

Current Concept Review

Health Equity for Children with Disabilities

Amy Houtrow, MD, PhD, MPH¹; Coleen Sabatini, MD, MPH²; Jessica Jarvis, PhD¹

¹Department of Physical Medicine and Rehabilitation, University of Pittsburgh, School of Medicine, Pittsburgh, PA;

²Department of Orthopedic Surgery, University of California San Francisco, San Francisco, CA

Correspondence: Amy Houtrow, MD, PhD, MPH, Department of Physical Medicine and Rehabilitation, University of Pittsburgh, School of Medicine, 4401 Penn Ave. PF5113, Pittsburgh, PA 15224. E-mail: rehab@chp.edu

Received: December 17, 2022; Accepted: December 18, 2022; Published: February 1, 2023

DOI: 10.55275/JPOSNA-2023-634

Abstract

Like all children, children with disabilities deserve the fair and just opportunity to be as healthy as possible. There are many barriers to optimal health for children with disabilities. Eliminating health disparities requires removing or minimizing the obstacles that keep children from being healthy. Because pediatric orthopaedic surgeons are often engaged in the clinical management of children with temporary or permanent disabilities, they are uniquely suited to advocate for inclusive orthopaedic care for all children regardless of their circumstances. Pediatric orthopaedic surgeons can promote health equity for children with disabilities by recognizing how ableist beliefs and actions negatively impact the clinical care of children with disabilities and can take action by addressing biases in their clinical practices and beyond.

Key Concepts

- Children with disabilities face discrimination in healthcare which put them at risk for worsening health disparities.
- Health equity for children with disabilities is defined as the “fair and just opportunity to be as healthy as possible and thrive throughout their lives (e.g., from school to the workforce), without discrimination, and regardless of the circumstances in which they were born or live,” according to the Maternal and Child Health Bureau’s *Blueprint for Change*.
- Orthopaedic surgeons can promote health equity in their practices by fostering an inclusive clinical environment, employing sensitivity in communication, checking and addressing personal biases, seeking practice-level changes, and engaging with the disability community to better understand their lived expertise.

Introduction

Understanding diversity, equity, and inclusion has necessarily become an important part of healthcare and we must value each person and respect the profound ways their identity, culture, background, experience, status, abilities, and opinion impact their health and the

care provided. The opportunity to attain optimal health is considered a fundamental human right, but there is an abundance of evidence demonstrating that many children do not receive this opportunity.¹ In order to examine health equity for children with disabilities, this review

focuses on this group and how we can better understand the issues they face.

Framing Childhood Health, Disability, and Health Equity

For this review, we must first define health and conceptualize the abling/disabling process and facilitating factors. *Health* is not just the absence of disease but is a “state of complete physical, mental, and social well-being,” according to the World Health Organization’s (WHO) Constitution.² For children, health has been defined by the Institute of Medicine (IOM), now the National Academy of Medicine, as the extent to which a child or children are “able or enabled to a) develop and realize their potential; b) satisfy their needs; and c) develop the capacities that allow them to interact successfully with their biological, physical, and social environments.”³

Disability is a complex and dynamic concept. As shown in Figure 1, the WHO frames disability as resulting from the interaction of health conditions and contextual factors, such as personal choices and circumstances and the physical and sensory environments.¹ Functioning is framed in three distinct ways: 1) body parts or structure (e.g., muscle strength); 2) activity completion (e.g., climbing stairs, brushing teeth); and 3) participation in society (i.e., attendance and involvement in broader sets and sequences of activities, such as school field trips, community events, etc.).⁴

Childhood disability can be understood as “an environmentally contextualized health-related

limitation in a child’s existing or emerging capacity to perform developmentally appropriate activities and participate, as desired, in society.”⁵ The environmental contextualization is paramount to understanding and promoting health and health equity. There is a wealth of evidence demonstrating that health is impacted by factors unrelated to a child’s biology or personal choices. When those factors negatively and differentially impact certain groups of children, we consider them to be sources of *health disparities*, i.e., avoidable health differences.⁶ These factors, such as access to healthcare, minoritized race, and socioeconomic status, are deeply rooted in social and political contexts and are often referred to as the social determinants of health. More simply put, social determinants of health are the conditions in which children are born into, live, learn, play, and grow up.⁷

For children with disabilities, the disparities resulting from these determinants puts them at increased risk for new or worsened health disparities across their lifespan. This process is demonstrated in Meade’s Model of Healthcare Disparities and Disability. This model demonstrates how environmental (e.g., provider attitudes and treatment of people with disabilities) and personal characteristics (e.g., rural locale, religious beliefs) interact to determine a person’s functioning and their access to care.⁸ Delayed or lack of healthcare services due to poor access can then negatively impact their health status (e.g., new cognitive impairments) and/or personal factors (e.g., care avoidance), further inhibiting access to care in the future and exacerbating disparities.

