

Health Equity for Children and Youth With Special Health Care Needs: A Vision for the Future

Amy Houtrow, MD, PhD, MPH,^{a,b} Alison J. Martin, PhD, MA,^{c,d} Debbi Harris, MA, MS,^{e,f} Diana Cejas, MD, MPH,^g Rachel Hutson, MSN, RN, CPNP,^h Yasmin Mazloomdoost, MPH, MSW,ⁱ Rishi K. Agrawal, MD^{j,k}

abstract

Health equity is a key pillar in supporting a future in which CYSHCN enjoy a full life and thrive, as envisioned by experts and community partners who gathered in 2019 and 2020 to develop the *Blueprint for Change: Guiding Principles for a System of Services for Children and Youth With Special Health Care Needs and Their Families*. However, a variety of contextual factors impact health outcomes across the life course and intergenerationally and must be addressed to achieve this goal. For example, poverty and discrimination, including by some health care professionals and systems, are important, modifiable root causes of poor health outcomes. There are numerous barriers to achieving health equity, including political will, lack of resources, insufficient training, and limited cross-sector collaborations. Political, cultural, societal, and environmental interventions are necessary to eliminate health disparities and achieve health equity. The entities that serve CYSHCN should be equitably designed and implemented to improve health outcomes and address health disparities. Many entities that serve CYSHCN are taking positive steps through workforce development, policy changes, community engagement, and other means. The purpose of this article is to frame health equity for CYSHCN, detail their health disparities, review barriers to health equity, provide examples of strategies to advance health equity for them, and describe a path toward the future in which all CYSHCN have a fair and just opportunity to be as healthy as possible.

^aDepartments of Physical Medicine Rehabilitation and ^bPediatrics, University of Pittsburgh, Pittsburgh, Pennsylvania; ^cOregon Center for Children and Youth with Special Health Needs, School of Public Health, Oregon Health and Science University-Portland State University, Portland, Oregon; ^dInstitute on Development and Disability, Oregon Health and Science University, Portland, Oregon; ^eThe Arc of the United States, Washington, District of Columbia; ^fFamily Voices of Minnesota, St. Paul, Minnesota; ^gCarolina Institute for Developmental Disabilities, University of North Carolina at Chapel Hill, Carrboro, North Carolina; ^hTitle V Maternal and Child Health, Colorado Department of Public Health and Environment, Denver, Colorado; ⁱHealth Resources and Services Administration, Rockville, Maryland; ^jAnn and Robert H. Lurie Children's Hospital of Chicago, Chicago, Illinois; and ^kDepartment of Pediatrics, Feinberg School of Medicine, Northwestern University, Chicago, Illinois

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Address correspondence to Amy Houtrow, MD, PhD, MPH, 4401 Penn Ave FP 5113, Pittsburgh PA, 15224. E-mail: houtrow@upmc.edu

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All children and youth with special health care needs (CYSHCN), as currently identified, have chronic health conditions. Health, in this context, should be understood not as the absence of disease, but rather the extent to which children are “able or enabled to (1) develop and realize their potential; (2) satisfy their needs; and (3) develop the capacities that allow them to interact successfully with their biological, physical, and social environments.”¹ Numerous contextual factors unrelated to a child’s biology and personal choices impact the “extent to which children are able or enabled” to be as healthy as possible. Contextual factors that differentially and negatively impact certain groups of children, such as those living in poverty or members of oppressed or minoritized (Table 1) racial groups, are the sources of health disparities.^{2–4} These contextual factors are often referred to as social determinants of health: the conditions in which children are born into, live, learn, play and grow up.⁵ Whether they be cultural, political, environmental or interpersonal, contextual factors influence health across the life course and generations.⁵ Children of various backgrounds, including

those with intersectional identities, are subject to health disparities through the mechanisms of poverty and discrimination—such as, but not limited to, racism, classism, and ableism in all forms from personally-mediated (differential beliefs and actions) to structural discrimination—and their downstream consequences. These consequences include limited access to quality education, stable housing, nutrient-rich balanced diets, safe neighborhoods, and health care.^{6–11} Eliminating the factors that inhibit children from thriving and from having a fair and just opportunity to be as healthy as possible is necessary for achieving health equity for CYSHCN.^{12,13}

Data

Data from the 2016 through 2019 years of the National Survey of Children’s Health (NSCH), funded and directed by the Health Resources and Services Administration’s (HRSA) Maternal and Child Health Bureau (MCHB), identify the magnitude of differences in the prevalence and impact of special health care needs among children based on the contextual factors in which they live (see Ghandour et al¹⁴ for methodologic

details; see Fig 1A for the prevalence of SHCN). Overall, 19.4% of non-CYSHCN in the United States live in poverty, whereas 23.8% of CYSHCN do. Additionally, CYSHCN are overrepresented in poorer and more rural states, such as Mississippi, Louisiana, Kentucky, and West Virginia.¹⁴ Data from the NSCH demonstrate that minoritized race, poverty, and special health care needs often track together; for example, 43.4% of Black CYSHCN live in poverty compared with 33.6% of Black non-CYSHCN and only 10.9% of White non-CYSHCN.

