

## Strategies for State Title V and Medicaid Programs to Promote Health Equity for Children of Color with Special Health Care Needs



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## Introduction

State Title V and Medicaid programs provide services for children and youth with special health care needs (CYSHCN) to support their physical, behavioral, and developmental care. States are also advancing health equity goals to address disparate outcomes experienced by people of color. With evidence of existing inequities laid bare by the COVID-19 pandemic, states are finding opportunities to unite these efforts to improve care for CYSHCN of color. Key areas where states are strengthening health equity for CYSHCN include initiatives in family partnership, Medicaid managed care (MMC) programs, quality measurement and performance reporting, and cross-sector partnerships.

As states focus on supports for CYSHCN of color, it is important to reflect on the significant disparities in access to care they experience. Only 9.3 percent of Latinx (self-identified as Hispanic), 9.5 percent of Indigenous (self-identified as American Indian/Alaska Native), 11.2 percent of Asian, and 14.4 percent of Black CYSHCN receive all six components of a well-functioning system of care, as compared to 15.6 percent of White CYSHCN.<sup>1</sup> Racial disparities also persist for CYSHCN of color when accessing other vital components of care. For example, while disparate access to medical homes exists for all CYSHCN of color, Latinx and Indigenous CYSHCN experience greater disparities compared to White CYSHCN.<sup>2</sup> Youth with special health care needs (YSHCN) of color are also less likely to receive services necessary to make transitions to adult health care with only 19.6 percent of Asian, 20 percent of Indigenous, 20.6 percent of Latinx, and 21.4 percent of Black YSHCN ages 12 to 17 accessing transition services, as compared to 23.7 percent of White youth.<sup>3</sup>

The role racism plays in the developmental and health outcomes of children is important to consider as states promote health equity for CYSHCN of color.<sup>4</sup> Racism negatively affects millions of people, preventing them from attaining their highest level of health and potentially impacting every aspect of a person's social, economic, emotional, and physical well-being.<sup>5</sup> Families of color disproportionately face unique issues tied to historical inequities when accessing care, including inadequate housing, educational, income, and wealth gaps, provider language barriers, and discrimination.<sup>6</sup> Acknowledging and addressing these inequities along with racism's impact on care delivery can be an important component of state health equity efforts.

The COVID-19 pandemic has amplified longstanding systemic disparities in access to care for CYSHCN of color. Children of color are more likely to face health complications related to COVID-19 such as disproportionate rates of hospitalization.<sup>7</sup> Their families have also experienced higher rates of socioeconomic hardship, lack of health care access, and racism during the pandemic.<sup>8</sup> These inequities, coupled with the fact that CYSHCN are more likely to have a disruption in care during this unprecedented time, present opportunities for state Title V and Medicaid programs to improve and advance equity within systems of care for CYSHCN of color and their families.<sup>9</sup>

In addition to state efforts, policies and guidance issued by Federal agencies may serve as leverage points to address racial inequities among CYSHCN. In April 2021, the Centers for Disease Control and Prevention (CDC) declared racism a public health emergency.<sup>10</sup> The CDC also developed a Health Equity Style Guide as a resource of best practices when discussing health inequity and developing policy.<sup>11</sup> The Maternal and Child Health Bureau (MCHB) within the Health Resources and Services Administration (HRSA) issued guidance for state Title V programs that includes health equity in the development of state performance measures.<sup>12</sup> Further, MCHB's recently published Strategic Plan for FY 2019 - 2022 includes specific goals around health equity.<sup>13</sup> The Centers for Medicare and Medicaid Services (CMS) Office on Minority Health is supporting local and federal partners to eliminate health disparities experienced by people, including people belonging to racial and ethnic minority groups.<sup>14</sup> CMS also developed a set of Race, Ethnicity, and Language (REaL) data collection resources to help advance opportunities to leverage data for monitoring and addressing health disparities.<sup>15</sup>

National organizations that play a key role in state policy efforts are also supporting health equity initiatives. In March 2021, the National Committee for Quality Assurance (NCQA), the organization that oversees health plan accreditation and quality measures, issued a proposed Health Equity Strategy to inform updates to Health Plan Accreditation in 2022.<sup>16</sup> This focus on health equity creates additional opportunities for state Medicaid programs to build health equity measures into quality strategies for CYSHCN.

