



CommunicationFIRST

Because communication is a human right.

Comments of CommunicationFIRST

in Response to the US Department of Health and Human Services Notice of Public Rulemaking (NPRM) under Section 1557 of the Affordable Care Act

Docket ID: HHS-OS-2022-0012, RIN: 0945-AA17
Nondiscrimination in Health Programs and Activities
87 Fed. Reg. 47,824 (Aug. 4, 2022)

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October 3, 2022

I. About CommunicationFIRST

CommunicationFIRST is the only nonprofit organization dedicated to protecting and advancing the civil rights and interests of the more than 5 million children and adults in the United States who cannot rely on speech alone to be heard and understood due to a congenital, developmental, or acquired disability or condition. We must rely on multiple means of augmentative and alternative communication (AAC) strategies and tools to express ourselves, be heard, and live full lives. As a disability-led and cross-disability civil rights organization launched in 2019, we advocate to ensure that every person has the support they need to effectively communicate. **Effective communication is vital to safeguarding the right of our members¹ to receive discrimination-free, high-quality health care.**

We welcome the opportunity to provide comments and recommendations on the Department's NPRM to implement and enforce Section 1557 of the Affordable Care Act (ACA). CommunicationFIRST also has signed on to, endorses, and incorporates herein the comments submitted on this NPRM by the Consortium for Constituents with Disabilities (CCD), of which we are a member.

¹ In these comments, we use the terms "constituents" and "members" to refer to all people who require AAC.



II. What AAC Is and Why it Matters

Over 25 different disabilities and long-term conditions can cause or contribute to someone not producing spoken language in a manner others can understand. These disabilities can occur during infancy, childhood, adolescence, one's career, or later in life, and concomitantly result in the need for support in education, communication, community living, health, personal well-being, employment, financial security, and most other aspects of life.

In general, AAC refers to the following:

What Augmentative and Alternative Communication (AAC) Is and Why It Matters

AAC refers to the tools, strategies, and support persons with little to no understandable oral speech must use to effectively communicate. It typically includes using one or more of the following means of expression:

- Gestures, body language, facial expressions, and eye gaze
- Writing, typing, texting, signing, pointing to letters, words, phrases, or pictures
- Electronic devices that can generate spoken and written messages
- Someone who repeats another person's unclear speech so others can understand it

AAC is used to supplement or replace a person's speech.

AAC can be used all the time or some of the time based on the individual's needs.

Persons who need AAC typically have significant disabilities and extensive services and support needs beyond communication.

Some may use sign language occasionally but, as is true of spoken words, they cannot rely on it as their primary expressive means.

Research shows Black, brown, non-English-using people, and those from other marginalized communities have a greater need for AAC and face greater barriers to obtaining it as well as greater discrimination.

CommunicationFIRST believes that all individuals who require AAC must have access to not just any form of it, but to **robust, language-based AAC**. All people who have little to no understandable speech must be afforded ready access to the education, tools, training, and support that can enable them to effectively communicate with others by spelling, writing, texting, typing, and other forms of written language.



Absent the opportunity to learn and the tools and supports necessary to use language to communicate, the lives of people who cannot rely on speech become small, and far more dangerous. Despite the recent proliferation of digital, mobile, and other technologies in the AAC world, the National Academies of Sciences, Engineering, and Medicine reported to Congress in 2017 that, “(i)ndividuals who communicate with AAC experience significant barriers to obtaining and learning to use AAC technology.”² In fact, **our members encounter enormous barriers to AAC technology, tools, and strategies at every turn, lack access to the means to effectively communicate, and endure acts of conscious and unconscious prejudice, discrimination, and dehumanization daily.**

