



Nothing about us without us!

Medical Treatment

Medical Treatment Question 1: We recognize that the line between disabilities may in some cases be more difficult to draw than in these examples, and we welcome comment on the best way of articulating the relevant distinctions.

We appreciate that the Department of Health and Human Services (HHS) is addressing this important issue. The language in the preamble cautioning providers not to rely on stereotypes or assumptions about disabilities is helpful in drawing relevant distinctions between long-term disabilities and “separately diagnosable” conditions. *See* Discrimination on the Basis of Disability in Health and Human Service Programs or Activities, 88 Fed. Reg. 63392, 63403 (proposed Sept. 14, 2023) (to be codified at 45 C.F.R. pt. 84). However, we ask that HHS make three additions to the proposed rule. First, we recommend that HHS explicitly require providers to find and document that a person’s disability would affect the near-term treatment outcome before denying them care or deviating from the standard of care because of their disability. Particularly where providers propose denying a patient some or all life-extending care that would be standard for a nondisabled patient on the basis of disability, medical professionals should be required to explain and document an evidence-based reason that the disability would affect near-term survival, increase the odds of significant side effects as described in the commentary, or otherwise have significance for the near-term treatment outcome for denials of care.

To expand on the example in the commentary, people with Down Syndrome are more prone to heart issues.¹ If a person with Down Syndrome presents with a heart problem, the proposed rule appears to require that they receive the standard of care unless there is some medically significant reason not to provide that. However, we are concerned about the enforcement of this provision without a requirement that medical providers document their reason for deviating from the standard of care. Tackling discrimination in medical settings is always challenging because of the information imbalance inherent to the doctor-patient relationship. Requiring providers to explain deviations from what would be the standard of care in a nondisabled patient will make the Department’s position that disabled people should generally receive the standard of care unless a specific aspect of their disability medically precludes it more effective in protecting the rights of people with disabilities.

This is particularly important in the transplant context. If HHS chooses to expand protections for people with disabilities in this way, transplantation would provide a valuable example. Excluding a disabled patient who would otherwise be a good candidate for organ transplantation from consideration for that treatment because their disability— related or unrelated to their organ failure— may shorten statistical life expectancy, would not meet a test that emphasizes maintaining the standard of care unless there are pressing, near-term reasons to deviate from it or the patient expresses preferences inconsistent with it.

¹ See Konstantinos Dimopoulos et al., *Cardiovascular Complications of Down Syndrome: Scoping Review and Expert Consensus*, 147 *Circulation* 5 (2023).

Second, explicitly cautioning providers not to make treatment contingent on long-term survival predictions in the text of the rule would be a useful protection for the disability community. Providers should also take the support a potential transplant patient has available to them into consideration.

Third, while we appreciate the Department's inclusion of the problem of transplant discrimination in the commentary on the rule, we ask for additional examples, additional language tying the commentary to the rule, and explicit additions to the language of the rule. While we understand that not every situation covered by the proposed rule can be delineated in the rule text or even examples, organ transplantation is an inherently time-sensitive matter with life-or-death stakes. Because of the time it can take for individuals who believe they have experienced discrimination to vindicate their rights, black letter law on topics of this nature is essential. For that reason, we would value language prohibiting the consideration of disability in transplantation except where it is relevant to health outcomes likely to materialize within five years of the date of surgery and requiring that a patient's capacity to follow post-transplant care is considered in light of the totality of the person's natural and paid supports. As an example, we suggest a patient without the executive function skills to effectuate post-treatment care may have support available to them via home and community based services (HCBS), family members, or other caregivers to help with this, thus removing it as a barrier to receiving a transplant.

Medical Treatment Question 2: The Department seeks comment on other examples of the discriminatory provision of medical treatment to people with disabilities.

We are grateful for the comprehensive examples HHS provided, including organ transplantation, crisis standards of care, and pressure on patients to turn down curative or life-extending care because of ableist assumptions about disabled peoples' quality of life. We especially appreciate the language specifying that nothing in Section 504 authorizes a guardian to decline food, water, or life-sustaining care.

It would be beneficial for the Department to add language limiting restraint and seclusion in medical settings. The Department briefly touched on the harms of restraint in the context of psychiatric residential treatment facilities (PRTFs). However, there are broader problems with restraint and seclusion across health care settings.²

Restraint is a common experience for people with disabilities. It is especially prevalent for people with IDD, mental health disabilities, or both.³ However, it is also an issue for people with other disabilities.⁴ and/or IDD as it can occur when someone seeks care for a mental health crisis and staff fail to take appropriate deescalation measures. It can also transpire when providers fail to accommodate patients or are too impatient to delay non-urgent care until the individual is calm, measures like sedation are possible, or that care can be delivered in an environment more

² See Autistic Self Advocacy Network, *Autistic Self Advocacy Network Comments Re: SAFE Initiative Call for Testimony* (Aug. 29, 2023), <https://autisticadvocacy.org/2022/08/autistic-self-advocacy-network-comments-re-safe-initiative-call-for-testimony/> (In these comments, ASAN outlined the problem of restraint in health care settings. While our comments were focused on children with IDD, our conclusions about the unavoidable harms of restraint and seclusion also apply to adults).

³ *Id.*

⁴ *Id.*

compatible with a patient's sensory needs.⁵ Restraint is an inherently harmful practice. It comes with serious risks of physical harm, including death.⁶ It is often psychologically traumatizing.⁷ People who have experienced restraint in health care settings sometimes become fearful of seeking needed medical treatment in the future.⁸ Addressing this issue would help to end a common form of disability discrimination in health care with significant adverse health effects.

Additional, helpful inclusions that would address barriers disabled people encounter in hospitals include preserving access to AAC and promoting full program access for wheelchair users. AAC users are often separated from their communication tools in these settings. We have heard many stories of facilities citing privacy concerns about any communication device equipped with a camera. If HHS added language to address this, it would help ensure people with communication disabilities are able to participate in their own care. Similarly, wheelchair users have been denied access to some kinds of inpatient care because they cannot complete activities of daily living independently.

We appreciate the Department's instructions to medical providers on the topic of service animals. Because many entities covered by federal disability rights statutes are flagrantly violating the rights of service animal handlers, we believe requirements on service animals will be largely ignored without significant guidance and enforcement. We hope this will be an area where the Department invests the time and resources it will take to ensure compliance.

⁵ See CommunicationFIRST, *Reflections on health care access* (last visited Oct. 12, 2023)

<https://communicationfirst.org/reflections-on-health-care-access/> (Contains firsthand accounts of people with communication disabilities, many of whom have IDD, mental health disabilities, or both, navigating the intersection of health care and their access needs.).

⁶ See Edward Stern, *The risks of restraint and seclusion*, *New England Psychologist*, Aug. 21, 2010, <https://www.nepsy.com/articles/columnists/the-risks-of-restraint-and-seclusion/> (Explaining the risk of physical harm involved in restraint).

⁷ See Kassam-Adams, N., & Butler, L., *What do clinicians caring for children need to know about pediatric medical traumatic stress and the ethics of trauma-informed approaches?*, 19 *AMA Journal of Ethics* 8, 793–801 (2017) (on the effects of medical trauma in children); see also The National Child Traumatic Stress Network, *Effects* (last accessed Nov. 10, 2023), <https://www.nctsn.org/what-is-child-trauma/trauma-types/medical-trauma/effects> (On the effects of medical trauma in children.); Domonique Parkes and Prasanna Tadi, *Patient Restraint and Seclusion*, *StatPearls* (Nov. 14, 2022) (A non-age-specific explanation of the risks of restraint including psychosocial harms such as depression and isolation.); Marie Chieze, Samia Hurst, Stefan Kaiser, and Othman Sentissi, *Effects of Seclusion and Restraint in Adult Psychiatry: A Systematic Review* 16 *Front Psychiatry* 10, 491 (2019) (Describing high rates of PTSD arising from restraint and seclusion incidents in adult psychiatric settings.).

⁸ See Nicolaidis, C., Raymaker, D., McDonald, K., Dern, S., Boisclair, W. C., Ashkenazy, E., & Baggs, A., *Comparison of healthcare experiences in autistic and non-autistic adults: A cross-sectional online survey facilitated by an academic-community partnership*, 28 *Journal of General Internal Medicine* 6, 761–769 (2013) (On self-reported health care disparities in autistic adults); see also Leslie Goldman, *What You Need to Know About Medical Trauma*, *HealthCentral* (Apr. 19, 2021), <https://www.healthcentral.com/article/what-to-know-about-medical-trauma> (A doctor recounts experiencing medical trauma during her own illness and becoming fearful, at times avoidant, of medical care.); April Boykin, *The Psychology Behind Medical Care Avoidance*, *Nashville Medical News*, Mar. 7, 2022, <https://www.nashvillemedicalnews.com/article/4590/the-psychology-behind-medical-care-avoidance> (Explaining that “dislike or distrust of health care providers, fear or dislike of medical treatments... [and] the experience of prejudice in healthcare” are among the factors that lead some people to avoid routine and primary care and decline to seek medical attention at the first sign that new health issues are developing. People who are reluctant to seek care for reasons including trauma experience worse health outcomes.).

Medical Treatment Question 3: *The Department seeks comment, including from health care professionals and people with disabilities, on the examples described in this section, whether additional examples are needed, and on the appropriate balance between prohibiting discriminatory conduct and ensuring legitimate professional judgments.*

We appreciate HHS' focus on experiences that have been common, sometimes lethal, problems for the IDD community. We believe the selected examples will enhance the safety of people with intellectual and developmental disabilities in health care. We value HHS' clear statement that disabled people should not be denied life-extending treatment based on others' stereotypes and assumptions. We support the Department's assertion that people with disabilities should receive care so long as they consent and are able to benefit from it.

We particularly appreciate the inclusion of the example of a patient with a disability who could recover from an acute respiratory crisis given a ventilator. The Department's position that denying lifesaving care to a patient with cognitive disability where it would be provided to one without violates proposed § 84.56(b)(1)(iii) will help patients and caregivers quickly address discrimination when hours may be the difference between survival and death. The example features a person with Alzheimer's disease who is in short-term respiratory distress, but the cognitive disability in question could just as easily be a form of DD. IDD is addressed directly in the example describing how withholding antibiotics to treat a curable respiratory infection in a teen with IDD would be discriminatory. HHS' assertion that providers should make judgments about whether a given treatment will achieve the patient's goals, not about patient quality of life as perceived by the medical provider, will prevent premature deaths. The example of the inappropriate provision of care on the basis of disability puts medical professionals on notice that failing to break with the long history of devaluing disabled lives may come with legal liability.

Again, to ensure that these provisions are enforceable, it would be helpful to include language in the regulation or examples requiring medical providers to consider what they would do for a similarly-situated nondisabled patient. Mandating documentation in the medical chart when a provider wants to deviate from what would be the standard of care in a nondisabled patient could both prevent discrimination— by getting physicians to pause and consider the appropriateness of their plans— and make it easier for patients and their caregivers to address. This could be a useful accountability measure.

