



Nothing about us without us!

October 3, 2022

Melanie Fontes Rainer
Director
Office of Civil Rights
Department of Health and Human Services

**Re: Notice of Proposed Rulemaking: Docket ID: HHS–OS–2022–0012, RIN:
0945–AA17, Nondiscrimination in Health Programs and Activities**

Dear Director Fontes Rainer:

The Autistic Self Advocacy Network appreciate the opportunity to offer comments on the above-captioned rule proposed by the Department of Health and Human Services. The proposed rule reinstates many of the regulations that were properly promulgated as part of the 2016 Rule, and offers improvements upon this prior rulemaking, as well as bringing interpretations of Section 1557 protections in alignment with the Affordable Care Act statute. We have previously joined coalition comments on the 2016 Rule, and are grateful to see much of our prior feedback reflected in the current proposed rule.

ASAN is a disability rights organization that primarily serves autistic adults. ASAN has published multiple resources that help autistic adults understand and advocate for their rights as they relate to health care, including *Our Bodies, Our Rights: What’s Going On at the Supreme Court?*¹; *A Self-Advocate’s Guide to Medicaid*²; and *Organ Transplantation and People with Disabilities: A Toolkit for State Advocates*³

¹ “Our Bodies, Our Rights: What’s Going On at the Supreme Court?” Autistic Self Advocacy Network <https://autisticadvocacy.org/policy/toolkits/ourbodies/>

² “A Self-Advocate’s Guide to Medicaid” Autistic Self Advocacy Network <https://autisticadvocacy.org/policy/toolkits/medicaid/>

³ “Organ Transplantation and People with Disabilities: A Toolkit for State Advocates” Autistic Self Advocacy Network <https://autisticadvocacy.org/policy/toolkits/organs/>

The antidiscrimination protections are particularly essential to ensure that our community has accessible, equitable health care. Members of the autistic community often have particular access needs related to effective communication and language access that are frequently unmet by providers, leading to autistic individuals, like others with intellectual and developmental disabilities, being disproportionately medically underserved. Moreover, autistic individuals are more likely to experience sex, gender and orientation discrimination— autistic individuals are more likely to identify as LGBTQ+ and gender-diverse- and less likely to receive adequate or appropriate health care across a variety of health domains, including reproductive and sexual health care. One report from the Center for American Progress found that data “reveal that LGBTQI+ communities encounter discrimination and other challenges when interacting with health care providers and health insurers, underscoring the importance of strengthening nondiscrimination protections through Section 1557 of the Affordable Care Act.”⁴

Finally, as with many other people with disabilities, particularly others with IDD, autistic individuals are more likely to rely on home and community-based services in order to maintain access to health care, as well as in order to sustain our ability to live, work, and participate in our communities. It is essential that these services be provided in a comprehensive, non-discriminatory manner which facilitates our full, self-determined access to these aspects of our lives. When we encounter discrimination in services that we require to remain free and independent in our communities, it impacts our ability to access health care. It also affects every other aspect of our health and autonomy, including our ability to live in our homes, to work, have security, and be part of a community.

Please find below our detailed responses to the inquiries contained in the proposed rule:

§ 92.4 Definitions

With respect to proposed revisions to the 2016 language access definitions, ASAN greatly appreciates the clarification that an LEP individual may require accommodation

⁴ “Advancing Health Care Nondiscrimination Protections for LGBTQI+ Communities”
<https://www.americanprogress.org/article/advancing-health-care-nondiscrimination-protections-for-lgbtqi-communities/>

for some forms of communication but not others. While language access is frequently understood as a separate consideration from effective communication, this particular concern is particularly relevant to those experiencing intersecting access issues. LEP individuals who also have disabilities impacting communication needs, including autistic LEP individuals, are likely to need multiple accommodations and more likely to need greater accommodation for specific domains of language access in particular.

ASAN supports the Department's reading of Section 1557 as applying broadly to all health activities and programs that receive federal funding, including all programs administered via Medicare, and not simply those administered under Title 1 of the ACA. The proposed rule notes that all Medicaid services are presumed to be covered under this rule as a health program or activity. ASAN supports this interpretation, and strongly urges HHS to explicitly state this in the regulatory language. Of major concern to us is any ambiguity over discrimination through benefit design or structure, or through Medicaid waiver services. Home and Community-Based Services are provided through 1915(c) Medicaid waivers, with a great deal of discretion on design and implementation of these waiver services being delegated to the states. When these services are delivered in a discriminatory manner, or access to these services is limited by lack of accommodation, it adversely impacts other aspects of our ability to participate in health care and independent living in our communities. As such, discrimination in these services would not only constitute discrimination on bases such as sex and orientation but would likely constitute discrimination on the basis of disability as understood under the ADA and Section 504 of the Rehabilitation act.

We are similarly concerned about the impact on the implementation of 1115 demonstration waivers if the rule does not explicitly discuss its applicability to Medicaid 1115 demonstrations in regulatory language. 1115 waivers are an essential avenue for innovative approaches to Medicaid services such as funding interventions into social determinants of health. Many of these include provision of services that would fall outside of conventional understandings of health care, such as supportive services for housing and employment. They may thus include funding of providers and services with greater need for technical assistance and support for compliance with these nondiscrimination rules. Moreover, explicitly including Medicaid and 1115 waivers in

regulatory language is essential to protect efforts to apply nondiscrimination standards to waiver activities. As we have seen in recent district court decisions concerning 1115 waivers, CMS experiences greater challenges in addressing discriminatory elements of improvidently-granted waivers such as those which restrict Medicaid eligibility in a discriminatory manner. For example, in a recent district court ruling on Georgia's Pathways waiver -a waiver that conditioned Medicaid expansion on work requirements- the court ruled that "health equity" was an impermissible basis for rescinding a waiver imposing work requirements on Medicaid eligibility under current regulatory language.⁵ Yet, the discriminatory impact of conditioning Medicaid eligibility on work requirements are well documented and substantial. We believe that 1115 waivers can and should be used to address the social determinants of health which significantly effect individual health outcomes and that additional regulatory support for oversight of 1115 waivers would be beneficial to ensuring that these waivers are being used as intended, to innovate service delivery, rather than to restrict benefits access in a discriminatory manner.

