

Response to the Proposed Rule on Discrimination on the Basis of Disability in Health and Human Service Programs or Activities

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Submitted to:

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Introduction

Mathematica and its Center for Studying Disability Policy support the proposed rule to update the U.S. Department of Health and Human Services (HHS) Section 504 regulations. If appropriately enforced, the proposed rule will protect the civil rights of people with disabilities by clarifying how Section 504 of the Rehabilitation Act of 1973 applies to several areas affected by HHS programs and policies. The updated regulations should remove barriers to programs and resources, thereby decreasing discrimination and empowering people with disabilities to live the lives they want. This comment shares Mathematica's perspective on the value of the proposed rule changes and cites additional evidence in support of updating the regulations.

Mathematica's perspective

By updating its Section 504 regulations and ensuring robust enforcement of them, HHS will protect the civil rights of people with disabilities in a variety of settings. For example, the updated regulations will improve physical access to health care and help ensure that medical and research decisions are not made using criteria that discriminate against people with disabilities. Without updated regulations from HHS that provide clear instructions about how to promote access and inclusion for people with disabilities, inequity and discrimination will continue unchallenged across medical, social service, public health, and other settings.

Protecting the civil rights of the disability community closely aligns with Mathematica's mission to improve public well-being by using data and evidence that meet the highest quality standards. As the evidence we cite below and the proposed rule suggest, updating the Section 504 regulations at HHS will improve access and inclusion for people with disabilities, which are critical to building a more equitable and just world for all people.

Updating HHS's Section 504 regulations is of special interest to Mathematica because of our commitment to advancing and improving disability policies and programs. Mathematica's Center for Studying Disability Policy works to share new evidence and inform policy discussions within the disability community. Mathematica has extensive expertise with programs administered by HHS that serve people with disabilities and other populations, including programs such as Temporary Assistance for Needy Families, Medicare, and Medicaid. Beyond HHS, Mathematica has expertise studying programs that provide employment and income supports to people with disabilities, such as Social Security Disability Insurance, Supplemental Security Income, and Vocational Rehabilitation. The evidence we have uncovered through our work across these efforts clearly shows that program milestones and outcomes for people with disabilities improve as barriers to access and inclusion are removed. Updated Section 504 regulations that better protect the civil rights of people with disabilities should improve service provision at HHS, resulting in healthier and better-supported beneficiaries across HHS programs.

The proposed rule change by HHS also aligns with Mathematica's commitment to diversity, equity, and inclusion. Our growing portfolio of equity-focused research strives to expand understanding of how barriers to access and inclusion affect critical outcomes, such as health, employment, education, family life, and well-being. We build project teams with lived experiences that provide an authentic understanding of the communities affected by our work. We also have a disability employee resource group that brings people with disabilities and allies together to share stories of lived experience, forge connections, and brainstorm strategies to advance equity and inclusion.

Protecting the civil rights of people with disabilities promotes public well-being in two distinct ways. First, it enables people with disabilities to lead lives they find meaningful. Second, it provides a societal benefit by allowing the full participation of people with disabilities. Whether through work, politics, art, sports, or other endeavors, the disability community has much to contribute to our world. With barriers removed, supports offered, and rights protected, people with disabilities can fully participate and make those valuable contributions. Our society can also learn from the lived experiences of people with disabilities, whose perspectives have been forged by overcoming substantive barriers to achieve their goals. When we fully include people with disabilities, others can benefit from their insights and strengths, which could promote a deeper level of empathy, creative problem-solving, patience, and resilience.

Our work and experiences as an organization committed to incorporating disability inclusion best practices have shown there are often opportunities to improve accessibility beyond what the law currently requires. Mathematica hopes the updated HHS Section 504 regulations will highlight new ways to promote access and improve inclusion.

Supporting evidence

The supplementary information for the proposed rule motivates why the Section 504 regulations require updating. HHS provides evidence for several areas—such as medical treatment, value assessment methods, child welfare, web and mobile accessibility, accessible medical equipment, and integration—in which regulatory reform should improve conditions for people with disabilities. The supplementary information is thorough and motivates the proposed rule well. Our review of the literature found a few pieces of additional evidence that support HHS’s updates. We encourage robust enforcement of the Section 504 regulations to protect the rights of people with disabilities in health care settings.

Medical treatment decisions. The proposed rule should promote promising strategies to dismantle biases and stereotypes against people with disabilities, which are widespread in medical treatment and threaten patients’ civil rights. In health care settings, biases or stereotypes that value the lives of people with disabilities less than others should not influence treatment decisions. Nevertheless, implicit bias against people with disabilities is pervasive. A recent meta-analysis found evidence that people with disabilities are sometimes stereotyped as “incompetent, cold and child-like” (Antonopoulos et al. 2023). Implicit bias is deeply ingrained in society, even among people who regularly work with members of the disability community. For example, a recent study revealed that 82 percent of workers in disability-focused professions implicitly preferred people without disabilities (Friedman 2023).