The appropriate balance between medical judgment and protecting people with disabilities from discrimination in settings where the stakes are life and death must err on the side of giving disabled individuals the opportunity to survive. Bias in medical professionals is well known.⁹ This problem

⁹ See Chloë FitzGerald and Samia Hurst, *Implicit bias in healthcare professionals: a systematic review*, 18 BMC Medical Ethics 1, 19 (2017) (Meta-analysis of 49 articles on implicit race and gender bias in the provision of medical care concludes that "healthcare professionals exhibit the same levels of implicit bias as the wider population" and that bias is "likely to influence diagnosis and treatment decisions and levels of care in some circumstances[.]"); see also Elizabeth Chapman, Anna Kaatz, and Molly Carnes, *Physicians and Implicit Bias: How Doctors May Unwittingly Perpetuate Health Care Disparities*, Journal of General Internal Medicine 28, 1504–1510 (2013) (Exploring how physicians' implicit biases entrench health care disparities.); R. Casanova-Perez et al., *Healthcare biases experienced by BIPOC and LGBTQ+ patients*. AMIA Annual Symposium Proceedings, 275-284 (2021) (On discrimination against BIPOC and LGBTQ people in health care); Andrés J. Gallegos, *Misperceptions Of People With Disabilities Lead To Low-Quality Care: How Policy Makers Can Counter The Harm And Injustice*, Health Affairs, Apr. 1, 2021, <https://www.healthaffairs.org/content/forefront/misperceptions-people-disabilities-lead-low-quality-care-p>

adds risk to seeking care for members of marginalized groups including people of color, LGBTQIA+ people, and people with disabilities. Years of scholarship support the existence of these biases.¹⁰ Discrimination in health care is one of the most universal experiences among the varied disability community subgroups.¹¹ Its effects can be especially severe for multiply-marginalized disabled people.¹²

This issue is much discussed in the disability community, partly because it worsens the quality of care.¹³ Discrimination in health care is also a common subject of concern because it makes many disabled people fearful of interactions with the health care system, especially situations where

olicy-makers-can-counter-harm (Article describes how providers' bias leads to poor health outcomes in people with disabilities.).

¹⁰ See Clarissa Kripke, *Patients with Disabilities: Avoiding Bias When Discussing Goals of Care*, 93 *American Family Physician* 192 (2017) (“[f]alse assumptions about patients' quality of life can affect prognosis” and even “result in premature withdrawal of life-preserving care.”); see also National Council on Disability, *Medical Futility and Disability Bias*, 9-10 (2019) (“It has been well documented that healthcare providers significantly undervalue life with a disability... As a result, healthcare providers remain largely unaware of the high quality of life and happiness that many people with disabilities experience. This lack of awareness has impacted medical futility decision making and, in some cases, robbed people with disabilities of their chance to recover.”); L.I. Iezzoni, et al., *Physicians' perceptions of people with disability and their health care*, 40 *Health Affairs* 2, 297–306 (2021) (Study explored many aspects of physician perceptions about people with disabilities. 82.4% of doctors reported believing that people with significant disabilities have a lower quality of life than their nondisabled peers).

¹¹ See Maggi Budd, Omar Sultan Haque, and Michael Ashley Stein, *Biases in the evaluation of self-harm in patients with disability due to spinal cord injury*, 6 *Spinal Cord Series and Cases* 23 (2020) (Article explores the way in which medical provider biases can affect decision-making and assumptions to the point that providers may struggle to accurately assess the risk of self-harm, self-neglect, and suicide in patients with spinal cord injuries.); see also A. Bacherini, S.M. Haverkamp, and G. Balboni, *A new measure of physicians' erroneous assumptions towards adults with intellectual disability: A first study*, 67 *Journal of Intellectual Disability Research* 5, 447-461 (2023) (Exploring and seeking to develop a metric for negative provider assumptions about people with intellectual and developmental disabilities.).

¹² See HealthCity Editors, *People of Color With Disabilities Face Double Discrimination*, Boston Medical Center (Aug. 24, 2023),

<https://healthcity.bmc.org/population-health/people-color-disabilities-face-double-discrimination> (On the challenges of navigating health care as a disabled person of color.); see also *Women With Disabilities Experience Barriers to Access and Disparities in Health Care*, Mount Sinai (Jun. 30, 2022),

<https://health.mountsinai.org/blog/women-with-disabilities-experience-barriers-to-access-and-disparities-in-health-care/> (On barriers and discrimination disabled women, especially disabled women of color, encounter in medical settings.).

¹³ See Harvard Law School Project on Disability, *Disability Bias in Health Care Unearthing the influence of bias on health care policies and clinical decision-making* (Oct. 20, 2021) (Describes the types of bias medical professionals have against patients with disabilities and how they weaken quality of care, especially when health care providers are under time- and resource pressure.); see also Laura VanPuymbrouck, Carlie Friedman, and Heather Feldner, *Explicit and implicit disability attitudes of healthcare providers*, 65 *Rehabilitation Psychology* 2, 101-112 (2020) (Explaining that provider biases affect health outcomes for patients with disabilities.); FitzGerald, *supra* (“The evidence indicates that healthcare professionals exhibit the same levels of implicit bias as the wider population... Correlational evidence indicates that biases are likely to influence diagnosis and treatment decisions and levels of care in some circumstances...”); World Health Organization, *Health inequities lead to early death in many persons with disabilities* (Dec. 2, 2022), <https://www.who.int/news/item/02-12-2022-health-inequities-lead-to-early-death-in-many-persons-with-disabilities> (Exploring the effects of health care inequities on disabled people.).

inpatient care is necessary.¹⁴ Some, particularly those who have survived traumatizing experiences of medical discrimination or have close contacts who did not, even become reluctant to seek care.¹⁵

The medical community has repeatedly demonstrated its inability to address this issue on its own at present.¹⁶ New allegations of discrimination of all kinds arise frequently in many areas of society, but the experiences of the disability community suggest that this is particularly common in medical settings. Many of these allegations are ultimately substantiated. There is no way to know how many materially harm patients and how many more cause indignities and emotional distress for marginalized people, including people with disabilities. If the medical field had the inclination and capacity to independently solve these problems, it would have done so. It has not, so the Department must intervene to prevent harms to patients with disabilities including premature

¹⁴ These are widespread concerns within the disability community that have been discussed in social and advocacy settings for many years. See Emma Yasinski, *For Many Disabled Patients, the Doctor Is Often Not In*, Undark, Nov. 11, 2022, <https://undark.org/2022/11/07/for-many-disabled-patients-the-doctor-is-often-not-in/> (Patients with disabilities describe receiving low-quality care when they are able to access care at all. In some instances, this led to outcomes like a delayed cancer diagnosis). However, the COVID-19 pandemic brought an unusual amount of public attention to the issue. See Alice Wong, *I'm disabled and need a ventilator to live. Am I expendable during this pandemic?*, Vox, Apr. 4, 2020, <https://www.vox.com/first-person/2020/4/4/21204261/coronavirus-covid-19-disabled-people-disabilities-triage> (A notable disabled activist discusses the possibility that doctors might deny her care in a triage situation based on stereotypes and assumptions about people with disabilities.); see also Robin Wright, *Who Is "Worthy"? Deaf-Blind People Fear That Doctors Won't Save Them from the Coronavirus*, The New Yorker, Apr. 28, 2020, <https://www.newyorker.com/news/our-columnists/who-is-worthy-deaf-blind-people-fear-that-doctors-wont-save-them-from-the-coronavirus>.

¹⁵ Even before the pandemic, people with disabilities have had to engage in life-or-death struggles for medical care. See National Disability Rights Network and Disability Rights Washington, *Devaluing People with Disabilities Medical Procedures that Violate Civil Rights* (2012) (Report discusses numerous cases where disabled people were presumed not to want or be able to benefit from life-saving treatment, sometimes despite their expressed wishes. Some of these incidents had life-threatening consequences). As the Department knows, COVID-19 intensified these longstanding concerns. See Katie Savin and Laura Guidry-Grimes, *Confronting Disability Discrimination During the Pandemic*, The Hastings Center (Apr. 2, 2020), <https://www.thehastingscenter.org/confronting-disability-discrimination-during-the-pandemic/> ("Feeling that their lives are undervalued, disabled people report fears of inpatient hospital treatment due to concerns of undertreatment, including premature referrals to hospice care and unwanted withdrawal of life-sustaining treatment."); see also Joel Michael Reynolds, Laura Guidry-Grimes, and Katie Savin, *Against Personal Ventilator Reallocation*, 30 *Cambridge Quarterly of Healthcare Ethics* 2, 272-284 (2020) (The article discusses these dangers taken to their most extreme in the early days of COVID-19. When medical rationing was an imminent possibility, long-term ventilator users feared that their ventilators might be reallocated to other patients, especially if they sought inpatient care. This issue went unmitigated in many states until HHS intervened.).

¹⁶ There are measures medical disciplines might take to avoid harm to marginalized people, including people with disabilities, but the field has not made enough progress as of yet. See Mary Alice Keller, *Doctors and Disability: Improving Inclusion in Medical Education*, 3 *HCA Healthcare Journal of Medicine* 3 (2022) (The article suggests that improving training on disability in medical education might eventually help to address this problem.); see also Hanna Leonard, Alyssa Thorn and Mallory Finn, *Combating the Lack of Implicit Bias Training in Medical Education*, Kennedy Krieger Institute (last accessed Nov. 10, 2023), <https://www.kennedykrieger.org/community/initiatives/maryland-center-developmental-disabilities/information-dissemination/posters/combating-lack-implicit-bias-training-medical-education> (Explaining that there is insufficient implicit bias training in medical education and making recommendations to address that.). Lack of inclusion of people with disabilities in the medical field may contribute to this problem. See Mollie Frost, *Doctors with disability reflect on challenges*, ACP Internist (Feb. 2020), <https://acpinternist.org/archives/2020/02/doctors-with-disability-reflect-on-challenges.htm>.

death. Even if stricter standards cause occasional difficulties and delays for medical professionals, they will often be lifesaving for people with disabilities. This balance of harms and the power imbalance between medical professionals and all patients, especially marginalized patients, in health care settings demonstrates a need for regulations that err on the side of protecting people with disabilities from harm at the hands of the medical system. For this reason, HHS should protect vulnerable people who are frequently subjected to dangerous discrimination even if it comes at the expense of a degree of inconvenience for health care professionals and systems.

Medical Treatment Question 4: The Department seeks comment from all stakeholders on the risks and benefits of the proposed regulatory choices that the Department has put forth in this section.