Similarly, disability, ie, activity limitations caused by chronic conditions, is more common among children living in poverty and those of minoritized race.¹⁵ Our analysis demonstrates that the presence of disability (meeting the CSHCN Screener functional limitation criterion)¹⁶ is associated with poverty-driven and minoritized differences among CYSHCN (Fig 1B). There is an inverse stepwise relationship between household income, such that 31.3% of CYSHCN living in poverty have disabilities compared with 20.8% of those living above 400% of the federal poverty level (FPL). Whereas 22.9% of

TABLE 1 Important Health Equity Concepts

Concept	Description
Discrimination	Discrimination, marginalization, and oppression are culturally embedded, institutionalized, normalized, personally mediated, internalized, and structured within our social and political systems. Racism is the assignment of value and structuring of opportunity based on race that unfairly advantages certain individuals over others; classism is the oppression of one group by another based on economic distinctions derived from one’s situation within the system of production and distribution; and ableism is stereotyping, prejudice, discrimination, and social oppression directed toward people with disabilities.
Health disparities	Preventable or avoidable differences in the experience of disease or disease severity based on membership in a disadvantaged or oppressed group.
Health equity	The Health Resources and Services Administration (HRSA) definition of health equity is “the absence of disparities or avoidable differences among socioeconomic and demographic groups or geographic areas in health status and health outcomes”
Intersectional identities	The multidimensional lived experiences of marginalized, minoritized, or oppressed people.
Minoritized	The term “minority” has been criticized for attempting to erase the forces (eg, racism and colonialism) that produce the effects of minoritization. This term is used in this document to acknowledge the oppression and discrimination inflicted upon certain groups of individuals in our society. Minoritized groups are those that are considered a minority by the socially dominant group based on what they are not or what they lack.
Social determinants of health	The conditions in which children are born into, live, learn, play and grow up.

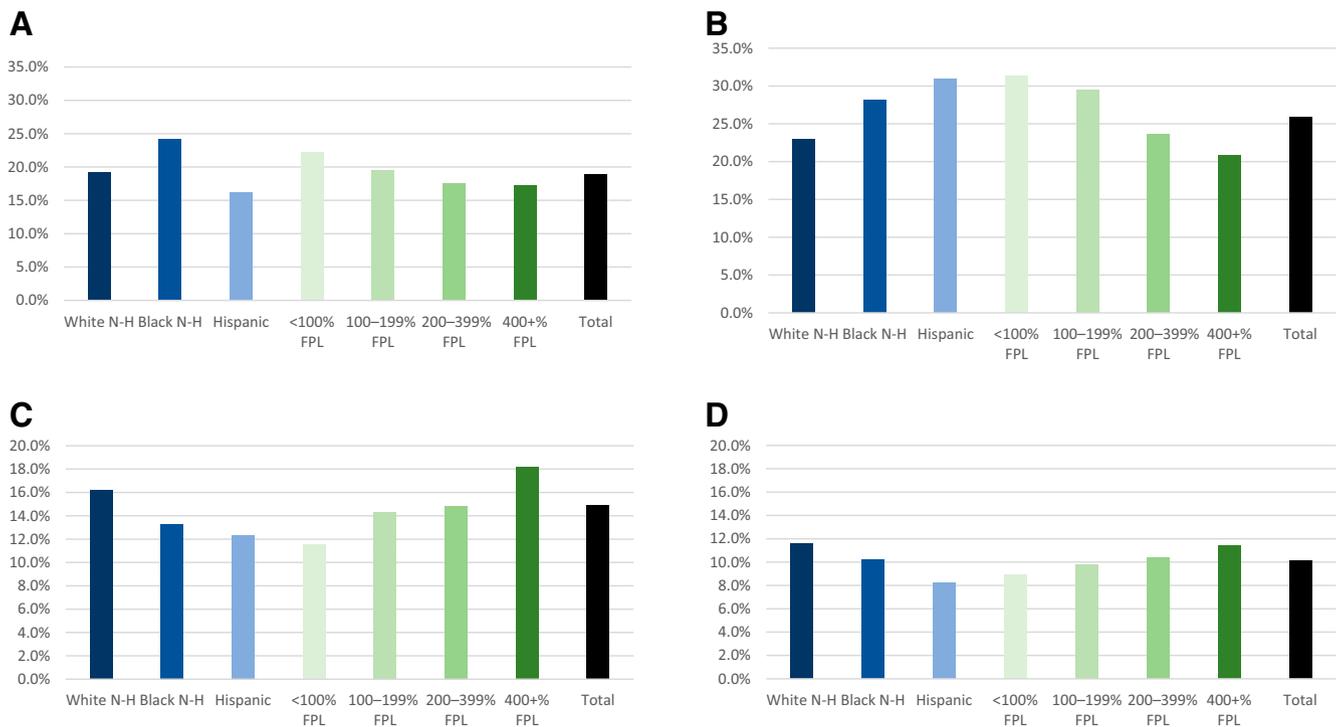


FIGURE 1

(A) Prevalence of SHCN, (B) prevalence of disabilities among CYSHCN, (C) care in a well-functioning system for CYSHCN, and (D) care in a well-functioning system for CYSHCN with disabilities. N-H, Non-Hispanic; FPL, federal poverty level.

White CYSHCN have disabilities, 30.9% of Hispanic CYSHCN do. As demonstrated by other studies, CYSHCN with disabilities and complex health care needs, minoritized CYSHCN, and those living in or near poverty more commonly have unmet needs and limited access to a pediatric medical home and a well-functioning system of care (a MCHB national outcome measure focused on multiple aspects of health care delivery).^{17–23} These inequities are long-standing.^{24–27} As shown in Fig 1C, receipt of care in a well-functioning system differs by race and family income, such that White non-Hispanic children and children in more financially resourced families more commonly report such receipt. Similarly, Fig 1D demonstrates that fewer CYSHCN with disabilities reported receipt of care in a well-functioning system compared to CYSHCN generally and that the same patterns of inequities

exist—ie, White non-Hispanic children and children in more financially resourced families more commonly report receiving care in a well-functioning system.

Unequal treatment and discrimination in the systems that serve CYSHCN are not always easily recognized but are a part of the lived experience of many of them and their families as described by author D.H. who offers the first narrative in Table 2 to demonstrate permissive racism, ie, the continued tolerance for racism as a part of life experienced by her family. Ableist thinking among health care professionals, that disability is an indicator of inferiority and must be fixed, is also common and serves as a barrier to health equity, as described by author D.C. in the second narrative in Table 2.^{28,29} Ableism is also evident when the only framing of disability is as a

tragic loss, as described by author D.H. in the third narrative in Table 2.

