

National Resource Center

FOR PATIENT/FAMILY-CENTERED MEDICAL HOME

National Resource Center for Patient/Family-Centered Medical Home: Health Equity Literature Review Table

This literature table* outlines recent data pertaining to children and youth with special health care needs (CYSHCN) and children with disabilities (CWD) through the lens of equity. The table below provides a snapshot of peer-reviewed research and other articles, highlighting the critical need for underrepresented and underserved CYSHCN, CWD and their families to receive care through the family-centered medical home model. This table will be regularly updated to reflect the newest publications related to CYSHCN, CWD and family-centered care.

The Health Resources and Services Administration defines health equity as: the absence of disparities or avoidable differences among socioeconomic and demographic groups or geographic areas in health state and health outcomes such as disease, disability, or mortalities.” Further, HRSA defines health inequalities as inequalities that are deemed to be unfair, unjust, unavoidable, or unnecessary, that can be reduced or remedied through policy action.”¹

Additional [literature on medical home](#) can be found on the National Resource Center for Patient/Family-Centered Medical Home website.

*The articles, background, and key findings/recommendations in this literature table reflect those of the author and do not represent the official view of, nor are an endorsement of, the American Academy of Pediatrics.

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¹ Health Resources and Services Administration. “Health Equity Report 2017.” <https://www.hrsa.gov/sites/default/files/hrsa/health-equity/2017-HRSA-health-equity-report.pdf>

Yr	Reference	Background	Key Findings/ Recommendations	Key Words
2019	Martone CM, Gjelsvik AJ. Adolescent access to patient-centered medical homes. <i>Pediatr.</i> 2019 Oct;213:171-179. doi: 10.1016/j.jpeds.2019.06.036.	OBJECTIVES: To analyze the distribution of patient-centered medical homes (PCMHs) among US adolescents, and to examine whether disparities exist among subgroups.	CONCLUSIONS: PCMH access was lower among minorities, those living in poverty, and those with multiple special health care needs. These disparities in PCMH access among these typically underserved groups call for further study and interventions that would make PCMHs more accessible to all adolescents.	PCMH, disparities, adolescents, minorities, poverty
2019	Network for Public Health Law. Equity assessment framework for public health laws and policies. Networkforphl.org. May 2019. Accessed February 2, 2021. https://www.networkforphl.org/wp-content/uploads/2020/08/Equity-Assessment-Framework-for-Public-Health-Laws-and-Policies.pdf .	The framework provides a way to assess the equity implications of existing or proposed laws or policies.	This assessment framework can be utilized as a guide in the discussion around how equity is considered in both process and outcomes and may help identify opportunities for improvement.	Health equity assessment, health equity policies/framework
2019	Payakachat N, Long CR, et al. Prevalence, health and resource utilization, and unmet healthcare needs of native Hawaiian and Pacific Islander children with developmental disabilities. <i>Am J Intellect Dev Disabil.</i> 2019 May;124(3):234-247. doi: 10.1352/1944-7558-124.3.234.	Little is known about health limitations and service utilization among the Native Hawaiian and Pacific Islander (NHPI) children with developmental disabilities (DDs) due to limited data. Our study examined the prevalence of DDs, health limitations, services used, and the unmet needs of NHPI children aged 3 to 17 years using cross-sectional data from the 2014 NHPI National Health Interview Survey.	Results showed that prevalence of DDs among NHPI children was lower than American children of other races. DDs were negatively associated with health and functioning of NHPI children. There is a need to promote understanding of DDs among NHPI families and to inform public policy makers to identify appropriate intervention services for NHPI children.	NHPI children, Developmental disabilities, unmet need

