

September 16, 2022

Submitted electronically to: <http://www.regulations.gov>

Centers for Medicare & Medicaid Services
Department of Health and Human Services
Attention: CMS-1770-P
P.O. Box 8016
Baltimore, MD 21244-8016

Re: Comments in Response to the Center for Medicare & Medicaid Services' Proposed rule RIN Number 0945-AA17 [<https://www.federalregister.gov/documents/2022/08/04/2022-16217/nondiscrimination-in-health-programs-and-activities>]

To the Administrator,

We are submitting comments in response to the Centers for Medicare & Medicaid Services' (CMS) Proposed rule RIN Number 0945-AA17 to express our strong support for improving the health care system and stopping discrimination in the health-care system.

Institute for Exceptional Care (IEC) is a non-profit organization committed to transforming healthcare for people with intellectual and developmental disabilities (IDD). IEC is working with broad coalitions of clinical organizations, payers, purchasers, regulators, consumer advocates, and social service professionals to improve systems and processes of care that support better health and life outcomes.

Individuals with IDD are the subject of current and prevalent discriminatory practices. There is [physician bias](#), with 82 percent of clinicians believing that patients with disabilities have a lower quality of life than patients without disabilities even though many individuals with severe disabilities have a "good quality of life." Only (56.5 percent) of physicians strongly welcome patients with disabilities into their practices, and 40.7 percent of clinicians are "very confident" that they can "provide the same quality of care" to patients with disabilities. Biased [clinicians' assumptions](#) contribute to decisions about treatment with deadly results. During the early months of the coronavirus pandemic, patients with IDD were discriminated against. They were de-prioritized relative to other patients in terms of access to ventilator support and critical care beds. Some were denied the help of their caregivers or personal support personnel during hospitalization, which many need to effectively communicate their needs. Informal and formal Crisis Standards of Care documents, which related to rationing of healthcare, denied care to patients with specific disabilities. [Coronavirus](#) was more lethal for people with intellectual disability.

Although the [Americans with Disabilities Act](#) (ADA) mandates that people with disabilities receive equal care and accommodations so they can get proper care, problems with accommodations and equitable care persist. According to a 2019-2020 survey, nearly 36 percent of physicians know little or nothing about their ADA legal duties. There is a lack of accommodations in the physical environment, for alternative methods of communication, and

other aspects of care such as quiet spaces for those with sensory challenges. A large barrier for people with IDD is an [insufficient appointment time](#) with clinicians. It is not uncommon for clinicians to speak to the caregiver or support person, rather than the patient with IDD. [Patients with developmental disabilities](#) were less likely to say that they have a clinician who provided good explanations of clinical issues. [Qualified people with IDD](#) can also be denied access to public? programs and other benefits. [Many people with IDD are denied organ](#) transplants despite the Americans with Disabilities Act prohibiting this practice. According to a 2008 study, 44 percent of organ transplant centers said they would not add a child with a neurodevelopment disability to the organ transplant list.

Addressing Bias and Discrimination Through Better Training

To support providers in adhering to nondiscrimination requirements, CMS should support better education/training and resources for providers, most of whom receive little exposure to IDD. [Medical students](#) receive an average of 11 minutes of exposure to IDD, and there is no developmental medicine specialty for adult care clinicians. According [to a recent study](#), more than 75 percent of first-year medical students were more comfortable interacting with patients with disabilities after finishing training on disabilities.

Making IDD Visible in Healthcare Data

[Currently](#), many people with IDD are poorly identified – not “visible” – in typical healthcare data, such as insurance claims or electronic medical records and charts. Based on our preliminary data of national insurance claims and Epic’s Cosmos database of electronic health records, ostensible prevalence of IDD in typical healthcare data is a fraction (10-25%) of what would be expected based on monitoring data from the Centers for Disease Control and Prevention, the National Health Interview Survey, and other surveys of adults. This is likely due to a combination of factors (under-screening and diagnosis, lack of self-disclosure among adults, and loss of clinical history during care transitions, such as adolescence into adulthood.). These data gaps pose a foundational barrier to (1) addressing disparities in access and quality of care; (2) measuring and improving quality of care; (3) understanding true utilization, cost, and outcome patterns among people with IDD;(4) effectively targeting services and supports (some unlabeled people with IDD hence currently manifest as “high-cost, high-need” patients because their underlying needs aren’t being met); (5) creating credible business cases for smarter investments in IDD care; and (6) drawing sustained clinical attention to this large and growing population.