Vision for the Future

The MCHB gathered experts and stakeholders from across the country to inform the *Blueprint for Change: Guiding Principles for a System of Services for CYSHCN and their Families* (hereafter referred to as *Blueprint for Change*). The *Blueprint for Change* envisions a future in which CYSHCN “enjoy a full life from childhood through adulthood and thrive in a system that supports their families and social, health, and emotional needs, ensuring their dignity, autonomy, independence, and active participation in their communities.”

As described in the *Blueprint for Change* and consistent with Healthy People 2030, a key pillar of the future envisioned is that “all CYSHCN have a fair and just opportunity to be as healthy as

TABLE 2 The Lived Experience of Discrimination and Health System Dysfunction as Told by Authors D.H. and D.C.

Type of Discrimination	Lived Experience
Permissive racism	Nurse Sara (not her real name) is young and remarkably tall. I take a step back, slightly straining my neck to meet her gaze. She looks just beyond me though, her focus instead a calculated scan of the house. She's new here—to our home as a potential caregiver, as well as to the nursing profession. Children like ours, the ones with complex medical histories, need lots of orientation. They're tricky. The best way to make accurate assessments is to respect and learn from the lived experience of the people who have been the constants in their wildly unpredictable lives. Our home is nurse Sara's first job. Here I am, attempting to go over essential parts of Josh's medical history, the nuances of his behaviors that must inform his most basic assessments and care—and nurse Sara is not at all interested. "Listen," she says, with the commanding and familiar air of putting me in my place, "I'm the nurse here, and you're just the mom." I call the agency to express concern; this sort of attitude among home care nurses almost always ends in an unplanned hospitalization. The agency defends nurse Sara's indiscretion. Interruption in care and reimbursement dollars is sometimes a far greater evil than the skewed dynamic of being disrespected and diminished in one's own home. "She's from a small town, and she's not used to people like you," the coordinator says. "Like us? Suburbanites?" "Um, no." "Military families?" "Black people. She's just not used to being around Black people. It makes her uncomfortable." They ask that I be patient, teach her, allow her to allay any fears. But I am emotionally exhausted after years of various versions of the same scenarios. This is my house. My safe place. Nurse Sara is not invited back. – D.H.
Ableist thinking and ableist treatment	"You can't fix those kids. What's the point?" We were in our third year of medical school, but my classmate had already learned an unspoken rule of healthcare. I'd told him that I intended to go into pediatric neurology, that I wanted to work with disabled children, those with the highest needs and the most limited access, and he scoffed at me. "You can't do anything," he'd said. "You can't fix genetic conditions or brain malformations, or intellectual disabilities, so why even try?" The 2 of us had just a few months of clinical experience under our belts and yet that had been time enough for my classmate to internalize ableist ideas about disability and quality of life. He already saw disabilities and chronic illnesses as problems to be fixed rather than seeing disabled and chronically ill patients as people in need of support and high-quality care. Unfortunately, that kind of thinking is more common in medicine than not. It's woven into training curricula, reinforced through biased texts and journal articles, evidenced by the way that we provide care. Individual and systemic discrimination working together to negatively affect children's health. I quickly learned that their disabilities weren't the problem. Not the biggest problem anyway. I sat down with 1 patient after another, asked about their illnesses during follow up appointments, admitted them to the inpatient units, transferred them, and got them ready to go home. Their symptoms may have been different but so many of their stories were the same. Their autism wasn't the problem. It was the fact that they couldn't get accommodations at school without getting costly neuropsychological testing to prove that they needed them. Or their cerebral palsy wasn't the issue; it was that their mobility devices weren't covered by insurance. – D.C.
Demonstrates ableism through unwillingness to say the word disability and portraying disability as a tragedy	"The results have come back, Mrs. Harris. The blood from the hemorrhage your son experienced at birth has resorbed into the brain. There was just so much of it, and it has eaten away at the intact tissue." The other parents stare at me, expressions marked with pity—and relief that this bearer of grim news has not come for any of their children. I try hurriedly to arrange jangled thoughts into proper questions, searching for a bit of hope to break through the heaviness this man brings. The doctor places a gentle hand on the damp cuff of my gown, then proceeds to cut into my heart, like surgeons often do, but with indelible, scarring words, announced in front of this curious crowd of common strangers. "I'm afraid the prognosis is poor, Mrs. Harris. Your boy will most certainly be severely, profoundly ... umm...I'm so sorry." <i>For your loss</i> ... I think he wants to say, but his words drop into a vacuous silence as he lets go of my arm and walks away. – D.H.
Demonstrates the need for culturally responsive care and respect for autonomy	As I savor those first moments snuggled into position on the sofa, anxious to discover Josh's new baby's scent, away from the sterile smells of the hospital, nurse David (not his real name) says, "I should take him now, really. He really needs to get hooked back up to everything," he says as he walks away with my baby. "If you have any questions, I'm here for a 12-hour shift. Go get some rest." Nurse David seems to stomp on boundaries that no one has established. Everything about us is different. Our values. Our safe space. Our communication styles. One day, nurse David bursts suddenly through the doorway of our bedroom—an assumed restricted zone—as I'm dressing. He shrugs away my obvious shock and embarrassment. "Don't worry," he says. "I'm a nurse. You don't have anything I haven't seen before." I feel as though I am sacrificing my agency as a mother to keep my child at home, and the agency of the privacy of my body to assimilate to this strange caregiver. Eventually, he dissolves into a long trail of homecare nurses who become unwitting players in a remarkable game of sacrifice, trade-offs, and the gradual, painful loss of our unique culture as a family. I learn to keep peace and get more nursing hours by accommodating a diversity of personalities, values, and traditions—at the expense of our own. Because this life is unfamiliar to me, and my role within the system that supports it remains unclear, bit by bit, shift after shift, I become a stranger in my own home. –D.H.

possible and thrive throughout their lives (eg, from school to the workforce), without discrimination, and regardless of the circumstances in which they were born or live” (Table 3).^{29,30} Underlying values that guide this work include the following: all children should be equally valued; resources to promote health should be distributed fairly; commitment to health equity represents justice in health; and progress is measured by a reduction in health disparities.³¹ Achieving this future requires that disparities are addressed at their root causes (Health Equity Principle 1, Table 3).²⁹ Until disparities are eliminated at their root causes, the sectors, systems, and programs that fund, oversee, and/or deliver services and supports for CYSHCN must address the consequences of disparities to improve health outcomes equitably for CYSHCN (Health Equity Principle 2, Table 3).²⁹