§ 92.7 Designation and Responsibilities of a Section 1557

Coordinator

In this section the Department requests feedback on whether OCR should extend requirements to designate a Section 1557 Coordinator to covered entities with fewer than 15 employees. We believe that they should. Accessibility and nondiscrimination are not optional. Failure to provide accommodations and supports creates access barriers to health care that harm the health of those of us with disabilities, and increase. ASAN has previously joined comments on the 2020 rule discussing the impact of this exception.⁶ As we discussed then, the American Medical Association's (AMA's) Physician Practice Benchmark Survey from 2012-16 found that most physicians still work in small practices, with 57.8% in practices of 10 or fewer physicians and 37.9% working in practices with fewer than 5 physicians in 2016. 67 Physicians in single specialty practices were even

⁵Georgia v Brooks-Lasure, ¶307,484, (Aug. 19, 2022)

⁶ "RE: HHS Docket No. HHS-OCR-2019-0007, RIN 0945-AA11, Comments in Response to Section 1557 NPRM" August 13, 2019. Retrieved 9/30: <https://www.c-c-d.org/fichiers/CCD-1557-Comments-FINAL.pdf>

more likely to be in smaller practices. A practice with 10 physicians may or may not have 15 or fewer employees, but a practice with 5 physicians is very likely to have fewer than 15 employees. This is especially common in rural areas, where few large providers are available, and for the specialized services many people with disabilities rely on because of specialists tending to work in small practices. In these situations, compliance and the prompt resolution of compliance issues are particularly critical because health care consumers may have few alternative providers available.

Moreover, as noted in the Notice, this requirement does not obligate entities to hire a new employee. Rather, they may designate an existing employee as coordinator. This should make the economic impact of this designation minimal. In fact, as the Department noted, the presence of a coordinator and a standardized grievance procedure helps to resolve concerns promptly within the entity, leading to lower compliance costs and improved outcomes. Rather than burdening smaller providers, the designation of an appointed coordinator should ease their compliance with 1557 requirements. Coordinators would also serve as points of contact for covered entities' training and technical assistance, ensuring that these providers are aware of possible accommodations and appropriate procedures.

§ 92.8 Policies and Procedures

We appreciate and support the Department's expectation that all providers, irrespective of size, are expected to develop Section 1557 policies and procedures. As stated above, provider size should not determine whether providers are expected to meet requirements under 1557. Given the large number of small providers, an exception for small providers or reliance on voluntary compliance would leave a large number of patients -particularly those with disabilities, in rural communities with limited provider access, or otherwise under-served- largely unprotected by these rules.

We agree with the decision to provide template policies and procedures for use by smaller entities. This will simplify compliance and ensure that providers are aware of their obligations and can inform patients of their rights under 1557. That said, it is essential that any such templates be robust and as widely applicable as possible among

the diverse entities covered by 1557. This is especially vital should policies derived from these templates be presumed to be in compliance with the rule. We strongly urge the Department to ensure that the development of these template policies and procedures be generated through a transparent process, including a public comment period, to ensure that any such policies and procedures adequately protect the rights of patients. As the Department notes, policies and procedures are not a panacea that will prevent all instances of discrimination. It is therefore essential that the Department recommend policies that reduce the risk of discrimination and provide providers with additional technical assistance to ensure compliance.

We also believe that it is essential that all covered entities establish a grievance process. As with 1557 coordinators, we note that size of provider does not protect patients from discrimination or lack of access. Medically underserved individuals, including people with disabilities and those in rural communities, are more likely to rely on the small providers that constitute the overwhelming majority of health providers overall. In the absence of an established grievance process, there is limited opportunity to raise concerns when discrimination occurs. This weakens civil rights protections for patients. Moreover, the Department notes in this notice “that a majority of patients in [historically marginalized] communities desire a method for submitting grievances to health care providers so that the providers can address the patients’ problems... [supporting] the supposition that, for patients of color, trust in their health care providers would increase if these patients could voice their concerns directly to their health care providers, thus, improving these patients’ overall health care experiences”. In light of this evidence, it is essential that all providers, including small ones, establish and utilize a grievance process.

Regarding record retention, we support the addition of a record retention policy for the reasons covered in the NPRM. We believe that maintaining records of prior incidents can help identify patterns of discrimination and better support corrective actions, particularly if a change in policy is warranted. However, we retain significant concerns about data protection with regards to any such records. We urge the implementation of safeguards regarding use of retained grievance reporting data as well as de-identification requirements. Particularly given provisions that would allow these records to be disclosed pursuant to applicable law, it is critical to the privacy and safety of

marginalized patients that any discrimination claims be deidentified. We are particularly sensitive to the possibility that malign state or future federal actors might seek records as part of efforts to target vulnerable communities such as LGBTQ+ individuals or individuals seeking reproductive health care. This could result in discrimination arising from these statuses or intersecting identities. It is imperative that any records produced under this rule be safeguarded against being used against individuals filing grievances on the basis of their identities or medical decisions, and providers who provide appropriate medical care to these individuals.