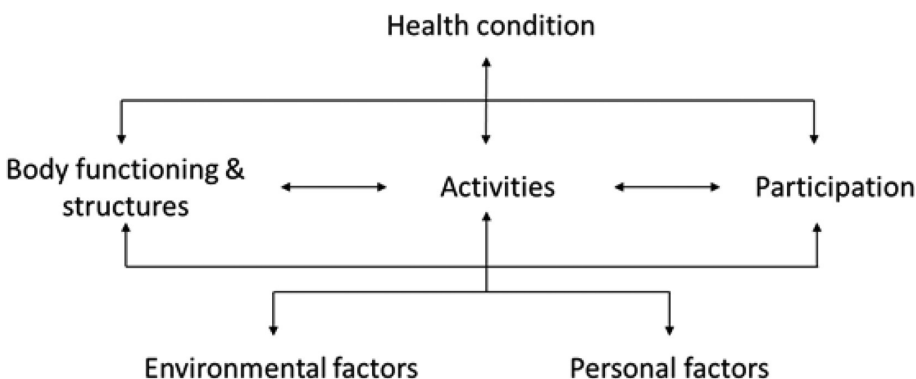


Figure 1. The International Classification of Functioning, Disability and Health (ICF).

In their *Blueprint for Change*, the Maternal and Child Health Bureau (MCHB) identified health equity as a key pillar to assuring that children and youth with special healthcare needs (CYSHCN), among whom are children with disabilities, can enjoy full lives 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.⁹ It defines health equity as the “fair and just opportunity to be as healthy as possible and thrive throughout their lives (e.g., from school to the workforce), without discrimination, and regardless of

the circumstances in which they were born or live.”⁶ In health, as in life generally, having a fair and just opportunity does not mean equal. Several years ago, a cartoon infographic circulated demonstrating the difference between equality and equity. Similarly, as demonstrated in Figure 2, only one of the three people hoping to view the baseball game can see over the fence. A solution is to stand on crates. Those crates can be distributed equally or equitably. When they are distributed equally, the smallest person cannot see the baseball game and the tallest person has a crate they do not need. Like many people, the girl in the fourth panel

