

Health Equity for Disabled Children: What Can Be Done?

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October 2020



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Acknowledgments

Ashley Barker is a disabled woman who has been a part of the disability community for more than a decade. This paper uses language based on Ashley Barker's experience being a member and an activist in the disability community. For context, many in the disability community try to set the tone to be referred to identity first, just as other minority groups do. Most people refer to other minorities by identity first (i.e., Black woman) rather than person-first (i.e., a woman who is Black/African American). Many in the disability community prefer identity-first language (as reflected in this paper) to get the same recognition and advocacy efforts as other minorities. Several U.S. disability groups always have used identity-first terms, specifically the culturally Deaf community and the autistic rights community. Some people in the disability community, however, prefer person-first language, which puts the emphasis on the person first, followed by a description of the disability (i.e., a person who is epileptic). Therefore, it is up to the individual to engage in conversation with the disabled person to see how they prefer to be identified (i.e., a person with Autism vs. an autistic person).

Introduction

What minority population in the United States is considered an unrecognized health disparity? The disabled population,¹ which is considered the most unrecognized health disparity in the United States

The disabled are often unrecognized as a minority population, which creates a health disparity correlating to significant inequities that the disabled face in the healthcare system. It is important that public health officials and policymakers recognize this fact, as its implications lead to poorer health outcomes for the disabled at a rate four times that of non-disabled patients.²

When discussing child health equity, disability status is important because navigating healthcare as a disabled child is quite different than navigating the healthcare system as a disabled adult. Most children with a disability need interventions beyond quality clinical treatment, such as a stimulating environment to encourage cognitive development.³ For example, early intervention services help foster developmental growth in children and help better meet their needs. Early intervention can help empower disabled children and allow them to live fulfilling lives.⁴ When children enter the healthcare system, they do so with their parents as caretakers and decision-makers. This is even more important to consider for disabled children, as these children's environments and caretakers are significant parts of their lives.⁵

¹ Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health, 105*(Suppl 2), S198–S206. <https://ajph.aphapublications.org/doi/10.2105/AJPH.2014.302182>

² Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health, 105*(Suppl 2), S198–S206. <https://ajph.aphapublications.org/doi/10.2105/AJPH.2014.302182>

³ World Health Organization. (2008, July). Children are not little adults [Slides]. WHO. https://www.who.int/ceh/capacity/Children_are_not_little_adults.pdf

⁴ Centers for Disease Control and Prevention. Why act early if you're concerned about development? Retrieved from <https://www.cdc.gov/ncbddd/actearly/whyActEarly.html>.

⁵ World Health Organization. (2008, July). Children are not little adults [Slides]. WHO. <https://www.cdc.gov/ncbddd/actearly/whyActEarly.html>

In 2014, the U.S. Social Security Administration Supplement stated that 17.1 percent of children in the United States had a disability.⁶ In 2018–2019, the number of students aged 3–18 who received services for their schooling under the Individuals with Disabilities Education Act comprised 14 percent of all public school students.⁷ There is not consistent and adequate reporting of disabled children, but these two statistics show how crucial it is to discuss child health equity for disabled children.

There are multiple reasons why the disabled are unrecognized as a health disparity and why disabled children subsequently face many inequities in the healthcare system; these reasons include medical school curricula, lack of enforcement of the Americans with Disabilities Act (ADA), and lack of Federal efforts through funding or enforcement to reduce disparities among the disabled. There is no standard curriculum in medical school that provides adult and child disability training. Without adequate cultural humility and competence training in medical schools, physicians do not have the sufficient tools to care for their disabled patients properly. Furthermore, they do not have any cultural training for residencies, including pediatrics, leading to a gap in inequitable care for disabled children.⁸ Racial, ethnic, and sexual minorities are recognized as experiencing inequity in healthcare, leading to Federal efforts to reduce these disparities, yet we do not have any such efforts to reduce disability-related health inequities.^{9,10} Without funding and Federal enforcement of programs to address the inequities that those with disabilities face, children and their families will continue to face substantial healthcare barriers.

Summary

- The disabled are an unrecognized health disparity.
- 17.1 percent of children have a disability.⁵ Fourteen percent of public-school students are disabled.⁶
- There is no standard disability cultural sensitivity training in medical schools, residencies, and other healthcare schools.
- There is a lack of Federal efforts to reduce the inequities children and adults with disabilities face in healthcare.

