



November 13, 2023

School of Medicine  
Department of Pediatrics

Institute on Development  
and Disability

RE: Public comment on the Proposed Rule Section 504 of  
the Rehabilitation Act of 1973

Dear Department of Health and Human Services,

Today we submit public comment on behalf of the University Center for Excellence in Developmental Disabilities (UCEDD) at Oregon Health & Science University. Our UCEDD is one of 67 centers nationally, which work together under the guidance and support of the Association of University Centers on Disabilities, to promote health equity for people with disabilities (PWD). Our UCEDD, this work is done through Education, Research, Service and Information Dissemination. Among other aims across these core functions, we hope to improve practice through policy reform. The Proposed Rule includes several suggested updates that will improve health outcomes for the disabilities communities we partner with and work to support. Section 504 intends to protect PWD against discrimination based on their disability and continues to have tremendous impact 50 years after its passage. However, as the world evolves, it's important to consider how legislation must evolve with it to ensure equitable treatment and access today and in the future. We write this in support of the proposed ruling, with particular concern in the areas of medical treatment and use of value assessments.

We asked members of our team – all of whom work in partnership with PWD and many who identify as disabled themselves – to share their personal and professional experiences of discrimination based on disability. The questions we asked were a combination of those included in the proposal, written in plain language for accessibility purposes. Please find a summary of core themes below:

**How have you felt discriminated against by health care professionals (HCP) based on your disability or witnessed this occur within your work with people with disabilities (PWD)?**

*"I once had a doctor make some assumptions about me that led me to feel misunderstood. The misplaced shame made me not want to return to any medical setting."*

PWD are often denied resources, information, or provision of care due to reasons related to their disability. HCPs have their own biases, which can influence the medical advice and care they provide, including the decision to withhold treatment. HCPs often dismiss personal reporting and assume that patients' symptoms or their severity are due to the underlying disability, deserving of a 'medical futility' assessment, or fabricated altogether. Medical offices can be unwelcoming or unsafe environments for PWD, due to physical design, lack of accessible equipment, or failure on the part of the HCP to assess the unique needs of the patient. HCPs might provide inadequate care if they do not have the capacity to accommodate patients. Some wheelchair users are denied physical exams because the clinic is not set up to lift them. Individuals with speech or language differences are not able to communicate effectively because HCPs refuse to use augmentative and accessible communication devices. People with vision impairments are not given documents in an accessible format prior to appointments. Sometimes a HCP's solution is speaking to a disabled person's family members or caregivers. However, this can deny PWD their agency. Other providers deny care entirely because the practice does not feel prepared to care for PWD. Often, they will not offer to find alternative resources or providers.

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*The Institute Includes:*

Child Development and  
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University Affiliated Center for  
Excellence in Developmental  
Disabilities

Oregon Center for Children and  
Youth with Special Health  
Needs

Oregon Office on Disability and  
Health

**How can we reduce discrimination & correct misunderstandings about disability in healthcare spaces?**

*“People with disabilities should have information & appropriate support to make health care decisions...The medical professional & patient relationship should be a partnership.”*

PWD will experience better health outcomes if current and future HCPs were required to complete disability health competency courses. To create effective training, it is critical to include PWD in course development. We also must remove ableist barriers to succeeding in health professions and admissions processes. More inclusive practices will increase disability representation among professionals.

Amplifying the voices of PWD is central to reducing discrimination, by putting self-advocates on boards and in leadership positions in medical institutions, as well as investing in patient advocacy programs. This will help facilitate providing feedback to HCPs from people with lived experience.

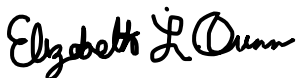
**In what ways are value assessments (VAs) potentially harmful to people with disabilities (PWD)?**

*“This gives a lot of power of literal life and death into the hands of health providers who have their own biases that impacts their decisions.”*

By using VAs to determine who is worthy of care, medical systems create a forced ranking of whose lives matter most. This compares someone's quality of life to the monetary value of a resource and prioritizes financials over their quality-of-life needs. As a result, PWD experience health inequities. When used to determine eligibility for PWD, these assessments do not consider individuals' subjective experience. Biased assumptions about quality-of-life criteria generate misinformation about PWD. Knowing they might be subject to unfair assessments that result in inequitable care, PWD experience significant trauma around the fear of getting sick, and not getting the care they need. In addition to organ transplantation and emergency resource access, VAs impact access to independent living for PWD. If an HCP says it is not possible or worth it for PWDs to live independent lives, patient privacy and autonomy might be compromised indefinitely. There are also implications for Medicaid coverage. For example, fertility care might not be covered based on a VA, but sterilization is.

By changing the legislation, we can hold HCPs accountable to providing equitable care to PWD and save countless individuals from experiencing undue trauma. Thank you for your consideration.

Respectfully,



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LEND Health Administration & Social Work Trainee  
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