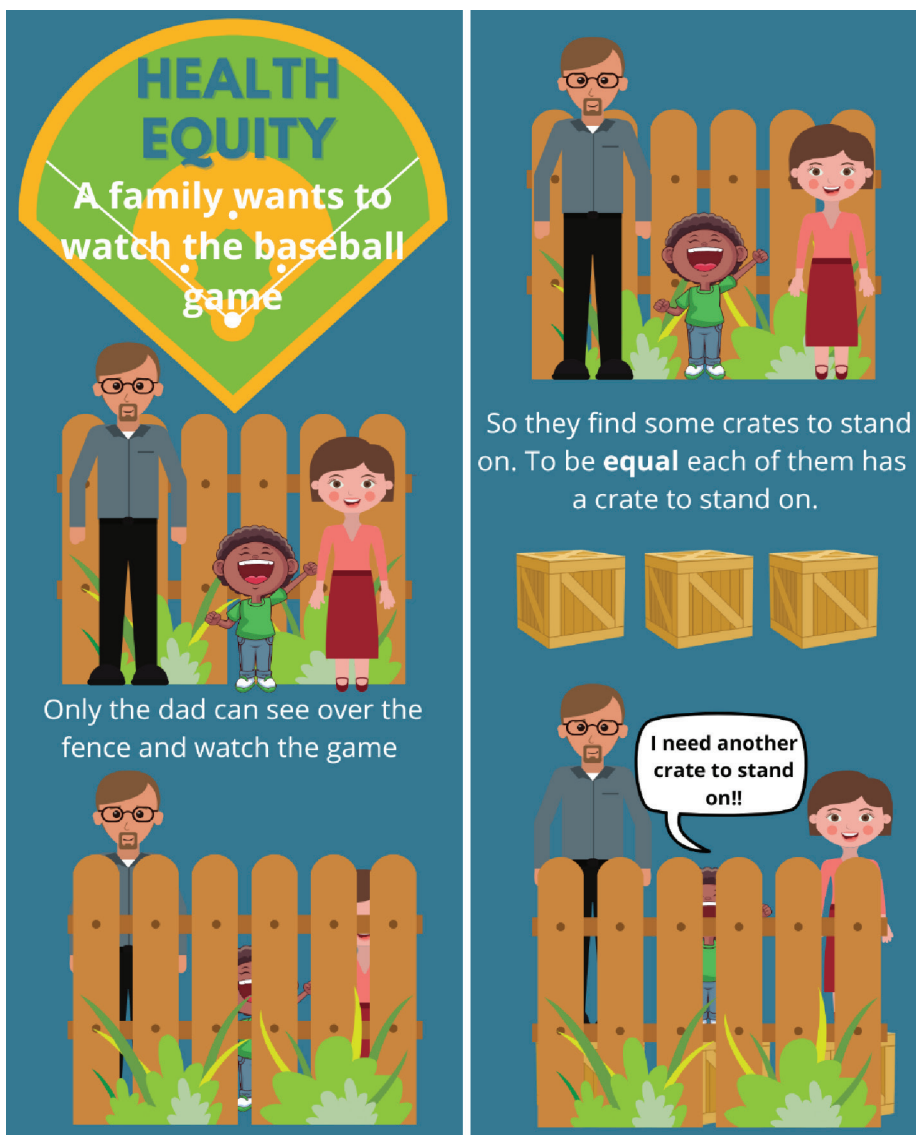


Figure 2. Equality, Equity, and Justice.



Figure 2. continued

identifies the fence as a problem that could be eliminated. If the fence (the injustice) was gone, the crates (the correction for the injustice) would not be needed. Totally removing the fence would be problematic but a redesign gives everyone a fair and just opportunity to see the baseball game.

The process toward achieving health equity is to remove obstacles that lead to poor health, such as poverty and discrimination and their downstream consequences, such as limited access to healthcare.

Health Equity and the Orthopaedic Surgeon

Orthopaedic surgeons, as the proverbial “carpenters of surgery,” can help reconstruct the metaphorical fences to help eliminate the root causes of disparities and can construct crates to address disparities when they are encountered clinically. The first step for the orthopaedic surgeon is to recognize and understand health disparities and healthcare inequities for children with disabilities. Briefly, among CYSHCN, disability is more commonly reported among children living in or near poverty and

by Black non-Hispanic and Hispanic children compared to White non-Hispanic children.⁶ Once children with disabilities enter the healthcare system, they are less likely to get the care and services they need.^{6,10,11} Compared to White patients, minoritized children have been found to receive less bystander care during a cardiac arrest, less pain medication in emergencies, and experience longer emergency wait times.^{12,13,14} The medical literature is replete with examples of how care and access to care is inequitable.¹⁵ Care differs based on discriminatory practices which has negative health consequences for those discriminated against.¹⁶

While most healthcare providers recognize and understand that racism is a cause of poor health and healthcare inequities,¹⁷ many are less familiar with ableism. Like racism, ableism is both structural and individual—it can be how systems operate as well as how people feel and act (discriminatory beliefs and actions). Ableism often manifests as disability bias—the belief that the life of a person with disabilities is less valuable than the lives of those without disability.¹⁸ Ableism is a system of beliefs and practices that frame disability as inherently negative and thus, qualitatively, a diminished way of being.¹⁹ When challenged with facts about racism or ableism in healthcare, doctors and other providers often are quick to say, “not me!” What they often mean is that they don’t consciously say or do racist or ableist things. And while that may be true, clinical care providers may unconsciously behave in these ways and are practicing in a system that has biases baked into its operations that clinicians may not be knowledgeable. Some of these discriminatory behaviors can be classified as microaggressions (everyday interactions and indignities that perpetuate stereotypes and inequalities for marginalized community members).²⁰ Examples of an ableist microaggression in the clinical setting including making jokes about a wheelchair user ‘zooming around,’ grabbing the hand of someone with vision impairments to guide their walking without asking them first, directing all communication only to the caregiver rather than a youth with disabilities, or talking to someone with developmental disabilities in ‘baby talk.’²¹ The clinician

might not mean to devalue those with disabilities, but does so with these types of actions.