How to Refer to the Disabled

“Disabled” is an identity that is often misunderstood or misused by people without disabilities. Many disabled people and non-disabled people have had conflicts and discussions surrounding the appropriate use of the word.¹¹ Simply put, “handicapped,” “impaired,” and “retarded” are words that are outdated and offensive. “Differently-abled,” “able-bodied,” or other words using “able” to describe a disabled person are not used in disability culture. Use of the word “able” was developed by a non-disabled individual, and many disabled individuals prefer not to identify as differently-abled or be referred to as such by non-disabled people.¹²

⁶ Taylor, D. M. (2018, November). American with disabilities: 2014: Household economic studies. Current Population Reports. <https://www.census.gov/content/dam/Census/library/publications/2018/demo/p70-152.pdf>.

⁷ National Center for Education Statistics. (2020, May). The condition of education - Students with disabilities. NCES. https://nces.ed.gov/programs/coe/indicator_cgg.asp.

⁸ WITH Foundation. (2019, June). Requiring disability training for doctors. <https://withfoundation.org/requiring-disability-training-for-doctors/>.

⁹ Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health*, 105(Suppl 2), S198–S206. <https://doi.org/10.2105/ajph.2014.302182>.

¹⁰ U.S. Department of Health & Human Services. (n.d.). A nation free of disparities in health and health care: HHS action plan to reduce racial and ethnic health disparities [Report]. https://www.minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf.

¹¹ National Youth Leadership Network & Kids As Self Advocates. (2006). Respectful disability language: Here’s what’s up! Association of University Centers on Disabilities. http://www.aucd.org/docs/add/sa_summits/Language%20Doc.pdf.

¹² National Youth Leadership Network & Kids As Self Advocates. (2006). Respectful disability language: Here’s what’s up! Association of University Centers on Disabilities. http://www.aucd.org/docs/add/sa_summits/Language%20Doc.pdf.

The disabled form a cultural, linguistic, and minority group that should be identified appropriately; the people that comprise this group are diverse in many ways. A wide range of disabilities (including mental, physical, intellectual, and other types of disabilities) are included in the community and protected under the ADA.

While there is unity in all disabled individuals identifying as such, there are many distinct identities within the disability community.¹³ For example, identifying as culturally Deaf (with a capital D) means an individual has been diagnosed with deafness, typically prefer to use American Sign Language (ASL), and proudly identify as part of the Deaf community. Alternatively, other individuals identify as deaf (with a lowercase d). These people may not use ASL and do not they identify with the culture.¹⁴

To correctly identify a disabled person, one should ask individuals what they prefer and do further research. In written policy and equitable conversations, it is important to use the correct terminology.

Equity vs. Equality

Equity vs. Equality for Kidney Disease Patients

ECONOMETRICA, INC.

Equality is when an African-American woman can seek out healthcare & receive care.

Equity is when an African-American girl who is Deaf has an opportunity to seek healthcare & receive care with the aid of an American Sign Language Interpreter.



Equality is generally defined as treating everyone as the same and providing the same access to all opportunities to all parties. *Equity* is defined as giving everyone the same access to all opportunities, but with proportional representation or resources that allow everyone to take advantage of those opportunities.¹⁵

One example of equality as it pertains to disabilities is that all disabled children and adults have the same opportunity and access to hospitals and medical care. *Equity* is when there is a wheelchair ramp available to enter the hospital, wheelchair lifts for magnetic resonance imaging (MRI), or an American Sign Language interpreter on staff.

¹³ Tezzoni, L. I. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs*, 30(10), 1947–1954. <https://doi.org/10.1377/hlthaff.2011.0613>.

¹⁴ Matheson, G. (n.d.). The difference between d/Deaf and hard of hearing. Access Innovation Media. <https://blog.ai-media.tv/blog/the-difference-between-deaf-and-hard-of-hearing>.

¹⁵ Strategic planning at Winston-Salem State University: Working toward equity. (n.d.). Winston-Salem State University. <https://www.wssu.edu/strategic-plan/documents/a-summary-of-equity-vs-equality.pdf>.

Enhancing Cultural Competency in Medical School

Over the years, we have seen a shift in encouraging and requiring medical schools to provide competency training to help dismantle inequities in the healthcare system. Research has shown that cultural competency/humility medical education could reduce health disparities. Not only can it reduce disparities, but it will better patient–physician interactions, leading to increased patient satisfaction and medical adherence, therefore improving health outcomes.¹⁶

These cultural competency trainings often leave out cultural competency for children and the disabled, however.¹⁷ Racial and ethnic minorities are used to define health disparity populations by Federal and State governments.