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2019	Smith B, Zhang J, et al. Effects of socioeconomic status on children with hearing loss. <i>Int J Pediatr Otorhinolaryngol.</i> 2019 Jan;116:114-117. doi: 10.1016/j.ijporl.2018.10.032.	Health care disparities are noted between different socioeconomic groups; it is crucial to recognize and correct disparities, if present, that extends to children with hearing loss. The objective of the study is to evaluate the effect of socioeconomic status (SES) on access to hearing rehabilitation and speech and language therapy and outcomes in children with hearing loss.	This study suggests that despite lower socioeconomic status, in children with hearing loss, Medicaid allows equivalent access to hearing rehabilitation and speech therapy as their privately insured counterparts and children achieve similar speech and language outcomes.	Hearing loss, SES, Access to rehabilitation and therapies
2019	Uchitel J, Alden E, et al. The rights of children for optimal development and nurturing care. <i>Pediatrics.</i> 2019 Dec;144(6) doi: 10.1542/peds. 2019-0487	World Health Organization and United Nations Children's Fund have launched the Nurturing Care Framework for Early Childhood Development (ECD), which calls for public policies that promote nurturing care interventions and addresses 5 interrelated components that are necessary for optimal ECD. This move is also complemented by the Human Capital Project of the World Bank, providing a focus on the need for investments in child health and nutrition and their long-term benefits.	In this article, the authors outline children's rights under international law, the underlying scientific evidence supporting attention to ECD, and the philosophy of nurturing care that ensures that children's rights are respected, protected, and fulfilled. They also provide pediatricians anywhere with the policy and rights-based frameworks that are essential for them to care for and advocate for children and families to ensure optimal developmental, health, and socioemotional outcomes. These recommendations do not necessarily reflect American Academy of Pediatrics policy.	Children's rights, Public policies, nurturing care interventions, policy and rights-based frameworks

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2018	<p>Artiga S,Hinton E. Beyond health care: The role of social determinants in promoting health and health equity. Kff.org. Published May 10, 2018. Accessed February 1, 2021. http://files.kff.org/attachment/issue-brief-beyond-health-care.</p>	<p>This brief provides an overview of social determinants of health (SDoH) and discusses several initiatives to address them.</p>	<p>There are several initiatives that have emerged to address social determinants of health within non-health sectors, federal, and state levels. By addressing social determinants of health, the authors contend progress can move towards improving health and reducing longstanding disparities within health care.</p>	
2018	<p>Dababnah S, Shaia WE, et al. "We had to keep pushing": Caregivers' perspectives on autism screening and referral practices of black children in primary care. <i>Intellect Dev Disabil.</i> 2018 Oct;56(5):321-336. doi: 10.1352/1934-9556-56.5.321.</p>	<p>Black children with autism spectrum disorder (ASD) are diagnosed later than their White peers, are more likely to be misdiagnosed, and are less likely to receive early intervention services or a developmental evaluation by three years old. Using a grounded theory approach, the authors solicited the perspectives of parents and other primary caregivers of Black children with ASD on barriers and facilitators to ASD screening and referrals in primary care.</p>	<p>First, while some caregivers noted their child's primary healthcare providers facilitated a timely ASD diagnosis, other participants reported these providers ignored early concerns about child developmental delays. Second, many participants felt racial bias negatively impacted caregiver-primary healthcare provider interactions. Third, legal/custodial issues slowed caregivers' abilities to follow up on referrals from their primary healthcare providers. Finally, caregivers described denial, shame, and stigma relating to ASD in the Black community as possible factors for delayed follow up to referrals. Differences based on socioeconomic status are discussed. Efforts to improve family-centered, culturally relevant care for all Black caregivers raising children with or at-risk for ASD are needed, particularly for those families</p>	<p>Autism, diagnosis, inequities, access to services, black children</p>

			experiencing the multiple effects of poverty.	
2018	Families USA. A framework for advancing health equity and value: Policy options for reducing health inequities by transforming health care delivery and payment systems. Familiesusa.org. June 20, 2018. Accessed February 1, 2021. https://www.familiesusa.org/wp-content/uploads/2018/06/FamiliesUSA_Policy-Options_Report.pdf .	Payment and delivery reform must be considered to advance health equity and improve the health of those currently experiencing disparities. More specifically, the health care system should reduce the negative impact of socially shaped barriers on people's health and their access to high-quality care.	This report provides a conceptual framework of six policy domains for health equity-focused transformation. This is a resource that health equity and health system transformation leaders can use to assist in policy development and prioritization that best serves their communities and constituencies.	
2018	Gilson KM, Johnson S et al. Supporting the mental health of mothers of children with a disability: Health professional perceptions of need, role, and challenges. <i>Child Care Health Dev.</i> 2018 Sep;44(5):721-729. doi: 10.1111/cch.12589.	OBJECTIVE: To compare healthcare transition planning in adolescents with Down syndrome with adolescents with other special healthcare needs.	Adolescents with Down syndrome experience disparities in access to transition services. Provider goals for adolescents with Down syndrome should encourage as much independence as possible in their personal care and social lives.	Health disparities, Down Syndrome, health care transition
2018	Jolles MP, Lee PJ, Javier JR. Shared decision-making and parental experiences with health services to meet their child's special health care needs: Racial and ethnic disparities. <i>Patient Educ Couns.</i> 2018 Oct;101(10):1753-1760. doi: 10.1016/j.pec.2018.05.022	Test the relationship between shared decision-making (SDM) and parental report of frustration with efforts to get services for their child and to address unmet health needs; assess SDM's influence on minority parents' service experiences.	SDM may be a promising engagement strategy to improve parental service experiences. The role of SDM on increasing Black parents' reports of service dissatisfaction, perhaps due to increased awareness of service challenges, should be investigated.	Shared Decision Making (SDM), quality of care, parent satisfaction, AA parents