§ 92.9 Training

The Department notes that it is seeking comment on the proposed standard of 1557 training for relevant health care staff. While we recognize that the range and diversity of covered entities present challenges to prescriptive training, we believe that all staff at covered entities should receive a minimum degree of training on their personal and institutional obligations under 1557, including information on the role of the 1557 Coordinator and the grievance process. Such training is particularly important for those in positions where they are likely to receive accommodation requests, address grievances, or develop and maintain relevant policies. However, it is critical that all employees of covered entities have some familiarity with the regulation and associated procedures as well as the identity and contact information for the 1557 coordinator and procedures for filing grievances. Making this training universal has minimal burden relative to more detailed training for what the Department defines as “relevant” staff but can still promote the ability of disabled individuals to seek accommodations when needed.

If the Department does not take this approach, we propose expanding the definition of “relevant” to take a more expansive view of what staff may be implicated in the accommodation and grievance processes or are likely to be aware of incidents of discrimination. Employees who may not have direct patient interaction or policy-making roles at covered entities may nevertheless have relevant 1557-related responsibilities or obligations. Many are likely to engage in incidental interaction with patients in the course of their work performance and would benefit from training on their responsibilities under the regulation.

We also urge the Department to engage in a somewhat more explicit approach to the nature and baseline standards of adequacy for training, rather than leaving all elements of the nature of training up to the covered entities. We recognize that the range of covered entities is extremely diverse. However, it remains the case that adequate training is critical to ensuring that all individuals are able to maintain access to care.

§ 92.10 Notice of Nondiscrimination and § 92.11 Notice of availability of language assistance services and auxiliary aids and services

We support the proposed changes to the notice requirements discussed in the Notice. We believe that providing the notice annually and upon request, as well as displaying it conspicuously at point of service, balances the burdens and concerns about the meaning of “significant” discussed in response to the 2016 Rule with the importance of communicating nondiscrimination and accommodations policies to patients and service recipients. It is important that these notices inform patients of their rights to request language and accessibility accommodations as well as information on grievance procedures.

In addition, the Notice requests additional information on the best way to provide this notice to individuals with disabilities who may need auxiliary aids and services for disabilities and for LEP individuals. We believe that one essential element of ensuring that these notices are comprehensible and accessible is ensuring that they are presented in plain language. Written notifications should not exceed a 4th grade reading level and should ideally be as low as 3rd grade. Notifications should limit information to one idea per sentence and be provided in enlarged text for ease of reading. Where practicable, notifications should be accompanied with visual aids or icons to assist with comprehension and should prominently include the contact information for the 1557 coordinator and as well as any other point of contact for assistance in the accommodation and grievance processes. In addition to aiding cognitive accessibility for individuals with intellectual and developmental disabilities, plain language notifications will ease the economic burden of presenting notifications in multiple languages, as simplified language also improves ease-of-translation. This is particularly relevant to LEP

individuals who have intellectual, cognitive and developmental disabilities, who are likely to face intersecting burden from translated, non-plain-language materials.

We also encourage the presentation of notifications in multiple formats in addition to written language, including videos with both audio and ASL. As with plain language, providing multiple notice formats is particularly beneficial to those experiencing intersecting barriers from lack of English proficiency and intellectual, cognitive, or developmental disability. As the Notice notes, LEP individuals may need language assistance for materials presented in one format but not others. This is especially true for individuals with disabilities, who may face particular barriers with language presented in one format or context but not others. Providing these materials in multiple formats would mitigate these barriers. Additionally, any notice produced electronically must be formatted in a manner compatible with screen readers to ensure meaningful accessibility.

We encourage the Department to develop example notifications that meet the above accessibility standards. These templates would be especially helpful to smaller providers, who may struggle to develop these materials independently, and would further reduce the anticipated burden associated with providing notifications.

Additionally, we appreciate the inclusion of the definition of the term “companion,” and HHS’s explanation that a companion may include a “family member, friend, or associate of an individual. . .” who is “an appropriate person with whom a covered entity should communicate.” However, we support CCD’s comments that the determination of who is appropriate must lie with the individual with a disability or their designated decision-maker pursuant to state law, not with the provider. Deferring to the individual with a disability is essential, as providers communicating with non-designated companions may violate privacy laws and undermines the autonomy of people with disabilities. We suggest that HHS add language to clarify that the determination of who is “appropriate” lies with the individual, not with the provider.

§ 92.101 Discrimination Prohibited

We welcome and support the Department's interpretation of prohibitions on sex discrimination as inclusive of gender identity and gender expression, as well as orientation, pregnancy status, and intersex status. As we discussed in our introductory paragraphs, these protections are especially critical for the autistic community. Autistic individuals are more likely to identify as LGBTQ. Moreover, LGBTQ individuals frequently face additional burdens impacting provider access, including provider discrimination. These burdens often have a disproportionate impact on autistic individuals, who face additional intersecting barriers due to our disabilities. In fact, many nonbinary and transgender autistic individuals face additional barriers in receiving appropriate health care on account of medical gatekeeping and discrimination on the basis of the intersection of disability and gender identity.

One particularly tragic example of the impacts of this discrimination occurred for Kayden Clarke.⁷ Kayden was an autistic transgender man who was killed by police who were called to respond to a mental health crisis. In the weeks prior to his death, Kayden had shared on social media his experiences and frustrations in seeking transgender-affirming care consistent with his gender identity, where he routinely experienced barriers and discrimination. In his last video, he describes being particularly devastated after a therapist told him that she would not approve his starting on hormones until after his autism spectrum disorder – which she referred to as a “disease” – was “cured.” Because autism has no “cure,” this amounted to a pronouncement that Kayden would never be eligible to transition. Kayden was frustrated that, although his diagnosis was included in his file, that therapist had apparently performed no research on autism prior to meeting with him and declaring him ineligible for hormone treatment. In light of the numerous suicide attempts that Kayden had described as related to his gender dysphoria, we cannot ignore the possibility that this failure to provide adequate care placed Kayden at heightened risk of experiencing a mental health crisis such as the one that gave rise to the call to the police who killed him.