The minority of those with disabilities is not recognized as a disparity population, even though people with disabilities are in poorer health on average compared to their non-disabled counterparts.¹⁸ This can lead to barriers within institutional policies as there is a lack of culture training and competence in healthcare. Until the culture of disability is integrated into medical education, we are not striving to change the attitudes and beliefs of individuals without disabilities that can lead to implicit or explicit bias.¹⁹ These biases affect access to healthcare: For example, many disabled children and their families may not want to seek healthcare due to the systemic medical biases these patients may face.²⁰

Why Is It Important?

The United States is becoming more diverse, and there is more understanding that culture significantly impacts healthcare and disparities. To advance healthcare, we need cultural competency in medical education.²¹ This shift in providing cultural competence training (CCT) is more focused and researched in adult environments, however, and is often not incorporated in pediatric settings.²²

Disabled children experience social, economic, and environmental disadvantages that lead them to be marginalized or even institutionalized.²³ These children face higher chances of their illness becoming chronic or contracting other chronic diseases: For example, learning disabilities are more common in children from families that are low income.²⁴ Disabled children face higher rates of unmet healthcare needs, financial obstacles, decreased access to care, and other leading causes of social determinants of poor health.²⁵

¹⁶ Kripalani, S., Bussey-Jones, J., Katz, M. G., & Genao, I. (2006). A prescription for cultural competence in medical education. *Journal of General Internal Medicine*, 21(10), 1116–1120. <https://doi.org/10.1111/j.1525-1497.2006.00557.x>.

¹⁷ Kripalani, S., Bussey-Jones, J., Katz, M. G., & Genao, I. (2006). A prescription for cultural competence in medical education. *Journal of General Internal Medicine*, 21(10), 1116–1120. <https://doi.org/10.1111/j.1525-1497.2006.00557.x>.

¹⁸ Oregon State University. (2015, February 26). People with disabilities experience unrecognized health disparities, new research shows. *ScienceDaily*. <https://www.sciencedaily.com/releases/2015/02/150226144928.htm>.

¹⁹ Tubbs, A. H. (2018, July 26). Mission possible: Achieving health equity through inclusive public health practice. Centers for Disease Control and Prevention. <https://blogs.cdc.gov/healthequity/2018/07/26/inclusivepractice/>.

²⁰ Shapiro, J. (2020, April 15). People with disabilities fear pandemic will worsen medical biases. *National Public Radio*. <https://www.npr.org/2020/04/15/828906002/people-with-disabilities-fear-pandemic-will-worsen-medical-biases>.

²¹ Kripalani, S., Bussey-Jones, J., Katz, M. G., & Genao, I. (2006). A prescription for cultural competence in medical education. *Journal of General Internal Medicine*, 21(10), 1116–1120. <https://doi.org/10.1111/j.1525-1497.2006.00557.x>.

²² Dabney, K., McClarin, L., Romano, E., Fitzgerald, D., Bayne, L., Oceanic, P., Nettles, A., & Holmes, L. (2016). Cultural competence in pediatrics: Health care provider knowledge, awareness, and skills. *International Journal of Environmental Research and Public Health*, 13(1), 14. <https://doi.org/10.3390/ijerph13010014>.

²³ Children’s Environmental Health Network. (n.d.). Children and health disparities. <https://cehn.org/our-work/policy/policy-factsheets/children-and-health-disparities/>.

²⁴ Children’s Environmental Health Network. (n.d.). Children and health disparities. <https://cehn.org/our-work/policy/policy-factsheets/children-and-health-disparities/>.

²⁵ Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health*, 105(Suppl 2), S198–S206. <https://doi.org/10.2105/ajph.2014.302182>.