Yr	Reference	Background	Key Findings/ Recommendations	Key Words
2018	<p>Policy Link. Counting a diverse nation: Disaggregation data on race and ethnicity to advance a culture of health. Policylink.org. 2018. Accessed February 2, 2021. https://www.policylink.org/resources-tools/counting-a-diverse-nation</p>	<p>This report analyzes the key focus areas in data disaggregation to advance a culture of health and provides background on why each area is important and how leaders in the field view the challenges and opportunities.</p>	<p>By improving data disaggregation, researchers, policymakers, and practitioners will be better able to influence the health environments, behaviors, and outcomes of communities across the U.S. The recommendations address conceptual, technical, and practical challenges to leveraging data disaggregation.</p>	
2018	<p>Ross SM, Smit E, et al. Patient-centered medical home and receipt of part c early intervention among young CSHCN and developmental disabilities versus delays. <i>Matern Child Health J.</i> 2018 Oct;22(10):1451-1461. doi: 10.1007/s10995-018-2540-z.</p>	<p>To determine, among a sample of young children with special health care needs (CSHCN) with developmental conditions, (1) characteristics associated with receipt of both patient-centered medical home (PCMH) and Part C early intervention, (2) the association between each PCMH criterion and receipt of Part C generally, and (3) for CSHCN with disabilities versus delays.</p>	<p>Concurrent PCMH and Part C access was low for young CSHCN with developmental conditions affecting their function. Given the overlapping mandates for PCMH and Part C, integrated efforts are warranted to identify if lack of concurrent services in fact reflects unmet service needs.</p>	<p>CSHCN, Patient-centered medical home, Part C, developmental conditions</p>

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2017	Acharya K, Msall ME. Health care disparities among children with special health care needs. <i>Pediatr Ann.</i> 2017 Oct 1;46(10):e358-e359. doi: 10.3928/19382359-20170921-02.	It is well known that children with special health care needs experience a variety of disparities and that these disparities are exacerbated by system fragmentation and missed opportunities. In this issue, it was decided to focus on aspects of health care disparities that have been underrepresented in the literature with respect to children and youth with special health care needs (CYSHCN), such as access to early childhood supports, delayed developmental and educational services, community participation, and behavioral health.	Reducing disparities for CYSHCN requires opportunities to share and develop collaborative models that integrate comprehensive primary care with developmental enrichment, behavioral health, and community participation.	Comprehensive care, CSHCN, access, community participation, behavioral health
2017	Arestad KE(1), MacPhee D, et al. Cultural adaptation of a pediatric functional assessment for rehabilitation outcomes research. <i>BMC Health Serv Res.</i> 2017 Sep 15;17(1):658. doi: 10.1186/s12913-017-2592-6.	The aims of this observational study are (a) to examine similarities and differences of culturally adapting a pediatric functional assessment with and without language translation, and (b) to examine the feasibility of cultural adaptation processes.	Results lend preliminary support to the need for and feasibility of cultural adaptation with and without language translation. Results inform decisions surrounding cultural adaptations with and without language translation and thereby enhance cultural competence and quality assessment of healthcare need within pediatric rehabilitation.	Cultural adaptation, rehabilitation, pediatric functional assessment