Access to care is often structured in ableist ways that prohibit children with disabilities from receiving the healthcare they need. For example, consider a new orthopaedic practice in a highly competitive area. The new practice is trying to maximize revenue quickly because there are many bills to pay. The practice manager recommends limiting the number of Medicaid patients because the reimbursement is lower and they’ve heard that Medicaid patients ‘no-show’ more frequently than those with private insurance. Upon the manager’s recommendation, access is restricted for Medicaid patients. That means access is restricted for children who are from low socioeconomic households, minoritized children (because they are more likely to be poor), and children with disabilities who are disproportionately covered by Medicaid. This example also highlights the importance of intersecting marginalized identities. Intersectionality recognizes that individuals can have more than one marginalized or oppressed identity which can influence and impact their experiences differently.²² While this hypothetical practice was seeking to maximize revenue, ultimately, the practice discriminated against children with marginalized and intersecting identities. The practice did not seek to construct a classist, racist, and ableist gateway to care but unknowingly contributed to categorically limiting certain children access to their services. This example serves to highlight how an individual practitioner may not be intentionally discriminating against certain subgroups of children but could be working in a system that was unintentionally designed to do so.

Acknowledging the impact of discrimination and marginalization on the health of children with disabilities, the orthopaedic surgeon can take several steps:²³

Foster an inclusive clinical environment. The physical and sensory environment should be designed to accommodate the needs of individuals with disabilities. While the Americans with Disabilities Act requires physical access to spaces such as hospitals and doctors’

offices, not all clinical spaces are fully accessible. Additionally, leverage the aesthetics of the environment to communicate inclusion through clear display of nondiscriminatory policy and incorporation of visual signals (e.g., rainbow-colored “safe space” signs, artwork displaying children with and without disabilities) may help ease fears of discrimination.

Employ sensitivity in communication. Whether intentional or unintentional, the language we use can lead to marginalization and stigmatization of individuals. For example, discussing disparities in a way that ignores the structures creating them can perpetuate bias and victim blaming. Use patient first language and non-gendered pronouns (they/them) until certain of patient’s pronouns. Speak with the patient directly, not just their caregiver, and avoid making assumptions about their health needs or accommodations required. For example, young adults with disabilities report that physician assumptions of sexual inactivity as a barrier to reproductive healthcare services.²⁴

Check yourself. Examine your personal biases, conscious and unconscious, and how lack of shared life experiences may shape your clinical decision-making to the patient’s detriment. Online resources such as the Harvard Implicit Assessment Tests serve as a quick and objective opportunity to examine implicit biases.²⁵ There is an inherent power differential between patient and physician, which can be relinquished in part by engaging the patient in shared decision-making.

Seek Practice Level Changes. If there are systemic inequities baked into the operations of the organization, seek to change them. Keep equity in mind when creating new policies. Work to develop a diverse workforce and foster cultural humility in the staff.²⁶ Use data to inform changes to policies and practices to assure that care is being delivered equitably and hold the practice accountable.

Engage with the community and follow their lead. Seek out opportunities that increase your exposure to individuals with disabilities and other historically

marginalized identities. Consume media (books, music, movies, news articles) that feature their narratives. Enroll in a cultural competency training session at a local resource center or online. Recognize and value the expertise of individuals with lived experience health inequities.

Conclusion

Promoting health equity for children with disabilities requires active engagement from physicians and other clinicians, healthcare administrators, insurers, policymakers, and society at large. While the barriers to health equity may feel insurmountable, our collective action can help assure that children with disabilities receive the high-quality care that will enable them to be as healthy as possible, participate fully in society, and thrive.

Disclaimer

The authors have no conflicts of interest to report.