More robust requirements for nondiscrimination in health care will not pose significant risks to people with disabilities. HHS has left providers room for professional judgment in the proposed rules. The Department does not propose to make practitioners work outside their scope of practice. The examples permit providers to consider disability to the extent of its relevance to the appropriate course of treatment. There is also no prohibition on futility determinations in and of themselves. The Department proposes to prohibit futility determinations on the basis of providers' value judgements regarding quality of life but leaves room for providers to discontinue treatments that have no hope of achieving the patient's goals. The Department merely states that "a recipient may not deny or limit that treatment if it would offer that treatment to a similarly situated person without the underlying disability." *See* 88 Fed. Reg. at 63405. Under such conditions, we believe health care providers will be able to work effectively. We do not believe the proposed regulation will hinder access to care, but will rather improve the availability and quality of care.

If effectively enforced, the proposed regulation is likely to bring about significant benefit for people with disabilities and members of other marginalized groups. ASAN expects it to increase health equity. The benefit of the proposed enhancements to nondiscrimination protections in health care is that they will save lives, reduce suffering, and improve quality of life. To the extent that they are followed and enforced, they may also reduce health disparities and improve disability community trust in the health care system. By making it safer to seek care as a disabled person, HHS has the opportunity to improve health outcomes for many people with disabilities, a significant number of whom are also members of other marginalized groups.¹⁷ We maintain that the proposed rule will protect people with disabilities in health care settings with minimal risk.

Medical Treatment Question 5: The Department also seeks comment on whether the term "medical treatment" adequately encompasses the range of services that should be covered under this nondiscrimination provision.

We generally support HHS' definition of medical treatment. We also support the expansion of the definition the Consortium for Constituents with Disabilities has suggested in its comments because

¹⁷ National Disability Institute, *Financial Inequality: Disability, Race and Poverty in America*, 5-6 (2019) (People with disabilities are disproportionately likely to be people of color and to live in poverty); *see also* Martha Ross and Nicole Bateman, *Disability rates among working-age adults are shaped by race, place, and education*, Brookings (May 15, 2018), <https://www.brookings.edu/articles/disability-rates-among-working-age-adults-are-shaped-by-race-place-and-education/>; Movement Advancement Project, *LGBT People with Disabilities*, 1 (2019) (LGBTQ people are disproportionately likely to have a disability.); U.S. Dep't. Of Labor Office of Disability Policy, *Spotlight on Women with Disabilities*, 4 (2021) (Women have a slightly higher disability rate than men, though there are some nuances to the relationship between disability and gender when disability rates are broken down by both gender and age.).

this would broaden the protections from discrimination outlined in the proposed rule. More people in more settings would be obviously and indisputably covered, making it easier for them to vindicate their rights. We would appreciate the Department specifying that this definition is not location dependent so it is clear that it applies to both hospitals and non-hospital-affiliated providers.

Beyond these modest changes, we do not believe the definition should be altered. Expanding it further would risk over-medicalizing the lives of people with disabilities. While non-medical aspects of life like housing and transportation can affect health and may be areas in which some people with disabilities need support, these other areas of life should not be considered medical.

Over-medicalizing the lives of disabled persons raises risks to privacy, autonomy, dignity of risk, and the opportunity to have a rich, fulfilling life experience. Even people with significant medical needs should not experience their lives as a string of treatment settings.

Additional Comments

We are grateful to HHS for addressing the issue of patient assessment, an area of concern for us for years.¹⁸ The Department's efforts to address the tools health care providers use to assess patients' health and likely outcomes are key parts of the proposed rule. These ways of measuring patients' conditions have often led to discrimination and denials of care for people with disabilities.¹⁹ While we will never know the full extent of the harm health care providers have enacted on people with disabilities by improperly applying these tools, the problem likely predates the COVID-19 pandemic. However, as the Department knows, medical rationing schemes developed in response to COVID-19 have highlighted the issue.²⁰

¹⁸ See Autistic Self Advocacy Network, *ASAN Condemns Hospital Policies that Value Profits Over Patients* (Aug. 10, 2023), <https://autisticadvocacy.org/2023/08/asan-condemns-hospital-policies-that-value-profits-over-patients/> (ASAN has recently expressed concern about hospital policies that push patients away from pursuing curative care where patients were seriously ill but continuing to provide care was not futile.); see also Autistic Self Advocacy Network, *Medical Rationing Complaint Filed by ASAN and Partners Resolved* (Jun. 26, 2020), <https://autisticadvocacy.org/2020/06/medical-rationing-complaint-filed-by-asan-and-partners-resolved/> (As the Department knows, ASAN was one of a number of national disability rights organizations that supported local advocates' challenges to states discriminatory medical rationing policies in 2020.); Autistic Self Advocacy Network, *What We Believe* (last accessed Nov. 10, 2023), <https://autisticadvocacy.org/about-asan/what-we-believe/> (ASAN has long opposed uses of QALYs that devalue the lives of people with disabilities and limit access to treatment.).

¹⁹ See, e.g. The Cochran Firm New Orleans, *Limitations of the [sic] Glasgow Coma Scale Scores* (last accessed Nov. 10, 2023), <https://cochranfirm.com/new-orleans/glasgow-coma-scale-2/> (Problems with the Glasgow Coma Scale are common enough that a private law firm using its website to seek business notes that "[a]nother potential issue with the GCS is the collection of valid scores. For example, the verbal response can be hindered by the presence of hearing loss, psychiatric disorders, dementia, developmental delay or injuries to the mouth or throat."); see also Rabia Belt, Camila Strassle, and Celina Maldavé, *Disability and Health in the Age of Triage*, Harvard Law Review Blog Essays, Jul. 1, 2020, <https://harvardlawreview.org/blog/2020/07/disability-and-health-in-the-age-of-triage/> ("The result is that tools like SOFA might systematically deprioritize people with certain disabilities, disproportionately increasing their mortality without maximizing the overall number of lives saved.").

²⁰ See Joseph Shapiro, *HHS Warns States Not To Put People With Disabilities At The Back Of The Line For Care*, National Public Radio, Mar. 28, 2020, <https://www.npr.org/2020/03/28/823254597/hhs-warns-states-not-to-put-people-with-disabilities-at-the-back-of-the-line-for>; see also Joseph Shapiro, *People With Disabilities Say Rationing Care Policies Violate Civil Rights*, National Public Radio, Mar. 23, 2020,

We understand that providers need standardized methods of assessing patients. There is nothing inherently discriminatory about giving practitioners a common language to convey a patient's condition. Indeed, these metrics may inform diagnosis or treatment plans and lead to better quality of care. These kinds of assessments are particularly necessary in triage situations.²¹ We are grateful for the Department's efforts to address the issue because the end of the public health emergency does not mean the end of triage standards of care. Whether at a local or national level, situations necessitating care rationing will come up in the future in the form of pandemics, mass shootings with high casualty counts, or natural disasters.

Measuring the likelihood of benefit from treatment in terms of short-term survival is necessary when patients and their caregivers must make decisions about whether to pursue aggressive treatment and in tragic circumstances where the demand for treatment overwhelms the supply. However, the tools for understanding how well a patient is likely to fare in the near term, such as the Glasgow Coma scale (GCS) and Sequential Organ Failure Assessment (SOFA), can have discriminatory results if used improperly. Unless providers make reasonable modifications to account for underlying disability, these assessment schemes can fail to distinguish between a disabled person's baseline and symptoms of an acute health crisis.²² This results in some disabled people scoring lower on these assessments, even if a symptom that results in a lower score is part of their daily life even when they are in optimal health. For example, someone could score lower on the movement section of the GCS if they have paralysis, even if that paralysis has nothing to do with the acute health crisis for which they are seeking care. A nonspeaking person may lose points for failing to exhibit speech even if that is a part of their healthy baseline. Unless providers adjust these methods to consider what is normal for a specific patient in light of that patient's disability, some disabled patients will be scored in ways that do not accurately reflect their health status.

<https://www.npr.org/2020/03/23/820398531/people-with-disabilities-say-rationing-care-policies-violate-civil-rights>.

²¹ Most states continue to have medical rationing plans that will be implemented if needed. See Disability Rights Education and Defense Fund, *State Medical Rationing Policies and Guidance Project* (last accessed Nov. 9, 2023), <https://dredf.org/state-medical-rationing-policies-and-guidance-project/>. Scoring systems, particularly SOFA, are common parts of state medical rationing plans created for or predating the COVID-19 pandemic. See Jackson S. Ennis et al., *Triage Procedures for Critical Care Resource Allocation During Scarcity*, 6 JAMA Network Open 8, e2329688 (2023).

²² Assessment tools can give disabled patients poor, questionably valid scores because they consider characteristics related to the person's underlying disability as if they were symptoms of the condition precipitating the hospital visit. Because those characteristics are part of the individual's healthy baseline, they have little relevance to the severity and survivability of the immediate health crisis. When providers rely on a score with this kind of validity problem, they may be too quick to decide curative care is futile or a bad investment of medical resources in a triage situation. See Laura Guidry-Grimes et al., *Disability Rights as a Necessary Framework for Crisis Standards of Care and the Future of Health Care*, 50 The Hastings Center Report 3, 28-32 (2020) ("Even if the design of SOFA scoring is not meant to be discriminatory on the basis of disability, it could nonetheless be implemented to have that effect. The use of SOFA must therefore be reviewed to ensure adequately individualized application of the scores—for example, accommodating nonverbal patients or patients with neuromuscular disabilities who cannot easily respond to commands.") (citation omitted); see also ACDIS Forums, *Glasgow Coma Scale in Chronic Conditions* (Feb. 2020), <https://forums.acdis.org/discussion/4939/glasgow-coma-scale-in-chronic-conditions> (A medical practitioner discussed the difficulty of applying the Glasgow Coma Scale to a nonspeaking patient with cerebral palsy and an intellectual disability who was in the hospital for an acute health crisis.);

The tendency of these tools to score many disabled people lower in the absence of reasonable modifications reinforces provider stereotypes about disabled people's quality of life.²³ Low scores will lead providers to view someone as so deathly ill that care is futile. This dynamic upholds fragility bias, a phenomenon where medical providers assume the worst about patients with disabilities' resilience.²⁴ In this way, applying standard patient assessment tools without reasonable modifications can lead to inappropriate withdrawals of care designed to be curative or life-extending. Requiring providers to make reasonable modifications to these tools— to consider disability as distinct from the symptoms of a new health issue— will allow for the nondiscriminatory use of these tools. This will not only improve access to care but may also encourage practitioners to listen more closely to patients and caregivers about what is normal for the patient. Especially in triage situations where not everyone who needs care will receive it, mandating the consideration of the patient's healthy baseline in the assessment will give people with disabilities a fairer chance to receive treatment and live.

We appreciate the Department's examples featuring people with developmental disabilities. We share HHS' concern about the unmodified application of these tools to people who may be nonspeaking or lack full control of their movements due to disabilities like autism or cerebral palsy. We agree with the Department that the unmodified use of these patient assessment schemes will lead to overly-pessimistic determinations about patient condition for some members of our community. This, in turn, may lead to underestimating some disabled patients' likelihood of benefiting from aggressive care and result in denials of care that are unwanted and premature. For these reasons, we are gratified that HHS is addressing this issue. We support the inclusion of the strongest possible requirements that providers make reasonable modifications to these tools in the rule and examples.