It is further important to address disabilities in cultural training in medical school because the U.S. healthcare system is not set up or structured to care effectively for people with disabilities.²⁶ Unfortunately, there is not a lot of reoccurring data on disabled children, or the implications of disability on health disparity. Nevertheless, the 2001–2005 National Health Interview Survey data states that disabled individuals have higher rates of risk factors and worse health outcomes due to inequities when compared to non-disabled individuals. Disabled people are more likely to be obese, smoke cigarettes, be physically inactive, and have higher rates of heart disease and cancer when compared to the non-disabled population.²⁷ Without proper inclusion of disabled children and adults in CCT, the United States will not advance healthcare equity; research shows that adding these trainings for providers will improve the care for the disabled population.²⁸

The Americans with Disabilities Act

There are Federal laws that exist for disabilities, but these laws do not target health inequities and are not adequately enforced. The ADA is one such law that aims to protect and prevent discrimination against those with disabilities, but inadequate enforcement of the ADA often contributes to healthcare disparities.²⁹

It will be important to include education about the ADA in CCT to allow the healthcare system to understand its purpose and what physicians and other providers can do to ensure their patients are being included in quality healthcare. It is the law that healthcare providers and entities must comply with the ADA, but too many do not comply and violate the needs of protected individuals.³⁰ Cultural sensitivity training that allows physicians to understand disability culture better may result in the ADA being more understood and more widely enforced. Far too often, hospitals face lawsuits because they do not have the proper accessibility equipment for their disabled patients.³¹ Many public buildings, including hospitals, do not have adequate wheelchair ramps and accessible doors, resulting in a building entirely inaccessible for those that need accommodations. Additional examples include not having a medically certified ASL interpreter, a lack of wheelchair accessible exam rooms/exam tables/imaging equipment (e.g., MRIs), and a lack of informational materials in Braille.³² We cannot advance health equity for disabled children without proper enforcement of the Federal law that ensures accessibility and non-discrimination.

Figure 1 quantifies the effect not enforcing the ADA has on the workplace and disabled individuals through the growth of ADA Title 111 Federal lawsuits.³³ Title 111 states that there can be no discrimination based on disability for public accommodations.³⁴ It requires that public buildings such as hospitals have accessible equipment or remove barriers to be more inclusive and accessible to the segment of the population that has disabilities.³⁵ There is a significant jump in Federal lawsuits against organizations and individuals not complying with or enforcing the ADA in 2019 as compared to 2014, illustrating that the lack

²⁶ Iezzoni, L. I. (2011). Eliminating health and health care disparities among the growing population of people with disabilities. *Health Affairs*, 30(10), 1947–1954. <https://doi.org/10.1377/hlthaff.2011.0613>.

²⁷ Altman, B., & Bernstein, A. (2008). *Disability and health in the United States, 2001–2005*. Hyattsville, MD: National Center for Health Statistics. <https://stacks.cdc.gov/view/cdc/6983>.

²⁸ Oregon State University. (2015, February 26). People with disabilities experience unrecognized health disparities, new research shows. *ScienceDaily*. <https://www.sciencedaily.com/releases/2015/02/150226144928.htm>.

²⁹ Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health*, 105(Suppl 2), S198–S206. <https://doi.org/10.2105/ajph.2014.302182>.

³⁰ Center for Disability Rights. Expanding and enforcing the Americans with Disabilities Act (ADA) [CDR Policy Position]. <https://cqrcengage.com/cdrnys/ada>.

³¹ U.S. Department of Justice. (n.d.). ADA enforcement. ADA. https://www.ada.gov/enforce_current.htm.

³² Center for Disability Rights. Expanding and enforcing the Americans with Disabilities Act (ADA) [CDR Policy Position]. <https://cqrcengage.com/cdrnys/ada>.

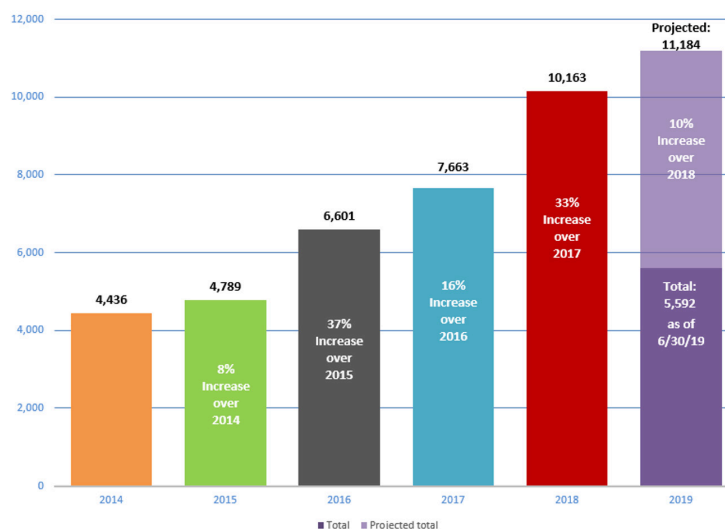
³³ Vu, M., Launey, K., & Ryan, S. (2019, July 26). Federal ADA Title III lawsuit numbers continue to climb in 2019. *Seyfarth Shaw LLP*. <https://www.adatitleiii.com/2019/07/federal-ada-title-iii-lawsuit-numbers-continue-to-climb-in-2019/>.

