

Health equity requires anti-ableism

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The AAP amended its bylaws last year to add broad anti-discrimination language that includes disability. As such, pediatricians have a key role to play in addressing the ableism that disabled youths* face, inside and outside of health care.

Ableism is prejudice and discrimination against disabled people that limits what they can do and become. It can take many forms at the individual and systemic levels. Disabled children and adolescents experience ableism when buildings they want to enter have no ramps, videos they want to watch have no captions or they are excluded from activities in which they want to participate. These challenges can be magnified for those with additional oppressed identities, such as girls, youths of color and LGBTQ youths. For example, Black disabled youths are more likely to receive out-of-school suspensions and enter the school-to-prison pipeline than other groups of youths who exhibit similar behaviors.

In health care, ableism can manifest as practices that are unwelcoming to disabled youths and parents, providers addressing all questions to a caregiver even when a disabled child can communicate, a physician examining a youth only in a wheelchair, and providers assuming a disabled adolescent has a lower quality of life than a nondisabled teen.

Health care often operates using the medical model of disability, which situates the problem in the person. However, the social model of disability considers limitations to be the result of a mismatch between a person and the environment. For example, in a world without stairs, being unable to climb them is not a problem.

Disability is a part of diversity. To best care for disabled patients, pediatricians need to address their medical, mental health and sexual health needs and advocate for their inclusion.

Following are strategies pediatricians can use to create an anti-ableist environment in their practice and beyond that aligns with the AAP Equity Agenda.

Make practices more accessible and inclusive. Just as pediatricians think about how to make their practices child-friendly, they should think about accessibility. Not all disabilities are visible, so ask families what they need to have a successful visit. Consider an accessibility audit of your physical space and processes. An accessibility checklist is available at <https://bit.ly/3eGLb2m>. Provide education for staff on disabilities and implicit bias.

Empower disabled patients in their own health care. It is important to listen to disabled youths, talk directly to them and teach communication and self-management skills so they can learn to advocate for their needs.

Connect families to supports. Introduce families with a disabled child to organizations and/or online support groups for families with their child’s condition. Those with lived experience can be an incredible resource for support and navigating systems of health care, education and community life.

Encourage disability pride. Pride in one’s disability identity, like other identities, is associated with higher self-esteem. Pediatricians can encourage youths to develop a positive disability identity by connecting them to the disability community and avoiding negative language about disability, especially the youth’s own. Convey how much you value youths for who they are, not who they would be if they were nondisabled. Don’t be afraid to say “disabled.” Find additional guidance on inclusive language in the AAP’s Words Matter document, <https://bit.ly/3uK8pe6>.

Be an advocate. Disabled children and adolescents have a right to access and inclusion. The Americans with Disabilities Act requires nondiscrimination against disabled people, and the Individuals with Disabilities Education Act entitles students to a free and appropriate public education in the least restrictive environment. Pediatricians can advocate for children and adolescents to receive the accommodations and services to which they are entitled from schools, insurers and others. Refer patients to and collaborate with legal advocates, such as those in medico-legal partnerships (<https://bit.ly/3BASGcb>), state protection and advocacy organizations (<https://bit.ly/3hSK29X>) and the U.S. Department of Justice Civil Rights Division (<https://www.ADA.gov>).

*The authors prefer to use identity-first language (disabled person), which many disabled people prefer over person-first language (person with a disability). When referring to specific individuals, it’s best to ask what they prefer.

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Resources

- [Information on ableism from Access Living](#)
- [AAP clinical report *The Individuals With Disabilities Education Act \(IDEA\) for Children With Special Educational Needs*](#)
- [Family Voices](#)
- [Center for Parent Information & Resources](#)
- [Information on improving the transition from pediatric to adult health care](#)
- [“Catastrophic Rupture: A Memoir of Healing” by K. Jane Lee, M.D., Ten16 Press, 2021](#)
- [Documentary “Crip Camp: A Disability Revolution” on Netflix](#)