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2017	Carter FA, Msall ME. Health disparities and child development after prematurity. <i>Pediatr Ann.</i> 2017 Oct 1;46(10):e360-e364. doi: 10.3928/19382359-20170919-02.	This article highlights recent research on the long-term impact of preterm birth with a focus on disparities in resource access and in outcomes at entry to kindergarten and early educational trajectories.	Ten key recommendations are provided for ensuring proactive management strategies for the long-term academic, behavioral, and social success of these at-risk children.	Health disparities, child development, prematurity
2017	Collins ME, Mudie LI, et al. Pediatric ophthalmology and childhood reading difficulties: Overview of reading development and assessments for the pediatric ophthalmologist. <i>J AAPOS.</i> 2017 Dec;21(6):433-436.e1. doi: 10.1016/j.jaapos.2017.06.017.	Reading difficulties are common in the pediatric population, and large socioeconomic disparities exist. In the United States 46% of white children achieved expected reading proficiency by the end of fourth grade, while only 21% of Hispanic and 18% of African American children were reading at the expected level. Reading is an involved cognitive process with many subskills; likewise, development of reading proficiency is a complex and continuous process.	Failure to achieve reading proficiency or even early difficulty with reading can affect a child's academic performance for years to come. Some studies suggest reading proficiency may be related to later success in life. Although many problems with reading are not related to vision, a vision assessment is recommended for children with reading difficulties and a suspected vision problem. The process of reading development as well as the varied educational assessments of reading are presented here for pediatric ophthalmologists.	Reading difficulties, Socioeconomic disparities

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2017	<p>Community Catalyst. Transforming hospital community benefit: Increasing community engagement and health equity investment in Connecticut. Communitycatalyst.org. October 2017. Accessed February 2, 2021. https://www.communitycatalyst.org/resources/publications/document/Community-Benefit-in-CT_Final.pdf.</p>	<p>This paper discusses state and local efforts used to strengthen the connection between hospital community benefit programs and health equity investments in Connecticut. It includes a comparative analysis of the state and federal frameworks governing community benefit for Connecticut hospitals, with a special focus on transparency and opportunities for health equity investment.</p>	<p>The 11 recommendations focus on public policies and institutional practices to increase transparency, community accountability, and evaluation for health equity impact.</p>	
2017	<p>Doshi P, Tilford JM, et al. Do insurance mandates affect racial disparities in outcomes for children with autism? <i>Matern Child Health J.</i> 2017 Feb;21(2):351-366. doi: 10.1007/s10995-016-2120-z.</p>	<p>The study investigated whether state mandates for private insurers to provide services for children with autism influence racial disparities in outcomes. The study used 2005/2006 and 2009/2010 waves of the National Survey of Children with Special Health Care Needs.</p>	<p>This study did not find evidence that state mandates on private insurers affected racial disparities in outcomes for children with autism.</p>	Insurance mandates

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2017	<p>National Quality Forum. A Roadmap for promoting health equity and eliminating disparities: The four I's for health equity. Qualityforum.org. Published September 2017. Accessed February 1, 2021 https://www.qualityforum.org/Publications/2017/09/A_Roadmap_for_Promoting_Health_Equity_and_Eliminating_Disparities_The_Four_I_s_for_Health_Equity.aspx.</p>	<p>This report presents a roadmap for reducing health and healthcare disparities through performance measurement and associated policy levers. The roadmap primarily focuses on ways in which the US healthcare system (i.e., providers and payers) can use more traditional pathways to eliminate disparities; however, it also identifies areas where collaboration and community partnerships can be used to expand the healthcare system's role to better address disparities.</p>	<p>The roadmap lays out four actions that healthcare stakeholders can employ to reduce disparities: identify and prioritize reducing health disparities; implement evidence-based interventions to reduce disparities; invest in the development and use of health equity performance measures; and incentivize the reduction of health disparities and achievement of health equity. To move towards the goal of health equity, stakeholders must reduce disparities and achieve meaningful progress.</p>	

