



November 13, 2023
Submitted via regulations.gov

Melanie Fontes Rainer, Director
Office of Civil Rights
U.S. Department of Health and Human Services
200 Independence Avenue, SW
Washington, DC 20201

Re: Notice of Proposed Rulemaking on Discrimination on the Basis of Disability in Health and Human Service Programs or Activities. Docket No: 2023-19149, RIN: 0945-AA15

Dear Director Fontes Rainer:

The Arc of the United States (The Arc) appreciates the opportunity to comment on and express our strong support for the proposed rule, *Discrimination on the Basis of Disability in Health and Human Service Programs or Activities*. The Arc is the largest national community-based organization advocating for people with intellectual and/or developmental disabilities (IDD) and their families. The Arc promotes and protects the human rights of people with IDD and actively supports their full inclusion and participation in the community throughout their lifetimes. The organization has long advocated that people with IDD must not experience disability-related discrimination in decisions to provide, delay, deny, or limit health care interventions or treatments. Our nearly 600 state and local chapters across the United States provide a wide range of services for people with IDD, including individual and systems advocacy, public education, family support, systems navigation, support coordination services, employment, housing, support groups, and recreation.

The Arc commends the Department of Health and Human Services (the Department) and the Office of Civil Rights for this proposed rule which updates, clarifies, and strengthens the implementing regulation for Section 504 of the Rehabilitation Act of 1973 (Section 504), the statute that prohibits discrimination against otherwise qualified individuals on the basis of disability in programs and activities that receive Federal financial assistance or are conducted by a Federal agency.

The Arc appreciates that the proposed rule establishes additional protections to ensure that an individual's health and wellbeing are the only justifiable basis for making medical decisions. People with disabilities experience greater health disparities and barriers to quality health care compared to people without disabilities. This is especially true for

people with IDD, who are systematically underserved by our healthcare system. Research suggests that although individuals with IDD are disproportionately high utilizers of healthcare services, they receive poorer quality of care, report poor experiences at hospitals, are less likely to receive preventative screenings and vaccinations, have poorer health outcomes, and shorter life expectancies.ⁱ People with IDD experience higher rates of preventable health conditions and poorly-managed chronic conditions including, but not limited to: poor dental health, undiagnosed hearing and vision impairments, arthritis, obesity, diabetes, high blood pressure, and cardiovascular disease.ⁱⁱ Research shows people with IDD also lack access to adequate OB/GYN services – especially providers well-versed in using supported decision-making. For example, people with IDD have much lower rates of routine breast and cervical cancer screenings, higher breast cancer mortality rates, higher rates of medical complications during pregnancy, and higher rates of postpartum hospital admissions.ⁱⁱⁱ

While there are many contributing factors to these disparities, discrimination and the stigma, exclusion, and devaluing the equal worth of people with IDD are critical problems faced by people with IDD. People with IDD and their family members frequently experience or observe discrimination from health care providers. They report that medical providers do not want to provide services to people with IDD, that they treat them differently, that they wrongly attribute health care issues to the fact that they have IDD, that appropriate treatment is not necessary due to their IDD, that they cannot see individuals with IDD because they do not have the expertise, and that they do not view people with IDD as reliable communicators of health issues. Many medical providers are not familiar with the support needs of individuals with IDD, refuse to allow a support person to accompany a patient with IDD during a procedure, and lack training in how to interact with someone using Alternative and Augmentative Communication (AAC) tools.

The most frequent concern expressed is that many people with IDD rely on Medicaid, which they access due to their disability, and many providers do not accept Medicaid. For example, many individuals with IDD and their families report significant challenges finding a dentist in their area that accepts Medicaid. While addressing that issue and others may be beyond the scope of the rulemaking, it remains an important concern regarding disability discrimination.

Another significant area of concern is that many mental health providers decline to treat people with IDD. More than a third of people with IDD have a co-occurring mental health condition, but they often experience barriers to accessing appropriate mental health services.^{iv} This includes several assumptions that people with IDD cannot benefit from mental health services, that nonverbal individuals cannot participate in therapy, that multiple medications are needed to control the behavior of some people with IDD, and that mental health professionals do not have the competency to serve people with IDD. Many individuals with IDD are also improperly prescribed medications for mental health conditions despite not having any psychiatric diagnosis.^v

As above, fully addressing these complex issues may be beyond the scope of this rulemaking and complicate the issue of fully identifying discriminatory actions versus

other complexities in the health care system. The addition of other examples in the rulemaking may be helpful to recipients for identifying where they need to modify their policies or practices and better understand the anti-discrimination provisions.

