



CommunicationFIRST

Because communication is a human right.

CommunicationFIRST Welcomes Long-Overdue Disability Rights Rule Proposal

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WASHINGTON, D.C. — [CommunicationFIRST](https://www.communicationfirst.org/), the nation's only civil rights organization led by and for people with speech-related disabilities, welcomes today's release by the US Department of Health and Human Services (HHS) of the long-awaited [proposed update](#) to its regulations implementing [Section 504](#) of the Rehabilitation Act of 1973, one of the nation's first civil rights laws explicitly protecting people with disabilities.

As HHS Secretary Xavier Becerra noted earlier today, this rule is "long overdue." In fact, this is the first time the regulations have been updated since the [504 Sit-In](#) in 1977, which was led in part by CommunicationFIRST's late co-founding Board Member [Judy Heumann](#).

For far too long, people with communication disabilities have been marginalized, discriminated against, and denied access to health care because of our disabilities. CommunicationFIRST had to spend the entire first year of its existence, which coincided with the start of the [COVID-19 pandemic](#), assisting members who were being [discriminated against](#) in health care settings.

We especially appreciate the parts of the proposed rule that will particularly impact people with speech-related disabilities, including:

- Supporting our right to receive health care and related supports in our communities, instead of in nursing homes and other institutions;
- Confirming our right to be accompanied by a communication support person in all health care settings;
- Confirming that we cannot be denied an organ transplant or other medical treatment based solely on our disabilities or presumed quality of life;
- Making clear that value-based measures like [QALYs](#) cannot be used to discriminate against us in deciding medical treatment options; and
- Making clear that supported decision-making is a reasonable accommodation.

CommunicationFIRST Policy Director [Bob Williams](#) commented, "I was a senior in high school when the original Section 504 rules were issued and doors of opportunities swung open for millions of us. But it is way past time for a refresh. Disability-based bias and discrimination persist, and in some instances have worsened, in the biomedical research, health care, and human services sectors."

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Williams continued, “We applaud the Secretary for releasing this proposed rule, which can prioritize and bring the enforcement of Section 504 into the 21st century. It will improve the lives and futures of millions of people with speech and other disabilities.”

CommunicationFIRST’s Board Chair [Jordyn Zimmerman](#) said, “I am often denied access to my communication device when receiving medical treatment. When this happens, I can’t communicate my symptoms, ask questions, or provide informed consent. It has been shocking to me that hospitals are unaware of a law that has been around for almost 50 years, and that I have to advocate for my basic rights to have the tools I need to communicate with my doctors. This rule is critical.”

Executive Director & Legal Director [Tauna Szymanski](#) remarked, “After having to file multiple complaints against hospitals during the pandemic, we know firsthand how necessary this rule is to clarify and ensure that the rights of people with expressive communication disabilities are enforced in health care settings.”

CommunicationFIRST looks forward to submitting constructive comments on the proposal in November, and hopes the rule will be finalized expeditiously.

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