CCD
CONSORTIUM FOR CITIZENS WITH DISABILITIES

September 7, 2021

The Honorable Chiquita Brooks-LaSure
Administrator
Centers for Medicare & Medicaid Services
Department of Health and Human Services
7500 Security Boulevard
Baltimore, MD 21244

RE: CMS-9909-IFC

The Consortium for Citizens with Disabilities (CCD) is the largest coalition of national organizations working together to advocate for federal public policy that ensures the self-determination, independence, empowerment, integration and inclusion of children and adults with disabilities in all aspects of society.

We, the undersigned members of the CCD Health Task Force, thank you for the opportunity to comment on this important consumer protection. We are strongly supportive of the efforts to protect people from surprise bills. Our comments here are limited to the accessibility of information and other areas of rulemaking with a particular impact on people with disabilities.

Notice & Consent and Network Adequacy

We appreciate that in some instances, individuals may wish to waive balance billing protections and knowingly and purposefully seek care from a nonparticipating provider. However, we are concerned that people with disabilities may disproportionately seek care from nonparticipating providers because of a lack of network adequacy. This is a particular burden for low-income individuals who cannot afford balance billing.

CMS cites the example of an individual with a complex health condition who may want to be treated by a specialist who is not in their plan's network. This is likely particularly true for those with complex and rare conditions who need to see one of a very few specialists in their conditions. These individuals may have no choice but to seek care out-of-network and subject themselves to balance billing, due to a failure of network adequacy on the part of their plans.

People with disabilities may also seek out-of-network care due to lack of accessibility among in-network providers. For example, a wheelchair user may receive primary care from a nonparticipating provider because that is the only provider in the area with an accessible office or accessible diagnostic medical equipment. Recent issue briefs from CMS highlight the lack of accessible medical care and recommend resources[1] and steps[2] to improve it, showing that lack of health care providers with accessible offices is a well-known problem. People with disabilities and chronic conditions should not have to seek care out-of-network and consent to unaffordable balance billing because their conditions are rare or treated by relatively few specialists, or because the in-network provider is not meeting accessibility standards.

We appreciate HHS' desire to strike a balance between consumer protection and a barrier to obtaining needed out-of-network care. We also appreciate that this rule represents an improvement over current practice by requiring a good faith estimate of charges. We urge CMS to, to the extent of its authority, conduct oversight of network practices by health plans to ensure network adequacy and appropriate use of single case agreements for enrollees with disabilities and complex, chronic, or rare conditions.

Post-Stabilization Services

We appreciate that CMS included protections for post-stabilization services, considering them emergency services (and therefore protected from balance billing) unless a number of conditions are met. The first condition is the ability to travel using non-medical transportation or nonemergency medical transportation. CMS should add lack of accessible transportation as a condition that creates an unreasonable travel burden on the patient at 45 CFR 149.410. We appreciate that CMS has considered other factors like ability to pay for a taxi, access to a car, or ability to take public transit. For patients with disabilities, the ability to find and pay for *accessible* transportation should also be taken into account.

Standards for Notice & Consent

In order to consent to waiving balance billing protections, patients must be given sufficient notice and providers must obtain consent. We appreciate CMS's request for input on whether the provisions and protections related to communication, language, and literacy sufficiently address existing barriers, including intersecting and overlapping barriers, and what additional policies it should consider. We strongly support the requirement that providers must make the notice available in the top 15 most common languages in the geographic region where the applicable facility is located. It is critical that these translated notices also be available in alternative formats so that an Arabic speaker who has low-vision, for example, can read the notice in large print in her own language. We have additional comments and recommendations on the disability access provisions.

Regulatory Context of Effective Communication

We appreciate that the "Supplementary Information" section of the Interim Rule references a number of federal civil rights nondiscrimination laws including section 1557 of the Affordable Care Act, title VI of the Civil Rights Act of 1964, section 504 of the Rehabilitation Act of 1973, and the Americans with Disabilities Act (ADA) of 1990. Within that list, Section 504, Titles II and III of the ADA, and Section 1557 establish a requirement in the healthcare context for effective communication with patients with disabilities. However, it is important to note that

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[1] https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/OMH-Modernizing-Health-Care-Physical-Accessibility.pdf

[2] https://www.cms.gov/About-CMS/Agency-Information/OMH/Downloads/Issue-Brief-Physical-AccessibilityBrief.pdf

while these laws are similar in their substance, they also differ both in their specific wording and in how cases have interpreted their application.[3]

For example, the effective communication regulations enacted under Title II and Title III of the ADA are essentially similar and obligate government entities and public accommodations, respectively, to:

- "furnish appropriate auxiliary aids and services where necessary"[4];
- assess "[t]he type of auxiliary aid or service necessary to ensure effective communication [which] will vary in accordance with the method of communication used by the individual; the nature, length, and complexity of the communication involved; and the context in which the communication is taking place"[5]; and
- bear the burden of justifying any refusal to provide auxiliary aids or services by demonstrating that the actions required would "fundamentally alter the nature of the goods, services, facilities, privileges, advantages, or accommodations being offered"[6] or constitute "an undue burden" on the public accommodation or entity.