While our comments do not specifically address the section on medical equipment accessibility, we frequently hear about physical access challenges from our networks. For example, people with IDD, their families, and supporters report that:

- Bathrooms within medical facilities often do not have automatically opening doors, adequate space to accommodate a wheelchair, or height-adjustable universal changing tables in family restrooms. Dental offices appear especially prone to inaccessible restrooms.
- Waiting rooms often do not have accessible seating for individuals with chronic pain or obesity. Crowds, harsh lighting, and noise in waiting rooms can also pose challenges for individuals with autism who have sensory processing challenges.
- Examination rooms frequently are too small to accommodate a wheelchair.
- Physician offices often lack adequate patient transfer or lifting equipment such as Hoyer lifts. Patients often wait for extended periods of time for transfers, and some medical staff have limited knowledge on how to correctly use the equipment.
- Medical equipment that people with IDD and their families frequently cite as inaccessible include: examination tables, dental chairs, eye examination equipment, scales, X-ray machines, mammography equipment, and other radiography equipment.
- Parking lots at medical facilities frequently have too few accessible parking spots, especially van-accessible parking spots.
- Many medical offices do not have automatically opening doors within buildings.
- At-home diagnostic, therapeutic, and monitoring equipment such as heart monitors are also frequently inaccessible.

In addition, the Arc supports the Consortium for Constituents with Disabilities (CCD)'s recommendations that HHS, in collaboration with the Access Board, develop and issue standards for individuals with non-mobility disabilities, including sensory disabilities, intellectual and developmental disabilities, and individuals with multiple disabilities. For example, the introduced bipartisan Medical Device Nonvisual Accessibility Act (H.R. 1328) requires covered devices to meet nonvisual accessibility standards.^{vi} If passed, HHS should incorporate similar requirements into 504 regulations. Although qualified individuals with any type of disability must be offered equal opportunity to access medical programs and services, regulated entities would benefit from specific technical guidance on how to fulfill their obligations and make their services accessible.

The proposed updated rules are necessary to ensure that people with IDD and other disabilities are not valued less than others; that children, parents, caregivers, foster parents, and prospective parents with disabilities do not face discrimination in a range of settings; and that websites, kiosks and mobile apps, weight scales, and exam tables used in medical settings are accessible to all patients.

The Arc also endorses the comprehensive comments submitted by CCD. The following comments will emphasize key points for people with IDD and provide additional examples where appropriate. Several of these examples were provided by people with IDD and their families through a communication we shared with our networks about the proposed rule in October 2023.

A. New Provisions Addressing Discrimination on the Basis of Disability Under Section 504 § 84.56 Medical Treatment

A.1 Discrimination Against People with Disabilities in Medical Treatment

We strongly support, in their entirety, the new regulatory provisions on discrimination in medical treatment (§ 84.56) and value assessment methods (§ 84.57). The commentary set forth in the Preamble (Fed. Reg 63,395-63,402) presents a compelling rationale and a persuasive legal analysis of the doctrinal basis for these provisions, as well as their application to organ transplantation, life-sustaining treatment, crisis standards of care, and participation in clinical research.

COVID-19 highlighted the elevated health risks and systemic inequities experienced by people with IDD—the group with among the highest rates of infection and death during the pandemic.^{vii} Given the impact of the pandemic on all people with disabilities, and the pervasive examples of discriminatory treatment decisions, denial of access to care, and decision-making criteria that devalued the lives of people with disabilities, these new provisions are essential protections against discrimination.

We also endorse, and wish to emphasize the importance of, language that prohibits disability-based discrimination in the informed consent process (§ 84.56(c)(2)(ii)), including the provision of medical advice and the process for providing information on available treatment options. These new regulatory requirements address the key forms of discrimination that were longstanding even before the pandemic and that were elevated during the pandemic. The provisions are consistent with both the purpose and case law of Section 504.