Autistic people's gender identities are real and should be respected; yet autistic

⁷ “ASAN Joint Statement on the Death of Kayden Clarke”
<https://autisticadvocacy.org/2016/02/asan-joint-statement-death-of-kayden-clarke/>

individuals are being denied basic access to medically necessary care as appropriate to our gender identities. Increasingly, this has extended into attacks on autistic individuals' gender identities and orientation, rooted in our disabilities, deriving from false and harmful claims that autistic individuals' gender identity or orientation are products of peer or caretaker influence rather than authentic identities that should be supported.

We urge the Department to provide greater specificity on the manner in which the rule applies to discrimination based on intersecting identities like those experienced by LGBTQ+ autistic individuals. As illustrated above, these forms of discrimination are particularly devastating to our community, and lead to our being denied essential, life-saving, medically necessary care on the basis of sex, gender identity, transgender status, and disability alike. In addition, we know that autistic individuals often face similar barriers and discrimination when seeking reproductive health care⁸. This is reflected in the drastically greater risk of pregnancy complication, including preterm birth, cesarean delivery, and pre-eclampsia⁹. For these reasons, we also propose that the definition for sex discrimination be amended to explicitly include discrimination on the basis of transgender status in addition to gender identity and expression more broadly.

We also appreciate that the Department has included pregnancy status discrimination in its definition of sex discrimination. However, we believe that it is important to explicitly include termination of pregnancy under this definition.

In the Notice, the Department requests feedback on whether the 2016 Rules's provisions on sex-based discrimination in criteria and methods of administration and selection of facility sites and locations that can have the effect of discriminating on the basis of sex. We strongly believe that a similar provision should be included in the current rule. This is particularly relevant to our community because despite ongoing efforts to provide long-

⁸ Doherty, A. J., Atherton, H., Boland, P., Hastings, R., Hives, L., Hood, K., James-Jenkinson, L., Leavey, R., Randell, E., Reed, J., Taggart, L., Wilson, N., & Chauhan, U. (2020). Barriers and facilitators to primary health care for people with intellectual disabilities and/or autism: an integrative review. *BJGP open*, 4(3), bjgpopen20X101030. <https://doi.org/10.3399/bjgpopen20X101030>

⁹McDonnell, C. G. and DeLucia, E. A. Pregnancy and Parenthood Among Autistic Adults: Implications for Advancing Maternal Health and Parental Well-Being. *Autism in Adulthood*. Mar 2021.100-115.<http://doi.org/10.1089/aut.2020.0046>

term supportive services in the homes and communities of people with disabilities, residential service provision remains extremely widespread for individuals with intellectual and developmental disabilities. Provider-owned or -controlled settings are particularly likely to be positioned to impose restrictions or conditions on recipients that may amount to sex discrimination as discussed above. In light of this, while discrimination on the basis of sex deserves particular attention and focus, it is also important to extend this to each of the enumerated grounds of section 1557's prohibition.

§ 92.201 Meaningful access for limited English proficient individuals

Accuracy of translated materials and communications can be critical to patients. Research shows that limited proficiency in English is highly correlated to unmet needs in the healthcare setting. With respect to autism diagnoses, one study showed “Latinx families with limited English proficiency are more likely than white families to experience hostility toward their language and report distrust in clinical professionals and the health care system, hence serving as additional barriers to receiving diagnosis which is crucially needed in order to obtain services.”¹⁰ Latinx children whose families’ preferred language is Spanish experienced difficulty being assessed with autism by predominantly English-speaking and white clinical professionals, and few received autism screenings in Spanish (Zuckerman et al. 2013), demonstrating that the process of assessment is not culturally and linguistically well-equipped to be used in Latinx communities (Zuckerman et al. 2021).¹¹ Consequently, the stated rule should ensure that individuals who prefer a non-English language and individuals with multiple disabilities facing structural barriers are guaranteed access to the appropriate communication tools necessary to make

¹⁰Angell AM, Solomon O. Understanding parents’ concerns about their children with autism taking public school transportation in Los Angeles County. *Autism*. 2018;22(4):401-413. doi:10.1177/1362361316680182; Zuckerman KE, Lindly OJ, Reyes NM, Chavez AE, Macias K, Smith KN, Reynolds A. Disparities in Diagnosis and Treatment of Autism in Latino and Non-Latino White Families. *Pediatrics*. 2017 May;139(5):e20163010. doi: 10.1542/peds.2016-3010. PMID: 28557734; PMCID: PMC5404727.

¹¹ Zuckerman KE, Mattox K, Donelan K, Batbayar O, Baghaee A, Bethell C. Pediatrician identification of Latino children at risk for autism spectrum disorder. *Pediatrics*. 2013 Sep;132(3):445-53. doi: 10.1542/peds.2013-0383. Epub 2013 Aug 19. PMID: 23958770; PMCID: PMC3876760; Zuckerman KE, Broder-Fingert S, Sheldrick RC. To reduce the average age of autism diagnosis, screen preschoolers in primary care. *Autism*. 2021 Feb;25(2):593-596. doi: 10.1177/1362361320968974. Epub 2020 Oct 30. PMID: 33126817.

effective communication possible, including sign language in a language they are familiar with, not simply American Sign Language as default.