Evidence suggests ableism and the disability-based discrimination it spawns are especially virulent in the fields of medicine and health care. According to National Public Radio, Sarah McSweeney, who used AAC, died in an Oregon hospital in May 2020, reportedly in significant part due to the blatant biases of members of her medical team and their judgment that her life was not worth saving.³ Those who knew McSweeney describe her as a vivacious 45-year-old woman with a passion for country music and life itself. Friends and advocates contend that when she was battling COVID, doctors refused to place her on a ventilator, not based on the her body’s reaction to the virus, but largely, if not entirely, on their deep-seated biases that her life was more expendable and less worth living than others, solely because of her disabilities. It is impossible to know exactly what happened to Sarah McSweeney. **But what her friends described as the discrimination that led to her death is not fantasy. It is the type of “othering” mistreatment that people with little to no understandable speech experience every day at the hands of medical professionals.**

The results are hopefully seldom fatal, but all of these acts are untenable and must end. Individuals with significant expressive disabilities will only receive the high-quality health care and common decency they have the right to, however, if laws like Section 1557 of the ACA and Section 504 of the Rehabilitation Act are vigorously enforced on their behalf by the HHS Office for Civil Rights (OCR).

² National Academies of Sciences, Engineering, and Medicine, Committee on the Use of Selected Assistive Products and Technologies in Eliminating or Reducing the Effects of Impairments; Flaubert, J.L., Spicer, C.M., Jette, A.M., eds., “Chapter 6: Augmentative and Alternative Communication and Voice Products and Technologies,” in *The Promise of Assistive Technology to Enhance Activity and Work Participation*, National Academies Press (2017), at <https://www.ncbi.nlm.nih.gov/books/NBK453284/>.

³ <https://www.npr.org/2020/12/14/945056176/as-hospitals-fear-being-overwhelmed-by-covid-19-do-the-disabled-get-the-same-acc>.



III. Comments and Recommendations

CommunicationFIRST applauds the Department's much-needed efforts to revise the Section 1557 regulations. In general, we believe the provisions included in the NPRM better reflect the Congressional intent, purpose, and statutory language of Section 1557 than the existing rules, and we are deeply appreciative of this. However, we will highlight several areas in which the NPRM is lacking or completely silent, which we strongly urge HHS to address in the final rules, OCR technical assistance and enforcement activities, and other means available to HHS as well as the Department of Justice. We make these recommendations knowing that human dignity, human rights, and our lives depend on a federal government that visibly and actively upholds them rather than looks away and ignores them, which unfortunately is still too often the case.

A. *The Right to Effective Communication*

The right to effective communication is centrally important to our lives. But it is a right that is all too frequently denied to us, particularly by health care professionals. This is due in part to the fact that the current regulatory framework that HHS and other agencies use to articulate and enforce that right largely fails to afford sufficient protection to those who require AAC. This is also true with respect to individuals who have a range of behavioral, cognitive, developmental, intellectual, language, learning, mental health, physical, sensory, speech, and multiple disabilities. Many who require AAC have co-occurring disabilities and health conditions. **We believe this denial of the human, civil, and legal right to communicate in health care settings is a problem of significant magnitude, and we urge OCR to take prompt action to address it.**

Since the first HEW 504 rules were issued in 1977, the basic duty to assure effective communication has revolved around the requirement to provide communication "auxiliary aids and services." The provision of auxiliary aids and services is a necessary but far from sufficient tool for avoiding and remedying effective communication discrimination. This is particularly true with regard to the estimated four to five million⁴ children, youth, working-age people, and older adults who cannot rely on natural speech to effectively communicate with most others. Instead, such individuals require, but too frequently lack meaningful, effective access to the robust language they need to express themselves and be understood. A major cause and effect of this is that we are subjected to age-old unwarranted and disproven assumptions and stereotypes that brand us as:

⁴ See CommunicationFIRST, "AAC Counts," at <https://communicationfirst.org/aac-counts/>.



- Less intelligent;
- Less capable or even devoid of language; and
- Having less of a human need, ability, or right to effectively communicate or have any say over our bodies and lives.