## **Strategies to Support Health Equity in Title V and Medicaid Programs**

State Medicaid and Title V programs both play important roles in providing health care and other important services and supports to CYSHCN, including CYSHCN of color, and their families. Federal law requires states denote at least 30 percent of state Title V Maternal and Child Health (MCH) Services Block Grant funds to programs, services, and supports for CYSHCN.<sup>17</sup> Medicaid and the Children’s Health Insurance Program (CHIP) cover 47 percent of CYSHCN, with 66 percent of those children and youth identifying as Black, Latinx, or another racial minority group.<sup>18</sup> As states continue to enhance broader health equity goals, Medicaid and Title V programs are uniquely positioned to advance supports for CYSHCN of color through programs, policies, and strategic partnerships.

### **Family Partnership**

Partnering with the families of CYSHCN, in particular families of color, can elevate understanding of inequities within child-serving systems and play a crucial role in advancing state health equity efforts. State Title V programs historically have strong partnerships with families and local communities, including those leading efforts to advance health equity. Federal Title V guidance encourages state programs to engage families of CYSHCN in a variety of program activities, such as the agency decision-making and policy process.<sup>19</sup> State Medicaid agencies are required under 42 CFR § 431.12 to have a medical care advisory committee that includes stakeholders such as providers, directors of child welfare and public health agencies, and consumers, among others.<sup>20</sup> As a best practice, some state Medicaid programs have also developed consumer-specific committees to inform their work. States can consider leveraging these activities to inform health equity initiatives in their programs serving CYSHCN of color.

Virginia’s Title V CYSHCN program employs parent coordinators who lead educational activities and trainings while partnering with families to help overcome barriers to care.<sup>21</sup> Parent coordinators typically have a child with a special health care need and provide families with resources and support. The state’s Title V program also partners with Virginia Commonwealth University in support of a “Cultural Broker” CYSHCN program that includes various representatives from families of color. Michigan’s Children’s Special Health Care Services Advisory Committee informs the state’s Title V program and is comprised of consumers, family members, and stakeholders with the aim of improving systems of care and quality of life for CYSHCN.<sup>22</sup> The Committee’s bylaws require that 25 percent of its membership be consumer representatives including family members and/or caregivers.

State Medicaid programs are also increasingly establishing opportunities for beneficiaries to provide programmatic feedback, including through Medicaid member advisory committees (MACs) comprised solely of Medicaid and CHIP members. Colorado has a Member Experience Advisory Council that informs the state’s Medicaid program, the first of its kind in the country.<sup>23</sup> The state also has a Children’s Disability Advisory Committee that makes recommendations to the Department of Health Care Policy and Financing regarding the benefits for CYSHCN in areas such as provider education interventions and application of standards.<sup>24</sup> Virginia’s Medicaid program partners with the parents of CYSHCN, including CYSHCN of color, through their Medicaid MAC. Members have made recommendations to the state Medicaid agency to

inform the programmatic decision-making process and other change management strategies.<sup>25,26</sup> Medicaid MACs and state Title V family partnership initiatives can engage family and consumer voices into the systems that serve them, while also playing a vital role in advancing equity.

## Medicaid Managed Care Programs

States are also incorporating health equity as a priority in their Medicaid managed care (MMC) programs through the contract procurement process. This approach can be an effective way to advance care for youth of color, as 47 states use some form of MMC to serve CYSHCN.<sup>27</sup> In the request for proposal (RFP) for Ohio's most recent iteration of their MMC program, the state requested managed care organizations (MCOs) include information about how they will advance health equity for members.<sup>28</sup> Louisiana also highlighted health equity as a main objective during their 2021 MMC procurement.<sup>29</sup> Bidding MCOs were required to demonstrate how they will utilize data to address inequities in care, including measures related to well-child visits in the first 15 months and childhood immunizations. The state also required MCO staffing and organizational strategies to promote equity along with an established capacity to engage community members to address racial disparities, among other initiatives.