The notice seeks comment on the use of machine translation in health programs and activities. We agree with the notice's assessment that machine translation should only be used sparingly and only in cases where no other reasonable alternative exists. Moreover, any machine translation should be additionally vetted for readability by someone fluent in the language, and should be accompanied with interpreter services; machine translation is particularly prone to syntactic and semantic errors that can alter meaning or render communications incomprehensible. One study investigating the error rate of Google translations from English of phrases for common medical communications found significant errors, with a substantially higher error rate for non-European languages.¹² Moreover, many of the translation errors constituted severe and consequential miscommunications that would introduce a serious risk of medical error and patient harm. This risk is particularly acute for people with intellectual and language processing disabilities who may have additional challenges interpreting mistranslated terms and may have limited means to alert providers to errors and request clarification.

§ 92.202 Effective Communication for Individuals With Disabilities

We support the provisions in this section regarding effective communication for people with disabilities. Effective communication is critical to ensuring that people with disabilities have access to quality health care. Research has shown that people with disabilities that impact communication have a more difficult time accessing health care, often delaying or foregoing care altogether.¹³

We also note that, since the HEW 504 rules were first issued, the basic duty to assure effective communication has revolved around the requirement to provide auxiliary aids and services. The provision of auxiliary aids and services is a necessary but insufficient tool for avoiding and remedying effective communication discrimination. This is

¹² Patil S, Davies P. Use of Google Translate in medical communication: evaluation of accuracy BMJ 2014; 349 :g7392 doi:10.1136/bmj.g7392

¹³ Michelle L. Stransky et al., *Adults with Communication Disabilities Experience Poorer Health and Healthcare Outcomes Compared to People without Communication Disabilities*, 33 J. Gen. Internal Med. 147 (2018), <https://link.springer.com/article/10.1007/s11606-018-4625-1>.

particularly true with regard to the estimated four to five million children, youth, working-age people, and older adults who cannot rely on natural speech to effectively communicate with most others.¹⁴ Instead, such individuals require, but frequently lack, effective access to the robust, language-based AAC they need to express themselves and be understood. A major cause and effect of this is that AAC users are subjected to age-old unwarranted and disproven assumptions stereotypes that brand them as categorically being less intelligent; being unable to use or even devoid of language; and, having less of a human need, ability, or right to effectively communicate.

Indeed, the very fact that someone requires robust language-based AAC – rather than spoken words to effectively communicate – is often used to assume they are incapable of “effective communication.” Unfortunately, doctors and other health professionals are not immune from such biases, which has led to the failure to obtain informed consent, lower quality of care, poor health outcomes, and the alleged preventable deaths of individuals with significant expressive disabilities.¹⁵ All of this is due to the continued refusal of health care professionals and systems to “do no harm” by meeting their legal obligations to effectively communicate with all and not just some patients with disabilities.

We are extremely appreciative that HHS OCR has taken repeated actions throughout the pandemic to prevent and remedy this form of discrimination. We, therefore, strongly urge HHS to incorporate the following OCR guidance directly into the final regulations as well as all its subsequent guidance, technical assistance, and enforcement activities: [Non Discrimination in Standards of Care -- March 28, 2020](#); and, [The Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19-- June 9, 2020](#)

¹⁴ Beukelman DR, Light J. Augmentative and alternative communication: Supporting children and adults with complex communication needs. 5th ed. Baltimore, MD: Paul H. Brookes Publishing Co.; 2020.

¹⁵ Joseph Shapiro, “As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access?” National Public Radio (Dec. 14, 2020); and, Iezzoni, L.I., Rao, S.R., Ressler, J., Bolcic-Jankovic, D., Agaronnik, N.D., Donelan, K, Lagu, T., & Campbell, E.G. (2021). “Physicians’ Perceptions of People with Disability and Their Health Care,” Health Affairs, 40:2, 297-306, and here: [Physicians’ Perceptions Of People With Disability And Their Health Care \(nih.gov\)](#).

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 U.S.: Refusing to effectively communicate with significant expressive disabilities or other disabilities based on ableism or other multiply marginalizing is bad medicine and violates several federal civil rights laws. Along similar lines, we believe it is critical that HHS stress in public communications and in regulations that health care professionals and facilities have an obligation to ensure that effective communication is available to Black, Indigenous, non-English-using, and other People of Color who are more likely to endure multiple forms of prejudice and discrimination.¹⁶ HHS should also:

- require covered entities to ensure, in a comprehensive and seamless manner, the effective communication rights of non-English-using people with significant expressive disabilities and other disabilities receive the comprehensive and well-coordinated language access and effective communication assistance they require.
- As noted above, ensure that technologies like machine translation are used with caution in order to assure accuracy in translation essential for safe, high-quality, and equitable care. This is critical for the health and well-being for individuals with any degree of atypical speech, are non-English-using, or who use a speech generating device.
- We encourage HHS to take concerted steps to ensure the effective communication rights of individuals with significant disabilities and other disabilities that recognize and affirm the fact that effective communication is integral to achieving the central purpose of Section 504, the ADA, and Section 1557: Integration into the American community.

¹⁶ Kulkarni and Palmer, [Culturally and Linguistically Diverse Student and Family Perspectives on Using Augmentative and Alternative Communication Devices](#), American Educational Research Association Annual Meeting (AERA) (2017); Davis, [Reflections of nine participants regarding their experiences of being African American and using augmentative and alternative communication across their lifespan at ...](#), Pennsylvania State University, 2025; Ellis, Charles & Mayo, Robert. (2019). [Young African American adults with aphasia: A case series](#).

§ 92.207 Nondiscrimination in Health Insurance Coverage and Other Health-Related Coverage

Benefit Design

Despite protections in the ACA, insurers still seek to avoid high-cost populations such as people with disabilities or chronic conditions, and others with high health needs. We support strong regulatory protections prohibiting discriminatory plan benefit design and marketing practices. We agree that the 2020 rule resulted in less protection for people who need health care and are protected under 1557, and support the Department's interpretation that Section 1557 applies to health insurance coverage.