Indeed, the very fact that we require robust language-based AAC – rather than spoken words – to effectively communicate is often used to stamp us as the “other” and incapable of “effective communication.” As noted, doctors and other health professionals are hardly immune from harboring and acting on such disability-based biases. These biases against people with expressive communication disabilities have led to medical professionals failing to even seek and obtain our informed consent, and to compromising the quality of our care, leading to poorer health outcomes and preventable deaths.⁵ It is common for physicians and other health professionals to lay their hands on us and “treat” us without even asking our permission. In addition to violating the ethical duty to “do no harm” as well as the legal obligation under Section 1557, Section 504, and the Americans with Disabilities Act (ADA) to effectively communicate with *all* patients with disabilities, such behavior inevitably makes for third-class medicine.

We are deeply appreciative that HHS OCR has taken repeated actions throughout the pandemic to prevent and remedy this form of insidious discrimination.⁶ We take these actions as a sign of the Department and OCR’s strong commitment to safeguarding and assuring the effective communication rights of individuals with a full range of disabilities. Incorporating the major tenets of these guidance documents into the rules and related assumptions will send a clear and long overdue message to health care professionals and facilities across the United States.

While we find OCR’s recent efforts promising, we are deeply distressed to note there is little mention made on the OCR website of the fact that the effective communication requirements of Section 504, the ADA, and Section 1557 are vital civil rights protections for people with speech disabilities, including those who require AAC.

⁵ CommunicationFIRST, “Reflections on Health Care Access from AAC Users,” at <https://communicationfirst.org/reflections-on-health-care-access/>.

⁶ See, e.g., <https://communicationfirst.org/covid-19/covid-19-guidance/> (federal communication-related guidance issued during COVID-19), and <https://communicationfirst.org/significant-victory-for-patients-with-disabilities-in-response-to-jo-int-communicationfirst-complaint-on-hospital-no-visitor-policies/> (OCR settlement in response to complaint challenging State of Connecticut and Hartford Hospital COVID-19 no-visitor policies that discriminated against patients with communication disabilities).



The Department of Justice views the right to effective communication under Section 504 and the ADA more broadly as requiring the covered entity to take action that “ensures the person with a vision, hearing, or speech disability can communicate with, receive information from, and convey information to” it.⁷ We believe this formulation better aligns with the parallel purposes and intents of Section 504, the ADA, and Section 1557 of the ACA. It is critical for HHS to incorporate and build upon that concept in the Section 1557 final rule, and we support the proposed revisions in the NPRM to 45 C.F.R. § 92.202 accordingly, especially the explicit reference in subsection (b) to those with speech-related disabilities. **The clear articulation and vigorous enforcement of the right to express ourselves are vital for our members and those with other types of communication disabilities.**

Recommendation 1: In addition to the proposed revisions to 45 C.F.R. § 92.202, which we endorse, we strongly urge HHS to incorporate the communication access provisions of OCR’s March 28, 2020 Bulletin on “Civil Rights, HIPAA, and the Coronavirus Disease 2019 (COVID-19)”⁸ (as well as subsequent related guidance, technical assistance, and enforcement activities) into the final Section 1557 regulations and preamble.

Recommendation 2: In 2014, the Departments of Education and Justice issued joint guidance that explains the ways in which the Individuals with Disabilities Education Act (IDEA), Section 504 of the Rehabilitation Act, and Title II of the ADA individually and collectively help to define and assure the the right to effective communication of students with disabilities.⁹ The joint guidance **elaborates on the types of accommodations, assistance, and opportunities that a student who requires AAC may need** in order to effectively communicate and to receive equally effective educational opportunities. To help reiterate that the effective communication provisions apply to those with speech-related disabilities (and not just those with vision and hearing disabilities), we urge HHS to include similar examples in the final rule’s preamble and accompanying guidance documents.

⁷ U.S. Department of Justice, “Effective Communication” (Guidance Document, Jan. 31, 2014), at <https://www.ada.gov/effective-comm.htm>.