Our remaining concern is that it is not clear where providers will get the information they need to modify value assessment tools to accommodate patients with disabilities. At times, patients will be able to communicate their own baselines. Caregivers will be able to provide input in some situations. Specific language encouraging providers to communicate with patients and their caregivers and loved ones about their experiences at baseline would be useful. This is especially important in crisis or triage situations where time pressure, exhaustion, and stress can bring providers' biases to the fore, deepening the risk that stereotypes and assumptions will undermine care.²⁵ This was a significant problem early in the COVID-19 pandemic, resulting in disabled people

²³ As the Department knows, these stereotypes are strong enough to have been codified into state rationing plans, necessitating HHS intervention to prevent life-threatening discrimination. *See* U.S. Dep't. of Health and Human Services, *OCR Reaches Early Case Resolution With Alabama After It Removes Discriminatory Ventilator Triage Guidelines* (Apr. 8, 2020), <https://public3.pagefreezer.com/content/HHS.gov/31-12-2020T08:51/https://www.hhs.gov/about/news/2020/04/08/ocr-reaches-early-case-resolution-alabama-after-it-removes-discriminatory-ventilator-triaging.html> (Alabama was not permitted to disadvantage patients with intellectual disabilities in rationing considerations. As there is not a clear causal link between intellectual disability in and of itself and whether or not a person will survive an acute respiratory crisis, this presumably represented some sort of value judgment about which kinds of lives are worth saving.)

²⁴ *See* Harvard Law, *Disability Bias in Health Care, supra*. ("Fragility bias" arises when clinicians perceive that patients with disabilities suffer more than non-disabled patients who present with the same medical facts, which can lead to more conservative treatments.").

²⁵ *See* Tiffani J. Johnson, Robert W. Hickey, Galen E. Switzer, Elizabeth Miller, Daniel G. Winger, Margaret Nguyen, Leslie R. M. Hausmann, and Richard A. Saladino, *The Impact of Cognitive Stressors in the Emergency Department on Physician Implicit Racial Bias*, 23 *Academic Emergency Medicine* 3, 297 (2016).

receiving substandard care even where rationing was not occurring.²⁶ Explicitly encouraging or requiring providers to communicate with patients and their caregivers about what symptoms are normal for a patient outside of the acute health crisis they are seeking care for may prevent overly pessimistic assessments of disabled patients' likelihood of survival, preventing discrimination and saving lives.

Value Assessment

Value Assessment Methods Question 1: The Department seeks comment on how value assessment tools and methods may provide unequal opportunities to individuals with disabilities.

We urge a more thorough condemnation of the reliance on quality-adjusted life-years (QALYs) in treatment settings because the metric is inherently discriminatory. The discussion of QALYs in HHS' commentary on the proposed rule suggests that it is possible to use QALYs in nondiscriminatory ways and that their nondiscriminatory use should remain permissible. However, QALYs inherently devalue disabled people's lives.²⁷ Consequently, it is not clear to us how the use of QALYs can be nondiscriminatory.

Value Assessment Methods Question 2: The Department seeks comment on other types of disability discrimination in value assessment not already specifically addressed within the proposed rulemaking.

The Department should also consider whether the discriminatory methodologies underpinning QALYs and similar and QALY-derived metrics, such as Equal-value Life Years Gained (EvLYGs), can lead to discrimination even for ostensibly permissible uses. For example, while EvLYGs may not contain the same discounting that QALYs do, they are designed using the same methodologies, relying on nondisabled perspectives of disability. These metrics are designed to be used as a supplementary tool alongside QALY analysis. Still, we have noted repeated efforts to carve out their use in recent legislative efforts to prohibit use of QALYs and related metrics. Because QALYs and associated metrics derive from a discriminatory methodology, they tend to facilitate discrimination. Therefore, we are asking for an explicit ban on QALYs and similar metrics in any federal program.

²⁶ In its most extreme form, this went as far as imposing an end-of-life care approach when patients and their caregivers wanted to pursue curative care. See Joseph Shapiro, *As Hospitals Fear Being Overwhelmed By COVID-19, Do The Disabled Get The Same Access?*, National Public Radio, Dec. 14, 2020, <https://www.npr.org/2020/12/14/945056176/as-hospitals-fear-being-overwhelmed-by-covid-19-do-the-disabled-get-the-same-acc> (A hospital allegedly resisted providing life-saving care to a lively, active woman with disabilities, insinuated she had no meaningful quality of life, and pushed for a DNR to be added to her chart in 2020, though it is not clear that the hospital was under crisis standards of care at the time. The woman died.); see also Patricia Ramos et al., *The COVID-19 Pandemic and People with Disabilities: Primary Concerns, the AUUCD Network Response, and Needs for the Future*, 10 (2021) ("Some healthcare providers have also unfairly pressured individuals with disabilities and/or their families to forgo life-sustaining treatment for COVID-19, or even adding Do Not Resuscitate (DNR) orders to individual medical records without consent."); The Arc, *Resolution of Federal Complaint Amidst Nationwide COVID-19 Surge Raises Bar in Prohibiting Blanket DNRs, Medical Discrimination Against People With Disabilities*, (Aug. 20, 2020), <https://thearc.org/blog/resolution-of-federal-complaint-amidst-nationwide-covid-19-surge-raises-bar-in-prohibiting-blanket-dnrs-medical-discrimination-against-people-with-disabilities/>.

²⁷ See Paul Schneider, *The QALY is ableist: on the unethical implications of health states worse than dead*, 31 *Quality of Life Research* 5 (2022) (On QALYs' ableism problem.); see also William S. Smith, *The U.S. shouldn't use the 'QALY' in drug cost-effectiveness reviews*, STAT, Feb. 22, 2019, <https://www.statnews.com/2019/02/22/qaly-drug-effectiveness-reviews/#:~:text=QALYs%20also%20disadvantage%20the%20disabled,and%20patients%20with%20chronic%20conditions> ("QALYs also disadvantage the disabled, who cannot achieve maximum QALY scores...").

Value Assessment Methods Question 3: The proposed value assessment provision applies specifically to contexts in which eligibility, referral for, or provision or withdrawal of an aid, benefit, or service is being determined. The preamble discussion of the provision clarifies that the provision would not apply to academic research alone. However, the Department seeks comment on the extent to which, despite this intended specificity, the provision would have a chilling effect on academic research.

We do not believe the standards in the proposed rule would chill academic research. If anything, the rule's failure to address the use of QALYs in research may permit some forms of discrimination to continue. Devaluing life with a disability in medical research will perpetuate some forms of discrimination in health care settings.²⁸ Marginalized people, including people with disabilities, have historically been used, abused, and devalued in medical research.²⁹ Even as those issues continue, people with disabilities are also under-included in medical research that could result in longer, better lives.³⁰ Promoting ethical research is crucial in and of itself and for the purpose of creating equitable clinical outcomes once that research is applied in health care settings.

Child Welfare

Child Welfare Question 1: The Department seeks comment on additional examples of the application of the most integrated setting requirement to child welfare programs and welcomes comments on any additional points for consideration regarding integration of children with disabilities in child welfare contexts.

We appreciate the Department's recognition of this critical issue. We are particularly grateful for HHS' efforts to address the fact that children in state custody are too often placed in institutions.³¹

²⁸ See Lorna L. Freath, Alistair S. Curry, David M. W. Cork, Ivana F. Audhya, and Katherine L. Gooch, *QALYs and ambulatory status: societal preferences for healthcare decision making*, 25 *Journal of Medical Economics* 1, 888-893 (2022) (On the ableism problem with QALYs.).

²⁹ See The Associated Press, *Review finds U.S. government conducted dozens of experiments on inmates and disabled people*, *Central NY News*, Feb. 27, 2011, https://www.syracuse.com/news/2011/02/review_finds_us_government_con.html (On federally-sponsored research on marginalized people who were not in a position to truly consent, including disabled people.); see also Western Pennsylvania Disability History & Action Consortium, *University of Pittsburgh Calls Attention to a Dishonorable History in Experimentation* (Aug. 15, 2018), <https://www.wpdhac.org/university-of-pittsburgh-calls-attention-to-a-dishonorable-history-in-experimentation/#:~:text=At%20Fernwald%20State%20School%20in,ended%20these%20kinds%20of%20abuses> ("At Fernwald State School in Waltham, Massachusetts, in the 1940s and 50s, children with disabilities were fed radioactive cereal as part of a scientific experiment."); U.S. Dep't. of Justice, *Justice Department Alleges Conditions at Iowa Institution for Individuals with Disabilities Violate the Constitution* (Dec. 22, 2020), <https://www.justice.gov/opa/pr/justice-department-alleges-conditions-iowa-institution-individuals-disabilities-violate> (The U.S. Department of Justice recently addressed allegations of unethical experiments on people with intellectual disabilities.).

³⁰ See Dianne Rios, Susan Magasi, Catherine Novak, and Mark Harniss, *Conducting Accessible Research: Including People With Disabilities in Public Health, Epidemiological, and Outcomes Studies*, 106 *American J. of Public Health* 12, 2137-2144 (2016) (On the underinclusion of people with disabilities in medical research.); see also Alicia R. Ouellette, *People with Disabilities in Human Subjects Research: A History of Exploitation, a Problem of Exclusion*, Albany Law School, May 10, 2021, https://papers.ssrn.com/sol3/papers.cfm?abstract_id=3492078 (On how people with disabilities have been both exploited in and excluded from medical research.).

³¹ See Cheri Williams, *Kids in Foster Care Belong in Families, Not Modern Day Orphanages*, *The Imprint*, Jan. 12, 2022, <https://imprintnews.org/foster-care/kids-in-foster-care-belong-families-not-modern-day-orphanages/61937> (Roughly 10% of children in foster care are institutionalized.).

There, they are exposed to a myriad of harms. Institutional settings are notorious for physical, sexual, and verbal abuse.³² They often experience neglect and negligent harms in these settings.³³ By their nature, facilities limit contact with adults unaffiliated with the institutional setting, making it difficult for children to report abuse and neglect to adults who might take protective action. Even in the absence of these ills, institutionalization has well-documented, adverse effects on child development.³⁴ It often limits access to quality education.³⁵ It tends to fray a child's ties to family, culture, and community by limiting access. These dangerous, low-quality environments set up some of the most vulnerable children with disabilities— youth in state custody— for poor outcomes in life. This issue has significant equity implications because children in state custody are disproportionately Black and LGBTQ+ as well as disproportionately disabled.³⁶ For this reason, we appreciate the Department's efforts to address discriminatory and harmful aspects of state child

³² See Human Rights Watch, *Children with disabilities: Deprivation of liberty in the name of care and treatment* (Mar. 7, 2017), <https://www.hrw.org/news/2017/03/07/children-disabilities-deprivation-liberty-name-care-and-treatment> (On the dangers of institutions for children.); see also Elaine Shelly, *What's Love Got to Do With It? An Argument Against Institutionalizing People with Severe Physical Disabilities*, 45 *Generations Journal* 2 (2021) (Shelly describes the perils of institutions in other segments of the lifespan, but children experience the same harms in institutions as adults. "Each time, the facilities fell short of the promises. Not just one facility, but at least 20 facilities in different parts of the country. None of them felt safe.").