A.1.1 Medical Treatment (§ 84.56)

Section 84.56(b)(2) - Denial of Treatment for a Separate Symptom or Condition

- *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 comments on the best way of articulating the relevant distinctions.*

Individuals with all types of disabilities should have equal access to, and the opportunity to receive, high quality medical treatment, consistent with established professional standards of care. We do not believe that further efforts to distinguish between or define the disability subject to discrimination is necessary or useful. The proposed regulations rightly underscore the importance of providing medical treatment consistent with these standards for all types of disabilities and the individual's informed choice, unless there is

objective, individualized medical evidence that the standard of care is contraindicated or would otherwise not be equally effective given the underlying disability.

We believe the concept of underlying disability is appropriate and workable when describing the denial of treatment for a separate condition or symptom (§ 84.56(b)(2)).

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

Individuals with IDD frequently experience the denial of clinically-appropriate treatment that would be offered to a similarly situated individual without IDD. In October 2023, The Arc sent a request to our networks for examples of discriminatory provision of medical treatment. Respondents ranged from people with IDD, to their family members, friends, Direct Support Professionals (DSPs), healthcare providers, and other professionals involved in services for people with IDD. Several shared anecdotes of disturbing and ableist interactions they directly experienced or observed in many programs and activities that receive HHS funding. For example, the mother of a person with disabilities in Clovis, California frequently heard biased and stigmatizing remarks from “[d]octors who say ‘he’s disabled, he’ll be fine. He doesn’t know the difference.’”

A common theme raised by individuals with IDD and their families is that they are often considered by medical staff to be “too difficult,” “uncooperative,” burdensome, or a ‘waste’ of limited time and resources. The mother of a person with Down Syndrome in North Bend, Washington reported encountering attitudes from medical staff that devalue the lives of people with disabilities:

“I have had dozens of comments by health care professionals about my ... son that were disparaging and derogatory. ... Comments like, ‘he isn’t worth helping, he isn’t worth saving, if you hadn’t had him, we wouldn’t be bothered with this now.’”

Conscious and unconscious bias, lack of disability competency or training in care for people with IDD, and resource constraints impact healthcare access and quality. Individuals with IDD that experience compounded discrimination include those with multiply-marginalized identities, and those with communication and behavioral challenges. Examples shared with The Arc included challenges accessing a broad variety of services from diagnostic testing, to preventative screenings, primary care, vaccinations, speech language pathology services, physical therapy, pain management, gastroenterology services, surgeries, mental health services, reproductive health services, oral health services, eye exams, emergency room services, and end-of-life care:

- Riverside, California: The parent of an individual with a disability said their son’s doctor refused to perform a hernia surgery because the doctor assumed the hernia did not impact his quality of life. According to the parent, the doctor stated, “if my son just sat on the couch, the hernia would not be a problem.”

- Las Vegas, Nevada: An individual with cystic fibrosis, autism, and communication challenges was denied medical procedures because, according to his parent, staff said it would be “too difficult” to perform the procedures on him. Multiple doctors also prescribed a lesser drug to the individual because they assumed a preferred drug could not be administered to him.
- Phoenix, MD: The parent of an individual with Down Syndrome said, “A dentist didn't see the merit of my child with [Down Syndrome] having braces; yet both of his sisters who had the same orthodontal problems [and he] absolutely needed braces.” The parent was also told by another provider that it was not important for her child to have a routine eye exam because of his disability.
- Beacon, NY: A child with autism was denied care from a pediatrician out of concern that his care needs would “overwhelm” the pediatrician’s practice. The pediatrician recommended alternative pediatricians that were an hour or more away by car. The child’s parent said: “My son has a care team of specialists that we see for all care related to his condition, but we need a pediatrician for vaccines and routine healthcare. Unfortunately, ‘just find another doctor’ doesn’t work in areas with few care providers.”

An area of medical treatment that merits further investigation is pain management. Evidence suggests that the pain management needs of adults with IDD are frequently neglected. One study found that as many as 48% of adults with IDD regularly experience pain and 10% experience high levels of chronic pain. This pain was due to a variety of factors including lack of care for menstrual pain, need for adaptation of wheelchairs, and lack of care for digestive, dental, and orthopedic conditions.^{viii} People with IDD report that their pain is often discounted by medical staff, they are not considered to be ‘reliable’ judges of their pain, prescriptions for pain killers and/or muscle relaxants are often denied, and they are frequently accused of drug-seeking behavior. In some cases, medical staff assume that people with IDD cannot consent to treatments that could potentially address their pain. For example, one individual with autism in Milwaukee, Wisconsin reported that it took 20 years for medical staff to diagnose and treat her severe menstrual pain. They said, “I was refused a hysterectomy and told I had to try every birth control available multiple times because I couldn’t be trusted to choose the hysterectomy for myself.”