ASAN has previously raised a number of concerns regarding benefits design structures that adversely affect autistic individuals. One particular issue of concern continues to be reimbursement structures that limit coverage for the types of speech-generating devices that are most useful and effective for autistic individuals. We have written in previous comments to CMS about the importance of multi-use speech-generating devices to our community.¹⁷ Nonspeaking autistic individuals frequently rely on speech-generating devices as assistive devices for their communication needs. Text, email and phone conversions are an essential part of communication, yet many insurers continue to exclude multiple-use devices from coverage, even when the relevant devices are less expensive than single-use speech generating devices. We also note that for autistic individuals, the type of AAC device can be essential in establishing meaningful communication assistance. Learning and acclimating to an unfamiliar form of technology can impose additional burdens. As we explained to CMS in 2015, speech-generating devices as a category can be considered durable medical equipment because they are not "generally" useful to people without disabilities. But, like a power-operated vehicle that may be appropriately used as a wheelchair, a tablet with speech-generating software that "may be appropriately used" as a speech-generating device may be covered as durable medical equipment. Yet, insurers frequently limit coverage of these devices, despite the fact they are frequently *less* expensive than a single-use alternative,

¹⁷ "ASAN Calls for Expanded Coverage of Assistive Communication Devices"
<https://autisticadvocacy.org/2015/05/asan-calls-for-expanded-coverage-of-assistive-communication-devices/>

while also employing interfaces that are more familiar, and thus more accessible to many autistic individuals who need such devices.

Another example of how insurer benefit creates discriminatory and adverse impacts for autistic individuals occurs in therapeutic support coverage. Many insurers cover provision of Applied Behavioral Analysis (or ABA) as an exclusive intervention for autism or opt to reimburse non-ABA modalities of therapy at a much lower rate¹⁸. ABA is a model of intervention focused on changing the external behaviors of autistic children, with the goal of making an autistic child look and act nonautistic. Ethical concerns have been raised within the autistic community as to how ABA and similar practices serve to “normalize” autistic children, via teaching children to hide their autistic traits. Hiding autistic traits has been linked to worse mental health outcomes and increased suicidality in autistic adults. Furthermore, these practices “normalize” autistic children at the expense of promoting key life skills, self-determination, and self-esteem.¹⁹ Frequently, these approaches also seek to impose a normative set of behaviors on autistic individuals that are rooted in cultural and sex and gender norms that can coerce autistic individuals to adopt cultural and gender signifiers that are not their own and do not reflect their authentic self. Many self-advocates who have experienced these approaches have compared them to orientation and gender identity “conversion therapy”.²⁰

Integration Mandate

We strongly support the Department’s inclusion of regulatory language supporting the receipt of services in the most integrated setting. Section 1557 explicitly references Section 504, which has regulatory requirements to provide services and programs in the most integrated setting appropriate to the needs of individuals with disabilities and has consistently been interpreted as requiring those receiving federal financial assistance to not segregate individuals with disabilities from their communities. Critically, Section 504

¹⁸ “Health Insurance and Medicaid Coverage for Autism Services: A Guide for Individuals and Families” <https://autisticadvocacy.org/wp-content/uploads/2015/07/Health-Insurance-and-Medicaid-Coverage-for-Autism-Services-A-Guide-for-Individuals-and-Families-7-9-15.pdf>

¹⁹ “For Whose Benefit?: Evidence, Ethics, and Effectiveness of Autism Interventions” <https://autisticadvocacy.org/policy/briefs/intervention-ethics/>

²⁰ “Autistic Conversion Therapy” Autistic Women and Nonbinary Network. <https://awnnetwork.org/autistic-conversion-therapy/>

also prohibits covered entities from utilizing criteria or methods of administration that “have the purpose of or effect defeating or substantially impairing accomplishment of the objectives of the recipient’s program or activity” or otherwise discriminates against people with disabilities. Therefore, covered entities under Section 1557 are prohibited from providing health programs and services in settings that are more segregated than are appropriate to the needs of people with disabilities, and from employing coverage policies, benefit design, coverage decisions, and other criteria and methods of administration that will do the same.

People with disabilities were historically segregated in institutional settings due to ablism and misconceptions about ability; this systemic discrimination continues today and is built into many of health care systems and processes. This needless segregation of individuals with disabilities identified clearly in *Olmstead v. L.C.*, 527 U.S. 581 (1999), continues through the structure and processes of health care today, as discussed in our previous comments. The ACA dramatically shifted what discrimination in health care and health-related services looks like, especially for non-public health plans. While Section 504 allowed various insurance policies that discriminated against people with disabilities, the ACA – and the incorporation of Section 504 in Section 1557 -- explicitly prohibited many of these same policies.

We greatly appreciate that the Department has provided an explicit mention in the regulatory text and extensive discussion in the proposed rule about the details of this discrimination. We believe that it is critical to ensure that we are able to receive the health care that we need in contexts that enable us to remain in our homes and our communities. When health care is only available to us in contexts that require us to enter institutions and lose our autonomy, it harms us. We are grateful for the Department’s efforts to ensure that our rights are protected.

Network Adequacy

We appreciate the Department’s attention to network adequacy and how plan choices regarding provider networks may violate Section 1557. The Department is correct that provider networks may limit or deny access to care for individuals with certain disabilities by excluding certain specialties or providers that treat high-cost enrollees. For example,

a plan that excluded all developmental pediatricians from their network would discriminate against people with developmental disabilities. Similarly, as touched on above, providers must have accessible medical diagnostic equipment in all facilities. If a plan does not have such providers in their network, then the network is inadequate for and discriminatory against people with disabilities.