³³ See Marinus van IJzendoorn, Jesus Palacios, Edmund Sonuga-Barke, Megan Gunnar, Panayiota Vorria, Robert McCall, Lucy LeMare, Marian Bakermans-Kranenburg, Natasha Dobrova-Krol, and Femmie Juffer, *Children in Institutional Care: Delayed Development and Resilience*, 76 *Monographs of the Society for Research in Child Dev.* 4, 8-30 ("Children exposed to institutional care often suffer from 'structural neglect' which may include minimum physical resources, unfavorable and unstable staffing patterns, and social-emotionally inadequate caregiver-child interactions."); see also S. Randall Hood, *When Children Suffer Neglect in Residential Treatment Facilities*, McGowan, Hood, Felder, & Phillips, LLC (Jan. 31, 2022), <https://www.mcgowanhood.com/2022/01/31/when-children-suffer-neglect-in-residential-treatment-facilities/> (The problem is common enough to warrant a full page on a private sector law firm website.).

³⁴ See *Reaching and Investing in Children at the Margins: Summary of a Joint Workshop by the National Academies of Sciences, Engineering, and Medicine; Open Society Foundations; and the International Step by Step Association (ISSA)*, Section 3 (On the unavoidable harm growing up in a facility environment does to children.); see also University of Minnesota, *In global report, U of M researchers find institutional care negatively impacts children's development* (Jun. 24, 2020), <https://twin-cities.umn.edu/news-events/global-report-u-m-researchers-find-institutional-care-negatively-impacts-childrens/> ("The authors found that institutional care is strongly associated with negative impacts on children's development, including physical growth, brain growth, cognition and attention. They also found significant, but smaller, negative associations between institutionalization and socioemotional development and mental health.").

³⁵ See National Disability Rights Network, *Desperation Without Dignity* 48 (2021) ("Education is a critical component of the child's placement at a RF, to ensure that children depart from the facility without stunted educational growth and are fully prepared for integration back into a community school. P&As report very limited education resources... residents complain about receiving the same educational instruction and assignments regardless of age or grade level.").

³⁶ See The Annie E. Casey Foundation, *Black Children Continue to Be Disproportionately Represented in Foster Care* (May 14, 2023), <https://www.aecf.org/blog/us-foster-care-population-by-race-and-ethnicity> (Black children are overrepresented in state care.); see also Human Rights Campaign, *LGBTQ+ Youth in the Foster Care System* (last accessed Nov. 9, 2023), <https://www.thehrcfoundation.org/professional-resources/lgbtq-youth-in-the-foster-care-system> (LGBTQ children are overrepresented in state custody.); Nuria Fuentes-Peláez, Carme Montserrat, Rosa Sitjes-Figueras, and Gemma Crous, *Breaking the silence on special needs children in foster care: The diversity of children in foster care, carers and processes*, 36 *Children and Society* 2, 183-200 (Disabled children are overrepresented in foster care.).

welfare systems, especially the language about institutionalization and the connections between this section and the provisions on the integration mandate.

However, we have several additional recommendations. First, we would like to see the Department encourage states to consider the likelihood of institutionalization in assessing whether removal from the child’s existing caregivers at the time of interaction with child welfare systems is in the best interest of the child. Due to the harms institutionalization causes and the frequency with which states place youth in their care in facilities, we believe this is a reasonable consideration for states in assessing whether a child belongs in state care.

Second, we would like to see the Department further address the use of chemical restraints in foster settings. Literature over the past decade reports excessive prescribing of psychotropic medications to children in foster care.³⁷ Overuse of antipsychotic medications with effects similar to those of other drugs used for chemical restraint, most frequently for ADHD or other non-FDA-approved uses, is an ongoing problem.³⁸ The differences in prescription policies in foster care are system-driven, not disability driven. There is substantial variation between the rate of prescription of these drugs at the state level and the system level.³⁹ This provides strong evidence that states are overprescribing psychotropic medications to youth in their care rather than ensuring these children’s access to comprehensive mental health supports are available by using existing methods to improve these services. Research suggests the problem is worst for children of color in state custody.⁴⁰

We do not believe overmedication for the convenience of caregivers is compatible with the integration mandate. Even when a child is physically present in a community setting, they are not able to engage in the active participation required for full inclusion in the community while overmedicated or chemically restrained. For this reason, we ask the Department to consider if this chemical restraint use in the foster system falls within its definition of “most integrated setting” and to encourage states to develop improved informed consent and monitoring practices for the prescription of antipsychotic medications to children in foster care. We would like to see HHS continue working on this issue, whether through the inclusion of yet stronger language in the proposed rule, the issuance of guidance, or enforcement under the integration mandate provisions or Section 504 and its enacting regulations more generally. While there have been some improvements on this issue in recent years— enough to demonstrate that progress is possible— it

³⁷ See PolicyLab, *Understanding and Addressing Antipsychotic Prescribing Practices for Medicaid-enrolled Children*, Children’s Hospital of Philadelphia (last accessed Nov. 9, 2023), <https://policylab.chop.edu/project/understanding-and-addressing-antipsychotic-prescribing-practices-medi-caid-enrolled-children>.

³⁸ *Id.*; see also PolicyLab, *Antipsychotic Prescribing to Children: An In-Depth Look at Foster Care and Medicaid Populations*, Children’s Hospital of Philadelphia (May 2015), <https://policylab.chop.edu/evidence-action-briefs/antipsychotic-prescribing-children-depth-look-foster-care-and-medicaid>.

³⁹ See David Rubin, H. Matone, Y. Huang, S. dosReis, Chris Feudtner, and Russell Localio, *Interstate variation in trends of psychotropic medication use among Medicaid-enrolled children in foster care*, 34 *Children and Youth Serv. Rev.* 8, 1492-1499 (2012); see also David M. Rubin, Chris Feudtner, Russell Localio, and David S. Mandell, *State Variation in Psychotropic Medication Use by Foster Care Children With Autism Spectrum Disorder*, 124 *Pediatrics* 2, e305-e312 (2009).

⁴⁰ See Lauren Vanderwerker, Ayse Akincigil, Mark Olsson, Tobias Gerhard, Sheree Neese-Todd, and Steven Crystal, *Foster Care, Externalizing Disorders, and Antipsychotic Use Among Medicaid Youth*, 65 *Psychiatric Services* 10, 1281-1284 (2015); see also Sarah J. Nemetz, *‘From Badness to Sickness’ and Back Again: The Use of Medication in the U.S. School and Foster Care Systems*, 7 *Tapestries: Interwoven voices of local and global identities* 1 (2018).

will likely take continuing federal intervention to excise this tendency from state child welfare agencies.⁴¹

Third, we believe the “troubled teen” industry offers additional examples of settings where children are subjected to harm. It is likely that marginalized youth- including teens with disabilities- bear the brunt of the impact. States are placing the children in their care in these programs.⁴² Lax state regulation and the resulting lack of accountability and training requirements for staff makes these settings exceptionally dangerous.⁴³ We believe an explicit mention in the examples for this section of the proposed rule is warranted.

Fourth, we hope the Department will clarify that group homes and similar settings should be recognized as a less integrated setting than a family home, whether in the final rule or in guidance. Real homes are the ideal childhood environment, whether that home is that of a child’s close or extended first family, fictive kin, or unrelated external caregivers. Few people would choose to have their children reared externally, even by the most qualified and caring professionals, for good reason. We hope HHS will continue to support the idea that all children should grow up as part of a family.

Fifth, we would like the Department to further emphasize the special dangers of out-of-state institutional placements that separate children and youth in state custody from any support networks they may have. We appreciate the brief mention in the examples for this section of the proposed rule. We hope HHS will continue to engage with this topic through guidance and enforcement. While all institutional placements are perilous, institutionalized persons including children are rarely more at risk than when distance makes visits from loved ones arduous and rare. Children placed in institutions potentially hundreds of miles from their support networks are at risk of having no loving adult to help them escape any abuse or neglect they experience.⁴⁴ For this

⁴¹See J.C. Nunces, T. Naccarato, and R.S. Stafford, *Antipsychotics in the California Foster Care System: A 10-Year Analysis*, 32. J. Child Adolescent Psychopharmacology, 400-407 (2022) (Antipsychotic prescriptions halved between 2011 and 2020. Racial-ethnic disparities reduced, but there is still a significant shortfall in proper authorization and health screenings.).

⁴² See Evelyn Tsisin, *The Troubled Teen Industry’s Troubling Lack of Oversight*, Penn Carey Law (Jul. 17, 2023), <https://www.law.upenn.edu/live/news/15963-the-troubled-teen-industrys-troubling-lack-of> (“Residents are often enrolled in these programs by parents with behavioral concerns, but youth may also be funneled into these facilities from foster care and juvenile detention.”).

⁴³ The populations the troubled teen industry seeks to absorb includes many youth who qualify as disabled under the ADA. However, the industry does not require specific staff training for serving these populations. See Nicolle Okoren, *The wilderness ‘therapy’ that teens say feels like abuse: ‘You are on guard at all times’*, The Guardian, Nov. 14, 2022, <https://www.theguardian.com/us-news/2022/nov/14/us-wilderness-therapy-camps-troubled-teen-industry-abuse> (“There is no national set training standards or background checks for employees in frontline positions. One organization’s hiring requirement might require a college degree and certifications for all staff, while another will simply require staffers to be over 18 years old.”). This has often resulted in bad outcomes for children. See #breakingcodesilence, *The Troubled Teen Industry* (last accessed Nov. 9, 2023), <https://bcsnetwork.org/the-troubled-teen-industry/> (“This industry has thrived for decades despite constant allegations of child abuse, neglect, dangerous treatment practices, and negligence resulting in death.”); see also Sarah Golightley, *Troubling the ‘troubled teen’ industry: Adult reflections on youth experiences of therapeutic boarding schools*, 10 Global Studies of Childhood 1 (2020).

⁴⁴ See David Jackson and Duaa Eldeib, *Thousands of Foster Children Were Sent Out of State to Mental Health Facilities Where Some Faced Abuse and Neglect*, Mother Jones, Mar. 12, 2020, <https://www.motherjones.com/crime-justice/2020/03/thousands-of-foster-children-were-sent-out-of-state-to-mental-health-facilities-where-some-faced-abuse-and-neglect/> (“Across the country, child welfare officials

reason, we hope the Department will continue to act to protect this extremely vulnerable population and discourage states from using out-of-state institutional placements for children in their care.