The *Blueprint for Change* has elevated health equity as a goal that permeates all aspects of programs and policies at the community, state, and national levels that affect CYSHCN and their families. The *Blueprint* acknowledges that the process to achieve health equity requires removing all obstacles and barriers to health, which includes transforming the structures, policies, and beliefs that systematically benefit certain groups of people over others.²⁹ This approach means not only measuring the actions of all community, state, and federal programs for adherence to health equity principles, but also raising the expectation that all programs serving CYSHCN will actively collaborate, promote, and engage in system redesign. All programs also must work toward eliminating the policies and systems that propagate the entrenched systematic oppression of certain groups of

children based on ability, race, indigenous status, class, gender identity, sexual orientation, nativity, religion, or other group designation.

In this special issue of *Pediatrics*, 3 other critical areas (pillars) are presented as part of the *Blueprint for Change*²⁹: quality of life and well-being, access to services, and financing for services. Health equity is thematically incorporated throughout all 3. (1) Quality of life and well-being: considerations of how to advance the well-being and quality of life for children and families, as described by Coleman et al, emphasize ensuring equitable advancement such that all children, regardless of their social, economic, environmental, and health circumstances, have the opportunity to achieve the best quality of life possible.³² (2) Access: as detailed by Kuo et al, certain children experience systematic access barriers to services and supports that require an equity-based access strategy.³³ (3) Financing: there are a multitude of reasons why CYSHCN and their families experience inequitable access, 1 of which is how services are financed, as described by Schiff et al.³⁴ To be equitable, CYSHCN and their families must be able to get all needed services and supports, regardless of their financial resources, social position, or type of coverage.³⁵

Challenges to Achieving the Envisioned Future

There are myriad complex challenges to achieving health equity for CYSHCN. For example, key stakeholders need to be willing to dismantle federal, state, and local policies and laws that codify unequal treatment and replace them with equitable policies and laws,²⁹ specifically those focused on health care, education, housing, public safety, criminal justice, employment, foster care, welfare, and other

sectors affecting health.^{36,37}

Although there have been political and legal advances regarding the civil rights of minoritized groups (eg, the Americans with Disabilities Act, the Rehabilitation Act of 1973, the Civil Rights Act of 1964), policies and laws that perpetuate unequal treatment are difficult to change, and existing rights are not always enforced.³⁸ Notably, the United States has opted not to ratify the United Nations Convention on the Rights of People with Disabilities or the United Nations Convention on the Rights of the Child,³⁹ and Congressional ratification is unlikely.⁴⁰ In addition, the United States is the only wealthy nation that does not view health care as a human right.³⁹ Although some prominent individuals and groups have called for universal health care coverage for children, they have yet to gain substantial political traction in nonprogressive circles.^{41,42} Civil rights in other arenas have been enacted legislatively but lag in implementation. For example, free appropriate public education in the least restrictive environment for children and youth with disabilities, provided under the Individuals with Disabilities Education Act Part B, has been implemented in only 21 states and the Republic of the Marshall Islands.⁴³ Societal norms, such as the entrenched racism and ableism described in the narratives above, also are substantial obstacles to health equity for CYSHCN.

In addition to these societal barriers, numerous operational barriers exist in achieving a future in which all CYSHCN thrive. Despite their connected purposes, the various agencies and service sectors that constitute systems of services for CYSHCN do not yet actively work together to coordinate activities for advancing health for CYSHCN.⁴⁴ These obstacles compound existing barriers related to availability and

TABLE 3 Health Equity Principles and Subcomponents in the Blueprint

Principle	Definition
Principle 1	Structural and systemic causal barriers to health equity, including discrimination (racism, ableism, classism, and the like), poverty, and other social risk factors are eliminated.
Subcomponent a	Service systems and policy makers recognize and address the fundamental causes of health disparities. Federal, state, and local policies and laws that codify oppression are dismantled and replaced with equitable policies and laws.
Subcomponent b	All sectors that serve CYSHCN, including but not limited to health care, public health, education, housing, nutrition, and income supports, collaborate with each other and policy makers to ensure that policies are coordinated, effective, and developed equitably to address the root causes of health disparities.
Subcomponent c	Surveillance systems identify, track, and cross-share data on social risk factors, including discrimination, that impact health outcomes and their consequences across the life course.
Principle 2	Sectors, systems, and programs that fund, deliver, and monitor services and supports for CYSHCN are equitably designed and implemented to reduce health disparities and improve health outcomes for all CYSHCN.
Subcomponent a	Entities that serve CYSHCN and their families coordinate policies, practices, and procedures across sectors to mitigate health effects of societal oppression.
Subcomponent b	Entities that serve CYSHCN and their families have an appropriately paid and diverse workforce trained in evidence-informed, equitable, and culturally responsive delivery of services and supports.
Subcomponent c	Entities that serve CYSHCN and their families develop and implement performance and outcomes measures to ensure system accountability for nondiscriminatory equitable services for CYSHCN.
Subcomponent d	Children and youth who are at risk of a special health care need are defined, identified, and supported by the entities designed to serve them to optimize their health outcomes.

access of services based on geography, transportation, tribal designation, cultural safety, and other issues,^{45,46} and present a clear barrier to addressing health equity.⁴⁷ Author D.H. describes the challenges her family faces with home care providers who are not culturally respectful, but who they must tolerate to receive services in the final narrative in Table 3.