In December 2020, Hawaii released an RFP for its MMC program, QUEST, that required bidding MCOs develop a "comprehensive cultural competency plan" that included efforts to address health disparities.<sup>30</sup> MCOs were also required to incorporate measurements related Social Determinants of Health (SDOH) in alignment with the MMC program's Quality Strategy and SDOH Transformation Plan. A focus on health equity in MMC programs has the potential to support CYSHCN of color enrolled in MMC while also presenting unique opportunities for mutual alignment with state Title V program health equity priorities. There are also additional opportunities for states to align activities in both Title V and MMC programs to advance health equity for CYSHCN. More information about MMC and Title V collaboration in this area can be found here: <https://ciswh.org/resources/strengthening-title-v-mmc-collaborations/>

## Quality Measurement and Performance Reporting

State Title V and Medicaid programs are also highlighting health equity in their quality and performance monitoring strategies in alignment with federal reporting requirements. Quality and performance measurement can be an opportunity for states to identify patterns in disparate outcomes while potentially gaining a better understanding of inequities faced by CYSHCN of color. In 2015, MCHB developed a three-tiered national performance measurement framework for Title V MCH Services Block Grant recipients that allows states flexibility to identify which measures best meet program needs.<sup>31</sup> States use this framework to develop a five-year State Action Plan to address priority areas. The framework includes National Outcomes Measures, National Performance Measures, and Evidence-based Strategy Measures. Many states choose to develop State Performance Measures (SPM) based on their Five-Year Needs Assessments that may relate to health equity, allowing for further opportunity to evaluate and support initiatives for CYSHCN of color.

Additional Title V performance measure publications and reports may include tools for state efforts to address health disparities. Colorado's Title V program captures specific data on CYSHCN annually via their Health Care Program (HCP) Snapshot reports.<sup>32</sup> These reports are used to demonstrate trends for youth across the state and include race/ethnicity specific indicators in their dashboards. Other potential health equity indicators, such as service utilization based on primary household language, are also included in the reports and can be important tools for identifying gaps in care. Minnesota's most recent maternal and child health needs assessment identified that more support was needed for Indigenous families, which has become a top priority for their Title V program.<sup>33</sup> The state has also embedded cultural responsiveness into their CYSHCN Program Quality Improvement activities.<sup>34</sup>

States that deliver Medicaid benefits through a MMC model are required under federal law 42 CFR § 438.350 to partner with an External Quality Review Organization (EQRO) to conduct an annual External Quality Review (EQR) of their contracted MCOs.<sup>35</sup> State Medicaid programs are leveraging both mandatory and optional EQRO activities to include a health equity focus in their MMC quality initiatives.<sup>36</sup> For example, Louisiana's most recent 2021 Managed Care Quality Strategy prioritizes evaluation of health disparities through EQRO activities such as Health Disparities Survey of each MCO.<sup>37</sup> For Medicaid agencies and their Medicaid MCO partners, NCQA guidance on quality measures has also impacted state quality strategies. For example, Pennsylvania's Medical Assistance and CHIP Managed Care Quality Strategy requires that MCOs either achieve or be working towards the NCQA distinction in Multicultural Health Care with the goal of incentivizing reduction in health disparities for beneficiaries.<sup>38</sup>

As part of their MMC quality publications, California's Department of Health Care Services (DHCS) contracts with the Health Services Advisory Group, Inc. (HSAG) as their EQRO to include a specific "Asian subpopulations health disparities analysis" in their 2019 - 2020 External Quality Review Technical Report, among other health disparity indicators.<sup>39</sup> Also in collaboration with HSAG, the state publishes Health Disparities Reports with the goal of assessing and improving disparate health outcomes across the state.<sup>40</sup> Medicaid and CHIP quality reports developed in collaboration with EQROs are often publicly available and can be stratified by race to identify potential disparities in outcomes for youth.

## Cross-Sector Collaboration

Cross-sector collaboration can help advance health equity goals through aligned resource allocation and the development of innovative solutions to advance health equity.<sup>41</sup> Child serving systems, including Title V and Medicaid programs, are integrating services to strengthen cross-sector partnership for CYSHCN in a variety of ways that can impact health equity. For example, Michigan's Children's Special Health Care Services (CSHCS) program is required by state Public Health Code, Public Act 368 of 1978, Part 58 to develop coordinated, culturally competent care for CYSHCN that is both community and family centered.<sup>42</sup> CSHCS partners with the state's Medicaid program along with its contracted Medicaid Health Plans to align goals for advancing health equity including in areas of care collaboration to avoid duplication of services.