However, the Title II regulations state that public entities "shall give primary consideration to the requests of individuals with disabilities" in providing auxiliary aids and services.[7] Regulations enacted under Title III of the ADA, state that public accommodations should "consult with individuals with disabilities whenever possible to determine what type of auxiliary aid is needed to ensure effective communication, but the ultimate decision as to what measures to take rests with the public accommodation, provided that the method chosen results in effective communication. In order to be effective, auxiliary aids and services must be provided in accessible formats, in a timely manner, and in such a way as to protect the privacy and independence of the individual with a disability."[8]

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[3] For example, the Third Circuit recognized a Deaf inmate's claim under Title II and Section 504 to his primary form of communication, American Sign Language (ASL), rather than the combination of lipreading and writing notes on paper that a state detention center offered as an auxiliary aid during such key moments as the inmate's initial intake and his medical evaluation. *Chisolm v. McManimon*, 275 F.3d 315 (3d Cir. 2001). On the other hand, prior to 2010 revisions of the Title III regulations, the Second Circuit has recognized that public accommodations need only provide an auxiliary aid or service that is effective in practice, such as having employees at a fast food restaurant read aloud a menu to a blind customer rather than the restaurant meeting the customer's preference for the entire menu in large print. *Camarillo v. Carrols*, Corp., 518 F.3d 153 (2d Cir. 2008). The Eighth Circuit has taken a similar position, recognizing that a medical school could not offer a hearing-impaired medical student only the auxiliary aid or service that the university judged sufficient, but was obligated to provide the student with meaningful access to its courses and not merely protection against effective exclusion; this entailed providing "reasonable auxiliary aids and services so that all individuals have an equal opportunity to gain 'a like' or 'equal' benefit." *Argenyi v Creighton University*, 703 F.3d 441, 456 (8th Cir 2013).

[4] 28 CFR § 35.160 (b)(1); 28 CFR § 36.303 (c)(1).

[5] 28 CFR § 35.160 (b)(2); 28 CFR § 36.303 (c)(1)(ii).

[6] 28 CFR § 36.303 (a). The wording of 28 CFR § 35.164 differs slightly ("This subpart does not require a public entity to take any action that it can demonstrate would result in a fundamental alteration in the nature of a service, program, or activity or in undue financial and administrative burdens") and provides greater detail into the steps a public entity must take if personnel believe that requested actions would constitute a fundamental alteration or undue burden.

[7] 28 CFR § 35.160 (b)(2).

[8] 28 CFR § 36.303 (c)(1)(ii).

In addition, regulations enacted under Section 1557 of the ACA explicitly incorporate the standards developed under Title II of the ADA, thereby placing those entities subject to Section 1557. This means entities that might have formerly been characterized as public accommodations are now required to give primary consideration to the disabled individual's request for auxiliary aids and services.[9]

Disability Effective Communication Barriers in Health Care

Research has established that when and how to provide effective communication remains problematic in the healthcare context. One qualitative study of 20 practicing physicians with a range of 8 to 51 years of practice in primary care or 4 specialties found that "[o]nly 5 physicians identified having accessible reading material in large font, while only 1 physician had any informational material available in braille."[10] Among the 25% who indicated that they had accessible materials, one noted the technical frustration of trying to adjust font size within an electronic medical record (EHR) and the resulting impediment to printing EHR content in large font, while another noted that his hospital had generic treatment consent documents available in Braille, but not condition-specific informational materials. These responses indicate that even those healthcare providers who offer some accessible formats may not make those formats uniformly available across a full range of informational materials and notices, or consistently provide patients and their families with a full range of auxiliary aids and services. Many of the physicians interviewed in the study reported difficulty communicating with patients with intellectual or developmental disabilities (IDD). They cited a practice of communicating with a caregiver or at least a preference for having the caregiver in the room, but without necessarily asking the patient if that was their preference. One physician shared their belief that people who had communication-related disabilities should bear some responsibility for ensuring effective communication, for example by bringing their own interpreter. The researchers conclude that their results "suggest that more physician education is required about effectively communicating with patients with disability."[11]