Sixth, communication is essential to integration. For this reason, we ask that the Department require that state child welfare agencies support AAC use in foster care. Robust communication is necessary for personal safety, quality education, and meaningful social relationships.⁴⁵ All children in state custody who may benefit from AAC should be encouraged to try multiple modalities. Children who are already using AAC should retain access to it by being allowed to keep the devices or other materials they bring into state care. Foster parents should also be trained in supporting AAC use. We do not know the extent to which this intervention is available to children in state custody, but the lack of data leads us to believe that access to AAC is even rarer among youth with communication disabilities in state care than it is among people who are nonspeaking in general. We hope HHS will take all appropriate action- within and beyond the proposed rule- to ensure AAC access for this extremely vulnerable population.

Seventh, HHS should require reasonable accommodations in mental health services for children in state care with developmental, intellectual, and communication disabilities. This could be addressed through the final rule or through guidance after it is finalized, but we hope HHS will take prompt action to address this pressing problem. Children and youth with intellectual and developmental disabilities are more likely to have mental health disabilities than the general population.⁴⁶ They are also more likely to have experienced trauma than their nondisabled peers.⁴⁷ However, states often fail to provide accessible mental health care to individuals receiving intellectual and developmental disability services. Instead, they rely on medication and behaviorism.⁴⁸ Trauma is a virtually

have sent thousands of foster children to mental health institutions in distant states, including facilities where children reported being beaten and sexually assaulted by other residents or mistreated by workers.”)

⁴⁵ See CommunicationFIRST, *Access. Opportunity. Justice.* (last accessed Nov. 9, 2023), <https://communicationfirst.org/our-work/> (“Those of us who cannot rely primarily on speech to be understood are the first to be separated and segregated from people without disabilities, the first to be denied access to meaningful educational, recreational, and employment opportunities, and the first to be institutionalized.”)

⁴⁶ See Laura A. Hughes-McCormack, Ewelina Rydzewska, Angela Henderson, Cecilia MacIntyre, Julie Rintoul, and Sally-Ann Cooper, *Prevalence of mental health conditions and relationship with general health in a whole-country population of people with intellectual disabilities compared with the general population*, 3 *BJPsych Open* 5, 243 (2017) (“Mental ill health is unevenly distributed across the population and appears to be more prevalent among people with intellectual disabilities compared with the general population.”); <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4814928/> (“...the co-occurrence rate of mental problems among youth with ID/IDD [is] as high as three to four times greater than the rate among typically developing youth[.]”).

⁴⁷ See The National Child Traumatic Stress Network and NADD, *Children with Intellectual and Developmental Disabilities Can Experience Traumatic Stress A Fact Sheet for Parents and Caregivers* (last accessed Nov. 9, 2023), <https://www.nctsn.org/sites/default/files/resources/fact-sheet/children-with-intellectual-and-developmental-disabilities-can-experience-traumatic-stress-for-parents-and-caregivers.pdf> (“Studies indicate that children with intellectual and developmental disabilities (IDD) experience trauma and stressful circumstances or events at higher rates than children without these disabilities.”).

⁴⁸ See Yaara Zisman-Ilani, *The Mental Health Crisis of Individuals With Intellectual and Developmental Disabilities*, *Psychiatry Online* (Mar. 2022), <https://ps.psychiatryonline.org/doi/10.1176/appi.ps.202200022> (“Even within mental health services and systems, individuals with IDD often encounter mental health professionals with low IDD literacy who receive little training about the needs of this population and relevant options for treatment and support. As a result, individuals with IDD are often misdiagnosed and prescribed as

universal experience among minors in state custody.⁴⁹ States' failure to provide a full suite of mental health services to promote trauma recovery is particularly unacceptable in this context. We encourage HHS to press states on the application of the integration mandate to mental health care.

Child Welfare Question 2: The Department invites comment on this list of prohibited activities in the child welfare context, especially on whether commenters believe it is complete.

We are grateful to the Department for developing such a thorough list of prohibited activities. As HHS is aware, child welfare authorities too often separate children with and without disabilities from their disabled parents. We share HHS' concern that too few states make appropriate efforts toward reunification when a child's caregiver has disabilities, especially IDD or a mental health disability. Separation is traumatizing to parents and children even if the ultimate outcome is reunification.⁵⁰ Weakened or severed family ties can be particularly damaging for children whose disabilities may be heritable and tend to run in families, because older relatives with similar disabilities serve as role models and sources of information on navigating the world with a particular disability. States' frequent exclusion of qualified, would-be parents and caregivers with disabilities from the ranks of approved external caregivers mean that these children are unlikely to encounter adults who can take over these roles. This may leave children adrift and intensify the harms of separation even when it is absolutely necessary to remove a child from their biological family.

We believe the Department's list of prohibited activities is nearly complete. However we would make one addition: we hope HHS will prohibit state agencies accepting its funding from declining to pursue reunification solely because a parent with disabilities is under legal guardianship. The parenting ability of adults under guardianship should be assessed individually rather than with sweeping denials of reunification solely because the parent is under guardianship. However, many adults with intellectual, developmental, and other disabilities are under guardianship.⁵¹ Because

the first-line treatment psychiatric medications, such as antipsychotics, antidepressants, and mood stabilizers, that are used off-label, not for the approved indication."); see also Hogg Foundation for Mental Health, *Policy Recommendation: Addressing the Mental Health and Wellness of Individuals with Intellectual Disabilities* 1 ("Too many systems of care for people with IDD continue to focus on controlling and managing challenging behaviors without adequate consideration of the potential for underlying mental health or medical conditions as the cause of the behavior.").

⁴⁹ See Concordia St. Paul, *Trauma and Children in Foster Care: a Comprehensive Overview* (Jul. 10, 2019), <https://www.csp.edu/publication/trauma-children-in-foster-care-a-comprehensive-overview/> ("Youth in foster care have increased rates of trauma exposure; rates have been estimated to reach 90 percent..."); see also Washington Fosters, *Understanding the Trauma in Foster Children* (Apr. 8, 2020), <https://foster.wachildrenandfamilies.org/blog/understanding-trauma-in-foster-children> ("Nearly every foster child has at least one traumatic experience in common: being removed from their home and their family. Many share other traumas as well, including incidents of abuse or neglect, which can come in many forms.").

⁵⁰ See *Id.*; see also Kathleen Kenny, *Mental Health Harm to Mothers When a Child Is Taken by Child Protective Services: Health Equity Considerations*, 63 *Can. J. Psychiatry* 5, 304-307 (2018) ("According to study results, mothers who lost custody of a child to foster care experienced significantly higher rates of depression, substance use, physician visits for mental illness, and prescriptions of psychotropic medications compared to mothers surviving the death of a child."); Vivek Sankaran, Christopher Church, and Monique Mitchell, *A Cure Worse Than the Disease? The Impact of Removal on Children and Their Families*, 102 *Marq. L. Rev.* 4, 1169 (2019) ("Child removals not only pose a psychological threat for the children who have been removed; family separation can cause ambiguity for the entire family.").

⁵¹ See Emily DiMatteo, Vilissa Thompson, and Osub Ahmed, *Rethinking Guardianship To Protect Disabled People's Reproductive Rights* (2022) ("According to some studies, almost 60 percent of people with intellectual

many states over-rely on guardianship, sometimes to an extent that is questionably in compliance with their own guardianship statutes and constitutionally dubious, this is not always strong evidence of a disabled parent's caregiving ability.⁵² Some states then assume that adults under guardianship are broadly incapacitated to the point that the possibility of childrearing is out of the question. This becomes a way in which stereotypes and assumptions about people with disabilities are used to limit who can parent, harming both parents and children. Because states engaged in this conduct are unlikely to stop irrationally treating their own poor performance at protecting their residents' most basic rights as a parenting aptitude test without federal intervention, stating this requirement in the final rule may be one of the simplest ways to address this issue. This presents an opportunity for HHS to take an additional step to ensure that families stay together except when removal is the only way to keep a child safe.

Child Welfare Question 3: The Department seeks comment on how agencies would implement these referral procedures, ensure that service providers use the methods described, and prohibit the use of IQ alone as the basis for a parenting assessment.

We appreciate the Department's recognition that prohibiting the use of IQ alone to determine parenting ability will prevent the avoidable destruction of family units. States often prevent people with IDD from rearing their children despite a growing body of evidence that IQ is a weak predictor of parenting ability.⁵³ Evaluations of parenting ability should include the consideration of present and available support in that parent's life, including natural support from family and community and paid caregiving support. Child welfare systems should be required to become familiar with adult home and community based services (HCBS) and facilitate HCBS for parents when necessary.

and developmental disabilities ages 18 to 22 who receive publicly funded services have guardians and report that schools often present guardianship as the main or default option to support young adults in decision-making." (*citation omitted*); see also National Core Indicators, What Do NCI Data Tell Us About People With IDD Who Have Guardians Compared to Those Who Don't (last accessed Nov. 9 2023), https://legacy.nationalcoreindicators.org/upload/core-indicators/NCI_Data_Highlight_Guardianship_2021_Final.pdf ("In the 2018-19 NCI In-Person Survey (IPS), 53.4% of respondents were reported to have a guardian (limited guardianship or full guardianship or unable to determine level of guardianship). The proportion of respondents with guardians varied by state and ranged from 14.6% to 86.4%.")

⁵² See American Civil Liberties Union, *Supported Decision Making & the Problems of Guardianship* (last accessed Nov. 9, 2023),

<https://www.aclu.org/issues/disability-rights/integration-and-autonomy-people-disabilities/supported-decision-making> ("Yet, Judges typically approve guardianship petitions without asking many questions. And once a guardianship is created, it can be almost impossible to undo. Even though guardianship has serious, life-long consequences, it is often imposed as a matter of course."); see also United States Senate Special Committee on Aging, *Ranking Member Braun: "Guardianship is supposed to mean protection"* (Mar. 30, 2023), <https://www.aging.senate.gov/press-releases/ranking-member-braun-guardianship-is-supposed-to-mean-protection> ("There are far too many difficult and painful stories of guardianship abuse, often for people who did not require a guardianship in the first place.")

⁵³ See The Arc, *Parents with Intellectual Disabilities* (last accessed Nov. 9, 2023),

<https://thearc.org/wp-content/uploads/forchapters/Parents%20with%20DD.pdf> ("Contrary to what many people think, people with intellectual disabilities can be good parents."); see also National Research Center for Parents with Disabilities, *Advice for Professionals Working with Parents with Intellectual Disabilities*, Brandeis (last accessed Nov. 9, 2023),

<https://heller.brandeis.edu/parents-with-disabilities/data-hub/advice-for-professionals/advice-intellectual-disabilities.html> ("Despite common stereotypes, parental IQ alone *does not* actually predict how well a parent will raise a child. Many of the correlates associated with worse outcomes for children of parents with intellectual disabilities can be attributed to social and environmental factors that stem from a lack of support and resources.") (*citations omitted*).

Assessments of parenting ability must be comprehensive and accessible. Professionals who have more familiarity with disability adaptations and supports, such as occupational therapists and others in the rehabilitation field, should be involved in the process. HHS should encourage states to include self-advocates, family members, and DD professionals in designing functional capacity assessments because these stakeholders have valuable perspectives. States should prioritize the inclusion of people with disabilities who are parenting successfully.