³⁴ U.S. Department of Justice. (n.d.). Public accommodations and commercial facilities (Title III). ADA. https://www.ada.gov/ada_title_III.htm.

³⁵ U.S. Department of Agriculture. (n.d.). Americans with Disabilities Act (ADA): Overview. USDA ARS. <https://www.ars.usda.gov/northeast-area/docs/eeocivil-rights/americans-with-disabilities-act-ada-overview/>.

of ADA enforcement is becoming more prominent. The number of cases is increasing from year to year, meaning that efforts to protect disabled citizens are worsening.

Figure 1. ADA Title III Lawsuits in Federal Court, January 2014 to June 2019



Note: Table reproduced from the following: Vu, M., Launey, K., & Ryan, S. (2019, July 26).

Federal ADA Title III lawsuit numbers continue to climb in 2019. Seyfarth Shaw LLP.

<https://www.adatitleiii.com/2019/07/federal-ada-title-iii-lawsuit-numbers-continue-to-climb-in-2019/>.

If we have no enforcement of the ADA and no education about the ADA in CCT, we cannot minimize the barriers to accessible quality healthcare for disabled children. We need Federal action to enforce the ADA and mandate disability cultural sensitivity training in medical education.

What Can Policy Do?

Policymakers must enforce the ADA. Policy, actions, and words must be inclusive, and legislation that encourages stronger enforcement of the ADA should be considered.³⁶ There are already many bills on the floors of the Senate and House of Representatives that revolve around medical education; with support to include disabilities, these bills can help guide the healthcare system toward a more equitable future for the disabled. H. R. 5432, the Medical Education for a Diverse America Act, was introduced in the House of Representatives on December 13, 2019. The main purpose of this policy is to approve spending time in residency to train on culturally and linguistically appropriate care.³⁷ The language of this bill is quite vague, and does not mention specific minorities; as we have seen how disabled children are often left out in medical education, policymakers must encourage this legislation to include language on disabilities and children. Advocating for the disability culture in language such as this helps drive the point that we need to improve healthcare for the disabled. Including language regarding children can also highlight the fact that we need better, culturally competent training for pediatrics.

³⁶ Reno, J. (2000, June 27). Looking back on a decade of progress: A special tenth anniversary status report from the Department of Justice. U.S. Department of Justice. <https://www.justice.gov/crt/enforcing-ada>.

³⁷ Medical Education for a Diverse America Act, H.R. 5432, 116th Cong. (2019). <https://www.congress.gov/bill/116th-congress/house-bill/5432/text>.

This can result in more culturally competent care, leading to better communication among healthcare providers and patients and subsequently better treatment outcomes for disabled children and adults.³⁸

Another example is H. R. 5469, the Pursuing Equity in Mental Health Act, which has been introduced with a purpose is to address mental health issues for children and particularly for children of color.³⁹ While this act revolves around disabled children, there is no real language about disabilities—the only mention of disability language in the bill is that school-based mental health programs carried out by this act will coincide with activities happening under the Individuals with Disabilities Education Act.⁴⁰ Mental health is a disability.⁴¹ While this act includes children already benefitting from some school-based programs, there is no equity language for disabled children.

This is an area in which policymakers can encourage a stronger push for disabled child health equity. This act is a great starting point, creating mental-health school-based programs, but to achieve health equity for disabled children, we need language specifying how this will integrate into healthcare. Is there going to be training for these providers on health equity for disabled children? A child with a mental health disorder is a child with a disability. These children can choose how they want to identify; they are protected under the ADA, however.⁴² There is a known stigma surrounding mental health, which is slowly reducing.⁴³ There is an even a more considerable stigma revolves around the disabled, however, which is not slowing.⁴⁴ By encouraging legislation such as H. R. 5469 to include language on disabled children, this legislation can show that pursuing equity in mental health will improve the inequities these children face. By encouraging this legislation to include language on medical education, we can advocate for the rights of disabled children to reach a more equitable healthcare system.⁴⁵

There are many pieces of legislation on the floors of Congress that should include language about disabilities and pediatrics. Policymakers have the power to engage in equitable conversations with their colleagues about the inequities disabled children face and how they can start improving it by including disability language in legislation. If policymakers include language about disabled children in their bills, they can create a rolling effect where health policy, public health, and healthcare providers start recognizing the segregation between individuals with and without disabilities.⁴⁶

We need Federal efforts to dismantle the inequities disabled children face in healthcare.