Unfortunately, better physician education on effective communication with people with disabilities and disability cultural competence is not necessarily forthcoming as over 80% of U.S. medical students report receiving no clinical training in treating people with intellectual and developmental disabilities.[12] In addition, only 40.7% of physicians in a recent qualitative study indicated that they were very confident in their ability to provide the same quality of care to patients with disabilities.[13]

State level reports reinforce the multiple effective communication barriers prevalent in the healthcare setting. For example, a commentary by state officials in North Carolina asserted that "health care providers have made the mistake of assuming a one size fits all mentality in the

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[9] 45 CFR § 92.102 (a).

[10] Nicole Agaronnik *et al.* "Communicating with Patients with Disability: Perspectives of Practicing Physicians." J. Gen. Int. Med., 34:7 (2019), 1139-1145, doi:10.1007/s11606-019-04911-0.

[11] *Id*.

[12] Special Olympics International, "Changing Attitudes Changing the World: The Health and Health Care of People with Intellectual Disabilities," (2005); *see also* Easterseals, *COVID-19's Impact on People with Disabilities* (April 2021), at p. 27, https://www.easterseals.com/shared-components/document-library/media-room/easterseals-study-on-the-impact-of-covid-full.pdf.

[13] Lisa I. Iezzoni *et al.*, "Physicians' Perceptions of People with Disabilities and Their Healthcare," Health Affairs 40:2 (2021), 297-306, doi:10.1377/hlthaff.2020.01452.

provision of accommodations for this population" and "[l]ack of sensitivity to and awareness of the needs and abilities of individuals who are blind, visually impaired, and deaf-blind presents a major barrier to accessing health care."[14]

Recommendation

Given the central importance of the notice and consent provisions in the Interim Rule and effective communication barriers people with disabilities face in accessing health care, we recommend that *all* healthcare entities that fall under the rule be required to give primary consideration to the requests of individuals with disabilities for specific auxiliary aids and services. This requirement should apply irrespective of whether an entity receives federal financial assistance so as to fall under Section 504, is subject to Section 1557 of the ACA, or is a public accommodation within the meaning of Title III of the ADA. Such a requirement will incentivize providers to proactively ask and record the effective communication preferences of people with disabilities in their electronic health records, which will in turn increase the chances that patients with effective communication needs will have those needs met consistently and timely across a range of general and individualized documents and notices. Having disability effective communication needs as well as the language access needs of plan members and patients on file will also help healthcare entities to plan ahead to meet the intersectional communication needs of people who require Chinese in large print, for example, or Spanish Braille.

The notice and consent provisions are an important consumer protection for all healthcare consumers, but their importance does not make the notice and consent conceptually simple, less technical, or unlikely to come up in emotionally difficult situations involving medical and financial risk. The Interim Rule applies to a specific heath care context where communications are inevitably complex, not to all public accommodations. Given the evidence of healthcare providers' poor understanding of the effective communication needs of people with disabilities and that governing regulations are consistently ignored or unknown, the Interim Rule should explicitly require covered entities to meet ADA Title II standards in all consumer interfaces, including the notice and consent provisions, as well as and in complaint and appeal procedures.

Thank you for the opportunity to comment. For more information, contact Rachel Patterson, Senior Director of Government Relations & Advocacy at the Epilepsy Foundation at rpatterson@efa.org or Natalie Kean Senior Staff Attorney at Justice in Aging at nkean@justiceinaging.org

Sincerely,

ALS Association
American Association on Health and Disability
American Council of the Blind
American Occupational Therapy Association (AOTA)
American Therapeutic Recreation Association

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[14] Jan Withers & Cynthia Speight, "Health Care for Individuals with Hearing Loss or Vision Loss: A Minefield of Barriers to Accessibility," N Carolina Med J., 78:2 (2017), 107-112, https://www.ncmedicaljournal.com/content/ncm/78/2/107.full.pdf.

Autistic Self Advocacy Network
Brain Injury Association of America
CommunicationFIRST
Disability Rights Education and Defense Fund (DREDF)
Easterseals
Epilepsy Foundation
Justice in Aging
Lakeshore Foundation
National Alliance on Mental Illness
National Center for Parent Leadership, Advocacy, and Community Empowerment (National PLACE)
National Council on Independent Living
National Disability Rights Network (NDRN)
The Arc of the United States
United Spinal Association