Evaluations should be written to emphasize what is essential to parenting, rather than the way in which most people in a given community complete that task, so as not to disadvantage parents who meet their families' needs in ways that are common for people with disabilities but may not be conventional in some parts of the country. For example, no parent should be penalized for taking a child to the pediatrician through public transit, ridesharing, or a ride from a loved one instead of driving the child to the appointment in a personal car. Once at the doctor's office, a parent's use of supported decision-making should be regarded as an equally acceptable means of ensuring that the child gets appropriate care. Parenting assessments should also be designed not to disadvantage parents who use auxiliary aids or services or reasonable accommodations to complete parenting tasks, such as utilizing accessibly formatted documents to keep up with a child's medical care, relying on a service animal to take a child out in public, or accepting help with household tasks from natural supports.

In addition to parenting assessments, child welfare tools for parents must be accessible. Parenting classes and their written materials, any assessments parents must complete, and information provided to parents must be accessible. HHS should make it clear that accessibility includes but is not limited to meeting the written communication needs of people with sensory disabilities. Some parents have other written communication needs, like plain language or Easy Read materials. Parents will require other learning accommodations such as more time to learn concepts, using more repetition than is standard, or individualized attention rather than large group instruction. State child welfare agencies must accommodate these needs. Parents should also be able to use a support person, including one familiar to the parent if requested, in their interactions with the child welfare agency.

Beyond its work on the proposed regulation, the Department should promote the inclusion of assistance with parenting tasks in Medicaid-funded HCBS through the Center for Medicare and Medicaid Services. There is a prevalent and growing need for this form of support as more HCBS recipients seek to have children. The coverage currently offered is inadequate for many families.⁵⁴ By leading states to do more to support families with disabled heads of household through their waiver programs, HHS could support children and parents alike.

Web Accessibility

ASAN is a signatory to the CCD comments on the proposed rule. We were among the organizations that drafted and edited those comments. They are consistent with our position on the web accessibility provisions. We do not have additional content to submit to HHS on this subject.

Medical Diagnostic Equipment

⁵⁴ Sara Luterman, *When federal assistance for 'daily living' doesn't include parenting*, The 19th, Dec. 3, 2021, <https://19thnews.org/2021/12/when-federal-assistance-for-daily-living-doesnt-include-parenting/> ("Her personal care assistants are technically prohibited from helping her with any parenting task.").

CCD's comments are consistent with ASAN's position on the medical diagnostic equipment section of the proposed rule.

Definitions

CCD's comments are consistent with ASAN's position on the definitions outlined in the proposed rule.

Child Care, Preschool, Elementary and Secondary, and Adult Education

Child Care, Preschool, Elementary and Secondary, and Adult Education Question 1: The Department wants to better understand potential impacts of the proposed rule on these recipients and requests comment on the application of the proposed rule to childcare providers and any potential barriers to compliance.

ASAN supports full access to all levels of education for people with disabilities, including people with IDD. Inclusion in these settings is crucial to both personal development and professional opportunity. ASAN is a signatory to the CCD comments on the proposed rule. We are also in agreement with the National Partnership for Women and Families' comments on this section of the proposed rule.

Health, Welfare and Social Services

Health, Welfare, and Social Services Question 1: The Department seeks comment on whether the application of the section should extend beyond hospitals (including inpatient, long-term hospitals, and psychiatric hospitals) and outpatient facilities. If so, what types of treatment programs, providers, or other facilities should be included in this section?

The framework HHS has created in this section will be beneficial to people with disabilities. We appreciate that the Department has expanded communication into a new, more comprehensive section. We appreciate the decision to reiterate that people living with substance use should not face discrimination when they seek medical care, and the specific mention of persons who are institutionalized retaining key educational rights. We are grateful for the retention of the provision encouraging infant care review committees in health care facilities. The explicit prohibition of discrimination through a contractor is particularly helpful given the prevalence of contractors in health care settings today.

We are hopeful that the mention of supported decision-making as an example of a reasonable modification will protect the autonomy of disabled patients and help them make decisions about their own care. This may help to address the problem of hospitals driving guardianship proceedings. Due to hospitals' often-misplaced concerns about liability in the absence of a guardian, we do not believe this problem will be completely solved except through enforcement. We ask that HHS prioritize holding hospitals accountable for compliance with this provision.

We also thank the Department for the provisions and examples encompassed by this section that delineate the boundaries of consent for medical care. The statement that patients are not required to accept the modifications and accommodations offered to them will support dignified health care experiences and promote personal choice. It may also prevent health care facilities mandating coercive measures for provider convenience and seeking to protect those decisions under the auspices of the Rehabilitation Act. Similarly, the language stating that Section 504 does not authorize guardians to decline what people need to survive is an essential safety measure.

Because of the important interests it protects, we would value the broadest possible application of this section of the proposed rule. We hope the Department will extend its protections across the widest possible range of health care settings.

Integration

Integration Question 1: In the discussion in the preamble of the proposed definition of “most integrated setting,” we solicit comments on whether the definition should be expanded.

We thank the Department for its efforts to provide a definition of “the most integrated setting” that is consistent with the integration mandate of Title II of the ADA and with prior guidance from the Department of Justice. By referring to the DOJ’s guidance, HHS offers a definition of “most integrated setting” that is both comprehensive and addresses many aspects of integration that are critical to highlight.⁵⁵ Notably, these elements of integration extend beyond mere interaction with nondisabled individuals to other aspects of everyday life and community living. This is critical for disabled people to live full and complete lives.

We particularly appreciate the emphasis on the agency of disabled people in determining whether and how they choose to participate in the community and choice in daily activities within this definition of integration. Many segregating settings offer low-quality opportunities for community interaction and activities. These are often limited to group excursions with pre-specified times and purposes. It is important that these rules emphasize that “community activity” does not meet the Department’s standards for integration when individuals are deprived of agency and choice in this way. The ability to choose when or whether to engage with the community is an integral component of autonomy and wellbeing.

However, we believe there are several additions to the proposed language and supplemental commentary or guidance that can provide further direction in ensuring that people with disabilities are able to meaningfully receive services in the most integrated environment. First, the definition for “most integrated setting” provided should be expanded. Integration means more than simple interaction with nondisabled peers. For this reason, the definition should include a broader standard of life activities that reflect the right of all people with disabilities to live lives that are substantially like those of nondisabled individuals. As ASAN and more than thirty other leading disability rights organizations indicated in the 2014 Key Principles for Community Integrations for People with Disabilities, this should include opportunities for people with disabilities to “be employed, have a place to call home, and be engaged in the community with family and friends”, to “have control over their own day, including which job or educational or leisure activities they pursue”, and to “have control over where and how they live, including the opportunity to live in their own apartment or home.”⁵⁶ A revised definition of “most integrated setting” that accounts for these aspects of community living will better reflect aspects of integration beyond mere interaction with nondisabled peers.

We additionally urge clarification that the most integrated setting lacks the characteristics that mark segregated settings, per the definition offered in proposed section 84.76(c). *See* 88 Fed. Reg. at

⁵⁵ *See U.S. Dep’t of Justice, Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.* (2020), https://www.ada.gov/olmstead/q&a_olmstead.htm (last accessed Nov. 9, 2023).

⁵⁶ *See Judge David L. Bazelon Center for Mental Health Law, Community Integration for People with Disabilities: Key Principles* (last accessed Nov. 9, 2023), <https://www.bazelon.org/wp-content/uploads/2017/10/Key-Principles.pdf>.

63508. Too many segregated settings provide limited and regimented community interaction or cite the presence of volunteers or staff to claim that they provide peer interaction. Nondisabled people would not consider this sufficient to make them feel part of their communities. HHS should make it clear to these settings that this approach falls short of integration.

Second, we encourage the department to take steps to ensure that the definition is meaningfully applied to adults under guardianship. Adults under guardianship do not retain full control over their rights and activities. They are particularly vulnerable to having their decisions ignored in favor of the choices of guardians or conservators. The Department should ensure that the choices salient to whether a disabled person is in the “most integrated setting” are those available to the disabled person to the extent that the individual’s wishes can be determined when all needed communication supports are in place. This means that communication support is crucial to integration.

Third, we suggest further clarification that physical presence in a setting that provides access to the community is a necessary but not sufficient component of integration. As the Department notes in its definition of segregated settings, a segregated setting may have a number of isolating characteristics that can also be present in settings that are in a community and permit some limited community interaction. *See Id.* Further, settings that may otherwise meet definitions for being community-based may nevertheless isolate people with disabilities by limiting community interaction. For example, referring a person with a disability to a regimented day program results in less meaningful integration than allowing them to decide what to do during the day and take the support they need with them. As a result, the department should include the additions to the definition recommended above and provide further instruction- either in the preamble or as guidance after issuing the rule- establishing that physical presence is not dispositive that someone is receiving services in the most integrated setting. HHS should explicitly state that physical presence does not carry the presumption of integration.

ASAN also supports the changes to the definition of “most integrated setting” proposed by CCD in its comments.

Integration Question 2: We seek comment on what may constitute a fundamental alteration for recipients who are not public entities, for example, an individual skilled nursing facility responsible for identifying and preparing individuals who can and want to be discharged to available community-based services.

Generally, we believe circumstances where integration mandate compliance is regarded as a fundamental alteration should be exceedingly rare. A growing number of private parties in health care and disability services are part of large, well-funded entities that offer diverse arrays of services to a range of populations.⁵⁷ Services that are currently provided to other patients or in

⁵⁷ See Brian Horowitz, *Larger hospital mergers expected in post-pandemic market*, Kaufman Hall says, HealthcareDive (Apr. 17, 2023), <https://www.healthcarediver.com/news/larger-mergers-hospitals-kaufman-hall/647790/>; see also Michael Furukawa, Laura Kimmey, David Jones, Rachel Machta, Jing Guo, and Eugene Rich, *Consolidation Of Providers Into Health Systems Increased Substantially 2016–18*, 39 Health Affairs 8 (2020) (“Provider consolidation into vertically integrated health systems increased from 2016 to 2018. More than half of US physicians and 72 percent of hospitals were affiliated with one of 637 health systems in 2018.”); Kara Hartnett, *‘We are seeing a massive consolidation within the industry’ In financial ruin, M&A or closures loom in senior living industry*, Nashville Post, Jul. 19, 2021,

other circumstances by the same entity should similarly not be considered fundamental alterations. For this reason, provision of services related to a disabled person's transition to community living should constitute a fundamental alteration if the non-public entity is required to provide a service it has never provided in the past and is not mandated to provide through other legal obligations. Because transition planning is integral to the person-centered planning already required under federal law, most elements of transition planning for individuals exiting segregated settings would nevertheless not constitute fundamental alterations.⁵⁸

This means that these facilities may be required to actively support individuals seeking to transition to community-based services. Such facilitation and support should not constitute a fundamental alteration. Even if this planning requires some knowledge of available services and supporting individuals in accessing services, this is part of the required activity under existing regulations, not a fundamental alteration of services being provided. It would be irrational for a covered private entity to assert that an action required of it by law would be a fundamental alteration.