Further, the systems that serve CYSHCN are not designed to address health equity and can exacerbate disparities in both the short and long term. Take, for example, the circumstances of providing primary pediatric care in the United States. Although comprehensive, coordinated care in a medical home is the standard of care, disparities exist in medical home access for CYSHCN of color. For example, 24.2% of Native Hawaiian or Other Pacific Islander CYSHCN, 33.7% of Hispanic CYSHCN, 37.1% of American Indian or Alaska Native CYSHCN, and 39.6% of Black CYSHCN receive care in a medical home, compared with 47.6% of White CYSHCN.¹⁴ Further, care coordination is not adequately or equitably delivered or paid

for.^{35,48,49} One result is that when some payors reimburse more money for services rendered (as is the case with most private payors compared with Medicaid)³⁵ or do not pay for care coordination, practices can be incentivized to structure their clinic schedules and clinical activities to see more patients with private insurance and children without chronic conditions.⁵⁰ In other words, these practices might choose to care for children who tend to be more economically advantaged, White non-Hispanic (because they are less likely to be poor), and without disabilities. Poor children, minoritized children, and CYSHCN are more commonly covered by Medicaid^{51,52} and therefore, can be crowded out from getting appointments to see their pediatricians. Also, they are less likely to get the medical home services they need to manage their health.^{18–20,53} Thus, the current payment structure disincentivizes health equity and promotes systemic ableism, classism, and racism in health care delivery.⁵⁴ These problems are compounded when implicit or explicit biases hinder the delivery of culturally responsive,

family-centered care—the hallmarks of the medical home.^{19,27}

Toward the Envisioned Future

The work to achieve the envisioned future is both internal to the entities that serve CYSHCN and collaborative between them and the people they serve; requiring organizational reflection and engagement to change operations and to develop collaborative capacity to hone the skills of doing this work together.⁵⁵ Most changes will occur incrementally because changing systems entails identifying which structures and processes perpetuate health disparities and then altering the power structures, policies, relationships, resources, routines, and values operating within a system to dismantle oppression and promote health equity.⁵⁶

Policy

Policy change that seeks to eliminate the root causes of health disparities as opposed to addressing the disparate outcomes after the fact would be the mechanism most likely to achieve health equity for CYSHCN, as described in Health Equity Principle 1 (Table 3).^{29,41}

Conceptually, this is “an ounce of prevention is worth a pound of cure.” For example, substantially reducing child poverty is both achievable and of long-term financial benefit.⁵⁷ Some of the actions that the American Rescue Plan Act outlines can reduce child poverty, support community health initiatives, enhance the Affordable Care Act, increase incentives to states to expand their Medicaid programs, and address social contributors to health.^{58,59} Also,

the enactment of nondiscrimination laws and policies, coupled with enforcement of existing nondiscrimination laws and policies (eg, the Americans with Disabilities Act; Individuals with Disabilities Education Act; and the treatment provisions of the Medicaid Early Periodic Screening, Diagnostic, and Treatment benefit), would help dismantle structural barriers to opportunities, as described in Health Equity Principle 1a (Table 3).

New state laws or changes also provides opportunity to alter agency structures and processes to fund, develop, and deliver services that reduce health disparities, as described in Principle 2. For example, Colorado enacted legislation making state grants more accessible to community organizations that represent minoritized communities (Table 4). These organizations are better positioned to address health disparities within their communities

TABLE 4 Examples of Systemic Actions to Promote Equity

Actions Toward Equity
Thirty-three states automatically enroll CYSHCN in Medicaid after approving them for Supplemental Security Income, which ensures continuous coverage for the duration of their Supplemental Security Income benefits. ^a
The Colorado Department of Public Health and Environment acknowledges in all of its data publications that generations-long social, economic, and environmental inequities have resulted in adverse health outcomes. ^b
Oregon's Title V CYSHCN agency contracted with culturally specific service organizations to conduct participatory needs assessment studies to collect better data describing minoritized communities. The data and results are co-owned and codisseminated with the organizations. ^c
Wisconsin's Title V agency revised its budget allocation process to prioritize funding to support community member-led organizations. Their leadership expects this change to support projects that advance equity. ^d
Recognizing that sibling child care is a barrier to accessing health care for CYSHCN and their families, a regional, Title V-funded care coordination team in Oregon revised transportation rules to ensure that siblings could travel to medical appointments with CYSHCN and their caregivers. ^e
Wisconsin's Title V staff attend Hmong Parent Teacher Association meetings to build relationships with this marginalized community. ^f
The Philadelphia police department, in collaboration with schools, developed a program that diverts youth to community-based services based on identified needs instead of having them face arrest and school removal. ^g
Oregon partnered with MCHB and the Census Bureau to purchase NSCH oversamples to ensure adequate data collection from minoritized communities (eg, Oregon oversamples households with children identifying as American Indian or Alaska Native, Asian, Black, Hispanic, and Pacific Islander). ^c
Colorado enacted legislation to make state grants more accessible to those community organizations better poised to address health disparities, based on their lived experience, than larger organizations without a culturally specific focus. ^h
The Massachusetts Department of Public Health's Racial Equity Initiative creates expectations for White non-Hispanic staff to learn about oppression without placing the educational burden on staff of color. ⁱ
The American Academy of Pediatrics developed an equity agenda to promote equity in child and adolescent health care. ^j
Iowa's Title V CYSHCN agency hires family navigators from minoritized communities and establishes them in geographical locations convenient to the population they intend to serve. ^k
Ten state Medicaid programs participated in health equity training for children with disabilities and medical complexity through HRSA's Children with Medical Complexity Collaborative Improvement and Innovation Network. ^l

^a AL, AZ, AK, CA, CO, DE, DC, GA, IN, IO, KY, LA, ME, MD, MA, MI, MS, MO, NJ, NM, NY, NC, OH, PA, RI, SC, TN, TX, VT, WA, WV, WI, and WY. Available at: <https://secure.ssa.gov/poms.nsf/lnx/0501715020>, Accessed September 5, 2021.

^b Colorado Office of Health Equity's *Statement on Structural Inequity*.

^c Oregon Health Authority Maternal and Child Health Section and Oregon Center for Children and Youth with Special Health Needs. *Maternal and Child Health Services Title V Block Grant. Oregon FY 2022 Application and FY 2020 Annual Report*. Portland, OR: Authors; 2021.