⁸ <https://www.hhs.gov/sites/default/files/ocr-bulletin-3-28-20.pdf>.

⁹ U.S. Departments of Justice and Education, “Frequently Asked Questions on Effective Communication for Students with Hearing, Vision, or Speech Disabilities in Public Elementary and Secondary Schools” (Nov. 12, 2014), at <https://www2.ed.gov/about/offices/list/ocr/docs/dcl-faqs-effective-communication-201411.pdf>.



Recommendation 3: Similarly, we encourage the Department to revise the proposed rule’s **definition of “auxiliary aids and services”** to include in the list of examples “different forms of augmentative and alternative communication tools, supports, and services that may be used by a person with speech-related disabilities.” Because the field of AAC is still in its relative infancy, and because the population of individuals who need AAC to communicate is so heterogeneous, there are no uniform or standardized AAC tools or supports, or “qualified” services similar to those adopted by many people with vision and hearing disabilities. **The Department must make clear that auxiliary aids and services include the provision of *individualized* and *tailored* aids and services** if that is what the patient requires to be afforded equal access and opportunity to benefit from the covered entity’s programs and services.

Recommendation 4: Similarly, we encourage the Department to revise proposed Section 92.8(e) (Effective communication procedures) to **more explicitly convey to both patients and covered entities that “auxiliary aids and services” are not limited to “qualified interpreters” and that the effective communication obligation is not limited to people with hearing-related communication disabilities.** As the draft provision now stands, we are concerned that facilities will assume this means their only obligation under the effective communication and auxiliary aids and services provisions is to provide ASL interpreters.

Recommendation 5: The DOJ-ED 2014 Effective Communication FAQ guidance clarifies that the obligation to provide auxiliary aids and services is required as long as the entity is aware of the individual’s communication disability, **even without the individual requesting the accommodation.**¹⁰ We urge HHS and DOJ to follow this approach in developing similar joint guidance regarding the obligations of covered entities to affirmatively seek out, determine, and provide communication-related accommodations where the need is apparent.

Recommendation 6: Many of our members experience significant barriers to effectively communicating with health care providers in terms of the inconsistency of the provision of auxiliary aids and services and other reasonable accommodations and modifications to ensure equal access and opportunity. In other words, a health care provider may agree to provide an auxiliary aid or service

¹⁰ *Id.* at 17 (“When the school district knows that a student needs assistance with communication because, for example, he or she has a hearing, vision, or speech disability, the school district also has an affirmative obligation to provide effective communication under Title II, *whether or not a parent requests specific auxiliary aids and services under Title II.*”) (emphasis added).



or other accommodation on one occasion, but then “forget” to do so again. In essence, the disabled patient is frequently presented with the additional barrier of having to request, and then monitor and enforce, the accommodation that is supposed to level the playing field for them. The onus of ensuring equal access and opportunity thus is placed, for all practical purposes, on the party (the patient) who often is least equipped to bear that burden. **CommunicationFIRST urges the Department to incorporate additional language in the final rule, preamble, and guidance to minimize the additional burdens patients with disabilities nearly always face in having to both repeatedly notify, request, monitor, and enforce the covered entity’s legal obligation to remove access barriers.** One way to do this would be to require covered entities to appoint a person whose role it is to (a) inquire as to whether the patient needs any communication-related or other accommodations to access health care; (b) ensure the patient is provided with all such accommodations promptly; (c) monitor the patient’s stay at the facility to ensure the accommodation is always provided and sufficient during the entire stay, especially if the patient’s needs change over time; and (d) ensure the facility is otherwise complying with its legal obligations to provide auxiliary aids and services and other accommodations so that the patient is not presented with the additional barrier of needing take extra steps to ensure they receive what they are legally entitled to, to file a grievance or administrative complaint, and otherwise expend energy and emotional and physical resources (when they are often least able to) simply to ensure the covered entity is complying with the letter of the law.