Many individuals with IDD also have gastrointestinal disorders and frequently experience inadequate treatment for abdominal pain. This problem is especially acute for individuals with communication challenges. For example, the mother of a nonverbal autistic individual in Milford Connecticut reported that, after a sudden spike in self-injury behaviors indicated her son might be having GI related abdominal pain, numerous GI doctors refused to run tests or provide treatment.

Another common healthcare quality issue encountered by individuals with IDD is diagnostic overshadowing. Diagnostic overshadowing occurs when a known underlying condition leads to assumptions about a patient that prevent physicians from making a new diagnosis. A relevant example of diagnostic overshadowing was shared with The Arc by a parent of a child with IDD from Trumbull, Connecticut, who said several doctors refused to test her son for Lyme Disease:

“I went to many different doctors telling them it’s not normal for a 10-year-old to complain about joint pain. I was told over and over again that ‘it’s part of his disability’ or ‘growing pains.’ My son was having neurological issues as well from the Lyme. Again, it was blamed on his disability. I was even told by one doctor that I needed mental help and to see a therapist. ... Finally, after 3 years I got a doctor to do the Lyme test. I was told he had [Lyme disease] at some point, the damage is permanent, and ‘[shame] on you. You should have brought him here 3 years ago.’”

Another example was shared by a parent of a child with Down Syndrome, who took her son to several doctors and speech language pathologists after her son experienced two febrile seizures and stopped talking. She reported, “Many had nothing to say. One said, ‘He has Down Syndrome. What do you expect? They don’t talk.’” Her son was later seen by a neurologist who confirmed damage “to the area of the brain that deals with language. He said, ‘had we known earlier, it’s possible we could’ve helped him.’ My son is nonverbal now.”

In addition to prohibited denials of treatment on the basis of specific types or degrees of disability, the failure to provide timely access to medical treatment can also result in disability discrimination, including the failure to provide reasonable modifications required for the individual to access and benefit from the recipients’ services and programs. Two frequently cited examples of this include mental health and oral health services.

Although people with IDD carry a higher risk for mental health issues and an elevated risk for suicidality, they are less likely to be diagnosed, and are often denied treatment. Examples shared with The Arc in October 2023 include:

- New Hudson, Michigan: An autistic individual reported that after being discharged from a hospital stay that included psychiatric care, they could not find a psychiatrist in the hospital’s network that would provide outpatient services to them due to their disability. They said, “When my POA requested a referral to one within the hospital’s list of doctors she was told their doctors didn’t treat disabled non-verbal patients. She was then advised to find one for me outside of their network. They proceeded to discharge me.”
- Bedford, Massachusetts: An individual with autism reported they were not allowed to join a therapy group due to their disability. They said: “A psychiatrist I was seeing at the time had referred me to the group, and I’d had a successful interview with one of the group facilitators. However, the person leading the group, who I’d never met, decided I wasn’t a good fit because my autism prevented me from picking up on non-verbal communication.”
- Colorado Springs, Colorado: A service provider for individuals with IDD reported challenges finding mental health providers that would work with people with intellectual disabilities. They reported, “Seeking Mental Health help - one of the first questions [asked] is ‘What is your IQ?’ If you state it is below 70 - they basically say they are not equipped to serve you and send you on your way.”

- Edgewater, Maryland: The mother of an individual with Down Syndrome reported that it took 6 years to find a therapist for her daughter. She said, “[My daughter] is verbal but it is difficult for her to verbalize her feelings. I initially attempted to get her some help because I thought she had been sexually assaulted. I was finally able to get her into the Trauma Center at Kennedy Krieger, but it was temporary.”

People with IDD also experience severe oral health disparities and challenges finding providers who can provide necessary accommodations. Due to sensory issues, many adults with IDD require longer dental appointments to ensure care is administered slowly, gently, and compassionately. In some cases, individuals with IDD may require or prefer sedation before receiving dental care. According to a National Council on Disability report, “dental services are more difficult to find than any other type of service for individuals with intellectual and developmental disabilities who live in the community. Families and support personnel also indicate that quality of care is lower than it should be, because dentists lack the skills required to work or communicate with people with intellectual and developmental disabilities.”^{ix} For example, the parent of a child with autism in Troy Michigan reported that their son was denied service from a dentist. They said, “My son has autism and was frightened by the dentist and the lights. He was under 5 years old at this time. We were treated with disdain and dismissed with a warning not to come back until he no longer expressed the behaviors of an autistic child.”

