

November 13, 2023

U.S. Department of Health and Human Services
Office for Civil Rights (OCR)
Attention: Disability NPRM, RIN 0945– AA15
Hubert H. Humphrey Building, Room 509F
200 Independence Avenue SW
Washington, DC 20201

SUBMITTED ELECTRONICALLY VIA <http://www.regulations.gov>

Re: DEPARTMENT OF HEALTH AND HUMAN SERVICES 45 CFR Part 84 RIN 0945–AA15 Discrimination on the Basis of Disability in Health and Human Service Programs or Activities

Dear Director Rainer:

The American Geriatrics Society (AGS) appreciates the opportunity to submit comments on the Discrimination on the Basis of Disability in Health and Human Service Programs or Activities proposed rule. The AGS is a not-for-profit organization comprised of nearly 6,000 physician and non-physician practitioners (NPPs) who are devoted to improving the health, independence and quality of life of all older adults. The AGS provides leadership to healthcare professionals, policy makers, and the public by implementing and advocating for programs in patient care, research, professional and public education, and public policy. The AGS' vision is a nation where we can all have a fair and equitable opportunity to contribute to our communities and maintain our health, safety, and independence as we age. The AGS believes in a just society, one where we all are supported by and able to contribute to communities where ageism, ableism, classism, homophobia, racism, sexism, xenophobia, and other forms of bias and discrimination no longer impact healthcare access, quality, and outcomes for older adults and their caregivers.

General Comment

In general, **we believe it is crucial that therapy or treatment options are discussed and offered in line with what matters most to the patient and supports people making shared decisions with their clinicians.** The AGS prioritizes what matters most to patients, their families, and other care partners who want to know whether a treatment provides clear and important benefits and is aligned with their care preferences. Several AGS papers that we encourage the department to review are: [Resource Allocation Strategies and Age-Related Considerations in the COVID-19 Era and Beyond](#); [AGS Position Statement: Making Medical Treatment Decisions for Unbefriended Older Adults](#); and [Person-Centered Care: A Definition and Essential Elements](#).

Our primary concern with this rule is that it could cause unintentional harm for anyone who is living with a disability and a concurrent medical condition for which treatment is available but where that

treatment may not align with a person's wishes, does not reflect consideration of prognosis, have greater risks than benefits, and potentially cause more harm than good. As currently drafted, the rule prioritizes treatment instead of careful consideration of whether the treatment itself is aligned with the wishes of the person who is living with a disability. Further, many of the examples provided are binary and do not reflect the heterogeneity of both younger and older individuals living with disability.

We offer comments and recommendations on the proposals below.

Denial of Treatment for a Separate Symptom or Condition

This section of the proposed rule addresses situations where a person with a disability seeks or consents to treatment for a separately diagnosable symptom or medical condition, whether or not the symptom or condition is a disability or connected to the disability. We appreciate that this section aims to make clear that a person with a disability may not be denied or limited clinically appropriate treatment if it would be offered to a similarly situated individual without an underlying disability. The rule does not consider the complexity of caring for someone living with disability who also has multiple chronic conditions. For example, the rule does not consider someone who has diabetes, kidney disease, AFib, and osteoarthritis that has led to their using a walker or other assistive device. If that person goes on to suffer from kidney failure, the appropriate first step would be to engage in discussions about what matters to the individual and their overall prognosis based on the totality of their disease burden. In instances where they lack capacity and there is no proxy, the case should be referred to an Ethics Committee or other decision-making body as organized by the health system where the patient is receiving care.

In general, **we believe it is crucial that therapy or treatment options are discussed and offered in line with what matters most to the patient and supports people making shared decisions with their clinicians.** The AGS prioritizes what matters most to patients, their families, and other care partners who want to know whether a treatment provides clear and important benefits and is aligned with their care preferences.

Provision of Medical Treatment

This section of the rule addresses the discriminatory provision of medical treatment. It states that if a medical professional provides an individual with a disability different treatment than the professional would provide an individual without a disability seeking assistance with the same condition— and there is nothing about the disability that impairs the effectiveness, or ease of administration of the treatment itself or has a medical effect on the condition to which the treatment is directed, then this provision (§ 84.56(b)(3)) has been violated. However, the proposal notes that a provider is not prohibited from providing services or equipment to an individual with an underlying disability that are different than that provided to others with the same condition when necessary to provide an effective service or treatment to the individual with a disability.