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2017	Williams K, Wargowski D, et al. Disparities in health supervision for children with down syndrome. <i>Clin Pediatr</i> (Phila). 2017 Dec;56(14):1319-1327. doi: 10.1177/0009922816685817. Epub 2017 Jan 30.	Increasing evidence suggests children with Down syndrome do not receive recommended health care services. The authors retrospectively assessed adherence to the 2001 American Academy of Pediatrics health supervision guidelines for 124 children with Down syndrome.	Cervical spine radiographs were completed for 94% of children, often preoperatively. Adherence to thyroid function recommendations was 61% (95% CI 54% to 67%); higher for children seen by a pediatrician (P = .002) and with known thyroid disease (P < .0001). Adherence to audiology and ophthalmology recommendations was 33% (95% CI 27% to 40%) and 43% (95% CI 37% to 50%), respectively. Adherence rates were higher for children referred to an otolaryngologist (P = .0002) and with known eye disease (P < .0001). Future efforts should identify barriers to care and improve adherence to recommended screening.	Down Syndrome, children, quality care, AAP health supervision guidelines

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2017	<p>Woolf, SH. Progress in achieving health equity requires attention to root causes. <i>Health Affairs.</i> 2017 Jun;36(6):984--991. doi: 10.1377/hlthaff.2017.0197</p>	<p>Although health care systems are taking important steps to reduce inequities, meaningful progress requires interventions outside the clinic, in sectors such as employment, housing, transportation, and public safety. Inequities exist in each of these sectors, and barriers to educational attainment, higher-income jobs, and social mobility limit the opportunity of disadvantaged people to improve their circumstances. Financial institutions and other stakeholders are investing in cross-sector collaborations to remove these barriers and thereby strengthen local economies and population health.</p>	<p>Health equity is achieved not only by treating illnesses but also by addressing the physical and social environments that shape health behavior and produce disease and by creating the opportunity for vulnerable populations to build social and economic resources. Prudent investments in infrastructure and social mobility are essential to public health.</p>	<p>Health disparities, access to care, health equity, education, children's health, systems of care, ethnic disparities, public health, health outcomes, population health</p>

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2016	Chin MH. Creating the business case for achieving health equity. <i>J Gen Intern Med.</i> 2016;31(7):792-796. doi:10.1007/s11606-016-3604-7	Health care organizations have increasingly acknowledged the presence of health care disparities across race/ethnicity and socioeconomic status, but significantly fewer have made health equity for diverse patients a true priority. This article focuses on the lack of financial incentives as a major barrier in achieving health equity.	To create a business case for equity, governmental and private payors can: 1) require health care organizations to report clinical performance data stratified by race, ethnicity, and socioeconomic status. 2) Incentivize preventive care and primary care. 3) Incentivize the reduction of health disparities with equity accountability measures in payment programs. 4) Align equity accountability measures across public and private payors. 5) Assist safety-net organizations. 6) Conduct demonstration projects to test payment and delivery system reform interventions to reduce disparities.	Business case, equity, disparities, payment, reimbursement
2016	Magaña S, Parish SL. Functional severity and Latino ethnicity in specialty services for children with autism spectrum disorder. <i>J Intellect Disabil Res.</i> 2016 May;60(5):424-34. doi: 10.1111/jir.12293.	In this study, the author examined whether there are ethnic disparities between Latino and White children with ASD in specialty autism-related services, and whether functional severity moderates the relationship between ethnicity and receipt of autism services.	Assertive policy initiatives are needed to address these disparities and ensure that these highly vulnerable children with severe functional limitations receive appropriate services and supports.	Ethnic disparities, autism