Section 84.56(c)(1) Professional Judgment in Treatment

- *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.*

In addition to examples of prohibited discriminatory judgments, the preamble would benefit from examples of best practices to mitigate the risk of discriminatory judgments. During the pandemic, disability advocates sought, and the Department’s Office of Civil Rights approved, complaint settlements that emphasized reliance on individualized assessments and objective medical evidence to reduce the risk of discriminatory allocation of life saving medical care.^x Additional strategies to reduce the exercise of discriminatory professional judgment include competency-based trainings on disability;^{xi} a structured process for requesting a second opinion/professional consultation; and the availability of a specially trained, independent review board—with a composition that reflects racial, ethnic, and disability diversity—to consider patient appeals of medical treatment decisions and report publicly on the outcome of those decisions.^{xii}

The Arc in particular has been a longtime advocate for improving competency-based trainings on disability and IDD. Far too often medical professionals ignore the health care issues raised by the person with IDD or their designated support person or wrongfully attribute their health care issue to the fact that they are a person with a

disability. Some medical professionals will refuse to see people with IDD. It is important that strong anti-discrimination provisions be in place in addition to other efforts to improve professional education about disability and competency-based care.

Although frequently explicit in nature, discriminatory decision-making in health care can also be grounded in implicit or unconscious bias which is harder to detect and can be cloaked by professional medical judgment. This reality makes the proposed rule, and its prohibition of discriminatory treatment decisions, critical to protecting equal access to medical care for persons with disabilities.

The proposed rule and its construction do not intrude on, or otherwise constrain, the exercise of professional judgment.^{xiii} The preamble makes clear that treatment professionals are not required to work outside their scope of practice or to provide treatment that is futile in light of the patient's treatment goals. At the same time, the presence of conscious and unconscious bias has been well-documented within the medical community, including in studies based on self-reported information from medical providers.^{xiv} The basis for prohibiting discrimination in medical treatment is also supported by authoritative research in this notice of proposed rulemaking (NPRM). Given the insidious nature of this bias, and its persistence over time, it is appropriate for HHS to clearly prohibit discriminatory treatment decisions like those described within the proposed rule. Discriminatory treatment decisions cannot be considered a legitimate or appropriate exercise of professional judgment.

Section 84.56, et seq. (Medical Treatment)

- *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.*

Given the pervasive and longstanding discrimination experienced by individuals with disabilities in access to health care, and the life altering consequences of resulting health disparities, the benefits associated with clearly prohibiting discriminatory medical treatment far outweigh any perceived risks. The proposed regulations place this history of discrimination in a present day medical and legal context, incorporating court decisions, professional research, and national expertise to support the proposed regulatory framework. Many of these discriminatory policies and practices were laid bare by the COVID-19 pandemic, including the withholding of medical care based on generalized assumptions, stereotypes, and misjudgments regarding the value and quality of life experienced by people with disabilities.

The regulations also recognize and rightly prohibit the kinds of discriminatory policies and protocols employed by many recipients during the pandemic. Examples range from hospitals requiring individuals with certain types of disabilities such as IDD to have a do not resuscitate (DNR) order in place, to institutional practices that pressure or steer individuals with disabilities and their agents towards DNR orders or other agreements to remove or withhold lifesaving care. As noted in the proposed rule, recipients also

designed Crisis Standards of Care that relied on discriminatory assessment tools, unreliable life expectancy calculations, and protocols that did not provide reasonable modifications needed to ensure equal access to life-saving treatment for individuals with disabilities. The HHS preamble should incorporate more explicit language on the need for reasonable modifications in the use of these tools.

The proposed regulations emphasize the importance of obtaining individuals' informed consent to treatment, but these provisions could be improved by underscoring and cross-referencing recipients' obligations to provide reasonable modifications needed to ensure effective communication and informed choice.