The proposed rule, however, is silent on the need to also consider not offering treatment where doing so does not align with the patients wishes, does not take into account their overall prognosis, does not consider whether the risks would outweigh the benefits, or creates a situation where the treatment could cause more harm than good. An example case would be a person residing in a nursing home who is without a proxy and has no advanced directive, and who is cognitively impaired, immobile, with bed

sores, and recurring pneumonias. Under the proposed rule, the nursing home would need to continue offering IV antibiotics because of the two existing disabilities (cognition and immobility) and the lack of a clear advance directive. We encourage the Department to include language that is focused on decision-making for people who are incapacitated that is in accordance with current health care practice.

In this section, the Department also seeks comment on other examples of the discriminatory provision of medical treatment to people with disabilities of which we provide a few here:

- Not providing/offering preventive care- cancer screening/ mammograms/pap smears in differently abled women.
- Not providing/offering vaccinations in disabled individuals.
- Providing treatment that is not aligned with a patients' wishes or goals of care; where risks outweigh the potential benefits; where there is potentially greater harm than good.

Most important is that patient preferences and values are prioritized with regard to any treatment plan in persons with a disability.

Professional Judgment in Treatment Proposed

This section specifically addresses professional judgment in treatment and its relationship to the proposed nondiscrimination provisions regarding medical treatment. We believe this section is reasonable and well-constructed. We appreciate that the Department has provided a specific example that takes into account the prognosis of a person living with disability who is in need of cardiac surgery where the individual is unlikely to survive the surgery. We encourage the Department to add similar specific examples throughout the sections of this rule that deal with healthcare. An additional example here would be the decision on whether to place a feeding tube in a person with advanced dementia instead of hand feeding which has fewer complications. Similar to cardiac surgery, the decision should factor in prognosis and whether the potential benefit of a feeding tube outweighs the harms.

Again, we want to highlight the importance of shared decision making in these situations and the importance of prognosis in making decisions.

Consent

This section addresses consent and in part references reports of individuals with disabilities pressured to agree to withdrawing or withholding life-sustaining care. In reviewing this section, we believe it may be helpful to include a positive example where discussions about limiting treatment is appropriate so that clinicians in those scenarios would be able to deliver care consistent with professional judgement while having discussions with shared decision making in a positive way. One example of shared decision-making where it is likely that treatment will be discontinued is for older adults with multiple chronic conditions who are on multiple drugs some of which may interact in ways that harm the person. A careful review of the patient's medications will often result in discontinuation of certain drugs and/or changing drugs in order to cause less harm.

Providing Information

This section addresses the information exchange between the provider and the patient with a disability concerning the provision of information and potential courses of treatment and their implications, including the option of foregoing treatment. This provision indicates that nothing in this section

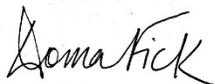
precludes a provider from providing an individual with a disability or their authorized representative with information regarding the implications of different courses of treatment based on current medical knowledge or the best available objective evidence. The rule notes that the ability of a person with a disability or their authorized representative to understand the available options and to make an informed decision about the medical treatment depends in part on the expertise and candor of the treating professionals. The department seeks comment on whether the term “medical treatment” adequately encompasses the range of services that should be covered under this nondiscrimination provision. We believe a better option to be “treatment options” which can encompass, but are not necessarily limited to, medical, surgical, and palliative care.

We also appreciate that the Department realizes that providing regulatory requirements concerning medical treatment requires careful consideration. We agree. For example, there are issues regarding health literacy and capacity that affect obtaining and understanding treatment options and health care information. In situations where patients have low health literacy or lack of capacity, irrespective of their disability status, it is always helpful for patients to have a health care advocate within family/friends.

We encourage the Department to consider how best to integrate these considerations throughout this section of the proposed rule with a particular emphasis on ensuring that the rule supports person-centered decision-making that is aligned with what matters to the person living with a disability.

The AGS appreciates the opportunity to provide the above comments and recommendations. We would be pleased to answer any questions you may have. Please contact Alanna Goldstein, agoldstein@americangeriatrics.org.

Sincerely,



Donna M. Fick, PhD, GCNS-BC, AGSF, FGSA, FAAN
President



Nancy E. Lundebjerg, MPA
Chief Executive Officer