^d Wisconsin Department of Health Services. *Maternal and Child Health Services Title V Block Grant. Wisconsin FY 2022 application / FY 2020 annual report*. Madison, WI: Authors. 2021.

^e Oregon Health Authority Maternal and Child Health Section and Oregon Center for Children and Youth with Special Health Needs. *Maternal and Child Health Services Title V Block Grant. Oregon FY 2020 Application and FY 2018 Annual Report*. Available at: https://mchb.tvisdata.hrsa.gov/uploadedfiles/StateSubmittedFiles/2020/OR/OR_TitleV_PrintVersion_FY20.pdf. Accessed September 5, 2021.

^f Western Regional Center for CYSHCN. *Western Regional Center for CYSHCN Mid-Year Report*. Chippewa Falls, WI. 2021.

^g Goldstein NES, Cole LM, Houck M, et al. Dismantling the school-to-prison pipeline: the Philadelphia police school diversion program. *Child Youth Serv Rev*. 2019;101:61–69.

^h Colorado Department of Public Health & Environment Contract Pay to Grantees Up Front HB21-1247, signed by the governor June 7.

ⁱ Campbell S, Buxton B. Organizational opportunities to address racial inequities. The Massachusetts Department of Public Health experience. Presented at: virtual 2021 Association of Maternal and Child Health Programs annual conference. May 27, 2021.

^j American Academy of Pediatrics. AAP equity agenda. Available at: <https://www.aap.org/en/about-the-aap/american-academy-of-pediatrics-equity-and-inclusion-efforts/aap-equity-agenda/>. Accessed July 20, 2021.

^k Division of Child and Community Health and Child Health Specialty Clinics, University of Iowa Stead Family Department of Pediatrics. *Maternal and Child Health Services Child Block Grant—Iowa FY 2020 application and FY 2018 annual report*. Iowa City, IA: Authors; 2021.

^l Collaborative for Improvement and Innovation Network. COIIN to advance care for CMC. Available at: <https://ciswh.org/project/coiin-cmc>. Accessed September 5, 2021.

because of their connections to the community and their members' lived experience with the issues

Research

Advancing health equity requires the knowledge that disparities persist. As described in Health Equity Principle 1c, surveillance systems are needed to track contextual risk factors impacting health outcomes and their consequences. Title V Maternal and Child Health Block Grant-receiving (Title V) agencies, health care systems, and other systems-of-care actors rely on NSCH data to describe their CYSHCN population; however, many jurisdictions lack sufficient data to describe them, let alone minoritized populations within the broader CYSHCN population. Some Title V CYSHCN agencies collaborate with minoritized communities to obtain data that describe minoritized community needs. For example, through a request for proposal process, Oregon's Title V CYSHCN agency contracted with culturally specific service organizations to conduct participatory needs assessment studies (Table 4). In addition to investing financial resources into and developing relationships with these communities, these organizations also co-own and co-disseminate the results with the Title V agency. Further, state-level policy, such as previously described in Colorado, facilitates such collaborations.

Research should be conducted that recognizes and reports discrimination as a cause of poor health across the life course and suggests strategies to both identify and intervene for children at risk for special health care needs and poor health.^{10,60} Research and rigorous program evaluation are required to assess how innovative strategies work for individual children and

communities, including the development of measures for equity. It is insufficient to solely report on disparities; evidence-driven solutions to reduce disparities are required. As described in Health Equity Principle 2c, using performance and outcome measures will help hold to account those entities serving CYSHCN and ensure adherence to nondiscriminatory equitable service delivery.²⁹ Additionally, implementation science strategies should be employed to ensure equitable dissemination of what methods work and how to scale them.⁶¹ Evaluations for programs and services should include how well they address health equity, as well as the presence of minoritized communities at the table to guide evaluative processes from needs assessments to programmatic evaluations.²⁹

Practice

Achieving health equity for CYSHCN requires that the entities funding, delivering, and/or monitoring services and supports are designed to be equitable without mechanisms that invertedly or purposefully unfairly advantage 1 group of children over another for said services and supports, as described in Health Equity Principle 2.²⁹ Collaboration across sectors that serve CYSHCN is needed, as noted in Health Equity Principle 2a.²⁹ These sectors include but are not limited to education, child welfare, vocational training, habilitation and rehabilitation, housing and community development, law enforcement and the criminal justice system, health care, nonprofits, transportation, and tribal and other governmental agencies. Not only do the sectors need to collaborate in new ways to become a system of services organized and coordinated to meet the multiple and changing needs of CYSHCN and their families,

but they also must collaborate with equity and justice at the center of their work and make the business case for equity.^{34,36,54,62} Such collaboration requires educating the existing workforce to recognize manifestations of oppression in day-to-day work practice, as described in Health Equity Principle 2b.

As eloquently shown in the narratives in Table 2, much work needs to be done to mitigate personally-mediated discrimination and implicit bias in health care and the public health sector to provide culturally responsive care.⁶³ Several strategies are being used in these settings across the country. For example, the Massachusetts Department of Public Health's Racial Equity Initiative employs multiple strategies to build such capacity in its workforce, including using affinity groups for White employees and those of color (Table 4). The groups hold White staff accountable for pursuing their learning about oppression without placing educational burden on or risking retraumatization of staff of color.⁶⁴ Advancing the workforce will also require pipeline development for those who serve CYSHCN and strategies to ensure that they are adequately paid for the work they do.⁶⁵ The examples in Table 4 represent promising small, important steps toward the envisioned future of health equity for CYSHCN.

CONCLUSIONS

In the envisioned future, the forces that create health disparities will be eliminated and all CYSHCN will have a fair and just opportunity to thrive. When threats to thriving are identified, programs, services, and supports specifically designed to advance health equity will be leveraged in a culturally responsive, child- and family-centered, evidence-informed, efficient, and

goal-directed way. Although this envisioned future currently is an aspiration, a more equitable future is within the nation's grasp by advancing equity in the policies, research, and practice of delivering health and related services for CYSHCN.