As the pandemic demonstrated, this may include modification of hospital visitor policies to allow for a designated support person to facilitate effective communication, offer behavior support, and assist with access to care. Advocates who obtained these modifications in individual states and recipient facilities did so in large part thanks to complaints involving the federal HHS Office of Civil Rights.^{xv} Including the example of designated support persons in the regulation's preamble would further underscore the legal obligation of recipients to make reasonable modifications, both individually and program wide, and to ensure effective communication and informed choice for individuals with disabilities seeking medical treatment.

Finally, the preamble should note that cultural competency should be embedded in both the treatment decision-making process as well as access to all necessary treatment options. For people with disabilities from BIPOC communities, accommodating the cultural differences of communities of color is necessary in all aspects of medical treatment.

- *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 propose the following highlighted additions (in bold) to the proposed definition of "medical treatment"^{xvi} to ensure it is fully inclusive of the range of conditions and treatment interventions utilized by individuals with disabilities.

"Medical treatment" is used in this section in a generic, nonspecific manner; it is intended to be broad and inclusive. It refers to the management and care of a patient to identify, address, treat, or ameliorate a physical, mental, **or behavioral** health condition, injury, disorder, or symptom, whether or not the condition constitutes a disability and whether the medical approach is preventive, curative, rehabilitative, **habilitative**, or palliative. It includes the use of a wide range of regimens for both physical, mental, **behavioral, and developmental** conditions, interventions, or procedures, such as surgery; the prescribing, dispensing, or management of medications; exercise; physical therapy; **clinical and** rehabilitation services; and the provision of durable medical equipment.

A.1.2 Value Assessment Methods (§84.57)

- *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 agree with the preamble’s analysis highlighting the deep problems with the Quality-Adjusted Life Year (QALY) value assessment tool. QALY relies on the discriminatory premise that using a treatment to extend the lives of people with disabilities and other chronic conditions is inherently less valuable than using that treatment to extend the lives of people without such conditions. For this reason, and as noted in the proposed rule’s preamble, it has been broadly criticized by disability experts.^{xvii} and its uses limited in federal programs like Medicare.^{xviii} A close analysis of existing federal restrictions on the use of QALYs indicates they are not comprehensive enough to fully safeguard the rights of people with disabilities, which supports the necessity of the proposed rule.^{xix}

- *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 Arc believes that the proposed rule should include a prohibition on the discriminatory use of assessment tools that devalue either the extension of life years for people with disabilities or the quality of life, including provision of treatment that alleviates suffering for people with disabilities and other chronic medical conditions. We urge the Department to consider the following amendment to the proposed Section 84.57:

Value assessment methods. A recipient shall not, directly or through contractual, licensing, or other arrangements, use any measure, assessment, or tool that discounts the value of life extension **or quality of life** on the basis of disability to deny or afford an unequal opportunity to qualified individuals with disabilities with respect to the eligibility or referral for, or provision or withdrawal of any aid, benefit, or service, including the terms or conditions under which they are made available.

A.1.3 Children, Parents, Caregivers, Foster Parents, and Prospective Parents with Disabilities in the Child Welfare System (§84.60)

The preamble (Pages 63411-63418) and proposed regulatory language in this section will be extremely helpful to the field, especially the intentional focus on the discrimination that is rampant in the child welfare system. The widespread discrimination in the child welfare system impacts parents, children, and, in cases such as the institutionalization of children, both children and their parents for whom it creates additional barriers to reunification.

The Arc has heard far too often about discrimination both when the parent is a person with IDD and when the child is a person with IDD. The Arc supports the inclusion of these provisions and highlights the suggestions by CCD to add a provision specifying

that children shall be placed in the most integrated setting appropriate to meet the needs of the child and to add that discrimination includes failing to make reasonable modification in policies, practices, or procedures when the modifications are necessary to avoid discrimination on the basis of disability.

- *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.*

The Arc appreciates the discussion in the preamble regarding the inappropriate use of stereotypes and generalizations about persons with disabilities or specific diagnosis or intelligence level alone to make decisions. Clearly stating that IQ alone is insufficient to make decisions will go a long way to addressing widespread discrimination against people with IDD. Assessments and decision-making in the child welfare context should be individualized and not include blanket assumptions or policies based on arbitrary criteria such as IQ score. A careful examination of the individual's situation and what services and supports they may need should be the foundation of state and federal policies. This may include services and supports available to people with IDD through other state agencies, universities, protection and advocacy systems, or community-based advocacy organizations. States should be familiar with these potential resources and incorporate them into the referral process.