State Title V programs are also connecting with additional cross-sector opportunities to engage in state-wide health equity efforts. Rhode Island's Department of Health adopted a public health planning and practice framework to improve health equity for people served by Title V, including CYSHCN.<sup>43</sup> The state's Title V program is embedded in their Health Equity Institute, creating unique opportunities for the advancement of state goals to address health disparities for those receiving maternal and child health services, including CYSHCN.<sup>44</sup> Oregon's Title V program focuses on health equity through "culturally and linguistically responsive" services that inform upstream cross-cutting needs. The state's efforts include integrated state-level staff teams, restructured strategies, and logic models and new supports for local Title V grantees, with a focus on cross-sector care coordination for CYSHCN.<sup>45</sup>

States are also collaborating with diverse stakeholder groups to further their reach. Colorado public health officials, including those from the state's Medicaid and Title V programs, partnered with the Colorado Health Institute to develop the "ABCs of Health Equity for Children and Youth with Special Health Care Needs".<sup>46</sup> Published in March 2020, this document outlines a cross-sector policy agenda for enhancing services for youth of color across the state, highlighting access to medical and non-medical services, enhancement of behavioral health care, and care coordination across systems.<sup>47</sup> California's Office of Health Equity, embedded within the California Department of Health, brings together cross-sector partners including those in state and local government and community-based agencies to advance health equity.<sup>48</sup> The office's Health in All Policies collaborative approach embeds health equity into cross-sector policy areas and has a

task force that includes state agencies in areas of the environment, community development, transportation, housing, traffic safety, and food and agriculture, among others.<sup>49</sup>

## Key Considerations

State Title V and Medicaid programs are striving to advance health equity through a variety of initiatives that can improve outcomes for CYSHCN of color and their families. As states continue to pursue opportunities in this area, they can consider the following:

- **Partner with families of CYSHCN of color in policy development, program design and implementation, and MMC contracting.** State Title V and Medicaid programs each have mechanisms to engage families of CYSHCN in the decision-making process for program development and improvement activities. States can consider options to ensure that the families of CYSHCN of color are included in both Title V family partnership efforts and Medicaid MACs as an opportunity to advance health equity. These efforts can help to center the voices of communities of color, which can be vital to combat interpersonal and systemic racism often experienced in health care delivery.<sup>50</sup>
- **Embed health equity initiatives specific to CYSHCN in MMC programs.** While states are highlighting health equity initiatives in MMC programs, they can also consider designing specific strategies or initiatives that consider the unique impact racism has on care access for CYSHCN of color. These activities can be incorporated into the MMC contracting process and require MCOs to pursue certain strategies to advance health equity for CYSHCN of color. State Title V programs can also work with Medicaid agencies and their MCO partners to further ensure access to specialty care, programs, and services that consider the unique needs of CYSHCN of color.
- **Ensure quality and performance measurement efforts include data on CYSHCN of color.** As states evolve quality strategies for both Title V and Medicaid programs, data derived from performance measure reporting can be a powerful tool to develop a more comprehensive picture of health inequities experienced by CYSHCN of color. Capturing and sharing performance measurement data related to racial disparities between Title V and Medicaid programs can also enable states to identify and address persistent inequities through diverse data sources. Opportunities to share data and quality metrics can also assist in aligned state priorities for CYSHCN along with improved identification of potential gaps in services for CYSHCN of color.
- **Leverage cross-sector collaborations to advance support CYSHCN of color.** As states navigate partnerships across child serving systems to advance health equity, they can consider opportunities to ensure close collaboration between Title V programs and Medicaid agencies. States can also consider activities that include diverse, community-focused stakeholder partners with vital insight into the needs of CYSHCN of color and their families. Creating a unified, holistic state approach to health equity for CYSHCN can assist states in advancing mutual program goals and priorities.

## Conclusion

Advancing health equity for CYSHCN of color is an important area where states are continuing to evolve their efforts. As states consider strategies and initiatives to enhance this work, key areas of consideration include the engagement of families of color, development of health equity initiatives specific to CYSHCN of color in MMC programs, quality and performance measurement strategies specific to CYSHCN of color, and cross-sector partnerships to support health equity for CYSHCN. Vital to these efforts is a strong partnership between Title V and Medicaid programs to align resource allocation, advance mutual health equity priorities, and improve outcomes for CYSHCN of color.

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