

POSITION STATEMENT:

The Society of Behavioral Medicine Supports Efforts to Decrease Health Disparities Experienced by Persons with Intellectual and Developmental Disabilities

(AUGUST 2025) Angela Caldwell, PhD, OTR/L, CLT; Keith Brazendale, PhD, MS; Emily Richard; Kishore Vellody, MD; April Bowling, MA, ScD

SUMMARY STATEMENT

The Society of Behavioral Medicine (SBM) supports policies that protect persons with intellectual and developmental disabilities from discrimination that impacts their access to equitable healthcare.

THE PROBLEM

Persons with intellectual and developmental disabilities (IDD), such as those with Down syndrome, Fragile X, cerebral palsy, and autism, face enormous health risks, primarily due to modifiable risk factors that are both systemic and personal. In fact, despite drastically improved life expectancy due to medical advances and de-institutionalization over the past 50 years, life expectancy for persons with IDD is still 20 years less, on average, than those without disabilities (Lauer & McCallion, 2015). Importantly, that gap is often due to preventable health factors such as access to health care rather than IDD-related symptoms or behaviors. Across the lifespan, persons with IDD face systemic barriers to receiving needed preventative and acute care and experience high rates of delayed treatment and unmet care needs when compared to individuals without developmental disabilities (Prokup et al., 2017).

Regardless of individual factors such as race, ethnicity, sex, gender, socioeconomic status, or disability status, all individuals should be treated as human beings whose lives must be respected and protected. Healthcare providers endorse misconceptions about persons with disabilities (i.e., they have a lower quality of life) and lack confidence in providing care to this population (Iezzoni et al., 2021). There is evidence that clinicians may not frequently promote essential health behaviors such as physical activity and proper nutrition to improve chronic disease risk factors when seeing persons with IDD (Bishop-Fitzpatrick et al., 2017). For example, according to the CDC, only 44% of people with disabilities received a physical activity recommendation from their doctor when they visited in the past year, compared to more than 75% of persons without disabilities (Albert et al., 2020).



The right to high-quality, available, and accessible health care has been recognized as a human right by the World Health Organization (World Health Organization, 2022). However, many persons with IDD still do not have equal access to high-quality care. These poor health outcomes are often worsened by limited and/or inequitable access to appropriate healthcare systems. Some of the potential barriers facing persons with IDD in accessing high-quality healthcare are a lack of available services, limited screening/diagnosis and referral pathways, cost of services/limited insurance options, social-communicative difficulties experienced by persons with IDD, and physician/provider competence and training (Malik-Soni et al., 2022). Clinicians, advocates, and researchers must make tangible, concerted efforts to ensure equal access to high-quality healthcare.

CURRENT POLICY

Despite these documented inequities, there are few policies in place to prevent discrimination in healthcare delivery and decision-making for persons with IDD. The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act of 1973 broadly prohibit discrimination based on disability status. Section 504 protects persons with disabilities from discrimination by employers and organizations that receive federal funding, ensuring reasonable accommodations are made. Last fall, the essential protection this legislation provides came under attack, with 17 states joining a lawsuit (Texas vs.

*Endorsing organizations do not write or have any control over position statement content.
Authors declare they have no conflicts of interest.*

Becerra) that included a count asking the courts to declare Section 504 unconstitutional. Other counts of the lawsuit were related to the inclusion of gender dysphoria as a potentially protected disability under Section 504 if those individuals meet the criteria to qualify for these protections. After strong advocacy from the disability community, the 17 states issued a report on April 11 formally stating that they were no longer interested in challenging the constitutionality of Section 504 under count 3. While this shift is a win for the disability community, the lawsuit continues to pose a threat to the rights of persons with disabilities (now known as *Texas vs. Kennedy*). In the updated lawsuit, the states will still challenge Section 504 regulations that protect community-based care, access to specialized medical equipment, and reasonable accommodations for some persons with disabilities. This lawsuit is a clear threat to the rights of persons with disabilities, specifically in the areas of healthcare, employment, and education.

Persons with IDD face discrimination when healthcare providers are making decisions about which patients should receive life-saving treatments, such as organ transplants, based on a lack of experience and commonly endorsed misconceptions (e.g., persons with IDD have a lower quality of life). In the 2019 report, *Organ Transplant Discrimination Against People with Disabilities*, the National Council on Disability (NCD) highlights various issues with the policies and procedures of organ transplant centers and the Organ Procurement and Transplantation Network that fuel discrimination against persons with disabilities in need of these services. The proposed Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R.1520) would prohibit covered entities from using a disability as a reason to deny an organ transplant or related service. It also prevents organ transplant centers from denying care or placing individuals on a waitlist based solely on disability status.

RECOMMENDATIONS

1. Fully fund and strengthen the Administration for Community Living (ACL) in the U.S. Department of Health and Human Services. This is necessary in order to ensure adequate staffing and resources and prevent disruption to critical services community-based services that persons with disabilities rely upon.
2. Pass the Charlotte Woodward Organ Transplant Discrimination Prevention Act (H.R.1520). This act would protect persons with disabilities from discrimination during healthcare decision-making related to organ transplants.

REFERENCES

1. Albert, F. A., Crowe, M. J., Malau-Aduli, A. E., & Malau-Aduli, B. S. (2020). Physical activity promotion: a systematic review of the perceptions of healthcare professionals. *International Journal of Environmental Research and Public Health*, 17(12), 4358. <https://doi.org/10.3390/ijerph17124358>
2. Bishop-Fitzpatrick L., Kind A. J. H. (2017). A scoping review of health disparities in autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(11), 3380-3391. <https://doi.org/10.1007/s10803-017-3251-9>
3. Centers for Disease Control. (2024, May 2). Increasing physical activity among adults with disabilities. *Disability and Health Promotion*. <https://www.cdc.gov/ncbddd/disabilityandhealth/pa.html>
4. Iezzoni, L. I., Rao, S. R., Ressler, J., Bolcic-Jankovic, D., Agaronnik, N. D., Donelan, K., ... & Campbell, E. G. (2021). Physicians' perceptions of people with disability and their health care: Study reports the results of a survey of physicians' perceptions of people with disability. *Health Affairs, (Project Hope)*, 40(2), 297-306. <https://doi.org/10.1377/hlthaff.2020.01452>
5. Lauer, E., & McCallion, P. (2015). Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 394-405. <https://doi.org/10.1111/jar.12191>
6. Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. S., ... & Frazier, T. W. (2022). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatric Research*, 91(5), 1028. <https://doi.org/10.1038/s41390-021-01465-y>
7. Organ Transplant Discrimination Against People with Disabilities. (2019, September 15) <https://www.ncd.gov/report/organ-transplant-discrimination-against-people-with-disabilities/>
8. Prokup, J. A., Andridge, R., Havercamp, S. M., & Yang, E. A. (2017). Health care disparities of Ohioans with developmental disabilities across the lifespan. *The Annals of Family Medicine*, 15(5), 471-474. <https://doi.org/10.1370/afm.2108>
9. World Health Organization. (2022). Global report on health equity for persons with disabilities. World Health Organization. <https://www.who.int/teams/noncommunicable-diseases/sensory-functions-disability-and-rehabilitation/global-report-on-health-equity-for-persons-with-disabilities>

ENDORSEMENTS



American
Occupational Therapy
Association