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ABBREVIATIONS

CYSHCN: children and youth with special health care needs

HRSA: Health Resources and Services Administration

MCHB: Maternal and Child Health Bureau

NSCH: National Survey of Children's Health

REFERENCES

- Institute of Medicine. *Children's Health, the Nation's Wealth: Assessing and Improving Child Health*. Washington, D.C.: National Academies Press; 2004
- Schickedanz A, Dreyer BP, Halfon N. Childhood poverty: understanding and preventing the adverse impacts of a most-prevalent risk to pediatric health and well-being. *Pediatr Clin North Am*. 2015; 62(5):1111–1135
- Pascoe JM, Wood DL, Duffee JH, Kuo A; Committee on Psychosocial Aspects of Child and Family Health; Council on Community Pediatrics. Mediators and adverse effects of child poverty in the United States. *Pediatrics*. 2016;137(4):e20160340
- Laurie T, Khan R. The concept of minority for the study of culture. *Continuum (N Y)*. 2017;31(1):1–12
- Braveman P, Barclay C. Health disparities beginning in childhood: a life-course perspective. *Pediatrics*. 2009;124(suppl 3): S163–S175
- Trent M, Dooley DG, Douge J, Section On Adolescent H; Council On Community Pediatrics, Committee on Adolescence. The impact of racism on child and adolescent health. *Pediatrics*. 2019;144(2): e20191765
- Bogart KR, Dunn DS. Ableism special issue introduction. *J Soc Issues*. 2019; 75(3):650–664
- Barone C. Bringing classism into the race & gender picture. *Race Gen Gen*. 1999;6(3):5–32
- Crenshaw K. Demarginalizing the intersection of race and sex: a black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum*. 1989; 1989(1):139–167
- Malawa Z, Gaarde J, Spellin S. Racism as a root cause approach: a new framework. *Pediatrics*. 2021;147(1): e2020015602
- Peterman DE. Socioeconomic status discrimination. *Va Law Rev*. 2018;104(7): 1283–1357
- Gehlert S, Sohmer D, Sacks T, Mininger C, McClintock M, Olopade O. Targeting health disparities: a model linking upstream determinants to downstream interventions. *Health Aff (Millwood)*. 2008;27(2):339–349
- US Department of Health and Human Services, Health Resources and Services Administration. Health equity report 2019-2020: special feature on housing and health inequalities. Rockville, MD: Office of Health Equity; 2020
- Ghandour R, Hirai A, Kennedy M. Children and youth with special health care needs: a profile. *Pediatrics*. 2021
- Houtrow AJ, Larson K, Olson LM, Newacheck PW, Halfon N. Changing trends of childhood disability, 2001-2011. *Pediatrics*. 2014;134(3):530–538
- Bethell CD, Read D, Neff J, et al. Comparison of the children with special health care needs screener to the questionnaire for identifying children with chronic conditions—revised. *Ambul Pediatr*. 2002;2(1):49–57
- Kuo DZ, Goudie A, Cohen E, et al. Inequities in health care needs for children with medical complexity. *Health Aff (Millwood)*. 2014;33(12):2190–2198
- Houtrow AJ, Okumura MJ, Hilton JF, Rehm RS. Profiling health and health-related services for children with special health care needs with and without disabilities. *Acad Pediatr*. 2011;11(6):508–516
- Pérez Jolles M, Thomas KC. Disparities in self-reported access to patient-centered medical home care for children with special health care needs. *Med Care*. 2018; 56(10):840–846
- Lichstein JC, Ghandour RM, Mann MY. Access to the medical home among children with and without special health care needs. *Pediatrics*. 2018;142(6): e20181795
- Strickland BB, van Dyck PC, Kogan MD, et al. Assessing and ensuring a comprehensive system of services for children with special health care needs: a public health approach. *Am J Public Health*. 2011;101(2):224–231
- Abdi FM, Seok D, Murphey D. *Children with special health care needs face challenges accessing information, support, and services*. Bethesda, MD: Child Trends; 2020
- Yu JA, McKernan G, Hagerman T, Schenker Y, Houtrow A. Most children with medical complexity do not receive care in well-functioning health care systems. *Hosp Pediatr*. 2021;11(2):183–191
- Huang ZJ, Kogan MD, Yu SM, Strickland B. Delayed or forgone care among children with special health care needs: an analysis of the 2001 National Survey of Children with Special Health Care Needs. *Ambul Pediatr*. 2005;5(1):60–67
- Strickland B, McPherson M, Weissman G, van Dyck P, Huang ZJ, Newacheck P. Access to the medical home: results of the National Survey of Children with Special Health Care Needs. *Pediatrics*. 2004;113(5 Suppl):1485–1492
- Benedict RE. Quality medical homes: meeting children's needs for therapeutic and supportive services. *Pediatrics*. 2008;121(1):e127–e134
- Raphael JL, Guadagnolo BA, Beal AC, Giardino AP. Racial and ethnic disparities in indicators of a primary care medical home for children. *Acad Pediatr*. 2009; 9(4):221–227
- Janz HL. Ableism: the undiagnosed malady afflicting medicine. *CMAJ*. 2019;191: E478–E9