Discrimination corresponds strongly to poor health outcomes. The pandemic was replete with care decisions that reflected discrimination against people with disabilities. Chicoine et al. (2022) recounted a case study during the pandemic in which an intensive care unit team repeatedly asked whether a patient with Down syndrome had a do-not-resuscitate order, even after the patient’s condition started to improve. Fortunately, the patient’s primary care physician was present to repeatedly share why the patient did not have a do-not-resuscitate order. More generally, providers’ biases can lead to suboptimal treatment decisions that can affect health outcomes. Binkley et al. (2022), for example, critiqued the use of visual assessments of patients to determine whether surgery was appropriate because biases can pervade this practice. Instead, surgeons should use data to create

outcome predictions that inform patient-centered decision making, enabling patients to decide how acceptable a likely surgical outcome is to their quality of life.

Excluding people with disabilities from clinical research has threatened the generalizability of findings and restricted access to treatment and other research benefits. For instance, Young et al. (2020) spotlighted how acute stroke interventions can be withheld from people with disabilities, in part because people with disabilities were excluded from clinical trials, so there was less data available to inform treatment decisions. Withholding acute stroke interventions could worsen health disparities and increase long-term costs. Conversely, when people with disabilities help select the services they receive, their quality of life improves (Friedman and VanPuymbrouck 2019a). This suggests studies should make research more inclusive by adopting universal design principles, making accommodations, and modifying processes as needed (Rios et al. 2016; Strickler and Haverkamp 2023). People with disabilities deserve the same person-centered care that people without disabilities receive.

Bias and stereotypes are rampant in the health care field—both structurally and attitudinally—and must be challenged if the number of health care providers with disabilities is expected to increase (Lindsay et al. 2023; Pereira-Lima et al. 2023). Fortunately, some interventions have shown promise at reducing bias and stereotypes. For instance, medical education interventions that help students learn directly from people with disabilities have shown some promise in building confidence, comfort, and knowledge for caring for people with disabilities (Kirshblum et al. 2020; Crane et al. 2021).

Value assessment methods. Prohibiting providers and institutions from using value assessment methods to place a lower value on the life extension of people with disabilities will help address a key form of discrimination in the medical community. Cryer (2021) noted that current value assessment methods failed to reflect society’s value of equity and emphasized that people affected by clinical decisions “must be at the center of the process.” The proposed rule will further protect the civil rights of people with disabilities by highlighting the insidious ways this practice condones discrimination.

Child welfare. Child welfare programs and activities, which focus on a critical and vulnerable time in the life course, should be free of bias and discrimination against people with disabilities. DeZelar and Lightfoot (2020) found that social service providers were more likely to refer parents with intellectual or other disabilities to child welfare than they referred parents without disabilities. The study authors posited that social service personnel might need training to recognize their biases, so they do not unfairly report parents with disabilities. We appreciate that HHS is issuing the proposed rule to help ensure that programs and activities providing services to children are free of disability-related discrimination.

Web content and mobile application accessibility. Accessible technological platforms are essential for ensuring equal access to providers and critical information. A study examining the accessibility of COVID-19 informational and vaccine registration websites found that some people with disabilities might have experienced accessibility-related barriers to obtaining critical information (Jo et al. 2022). Valdez et al. (2020) called attention to important design considerations for telehealth, such as compatibility with external assistive technology devices. The authors also emphasized the need to address any unintended consequences of telehealth for people with disabilities that could

exacerbate health disparities. The proposed rule will clarify how technology should be accessible so people with disabilities have equal access to services and information.

Accessible medical equipment. Accessible medical equipment is vital for ensuring that people with disabilities have equal access to preventative care and diagnostic information. Several articles that document cancer disparities among people with disabilities emphasized the role structural barriers, such as inaccessible medical equipment, play in creating disparities (Keegan et al. 2023; Hughes et al. 2022). Just 40 percent of physicians usually use accessible exam tables or chairs for patients with significant mobility limitations (Iezzoni et al. 2021). Providers do not always use accessible medical diagnostic equipment, even when it is available (Magasi and Marshall 2021). The proposed rule will clarify that these barriers to care are discriminatory and need to be eliminated.

Integration. People with disabilities deserve to be served in the most integrated setting possible. Integrated settings can offer people with disabilities a host of benefits. For instance, one study found that after transitioning to community services from institutional care, patients with disabilities had better satisfaction, safety, and access to care (Sheth et al. 2019). However, some services are not provided in an integrated setting. Friedman and VanPuymbrouck (2019b) found that states with more disability prejudice (as measured by an implicit bias test) dedicated less of their Medicaid long-term services and supports funding toward home and community-based services. The Olmstead decision (Olmstead v. L.C. 1999) requires that states provide services for people with disabilities in a community setting when it is appropriate and can be reasonably accommodated. Services that do not conform to this standard are considered discriminatory. The Olmstead decision seeks to advance the civil rights of people with disabilities by aiming to change decades of programmatic decisions rooted in widespread bias. The proposed rule reinforces the Olmstead decision by reemphasizing that unnecessary segregation is discriminatory.

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