A.3 Subpart H—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.*

The increased effective use of plain language is a necessary accommodation for millions of people with and without disabilities. Taking actions to ensure that people with disabilities can understand and use what they read or hear is vital to advancing equality of opportunity and equal protection of the law. While using plain language will not eliminate all the information barriers millions face, it is a major step in the right direction.

Plain language should be considered in all aspects of healthcare including explaining diagnosis and treatment options, informed consent, medical billing information, explanations of benefits by insurers, and other forms and medical information. Moving in this direction will directly benefit people with cognitive, developmental, intellectual, or neurological disabilities and millions of other health care recipients who struggle with processing complex information or experience low literacy. Advancing plain language efforts will also likely improve health outcomes by encouraging a better understanding of treatment options, improving compliance with medications, and other recommended health care services by the individuals and their designated support person.

- *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.*

The Arc urges the Department to embed the plain language requirements in this rule. The Arc is pleased to see the consideration of plain language as an auxiliary aid or service. We expect that developing policy and guidance about plain language as an auxiliary aid or service would achieve a higher level of consistent implementation by covered recipients. Recognizing that this may not be the only way to achieve more widespread adoption of the use of plain language, we urge the Department to continue its leadership on this issue. The Arc is willing to engage with the Department and other stakeholders on how to best achieve this goal.

Conclusion

Thank you for your consideration of our comments, The Arc appreciates the Department's comprehensive and thoughtful update and expansion of the rule. These changes are critical to preventing discrimination against people with IDD and we applaud your leadership in this effort. If you have any questions please contact Darcy Milburn, Director Social Security and Healthcare Policy, The Arc of the United States at Milburn@TheArc.org.

ⁱ Emily Lauer et al., Health Service Utilization Patterns Among Medicaid-Insured Adults With Intellectual and Developmental Disabilities: Implications for Access Needs in Outpatient Community-Based Medical Services. *J Ambul Care Manage.* (2021), <https://pubmed.ncbi.nlm.nih.gov/33492884/>; Sandra Marquis et al., Health policy narratives contributing to health inequities experienced by people with intellectual/developmental disabilities: New evidence from COVID-19. *Clinical Ethics.* (2023), <https://journals.sagepub.com/doi/10.1177/14777509231196704>.

ⁱⁱ See, American Association on Intellectual and Developmental Disabilities (AAIDD), DD and Health Disparities, <https://www.aaidd.org/intellectual-disability/intersectionality/idd-health-disparities>; Craig Escudé, Advancing Health Equity For People With Intellectual And Developmental Disabilities, *Health Affairs Forefront*, (Oct. 20220), <https://www.healthaffairs.org/content/forefront/advancing-health-equity-people-intellectual-and->

developmental-disabilities; Nebraska Dept. of Health and Human Services, Health Disparities in Individuals with Intellectual and Developmental Disabilities, <https://dhhs.ne.gov/Documents/Henrichs.pdf>; Scott D Landes et.al., COVID-19 Outcomes Among People with Intellectual and Developmental Disability in California: The Importance of Type of Residence and Skilled Nursing Care Needs, *Disability and Health Journal*. (Apr. 2021), <https://pubmed.ncbi.nlm.nih.gov/33309535/>; Susan Havercamp et al., National Health Surveillance of Adults with Disabilities, Adults with Intellectual and Developmental Disabilities, and Adults with No Disabilities, 8 *Disability & Health J.* 165 (2015), <https://doi.org/10.1016/j.dhjo.2014.11.002>.

ⁱⁱⁱ The Arc of California, October is Breast Cancer Awareness Month, <https://thearc.org/october-is-breast-cancer-awareness-month/#:~:text=Women%20with%20intellectual%20and%20developmental,screenings%20and%20higher%20mortality%20rates>.

^{iv} Nebraska Dept. of Health and Human Services, Health Disparities in Individuals with Intellectual and Developmental Disabilities, <https://dhhs.ne.gov/Documents/Henrichs.pdf>; ACL, ACL Launches Center to Improve Support for People Who Have Both Intellectual and Developmental Disabilities and Mental Health Disabilities, (Sept 2022), <https://acl.gov/news-and-events/announcements/acl-launches-center-improve-support-people-who-have-both-intellectual>.

^v See, National Council on Disability, *The Current State of Health Care for People with Disabilities*, (Sept. 2009), <https://ncd.gov/publications/2009/Sept302009>.