The focus on network adequacy is particularly important given the recent Supreme Court decision in *Marietta Memorial Hospital Employee Health Benefit Plan v. DaVita Inc.* While addressing a different statutory provision, we believe that the case is a clear example of discrimination based on disability. We are disappointed in the decision that the Court reached. Not covering a service that is universally used by disabled individuals is discrimination that 1557 would prohibit--a plan could not choose to exclude epilepsy or HIV medication or choose have no specialists in intellectual and developmental disabilities at all in their networks.

We have observed similar denials of claims related to speech-generating AAC devices. Several of our constituents have reported receiving referrals for a specific AAC device which matches their accessibility needs as evaluated by a speech specialist. These individuals have plans which cover AAC devices and the relevant speech specialists to identify the appropriate device. However, when they attempt to obtain these devices, they are told that the *device manufacturers* are out-of-network. Networks that do not include comprehensive coverage of the medical devices and assistive devices that will meet our medical needs are not providing meaningful coverage of the medical devices we need. We would additionally argue that a benefit structure that purports to cover devices but places the manufacturers of these devices out-of-network additionally constitutes discriminatory benefit design.

Another topic of concern relates to provider networks for long-term support services through HCBS. We have routinely seen that limited provider options have directly impacted disabled people's ability to access necessary services to support community living. This is often particularly pronounced in HCBS because of an ongoing provider shortage which has left many providers under staffed, and even forced consolidation and

closure of provider programs. This has hurt disabled people, who often find additional difficulty accessing services that may now be located further away.

Similarly, we wish to raise concerns with the narrowing of provider networks related to provider consolidation, particularly as it relates to religiously-affiliated providers. In many cases this has engendered provider networks where individuals have severely limited access to non-religiously affiliated providers. This has led many to limited networks where patients may experience reduced access to critical health care such as LGBTQ+-affirming care, as well as many services related to sexual and reproductive health, including contraception, family-planning services, and abortion. In fact, 1 out of 6 acute care hospitals in the US were Catholic-affiliated as of 2016, with 52 geographic regions where Catholic networks were the sole providers of acute care.²¹ These religiously-affiliated networks have grown considerably in recent years, and often extend religious restrictions on care to affiliates, partners, and to providers acquired through merger and acquisition, leading to considerable opacity as to the existence of religious restrictions at all, and further reducing patient agency in avoiding situations where they will experience discrimination or denial of care. We request that the Department provide greater scrutiny to the impact of provider network consolidation in creating discriminatory impacts on health care recipients.

Value Assessment

We appreciate the Department's recognition of concerns over discriminatory value assessment methodologies. The disability community has long been concerned with a particular tool used in value assessment known as the Quality-Adjusted Life Year (QALY). In order to calculate the benefit received from treatment, the QALY measures how much less "quality" a year of life lived with a disability has compared to a year of life in "perfect health." Health care practitioners can then measure the number of QALYs the person would have with and without treatment. This ostensibly allows them to measure

²¹ Community Catalyst, *Bigger and Bigger: The Growth of Catholic Health Systems*, 2020, available at <https://www.communitycatalyst.org/resources/publications/document/2020-Cath-Hosp-Report-2020-31.pdf>.

benefits to longevity and health-related quality of life from treatment at the same time. In practice, the QALY instead can become discriminatory.

QALYs are based on the assumption that a year of life with a disability is of inherently lower quality and lower value to the individual than life without a disability. For example, the most common methodologies used to calculate the QALY presume that not being able to walk or move means that the person's quality of life is lower. If a person can't walk, many versions of the QALY value their starting health-related quality of life less, even though many people who cannot walk report no less quality of life. An additional concern is that these measures -and the relative value assigned to years of life with disability- are derived from surveys of the general public on their preferences for different "health states." In practice, the surveys rely on the speculation of non-disabled people with regards to the experience of being disabled. There is significant evidence that the general public has negative attitudes toward disability and people with disabilities. Congress recognized that people with disabilities face discrimination from the general public when it passed disability civil rights statutes, including the Rehabilitation Act, Individuals with Disabilities Education Act, and Americans with Disabilities Act.

While we are concerned about the use of an inherently discriminatory metric in any health-related context, we are most concerned about the use of QALYs in making coverage and access determinations, such as benefit design, formulary design, and utilization management. These are decisions about what treatments - and sometimes *whose* treatments - get paid for by insurers and provided to beneficiaries. When these decisions are based on the QALY, treatments that either only extend the life of a disabled person or do not improve upon the specific issues measured by the QALY are valued less than other treatments. Health insurers relying on the QALY would, due to the number of QALYs gained being greater, value treatments that restore perfect health over treatments that maintain good health in a disabled person.

The National Council on Disability (NCD) produced a series of reports in 2019 regarding bioethics and the ways in which the lives of people with disabilities are undervalued in the health care system. NCD recommended that OCR, in conjunction with other applicable agencies, issue guidance that "payment decisions should not rely on cost-

effectiveness research or reports that are developed using QALYs” and that “covered health insurance programs should not rely on cost-effectiveness research or reports that gather input from the public on health preferences that do not include the input of people with disabilities and chronic illnesses.” We support these recommendations. We also support the NCD recommendation that federal programs, including Medicaid, should not rely on cost-effectiveness research or reports that gather input from the public on health preferences that do not include the input of people with disabilities and chronic illnesses.

We would be similarly concerned about value assessment methods and metrics that measure the cost effectiveness of treatments relative to health outcomes in a way that discriminates on the basis of race, color, national origin, sex, or age. For example, older people are expected to live fewer years than younger people; value assessment metrics that value the years of life a treatment adds may discriminate based on age. Some health care treatments may work less effectively in someone with comorbid conditions, and many racial and ethnic minorities experience health disparities and multiple chronic conditions. A value assessment that measures outcomes of a specific treatment may determine that it is not cost-effective to cover a treatment for racial and ethnic minorities. Such value assessments would be discriminatory and should not be allowed in any health program or activity that receives federal financial assistance. The government should not rely on instruments that are based on surveys of the general public about the value of life with a disability. These instruments reinforce discrimination that Congress has intended to address through civil rights and antidiscrimination statutes.