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2015	Earley E, Asti L, et al. Comparative analysis of health care needs among children with special health care needs in Ohio's metropolitan and Appalachian counties. <i>J Health Care Poor Underserved.</i> 2015 Aug;26(3):668-75. doi: 10.1353/hpu.2015.0105.	The study assessed whether children with special health care needs (CSHCN) living in Appalachian Ohio have differential health care utilization, unmet needs, and health outcomes compared with CSHCN in Ohio's metropolitan counties using a statewide Ohio survey.	The authors conclude that CSHCN in Appalachian and metropolitan areas face similar levels of health status and unmet needs, but results suggest a need for additional research on access to primary care services.	CSHCN, Appalachian Counties
2015	Gipson TT, Lance EI, et al. Disparities in identification of comorbid diagnoses in children with ADHD. <i>Clin Pediatr (Phila).</i> 2015 Apr;54(4):376-81. doi: 10.1177/0009922814553434.	This study explores disparities in identification of educationally relevant comorbidities and medication prescribing practices for children with attention-deficit hyperactivity disorder (ADHD) and either comprehensive neurodevelopmental evaluations or evaluations limited by insurance to behavior management with medication.	School-aged children with ADHD are likely to receive similar educational and medication management despite differences in evaluations. However, our data suggest that children who received comprehensive evaluations had greater identification of comorbid conditions that may influence academic, behavioral, and social outcomes.	ADHD, comorbidities, disparities
2015	Magaña S, Parish SL, et al. Have racial and ethnic disparities in the quality of health care relationships changed for children with developmental disabilities and ASD? <i>Am J Intellect Dev Disabil.</i> 2015 Nov;120(6):504-13. doi: 10.1352/1944-7558-120.6.504.	The aim of this study was to determine if racial and ethnic disparities in the quality of provider interaction have changed between 2006 and 2010 for children with developmental disabilities and autism spectrum disorders (ASD).	Black and Latino parents were significantly less likely than White parents to report that their provider spent enough time with their child and was sensitive to the family's values. Racial and ethnic disparities in health care quality were found to be unchanged over time. Research and policy implications are discussed.	Racial disparities, provider interaction, DD, ASDs

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2014	Dougherty D, Chen X, et al. Child and adolescent health care quality and disparities: Are we making progress? <i>Acad Pediatr.</i> 2014 Mar-Apr;14(2):137-48.	Children and adolescents are known to experience poor health care quality; some groups of children have poorer health care than others. The authors sought to examine trends over time in health care quality and disparities by race, ethnicity, income, insurance, gender, rurality, and special health care needs.	There was some progress in health care quality and reducing disparities in children's health care quality from 2000 to 2009; opportunities for targeting improvement strategies remain.	Child, adolescent, quality care, disparities
2014	Health Research & Educational Trust. A framework for stratifying race, ethnicity, and language data. Hpo.e.org. October 2014. Accessed February 2, 2021. http://www.hpo.e.org/Reports-HPOE/REAL-data-FINAL.pdf	Eliminating health care disparities is essential to improve quality of care for all patients. Hospitals and care systems are working to ensure every patient receives high-quality care. In addition, value-based purchasing and pay-for-quality programs necessitate that hospitals and care systems improve patient outcomes. One step in addressing health care disparities and improving patient outcomes is stratifying patient data by race, ethnicity, and language data.	By collecting and stratifying patient race, ethnicity, and language (REAL) data, hospitals and care systems can identify which, if any, health care disparities exist—and then target interventions to address the disparities. This guide provides a framework that includes five steps: 1) Assemble a working group that is focused on health care disparities data. 2) Validate the REAL data. 3) Identify the highest priority metrics for stratification. 4) Determine if stratification is possible on the selected metrics. 5) Stratify the data.	Health care, equity, stratifying, data, REAL

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2014	Park C, Tan X, et al. Racial health disparities among special health care needs children with mental disorders: Do medical homes cater to their needs? <i>Prim Care Community Health</i> . 2014 Oct;5(4):253-62. doi: 10.1177/2150131914539814.	The study examined racial/ethnic disparities among children with mental disorders in accessing care from the patient-centered medical home (PCMH).	There were significant racial/ethnic disparities among children with special health care needs (CSHCN) with mental disorders, indicating several sizeable effects of each of the 5 components on Hispanic, black, and other children compared with white children. These differences could be a potential to improve racial/ethnic disparities.	CSHCN, mental disorders, racial/ethnic disparities, access
2012	Chin MH, Clarke AR, et al. A roadmap and best practices for organizations to reduce racial and ethnic disparities in health care. <i>J Gen Intern Med</i> 27, 992–1000 (2012). https://doi.org/10.1007/s11606-012-2082-9	This paper outlines a roadmap and best practices for organizations, policymakers, and researchers striving to provide high-quality equitable care.	Organizations must design, implement, and sustain interventions based on the specific causes of disparities and their unique institutional environments and patient needs. Effective implementation and long-term sustainability require attention to all six steps: recognize disparities and commit to reducing them; implement a basic quality improvement structure and process; make equity an integral component of quality improvement efforts, design intervention(s); implement, evaluate, and adjust intervention(s); and sustain the intervention(s)	Disparities, quality of care, race, intervention, equity