^{vi} Medical Device Nonvisual Accessibility Act of 2023, H.R. 1328, 118th Cong. (2023), <https://www.congress.gov/bill/118th-congress/house-bill/1328/text?s=1&r=80&q=%7B%22search%22%3A%5B%22H.R.+6%22%5D%7D>.

^{vii} Thomas Jefferson University, After old age, intellectual disability is greatest risk factor for death from COVID-19, study finds. *ScienceDaily* (2021), <https://www.sciencedaily.com/releases/2021/03/210305123809.htm>; Scott D Landes et.al., COVID-19 Outcomes Among People with Intellectual and Developmental Disability in California: The Importance of Type of Residence and Skilled Nursing Care Needs, *Disability and Health Journal* (2020), <https://pubmed.ncbi.nlm.nih.gov/33309535/>.

^{viii} Sandra Marquis et al., Health policy narratives contributing to health inequities experienced by people with intellectual/developmental disabilities: New evidence from COVID-19. *Clinical Ethics*. (2023), <https://journals.sagepub.com/doi/10.1177/14777509231196704>.

^{ix} See, National Council on Disability, *The Current State of Health Care for People with Disabilities*, (Sept. 2009), <https://ncd.gov/publications/2009/Sept302009>.

^x See, e.g., NPRM at n. 83-87 (citing the HHS OCR's resolution of complaints and the provision of related technical assistance in Tennessee, Utah, and North Carolina).

^{xi} See National Council on Disability, *Medical Futility and Disability Bias*, at 12 (November 20, 2019), https://ncd.gov/sites/default/files/NCD_Medical_Futility_Report_508.pdf (stating "[m]edical and health professional schools should include disability competence as a component of or in addition to cultural competence training. Medical and health professional schools should be physically and programmatically accessible for students with disabilities in order to facilitate diversity among healthcare providers" and cited in NPRM at n. 65).

^{xii} *Id.* at 12 (recommending development of an independent review panel, especially in cases of medical futility decisions, that is not associated with the provider or facility and whose composition reflects racial, ethnic, and disability diversity).

^{xiii} See NPRM, Section 84.56(c) (1)(i) ("Nothing in this section requires the provision of medical treatment where the recipient has a legitimate, nondiscriminatory reason for denying or limiting that service, or where the disability renders the individual not qualified for the treatment.")

^{xiv} See, e.g., Lisa I. Iezzoni et al., *Physicians' Perceptions of People with Disability and Their Health Care*, 40 *Health Aff.* 297 (Feb. 2021), <https://pubmed.ncbi.nlm.nih.gov/33523739/> (citing GL Albrecht et al., *The Disability Paradox: High Quality of Life Against All Odds*, 48 *Soc. Sci. Med.* 977 (1999) and cited at NPRM at n. 67).

^{xv} See US Department of Health and Human Services, Press Release: OCR Resolves Complaints after State of Connecticut and Private Hospital Safeguard the Rights of Persons with Disabilities to Have Reasonable Access to Support Persons in Hospital Settings During COVID-19 (June 9, 2020), <https://www.hhs.gov/about/news/2020/06/09/ocr-resolvescomplaints-after-state-connecticut-private-hospital-safeguard-rights-persons.html>.

^{xvi} See NPRM at 63,395.

^{xvii} See NPRM at 63,409-63,410 and accompanying footnotes.

^{xviii} See *National Council on Disability, Quality-Adjusted Life Years and the Devaluation of Life with Disability*, at 45-46 (November 6, 2019), https://ncd.gov/sites/default/files/NCD_Quality_Adjusted_Life_Report_508.pdf.

^{xix} See Greg Phyllip Roggin, *The "Oregon Plan" and the ADA: Toward Reconciliation*, 45 *J. URBAN & CONTEMPORARY LAW* 219 (1994) (noting that a slightly altered version of this prioritized list that addressed some of the concerns about disability discrimination was later approved); Oregon Health Evidence Review Comm'n (HERC), *HERC Use of Quality Adjusted Life Years*, (last visited Oct. 25, 2023), <https://www.oregon.gov/oha/HPA/DSI-HERC/Documents/Background-HERC%20QALY%20policy.pdf> (noting that the state's Health Evidence Review Commission, which manages the list, still uses QALYs in a limited fashion).