Telehealth

IEC supports [telehealth](#), which can increase access to equitable health care for people with disabilities. Telehealth reduces travel. [Travel](#) can be particularly difficult for people with IDD. Public transportation is on a set schedule and does not go everywhere. Paratransit services need to be scheduled in advance, are not available in all places, and can be expensive. Frequently, rideshare options are not accessibility to mobility-impaired individuals and are expensive. Hospitals’ and clinics’ accessible parking is usually in high demand and might be in short supply. Travel can require a caregiver to accompany the person with IDD. Telehealth also

allows people with anxiety and other diagnosis to avoid environments they might find overwhelming. Telehealth also increases the number of specialists that patients with IDD can access, as location would less of a factor in specialist.

However, health-care providers need to be aware of disparities in access to technology and the Internet. [Telehealth](#) does not work for many physical exams. It is challenging for people with mobility and sensory disabilities to move in a way that is needed for certain telehealth visits. Some people with IDD might not be capable of explaining their medical issues in a telehealth session. Not all telehealth is covered by insurance. In addition, some people with IDD might find telehealth to be challenging because of the system being complicated and/or not having digital literacy. Many people with IDD might not have access to the Internet and other technology that telehealth requires.

Appropriate standards and accessibility requirements for websites, mobile applications, and medical diagnostic equipment

Plain language, easy read, and graphic language should always be used. Key aspects of [plain language](#) include use of active voice, brief sentences and paragraphs, common words, and design features (i.e. – Lists, headings, and tables). [Text in Easy Read](#) is accessible to people with learning and other disabilities. Prevalent Easy Read rules are the use of brief sentences, images representing each sentence, simplified language, large font, simple fonts, and minimal design elements. Easy Read documents tend to be longer than non-Easy Read materials. Graphic illustrations can allow people with IDD to better understand concepts.

Steps HHS can take to help covered entities meet their language access and effective communication responsibilities

HHS should not just focus on Limited-English proficiency. HHS should use Plain Language and Easy Read. It should also ensure that people with IDD can communicate in the way they would like (Verbal, AAC device, care-partner).

The ways in which provider networks limit or deny access to care for individuals on the basis of race, color, national origin, sex, age, or disability. This includes the extent to which the lack of availability of accessible medical diagnostic equipment in a provider network constitutes discriminatory benefit design or network inadequacy and/or limits or denies access to care for people with disabilities.

Medical providers must be more accessible to people with disability, which should already happen because of the ADA’s Titles [II](#) (pertaining to state and local government entities) and [III](#) (pertaining to Public Accommodations and Commercial Facilities). There are several ways that medical providers can address environmental concerns. Facilities can have [medically-accessible equipment](#), such as adjustable exam tables that would be used by patients with mobility impairments and accessible scales. Facilities can also provide sensory carts and/or have sensory rooms to accommodate patients with sensory problems. They could also not have loud TVs in waiting rooms. Many of these adjustments would help many other patients, not just people with IDD. Facilities should also allow accompaniment by care partners and other support personnel

Design features of insurance or plan benefits that result in segregation or institutionalization of individuals with disabilities or place them at serious risk of institutionalization or segregation

IEC opposes institutionalization. It is ideal for people with IDD to be in the community, not in institutions. There has been a [history of mistreatment](#) of institutionalized individuals. New York's Willowbrook State School for many patients with mental disabilities spurred the deinstitutionalization movement. Soon after it opened in 1947, this facility was "overfilled and understaffed." At full capacity in the mid-1950s, there was widespread hepatitis infection among patients and employees. In 1960, a measles outbreak caused 60 patient deaths. Although this facility was named a school, teaching occurred for only a small number of students for approximately two hours each day. The institution's patients were neglected. Some human body waste remains. Sexual and physical abuse and disease were common.

Examples of how state Medicaid agencies can avoid creating incentives for institutional services over home and community-based services through policies on reimbursement, scope of services, service authorization, and the like

Four-fifths of a million people with IDD use HCBS. [As of 2020](#), 810,300 people with IDD 1915(c) waiver participants, comprising 42.59 percent of total waiver participants. [However, people with IDD](#) are disproportionately on HCBS waiver waitlists. [As of 2020](#), 464,398 people with IDD represent 70.00 percent of the total 665,015 people who are on the 1915(c) and Section 1115 HCBS Waivers waitlists.

HHS should ensure better financing of HCBS. It should consider making part of HCBS coverage an essential plan benefit so commercial insurers will also support these services. Medicaid cannot finance all of HCBS.

In conclusion, IEC applauds the CMS for a proposal that directly addresses the healthcare of people with disabilities.

Sincerely,

Hoangmai Pham
President & CEO
Institute for Exceptional Care