B. The Right to Community and To Be Free from Unjustified Isolation in Health Care Settings

The actions of health care professionals and systems are invariably determined by policies, practices, methods, assessment criteria, culture, mores, and biases that either enable or eradicate a person’s ability and opportunities to effectively communicate throughout everyday life. **When the entity’s actions or inactions deter or preclude any chance of effective communication, that constitutes disability-based discrimination and must be defined and remedied as such.**

Moreover, when effective communication bias and discrimination occurs, it violates and frequently eviscerates a person’s sense of self, of being “worthy,” of being “valued,” of “belonging to one’s community,” of having control of one’s body, one’s health, and sometimes even life itself. When a person’s right to effective communication is violated repeatedly as is typical in the lives of children and adults who require AAC, our rights to



community integration, freedom from unjustifiable isolation, access to high quality health care, and informed consent are rendered moot.

These persistent variants of ostracism and exclusion are certainly not unique to health care settings, nor are they inflicted only by health care professionals. **But the power imbalances that exist between health care professionals and patients who require AAC are immense, exacerbating both the magnitude and frequency of harm.** The integration mandate in Section 504 and the ADA as affirmed by the U.S. Supreme Court’s decision in *Olmstead v. LC*, 527 U.S. 581 (1999), is not intended merely to prevent and remedy needless institutionalization. Rather, it is meant to assure all people with disabilities have access to and enjoy status as members-in-full of the American community. It is meant to assure that we are able to have all equality of opportunity, responsibilities, rights, and benefits associated with doing so.

In *Olmstead*, the Supreme Court found that unjustified isolation on the basis of unwarranted and stereotypic assumptions about people with disabilities constitutes disability discrimination. The Court described the effects of this isolation as including:

- “perpetuat(ing) unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life,” 527 U.S. at 600; and
- “severely diminish[ing] the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment,” *id.* at 601.

It further noted that people with disabilities should not have to endure institutionalization, and by extension other egregious isolation, to receive health care that those without disabilities can readily access “without sacrifice.” *Id.*

While the *Olmstead* decision centered on the need to avoid and remedy needless institutionalization, it is indisputable that equally untenable manifestations exist in plain sight in communities across the country, including in purportedly “integrated” residential and health care settings. Injustice that occurs at the intersections of the right to community integration, effective communication, language access, and quality of care should not be ignored or allowed to fester.

Recommendation 7: In issuing, implementing, providing technical assistance on, and enforcing final revised Section 1557 rules, **HHS should broaden the scope of and provide additional detail and clarification regarding what is meant by “the right to effective communication” and what constitutes “effective communication discrimination.”** In the 2014 DOJ-ED guidance on effective



communication, the agencies made clear that a variety of communication-related **accommodations, assistance, and opportunities may be needed by a student who requires AAC** in order to receive equal access and equal opportunity to educational programs, services, and activities. The guidance was not limited to discussing the mechanics of what is needed to qualify as an auxiliary aid or service. We urge HHS and DOJ to follow this approach in developing similar joint guidance on how Section 1557, Section 504, and Titles II, III, and IV of the ADA interact to ensure the rights of people with disabilities to access effective communication and community integration in health care settings.

C. *Additional Actions Needed*

We urge HHS to adopt the following additional measures in the final Section 1557 rules and accompanying implementation guidance:

Recommendation 8: In light of the fact that Black, indigenous, non-English-using, and people of color are more likely to acquire significant expressive and other disabilities and endure multiple forms of prejudice and discrimination,¹¹ **we urge HHS to inform and educate health care professionals, facilities, and systems on their obligation to take concerted steps to assure the effective communication rights of multiply marginalized people who need AAC.**

Recommendation 9: Furthermore, through its technical assistance on and enforcement of Section 1557, OCR should assure that individuals who are members of protected classes under both the Civil Rights Act of 1964 and Section 504 of the Rehabilitation Act or other laws **are well informed of their rights** and accorded the full protection of these laws.