As previously stated, racial and ethnic minorities are recognized federally as health disparities leading to programs targeting inequities, but disabled adults and children are left out.⁴⁷ A prime example of this can be found in the U.S. Department of Health

³⁸ Champaign County Health Care Consumers Disability Rights Task Force. (2008). Advice from people with disabilities on providing quality health care: What health care providers really need to know. Champaign County Health Care Consumers. <https://www.healthcareconsumers.org/advice-from-people-with-disabilities-on-providing-quality-health-care-what-health-care-providers-really-need-to-know/>.

³⁹ Pursuing Equity in Mental Health Act, H.R. 5469, 116th Cong. (2019). <https://www.congress.gov/bill/116th-congress/house-bill/5469/text>.

⁴⁰ Pursuing Equity in Mental Health Act, H.R. 5469, 116th Cong. (2019). <https://www.congress.gov/bill/116th-congress/house-bill/5469/text>.

⁴¹ Northeast ADA Center. (n.d.). Mental health conditions in the workplace and the ADA. ADA National Network. <https://adata.org/factsheet/health>.

⁴² Northeast ADA Center. (n.d.). Mental health conditions in the workplace and the ADA. ADA National Network. <https://adata.org/factsheet/health>.

⁴³ Committee on the Science of Changing Behavioral Health Social Norms, Board on Behavioral, Cognitive, and Sensory Sciences, Division of Behavioral and Social Sciences and Education, & National Academies of Sciences, Engineering, and Medicine. (2016). Ending discrimination against people with mental and substance use disorders: The evidence for stigma change. Washington (DC): National Academies Press (US). <https://www.ncbi.nlm.nih.gov/books/NBK384914/>.

⁴⁴ Hunter, E. (2017, August 8). “Disability is not inability”: Breaking down stigma and helping children into school. Theirworld. <https://theirworld.org/news/breaking-down-stigma-of-children-with-disabilities>.

⁴⁵ Hunter, E. (2017, August 8). “Disability is not inability”: Breaking down stigma and helping children into school. Theirworld. <https://theirworld.org/news/breaking-down-stigma-of-children-with-disabilities>.

⁴⁶ Oregon State University. (2015, February 26). People with disabilities experience unrecognized health disparities, new research shows. ScienceDaily. <https://www.sciencedaily.com/releases/2015/02/150226144928.htm>.

⁴⁷ Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. American Journal of Public Health, 105(Suppl 2), S198–S206. <https://doi.org/10.2105/ajph.2014.302182>.

and Human Services (HHS) Action Plan to Reduce Racial and Ethnic Health Disparities.⁴⁸ This action plan was the first Federal commitment to tackle healthcare barriers against minorities, but it failed to address healthcare barriers experienced by those with disabilities.⁴⁹

Disabled children can be covered under government insurance programs such as Medicaid and Children's Health Insurance Program. Children who receive health insurance under Medicaid or other federally supported programs are entitled to accessibility under the ADA (and specifically Section 504 of the Rehabilitation Act).⁵⁰ Not every hospital and physician's office honors this, however.⁵¹ These child enrollees face structural and programmatic inaccessibility, leading to inequities in care, quality, coverage, and finances.⁵²

The Importance of Federal Recognition

Without Federal recognition and measurements such as the HHS Action Plan, people with disabilities will continue to face disparities and poor health outcomes.⁵³ People with disabilities experience higher health disparity rates than any other demographic group.⁵⁴ When disabled children face these barriers, it subsequently leads to unnecessary costs that contribute to high healthcare costs in the United States.⁵⁵

If the Federal government can develop an equity framework for disabled children or include disabled children in the framework's language, we can focus on the inequities causing poor health outcomes in the United States. We can stop focusing on the child's disability as the barrier, but rather the prejudice that the non-disabled world presses upon disabled children.

