be consulted and considered as the Blueprint is finalized?**

We recognize the importance of family experience and using that information to improve care. We believe more needs to be done to incentivize family participation in surveys. We are concerned about tying surveys with current low levels of participation to payment. More needs to be done to explore the best ways to support families, who are overtaxed, in completing surveys.

We also need to be very deliberate when developing alternative payment models for CYSHCNs or subsets of this group. Small numbers and the claims volatility for some of these children do not lend itself to risk-based models. This is an area for additional research and analytics. National data on this population of children is essential to determine which payment models could work for CYSHCNs and what we need to do to drive quality improvement.

We believe continued national funding opportunities are necessary for key stakeholders to work together to improve the delivery system for CYSHCNs. National action plans informed by emerging best practices provide actionable blueprints for adoption. If additional funding is available in the future, we would hope to see a focus on technology models that better support care coordination, models supporting equitable access and support for improving analytical capabilities to improve care and spending where possible.

Thank you for the opportunity to comment. We look forward to partnering with MCHB to improve care for CYSHCNs and their families.

Sincerely,

A handwritten signature in black ink that reads "Aimee C. Ossman". The signature is written in a cursive, flowing style.

Aimee C. Ossman  
Vice President, Policy Analysis  
Children's Hospital Association