29. McLellan SE, Mann MY, Scott JA, Brown TW. A blueprint for change: guiding principles for a system of services for children and youth with special health care needs and their families. *Pediatrics*. 2022;149(suppl 7):e2021056150C
30. Hasbrouck L. Healthy people 2030: an improved framework. *Health Educ Behav*. 2021;48(2):113–114
31. Braveman PA, Kumanyika S, Fielding J, et al. Health disparities and health equity: the issue is justice. *Am J Public Health*. 2011;101(suppl 1):S149–S155
32. Coleman C. Quality of life and well-being for children and youth with special health care needs and their families: a vision for the future. *Pediatrics*. 2022;149(suppl 7):e2021056150G
33. Kuo D. Access to services for children and youth with special health care needs and their families: concepts and considerations for an integrated systems redesign. *Pediatrics*. 2022;149(suppl 7):e2021056150H
34. Schilff J. Financing care for children and youth with special health care needs in the next decade: reducing burden, advancing equity, and transforming systems. *Pediatrics*. 2022;149(suppl 7):e2021056150I
35. Hudak ML, Helm ME, White PH; Committee on Child Health. Principles of child health care financing. *Pediatrics*. 2017;140(3):e20172098
36. Woolf SH. Progress in achieving health equity requires attention to root causes. *Health Aff (Millwood)*. 2017;36(6):984–991
37. Sinko L, He Y, Tolliver D. Recognizing the role of health care providers in dismantling the trauma-to-prison pipeline. *Pediatrics*. 2021;147(5):e2020035915
38. Mishori R. The social determinants of health? time to focus on the political determinants of health! *Med Care*. 2019;57(7):491–493
39. Berwick DM. The moral determinants of health. *JAMA*. 2020;324(3):225–226
40. MehChu N. No Child Left Behind? An interest-convergence roadmap to the US ratification of the convention on the rights of the child. *NYU Annual Survey of American Law*. Available at: https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3633264. Accessed May 23, 2022
41. Perrin JM, Kenney GM, Rosenbaum S. Medicaid and child health equity. *N Engl J Med*. 2020;383(27):2595–2598
42. Levitt L. The language of health care reform. *JAMA*. 2021;325(3):215–216
43. US Department of Education. 2020 determination letters on state implementation of IDEA. Available at: <https://sites.ed.gov/idea/idea-files/2020-determination-letters-on-state-implementation-of-idea/>. Accessed September 17, 2021
44. Houtrow A, Valliere FR, Byers E; National Academies of Sciences, Engineering, and Medicine (US); Health and Medicine Division; Board on Health Care Services; Committee on Improving Health Outcomes for Children with Disabilities. *Opportunities for Improving Programs and Services for Children With Disabilities*. Washington, DC: National Academies Press; 2018
45. Linton JM, Green A; Council on Community Pediatrics. Providing care for children in immigrant families. *Pediatrics*. 2019;144(3):e20192077
46. Bell S, Deen JF, Fuentes M, Moore K. Committee on Native American Child Health. Caring for American Indian and Alaska Native children and adolescents. *Pediatrics*. 2021;147(4):e2021050498
47. Negussie Y, Geller A, DeVoe JE; National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Committee on Applying Neurobiological and Socio-Behavioral Sciences from Prenatal Through Early Childhood Development: A Health Equity Approach. *Vibrant and healthy kids: aligning science, practice, and policy to advance health equity*. Washington, DC: National Academies Press; 2019
48. American Academy of Pediatrics Council on Children with Disabilities. Care coordination in the medical home: integrating health and related systems of care for children with special health care needs. *Pediatrics*. 2005;116(5):1238–1244
49. Price J, Brandt ML, Hudak ML; Committee on Child Health Financing. Principles of financing the medical home for children. *Pediatrics*. 2020;145(1):e20193451
50. Berman S, Dolins J, Tang SF, Yudkowsky B. Factors that influence the willingness of private primary care pediatricians to accept more Medicaid patients. *Pediatrics*. 2002;110(2 Pt 1):239–248
51. Larson K, Cull WL, Racine AD, Olson LM. Trends in access to health care services for US children: 2000-2014. *Pediatrics*. 2016;138(6):e20162176
52. Musumeci M, Chidambaram P. *Medicaid's role for children with special health care needs: a look at eligibility, services, and spending*. San Francisco, CA: Kaiser Family Foundation; 2019
53. Weller BE, Faubert SJ, Ault AK. Youth access to medical homes and medical home components by race and ethnicity. *Matern Child Health J*. 2020;24(2):241–249
54. Chin MH. Creating the business case for achieving health equity. *J Gen Intern Med*. 2016;31(7):792–796
55. Foster-Fishman PG, Berkowitz SL, Lounsbury DW, Jacobson S, Allen NA. Building collaborative capacity in community coalitions: a review and integrative framework. *Am J Community Psychol*. 2001;29(2):241–261
56. Foster-Fishman PG, Nowell B, Yang H. Putting the system back into systems change: a framework for understanding and changing organizational and community systems. *Am J Community Psychol*. 2007;39(3–4):197–215
57. National Academies of Sciences E. *Medicine. A roadmap to reducing child poverty*. Washington, DC: National Academies Press; 2019
58. Keith K. The American Rescue Plan expands the ACA. *Health Aff (Millwood)*. 2021;40(5):696–697
59. Cooper LA, Sharfstein JM, Thornton RL. What the American Rescue Plan means for health equity. *JAMA Health Forum*. 2021;2(4):e210658
60. Boyd RW, Lindo EG, Weeks LD, McLemore MR. *On Racism: A New Standard for Publishing on Racial Health Inequities*. Washington, DC: Health Affairs Blog; 2020
61. Baciu A, Negussie Y, Geller A, Weinstein J; National Academies of Sciences, Engineering, and Medicine; Health and Medicine Division; Board on Population Health and Public Health Practice; Committee on Community-Based Solutions to Promote Health Equity in the United States.

Communities in Action: Pathways to Health Equity. Washington, DC: National Academies Press; 2017

62. Stroul BA, Friedman RM. A System of Care for Severely Emotionally Disturbed Children & Youth. Washington, D.C.: CASSP Technical Assistance Center; 1986
63. Chapman EN, Kaatz A, Carnes M. Physicians and implicit bias: how doctors may unwittingly perpetuate health care disparities. *J Gen Intern Med*. 2013;28(11):1504–1510
64. Just Lead Washington. Caucuses as a racial justice strategy: what we have learned. Available at: <https://justleadwa.org/wp-content/uploads/2019/07/Caucuses-as-a-Racial-Justice-Strategy-JustLead-WA.pdf> 2019. Accessed July 20, 2021
65. Spetz J, Stone RI, Chapman SA, Bryant N. Home and community-based workforce for patients with serious illness requires support to meet growing needs. *Health Aff*. 2019;38(6):902–909