¹¹ See, e.g., Alper, M. (2017). *Giving Voice: Mobile Communication, Disabilities, and Inequality*. MIT; Ellis, C., Peach, R. K., Hardy, R. Y., & Lindrooth, R. C. (2017). The influence of race on SLP utilization and costs among persons with aphasia. *Aphasiology*, 31(12), 1433-1440.

<https://doi.org/10.1080/02687038.2017.1303440>; Huer, M. B., Parette, H. P., & Saenz, T. I. (2001). Conversations with Mexican Americans regarding children with disabilities and augmentative and alternative communication. *Communication Disorders Quarterly*, 22(4), 197-206.

<https://doi.org/10.1177/152574010102200405>; Kulkarni, S. S., & Parmar, J. (2017). Culturally and linguistically diverse student and family perspectives of AAC. *Augmentative and Alternative Communication*, 33(3), 170-180. <https://doi.org/10.1080/07434618.2017.1346706>.



Recommendation 10: HHS should take concerted steps to assure the effective communication rights of **non-English-using people** with significant expressive and other disabilities are protected, and that they are offered and receive the comprehensive and well-coordinated language access and effective communication assistance they require to be afforded equal access to health care. The civil right to effective communication and the civil right to language access assistance are meant to help achieve the same simple justice: Affording a person who is disabled, non-English-using, or both, the aid, assistance, opportunity, and human respect they need and by right are entitled to effectively communicate with others. **We urge HHS to make clear in the final Section 1557 regulations that covered entities carry out both the effective communication and language access requirements in a well-coordinated, comprehensive, seamless, and equally effective manner as a standard operating procedure.** Currently, health facilities and systems can carry out these obligations through separate means and there may be justifiable administrative reasons to continue to do so. However, this does not negate the need for the Department to inform covered entities that both sets of requirements are of equal paramount importance, are closely interdependent with each other in many instances, must be implemented in a coordinated, co-equal, and equitable manner, and will be enforced as such. **While proposed revised Section 92.8(g) makes clear covered entities are *permitted* to combine the policies and procedures of these statutes, we encourage OCR guidance to *recommend* such coordination.**

Recommendation 11: HHS should take concerted steps to ensure that **technologies like machine translation are used only in the most exigent circumstances** in order to assure accuracy in translation essential for safe, high-quality, and equitable care. This is critical for the health and well-being of individuals with any degree of atypical speech, who are non-English-speaking, or who use a speech-generating device and other AAC strategies as well. Increasing use of technologies like machine translation, voice recognition, videophony, artificial intelligence, and a panoply of emerging technologies, devices, and apps is revolutionizing health care and other aspects of life. There is no question that the ubiquitous reliance on such technologies can and likely will improve the quality of health care as well as the health and wellness of many children and adults in this country. Yet, it is equally apparent that the unregulated over-reliance on these tools can and almost certainly will lead to inferior health care being provided to, and poorer health outcomes being experienced by those most marginalized in society. We can envision conditions under which the well-thought-out development and use of machine translation, voice recognition, videophony, and



similar technologies could one day be used on a large scale to provide high-quality health care that leads to better health and wellness outcomes for people with disabilities, including significant disabilities. We believe some of this work is being done today. But we are convinced and deeply concerned that machine translation and the other technologies we mentioned are not now developed or deployed well enough to permit their widespread use with people who have little to no understandable speech and may or may not have AAC, along with many other multiply marginalized individuals and communities as well.¹²

Recommendation 12: We also urge HHS to play a leading role in encouraging, regulating, and assuring that all **information and communication, interactive, and health technologies** that are used to effectively communicate, diagnose, obtain informed consent from, treat, and provide health care to individuals are designed, deployed, and used in ways that are readily accessible to, usable responsive, and assure the civil rights of people with disabilities, including significant expressive disabilities, and all marginalized individuals and communities. These current and emergent technologies must be properly viewed and eventually regulated in a manner analogous to medical equipment, because the role they play is as great as are their potential benefits and risks to our health and well-being. We recognize this cannot all be done immediately. But we strenuously recommend that HHS immediately take the first step of consulting with the Department of Justice, the U.S. Access Board, the disability and aging communities, health care educators and professionals, technology developers, futurists, and others to determine how these aims can be best achieved.