If government insurance programs do not work adequately with hospitals and their enrollees, the United States will continue to see a decline of accessible healthcare for the disabled. There will be insurance gaps, which is essential for policymakers to note when addressing this legislation issue. Disabled children will continue to lack accessible diagnostic equipment, accommodations, health literacy, and more without policymaker intervention.⁵⁶

Why Policy Is Necessary

People with disabilities have some civil rights protections under the ADA, but have a lesser degree of protection when compared to other minorities. Policymakers can help change that by encouraging disabilities to be federally recognized. Currently, disabilities are only federally recognized under the ADA, and the definitions provided are very narrow and often leave the disabled out. Writing a resolution to address the ADA definitions of disability would be the first step to help the Federal

⁴⁸ U.S. Department of Health & Human Services. (n.d.). A nation free of disparities in health and health care: HHS action plan to reduce racial and ethnic health disparities [Report]. https://www.minorityhealth.hhs.gov/npa/files/Plans/HHS/HHS_Plan_complete.pdf.

⁴⁹ Koh, H. K., Graham, G., & Glied, S. A. (2011). Reducing racial and ethnic disparities: The action plan from the Department of Health & Human Services. *Health Affairs*, 30(10), 1822–1829. <https://doi.org/10.1377/hlthaff.2011.0673>.

⁵⁰ National Council on Disability. (2009, September 30). The current state of health care for people with disabilities. <https://ncd.gov/publications/2009/Sept302009>.

⁵¹ Parker Harris, S., Gould, R., Mullin, C., & Caldwell, K. (2019). ADA research brief: Health care access and the ADA. ADA National Network. https://adata.org/research_brief/research-brief-health-care-access-and-ada.

⁵² National Council on Disability. (2009, September 30). The current state of health care for people with disabilities. <https://ncd.gov/publications/2009/Sept302009>.

⁵³ Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health*, 105(Suppl 2), S198–S206. <https://doi.org/10.2105/ajph.2014.302182>.

⁵⁴ Tubbs, A. H. (2018, July 26). Mission possible: Achieving health equity through inclusive public health practice. Centers for Disease Control and Prevention. <https://blogs.cdc.gov/healthequity/2018/07/26/inclusivepractice/>.

⁵⁵ Stabile, M., & Allin, S. (2012). The economic costs of childhood disability. *The Future of Children*, 22(1), 65–96. <https://doi.org/10.1353/foc.2012.0008>.

⁵⁶ Parker Harris, S., Gould, R., Mullin, C., & Caldwell, K. (2019). ADA research brief: Health care access and the ADA. ADA National Network. https://adata.org/research_brief/research-brief-health-care-access-and-ada.

government understand disability as a culture and not an “impairment.”⁵⁷ To advance equity for disabled children, we need reform in policy so that HHS can create guidance to reform how the United States sees disability.

Policymakers should advocate for both the Federal and State governments’ responsibility to ensure that disabled children enrollees do not face discrimination when seeking healthcare per Title V.⁵⁸ This can be done by engaging in equitable conversations with colleagues, acting as a public voice on enforcing the ADA, and integrating enforcement and nondiscrimination policies in health insurance legislation to protect disabled children.

There must also be policy changes within programs like Medicare, Medicaid, and the Children’s Health Insurance Program that supply these plans and their providers with information and training regarding disabled children. Policymakers need to create a framework that allows this country to understand that disability is more than simply something different about an individual, but a culture with its own inherent societal and healthcare frameworks. Only then can we improve health equity for disabled children.

Call to Action for Policymakers

Disabled children face many inequities in healthcare. Policymakers have the power and the voice to change that. Start today by including disabilities in your equitable conversations, include them in language, and advocate for disabled children. Additionally, you can pave the way for child disabled equity by:

1. Enforcing the ADA through legislation or collaboration with organizations such as the Centers for Medicare & Medicaid Services, ensuring government insurance is executing Title V.
2. Reforming and creating more inclusive and equitable healthcare legislation to protect the rights of disabled children.
3. Encouraging medical education to include disability curriculum.
4. Drafting legislation to mandate child disability medical education in medical schools and residencies.
5. Collaborating with governmental organizations, such as HHS, to get disabilities federally recognized as a minority to increase data collection and action plans to create a more equitable healthcare system.

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Acknowledgements:

Reviewers: Monique Sheppard, Ph.D., Kristie McNealy, M.D., and Jill Simmerman Lawrence, M.P.H.


Editors: Jonathan Fusfield, M.B.A., and Erin Detty

Graphics/Layout: Timothy Phelps

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