§ 92.210 Use of Clinical Algorithms in Decision-Making

We support the Department’s proposal to address clinical algorithms such that covered entities would be on notice that they cannot base decisions in reliance on discriminatory clinical algorithms. We are grateful for the Department’s recognition that while algorithms can improve the delivery of care, that they have an extensive and well-documented history, both within and beyond health care, of producing discriminatory effects.

Throughout the COVID-19 pandemic, we saw firsthand how profoundly discriminatory clinical algorithms could impact the care received and wellbeing of disabled individuals, and how these same algorithms can additionally create intersectional discrimination.

These were most readily apparent in the crisis standards of care protocols employed across acute care providers nationwide. These standards varied state-to-state, and often, where states lacked statewide standards, provider network-to-provider network. Frequently, crisis standards of care included discriminatory factors such as longer-term life expectancy, or perceived quality of life. In as number of cases, this led to the denial of critical care to individuals with intellectual disability or who were nonspeaking.²²

§ 92.302 Notification of Views Regarding Application of Federal Conscience and Religious Freedom Laws

Concerning the interaction of federal conscience and religious freedom laws, we recognize that the Department is obliged to enforce existing federal law in this area, and thus some constraint on the Department's rulemaking power where this might conflict with existing statutes. We strongly appreciate the Department's proposed framework of evaluating these refusals on a case-by-case basis evaluating the totality of context, as well as the Department's explicit acknowledgement that such exemptions must be weighed against the burdens they impose on the rights of patients. Nevertheless, we wish to raise significant concerns about the impact on expansive interpretations of existing federal religious objection laws and their impact on individuals experiencing discrimination and accessibility barriers in receiving care. We have previously raised concerns about the impact of religious refusals on disabled individuals in comments on the now-rescinded 2020 Religious Refusals Rule.²³

Many people with disabilities rely on Home and Community Based Services through Medicaid 1915(c) waivers. Because direct support services include assistance with activities of daily living and instrumental activities of daily living, they include assistance with activities such as scheduling, travel to, and attending medical visits, as well as taking medications. It is important to understand that in these circumstances, the services provided to individuals are meant to be self-directed— that is to say, only

²² "Examining How Crisis Standards of Care May Lead to Intersectional Medical Discrimination Against COVID-19 Patients." <https://autisticadvocacy.org/wp-content/uploads/2021/02/FINAL-Intersectional-Guide-Crisis-Care-2-10-21.pdf>

²³ "ASAN Condemns New Religious Refusals of Care Rule" <https://autisticadvocacy.org/2019/05/asan-condemns-new-religious-refusals-of-care-rule/>

support needs identified by the supported individual, and towards goals identified by that individual. In essence, these supports are an accessibility aide supporting community living and integration. They are meant to be an extension of the supported individual's wishes and intent as much as any other accessibility aide. As such, the impacts at risk on disabled individuals' ability to live independently and at their own direction in the community are pronounced in situations where support workers or agencies substitute their own judgment for that of the disabled individual being served. As with many other health care services, a substantial number of home and community-based service providers are religiously affiliated, and there is substantial risk that they may seek to deny services to disabled service recipients on religious grounds. In these scenarios, multiple protected classes are in play by definition— not only do these denials risk implicating sex, gender, orientation and pregnancy status discrimination, but by directly burdening disabled individuals right to access, seek and receive medical care through selective denial of needed supports, they additionally implicating disability status discrimination as well.

While we consider the notification approach suggested in the rule as a positive development, we do not think this is sufficient to protect the interests of disabled people who may encounter substantial barriers to living, receiving medical care, or pursuing social relations with peers and in their communities on the basis of provider religious exemptions. Rather we request that at a minimum, the Department additionally require entities and providers claiming exemptions on the basis of religious belief to both inform service recipients in plain, accessible language when they communicate this information to OCR, incorporating these notifications into existing tagline notifications where appropriate, and additionally inform patients and service recipients of alternative means to access these services if they wish to. While providers may not be required to provide services where protected by existing law, this does not extend to denying disabled individuals *their* autonomy rights and rights to seek self-directed care.

Finally, we note an additional, overlapping challenge in addressing conscience provisions that may burden disabled service recipients' ability to exercise autonomy in self-directed medical decision-making. We note that an additional related challenge faced by service providers in navigating how to properly support service recipients is

posed by a number of state laws, including laws like Texas's SB8 which target individuals who assist people in seeking or obtaining medical care including abortion care, as well as other targeted legal action, such as state executive determinations that trans-affirming care is presumptive reportable abuse. These laws and actions have the impact of further constraining those support personnel who do seek to faithfully represent and support a disabled person's self-directed interests, and in the latter cases may additionally put disabled individuals at risk of institutionalization or other forms of segregation from the community on the basis of LGBTQ+ identity.

Change in Interpretation—Medicare Part B Meets the Definition of Federal Financial Assistance

We support the proposed change of interpretation of the present definitions of Federal Financial Assistance to include Medicare Part B. We believe that this corrects a previous erroneous interpretation of Federal Financial Assistance which excluded providers who received payments from Medicare Part B. This change in interpretation can help ensure that people's rights to access health care is not limited to certain settings or providers.

ASAN thanks the Department for the opportunity to provide comments, which will further its development of robust, effective regulations protecting our rights to access health care. For more information on ASAN's positions on 1557 and nondiscrimination in health care, please contact Greg Robinson at grobinson@autisticadvocacy.org