One specific technological barrier facing many AAC users is the prevalent use of **“secure portals,”** which many health care providers insist their patients use, citing HIPAA requirements. These portals often require multiple keystrokes to access, and often will fail as a matter of design to preserve correspondence between the patient and provider. Most AAC users have significant manual and other fine motor impairments that impact their ability to use keyboards and computer mice, and these portals impose frustrating barriers for patients seeking to communicate with their providers. **We urge HHS to include a statement in the final rule’s preamble or elsewhere in guidance that a reasonable modification to ensure equal access to a covered entity’s programs and services can include communicating with**

¹² See, e.g., James Robinson, “I Stutter, But This What You’re Not Hearing,” *The New York Times* (Aug. 23, 2022), at <https://www.nytimes.com/2022/08/23/opinion/stutter-speech-listening.html> (providing just one powerful illustration and justification for our concern).



some other modality that is more accessible to the patient (including email), if the patient so requests.

Recommendation 13: We urge HHS to take concerted steps to assure **telehealth services** provide quality health care to people who require AAC, all people with disabilities, and multiply marginalized individuals and communities. Our concerns regarding the impacts telehealth increasingly will have on the design, accessibility, delivery, efficacy of how health care is provided and financed parallel those we outlined with regard to machine translation and other technologies. The difference is that telehealth has already become a dominant and integral feature of publicly and privately financed health care provided in the U.S. today. There is scant information available on the extent to which individuals who require AAC are receiving telehealth services currently, what their experiences with it have been, the opportunities and risks it presents, and actions that should be taken to make these services truly accessible and responsive to our constituents, people with disabilities generally, and multiply marginalized individuals and communities.

Recommendation 14: In finalizing, implementing, enforcing, and providing technical assistance on the revised Section 1557, **HHS should set core accessibility and effective communication requirements for telehealth services within a short timeframe.** HHS should make clear that such requirements are a starting point and will be revised over time. HHS also should consult with the Department of Justice, the U.S. Access Board, the disability and aging communities, health care educators and professionals, technology developers, futurists, and others to determine how telehealth services can be made truly accessible and responsive to our constituents, people with disabilities generally, and multiply marginalized individuals and communities.

Recommendation 15: HHS should take concerted steps to **strictly limit the use of clinical algorithms in health care decision making.** The dangerous biases implicit in, and the harmful health consequences that results from using, clinical algorithms are known to some extent to HHS, the health care world, and increasingly the public. The overall fact that the use of such algorithms produce worse outcomes for people who are Black, brown, indigenous, non-English-using, disabled, and multiply marginalized. We appreciate the Department's caution to health care providers in the proposed rulemaking on this point, and **specifically against the use of the Glasgow Coma Scale, especially as regards its explicit and intentional dehumanization of people with speech-related disabilities and people with other**



motor disabilities.¹³ However, it is imperative to note that we do not yet know the full implications of the use of clinical algorithms on people with significant communication disabilities. This is one of many reasons for pause. We are supportive of the recommendations HHS has made on this matter.

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CommunicationFIRST appreciates this opportunity to comment. If you have any questions, please do not hesitate to contact Bob Williams, Policy Director, or Tauna Szymanski, Executive Director, at info@communicationfirst.org. Thank you for considering these comments.

¹³ 87 Fed. Reg. 47,824, 47,882 (Aug. 4, 2022), <https://www.govinfo.gov/content/pkg/FR-2022-08-04/pdf/2022-16217.pdf>.