Similarly, we appreciate the Department's recognition that providing services beyond what states offer under Medicaid programs may not necessarily be a fundamental alteration. We agree with the example provided— while a State may be permitted to “cap” the number of individuals served under a particular waiver program, this does not exempt it from serving additional people to comply with the ADA or other laws. We encourage the Department to make explicit in the final rule that increasing such a cap does not necessarily constitute a fundamental alteration.

However, there are unusual circumstances where private entities should be permitted to raise a fundamental alteration defense. For example, covered private entities should not be required to create or replicate a public program from whole cloth where these services were not otherwise provided by the entity or required under existing law and regulation. Consistent with federal disability rights law, providers should also not be required to act significantly outside the scope of their training, expertise, job descriptions, and legal requirements.⁵⁹

Communications

Communications Question 1: The Department requests comment on the importance of providing information in plain language for individuals with cognitive, developmental, intellectual, or neurological disabilities.

https://www.nashvillepost.com/we-are-seeing-a-massive-consolidation-within-the-industry/article_ac1651a0-e889-11eb-a14b-2f31e5f4f720.html.

⁵⁸ See 42 CFR § 483.21(c); see also F-Tag F660 of Appendix PP of State Operations Manual.

⁵⁹ See, e.g. 28 C.F.R. § 35.130(b)(7)(i) (“A public entity shall make reasonable modifications in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability, unless the public entity can demonstrate that making the modifications would fundamentally alter the nature of the service, program, or activity.”); see also 42 U.S.C. § 12182(b)(2)(A)II (“...unless the entity can demonstrate that taking such steps would fundamentally alter the nature of the good, service, facility, privilege, advantage, or accommodation being offered...”).

We thank the Department for the opportunity to comment on providing information in plain language.⁶⁰ Provision of cognitively accessible materials, including health education resources, consent forms, and communications between health care professionals and individuals seeking health care, is an integral part of allowing people with cognitive disabilities to participate in their own health care. People cannot make informed medical decisions without understanding what is being discussed before, during, and after receiving care.⁶¹ There is no informed consent without patient access to consent forms and all necessary information about the treatment in a format the patient can understand. For some people with disabilities, this means the provision of medical information in plain language and its related format, Easy Read.⁶²

Providing materials in plain language may be a way to reduce the incidence of hospitals petitioning or provoking others to petition for guardianship over a person with cognitive, developmental, intellectual, or neurological disabilities. Guardianship, even in its limited forms, robs the people under it of their rights and substantially limits their ability to make choices about their lives. Because it removes an adult human being from the position of final authority over their own life, guardianship is a necessary evil at best. It is a legal status all disability community stakeholders should work to render obsolete. As discussed in our comments on the proposed regulation's child welfare provisions, it is frequently implemented even where it could be avoided with alternatives available today.

Hospital-driven guardianships are all too common and frequently lead to institutionalization.⁶³ Health care professionals and organizations should learn about the alternatives to guardianship. They should use all available measures to reduce the incidence of guardianship proceedings instigated or initiated by their organizations. In many jurisdictions, guardianship is predicated on a

⁶⁰ ASAN defines plain language materials as being written at a fifth to sixth grade reading level, using short sentences and paragraphs, using common words, defining uncommon or technical words, using concrete examples to help readers understand what is being said, avoiding unnecessary information, using clear and straightforward language, and using active voice instead of passive voice. This definition overlaps with, but also differs from, the federal Plain Language Guidelines. Notably, the federal guidelines stress that one should not write plain language documents at a specific grade level but write for the document's target audience. See Plain Language Action and Information Network, *Federal Plain Language Guidelines*, May 2011, <https://www.plainlanguage.gov/media/FederalPLGuidelines.pdf>.

⁶¹ See Cleveland Clinic, *Informed Consent* (last accessed Nov. 8, 2023), <https://my.clevelandclinic.org/health/treatments/24268-informed-consent> ("Informed consent is an ethical and legal requirement for medical treatment. You must understand and agree to testing and treatment before it can proceed." Communication access can support a person's capacity to understand a proposed treatment, avoiding the need for a surrogate decision-maker.)

⁶² See Autistic Self Advocacy Network, *One Idea Per Line: A Guide to Making Easy Read Resources* (last accessed Nov. 8, 2023), <https://autisticadvocacy.org/wp-content/uploads/2021/07/One-Idea-Per-Line.pdf> (Easy Read is similar to plain language in that it uses short sentences and paragraphs, common words, clear examples, and active voice. However, Easy Read is typically written at a third to fourth grade reading level, uses pictures or icons to illustrate every sentence, and is formatted to specific standards. The main audience of Easy Read is people with disabilities who have very low reading levels who may not be able to understand plain language.)

⁶³ See C.J. Ciaramella, *'They Just Took Me Away'*, Reason Magazine, May 2022, <https://reason.com/2022/04/30/they-just-took-me-away/>.

ruling that an individual cannot make their own decisions or communicate them effectively.⁶⁴ Providing disabled patients with health care materials in plain language and Easy Read would make these decisions substantially more accessible to those with a range of cognitive, developmental, intellectual, or neurological disabilities and thus reduce some of the impetus for guardianship applications.

ASAN also believes that provision of health care materials in plain language and Easy Read are already required by law in some instances because plain language and Easy Read are essential for effective communication with some people with disabilities.⁶⁵ Some people with cognitive, developmental, intellectual, or neurological disabilities, as well as some people with hearing or vision disabilities, require plain language and Easy Read materials in order to understand what is being communicated to them. While the ADA does not address plain language or Easy Read explicitly, the regulations enacting Titles II and III of the ADA define auxiliary aids or services expansively in the context of effective communication.⁶⁶ We believe that the health care experiences of many people with disabilities could be improved via plain language and Easy Read communications if the Department made health care professionals and organizations aware of the issue via the language of the proposed rule and its examples.

Medical care and decision-making are often complex enough to require plain language or Easy Read resources for some people with disabilities. Consider an individual with an intellectual disability who is trying to decide if they should have a surgery with a high likelihood of benefit and a moderate chance of severe complications. Whether to consent to this kind of procedure is a judgment call for any patient. Most people would take time outside of a medical appointment to decide. Many would seek a second opinion or advice from loved ones. A patient with an intellectual disability is especially likely to consult with friends or family and would benefit from a cognitively accessible version of information about the surgery and the consent form to take with them. Even if the individual is able to make a decision on the surgery using other accommodations within an appointment- via a doctor reading the standard consent form out loud to them and answering any questions- the patient should still have access to copies of these documents that they can understand on their own for their records.

Additionally, cognitive accessibility goes beyond these two written formats. Providing audio or video versions of “standard language” written materials may make said materials accessible to some people with cognitive disabilities and thus constitute effective communication. Similarly, a medical professional explaining a written form to a person with a disability orally using simpler terms or using visual aids or demonstrations to explain something may also make the explanation cognitively accessible to some people with disabilities in limited situations. This will obviously not be appropriate when the disabled patient is likely to need to revisit the information after leaving the doctor’s office. However, none of these accommodations are a substitute for plain language or Easy Read written materials if that is what a person with a disability requires to understand something.

⁶⁴ See Jennifer L. Wright, *ARTICLE: Protecting Who from What, and Why, and How?: A Proposal for an Integrative Approach to Adult Protective Proceedings*, 12 *Elder L.J.* 53, 55 (2004) (“If autonomous choice is impossible, then the law, under the doctrine of *parens patriae*, may intervene to protect the well-being of the incapacitated individual.”); see also Leslie Salzman, *ARTICLE: RETHINKING GUARDIANSHIP (AGAIN): SUBSTITUTED DECISION MAKING AS A VIOLATION OF THE INTEGRATION MANDATE OF TITLE II OF THE AMERICANS WITH DISABILITIES ACT*, 81 *U. Colo. L. Rev.* 157, 160 (2010) (“When an individual has a diminished ability to meet personal needs or manage property, a court may authorize a guardian to make crucial decisions on the individual's behalf.”).

⁶⁵ See, e.g. 28 C.F.R. § 36.303(c); see also 28 C.F.R. § 35.160(a)(1); 45 C.F.R. § 84.4.

⁶⁶ See 28 C.F.R. § 36.303(c); see also 28 C.F.R. § 35.160(a)(1).

Accommodations for cognitive, developmental, intellectual, or neurological disabilities are like accommodations for any other type of disability: they are not “one size fits all” and must be tailored to the specific person’s needs.

Communications Question 2: Additionally, the Department requests comment on whether plain language is more appropriately considered a reasonable modification that an individual must request, or if it should be considered an auxiliary aid or service.

ASAN appreciates any effort to protect access to cognitively accessible formats such as plain language and Easy Read on the Department’s part. As we have previously stated, cognitively accessible formats are essential for effective communication with people with a range of disabilities. For many people with cognitive, developmental, intellectual, or neurological disabilities, as well as some people with hearing or vision disabilities, even “standard language” materials are overly technical and thus inaccessible.

We believe that framing cognitively accessible formats either as auxiliary aids and services or a reasonable modification would offer useful protections. However, we would prefer the Department frame these formats as auxiliary aids and services so that cognitively accessible formats are more closely linked to other measures supporting effective communication in the minds of covered entities. We suspect that drawing this connection would promote compliance and put health care providers on notice that the Department takes cognitive accessibility particularly seriously.

We also stress here that, while people with hearing, vision, and speech disabilities make up a large portion of people with disabilities who need auxiliary aids and services, they are not the only people with disabilities who need auxiliary aids and services. Many people with cognitive, developmental, intellectual, or neurological disabilities also need auxiliary aids and services for effective communication in the form of cognitively accessible formats. For this reason, we would like to see the Department issue guidance to clarify its statement about when plain language translation may be a fundamental alteration. *See* 88 Fed. Reg. at 63490. We anticipate providers using this language to argue that virtually any plain language or Easy Read translation request is too arduous. We believe this could be addressed through guidance stating that it is never a fundamental alteration under Section 504 to provide plain language or Easy Read translation sufficient to comply with the effective communication mandate expressed throughout federal disability rights law.

Other Communications Comments

Like our colleagues at CommunicationFIRST, we believe that it would be beneficial for the Department to include a definition of AAC in the text of the rule, not just the preamble.

While we are grateful for HHS’ efforts to address communication in medical settings through the proposed rule, we do not believe that this will be sufficient to ensure effective communication for all people with disabilities in health care. Patients with many different disabilities struggle to get their communication needs met in these settings despite the existing legal protections. For example, many autistic people have experienced difficulties making medical appointments without using a telephone. These problems lead us to suspect that it will take ongoing programs of guidance and enforcement to bring medical providers into compliance. We hope the Department will continue to prioritize this issue.

NTAA

CCD’s comments are consistent with ASAN’s position on the NTAA provisions.