References

1. Grad FP. The preamble of the constitution of the World Health Organization. *Bull World Health Organ.* 2002;80:981-981.
2. World Health Organization. Constitution of the World Health Organization. 1946. Available at: <https://apps.who.int/gb/bd/PDF/bd47/EN/constitution-enpdf?ua=1>. Accessed September 10, 2022.
3. Institute of Medicine. Children’s Health, the Nation’s Wealth: Assessing and Improving Child Health. Washington DC, USA: National Academies Press; 2004.
4. Stucki G, Cieza A, Melvin J. The International Classification of Functioning, Disability and Health (ICF): a unifying model for the conceptual description of the rehabilitation strategy. *J Rehabil Med.* 2007;39(4):279-285.
5. Halfon N, Houtrow A, Larson K, et al. The changing landscape of disability in childhood. *Future Child.* 2012;22(1):13-42.
6. Houtrow A, Martin AJ, Harris D, et al. Health equity for children and youth with special health care needs: a vision for the future. *Pediatrics.* 2022;149(Suppl 7):e2021056150F.
7. Braveman P, Barclay C. Health disparities beginning in childhood: a life-course perspective. *Pediatrics.* 2009;124(Suppl 3):S163-S175.
8. Meade MA, Mahmoudi E, Lee SY. The intersection of disability and healthcare disparities: a conceptual framework. *Disabil Rehabil.* 2015;37(7):632-641.
9. McLellan SE, Mann MY, Scott JA, et al. 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.
10. Kuo DZ, Goudie A, Cohen E, et al. Inequities in health care needs for children with medical complexity. Research Support, N.I.H., Extramural. *Health Aff (Millwood).* 2014;33(12):2190-2198.
11. Houtrow AJ, Okumura MJ, Hilton JF, et al. Profiling health and health-related services for children with special health care needs with and without disabilities. *Acad Pediatr.* 2011;11(6):508-516.

12. Kennel J, Withers E, Parsons N, et al. Racial/Ethnic disparities in pain treatment: evidence from oregon emergency medical services agencies. *Med Care*. 2019;57(12):924-929.
13. Naim MY, Burke RV, McNally BF, et al. Association of bystander cardiopulmonary resuscitation with overall and neurologically favorable survival after pediatric out-of-hospital cardiac arrest in the United States: a report from the cardiac arrest registry to enhance survival surveillance registry. *JAMA Pediatr*. 2017;171(2):133-141.
14. James CA, Bourgeois FT, Shannon MW. Association of race/ethnicity with emergency department wait times. *Pediatrics*. 2005;115(3):e310-e315.
15. Copley M, Jimenez N, Kroshus E, et al. Disparities in use of subspecialty concussion care based on ethnicity. *J Racial Ethn Health Disparities*. 2020;7(3):571-576.
16. Trent M, Dooley DG, Dougé J, et al. The impact of racism on child and adolescent health. *Pediatrics*. 2019;144(2):e20191765.
17. Malawa Z, Gaarde J, Spellens S. Racism as a root cause approach: a new framework. *Pediatrics*. 2021;147(1):e2020015602.
18. Chicoine C, Hickey EE, Kirschner KL, et al. Ableism at the bedside: people with intellectual disabilities and COVID-19. *J Am Board Fam Med*. 2022;35(2):390-393.
19. Aydemir-Döke D, Herbert JT. Development and validation of the ableist microaggression impact questionnaire. *Rehabil Couns Bull*. 2021;66(1):36-45.
20. Kattari SK. The development and validation of the ableist microaggression inventory. *J Soc Serv Res*. 2019;45(3):400-417.
21. Kattari SK. Ableist microaggressions and the mental health of disabled adults. *Community Ment Health J*. 2020;56(6):1170-1179.
22. Crenshaw K. *On Intersectionality: Essential Writings*. NY, USA: New Press; 2019:pages.
23. Calancie L, Batdorf-Barnes A, Verbiest S, et al. Practical approaches for promoting health equity in communities. *Matern Child Health J*. 2022;26(Suppl 1):82-87.
24. Ride G, Newton DC. Exploring professionals' perceptions of the barriers and enablers to young people with physical disabilities accessing sexual and reproductive health services in Australia. *Sex Health*. 2018;15(4):312-317.
25. 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.
26. Day MA, Owens JM, Caldwell LS. Breaking barriers: a brief overview of diversity in orthopedic surgery. *Iowa Orthop J*. 2019;39(1):1-5.