



National Center for Public Policy Research

Able Americans appreciates the opportunity to comment on the proposed HHS rule changes relevant to Discrimination on the Basis of Disability in Health and Human Service Programs or Activities.

Able Americans, a project of the National Center for Public Policy Research, supports Americans living with intellectual, developmental and physical disabilities, advocating for innovative solutions that harness the free market, emphasize individual freedom and choice, and remove barriers to progress.

Context

For fifty years, the Rehabilitation Act (1973) has been the bedrock of regulations and policies directly related to preventing discrimination against people with disabilities. The precepts of the Rehabilitation Act, especially section 504 (1977), provided impetus for significant transformative legislation found in the Individuals with Disabilities Education Act (1975, IDEA) and its subsequent reauthorizations; the Americans with Disabilities Act (1990, ADA) and its amendments (2008); and Section 1557 of the Patient Protection and Affordable Care Act (2010, ACA).

Able Americans welcomes the attention to updating the Rehabilitation Act, which, overdue and necessary, will result in increased protections from discrimination for people with disabilities.

Overall, perhaps the most important aspect of the rule changes relates to their practicality and enhanced relief from discrimination in the real world. Many aspects of the rule changes, if adopted, will provide immediate and detailed clarity in significant areas in the lives of people with disabilities.

Comments on Selected Medical Aspects

There are many bioethical components that span medical bias, inter alia, organ transplantation, life-sustaining treatment, crisis standards of care, denial of medical treatment and value assessment methods. This comment will focus on these 5 areas because as they are more immediately connected to the physical and psychological wellbeing of people with disabilities.

Medical Bias: There is generally a medical bias against people with disabilities that transcends these 5 aspects. While this discrimination is not universal, nor always explicit, these biases are present and potentially significant (1). Where these biases exist, for example, the potential for medical recommendations and decisions for people with disabilities might well be different from those offered to people without disabilities, irrespective of disability characteristics, and would therefore imply discrimination (2). This state of affairs is exacerbated by a distinct lack of

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training in disability issues in medical school curricula (3). However, there seems to be an awareness among medical students that they would benefit from such training (3). Thus, these rule changes will not only lessen discrimination against people with disabilities, but they may encourage medical schools to include disability training in their curricula.

The issue of medical bias relates to the 5 bioethical components outlined above in the following ways:

First, there is universal agreement that the need for organs for transplantation far outstrips the number of available organs (4). This means that serious medical decisions must be made when allocating organs for transplant. As noted in the proposed rules, too often people with disabilities whose disability does not contribute to withholding of a transplanted organ are discriminated against because of the medical bias mentioned above (5). The proposed rule change in this regard can potentially lessen more than eliminate organ transplant biases by increasing awareness of medical bias, and by providing clear vectors for its amelioration. Aside from medical bias, clearer guardrails as noted in the rule change will enhance the voices of people with disabilities in being more proactive in their own decisions around organ transplantation and reduce the probability of organ transplantation discrimination.

Second, life-sustaining treatment is central to people with disabilities living active and productive lives, and the sheer characteristics of some disabilities determine the need for life-sustaining treatments and interventions. As with medical and transplantation biases noted above, the disability community is well aware that they may be offered different life-sustaining treatment or may have treatment denied based solely on the characteristics of their disability. Medical decisions about whether to implement or withhold life-sustaining treatment and interventions interact powerfully with medical bias (above) and the reliance on value assessment methods (below) to potentially deny necessary medical interventions. Implementing this rule has the potential to make people with disabilities more aware of their rights when confronted with inferior care, or in a situation where life sustaining care is denied (6).

Third, as the COVID emergency revealed, crisis standards of care, however well-meaning or necessary, hold the potential for discriminating against people with disabilities. Essentially, crisis standards of care are a form of triage to establish who qualifies for scarce medical resources during a public health emergency. Given their essential function of allocating medical resources in a crisis public health event, there is the potential for allocation decisions to discriminate against people with disabilities (7) given the general medical bias towards people with disabilities. During COVID, many people with disabilities were unable or unwilling to seek needed medical care due to various policies and procedures adopted by health entities.

Furthermore, COVID, by its very nature, determined severe and longstanding standards of care that were perhaps not well thought through as applied to people with disabilities.

Conversely, now that the crisis has passed, and the applicable critical care standards removed, there are anecdotal reports of discrimination and refusal to cooperate when people with disabilities request that health care providers revert to COVID care protocols as protection from

a disabling condition (e.g., autoimmune issues). The rule changes will drive change in this regard, as people with disabilities will not only know their rights under the law when these emergency events occur again, but will hopefully also participate in the planning of future crisis standards of care (8).

Fourth, in terms of denial of medical treatment, people with disabilities often have medical treatment withheld solely based on their disability characteristics, which is clearly discriminatory. Denial of treatment issues related to medical bias and discrimination are not only connected to everyday living, but also a serious concern in end of life care and expensive medical interventions. It is perhaps in end of life care that denial of treatment issues are most pressing, as a medical culture that more frequently embraces futile care blurred with cost-benefit ratios will increasingly embrace utility over the rights of people with disabilities to access certain medical interventions that they rightfully should receive even at the end of their lives (9).

The proposed rule will therefore potentially (a) have a significant effect in curbing denial of care to people with disabilities based solely on their disability characteristics, and (b) promote the medical rights of people with disabilities now further enshrined in law.

Fifth, value assessment methods have the potential to either provide an equitable medical estimate of potential for resource allocation or be used as formalized instruments of bias to discriminate against people with disabilities. Clearly, although widely used, the Quality Adjusted Life Year (QALY) assessment is not recommended, despite calls for overcoming resistance to the method (11).

However, there is an important undergirding principle that defines value assessment methods irrespective of their design: They are designed to dictate allocation of medical resources based on a number of factors, including disability characteristics, as a form of cost-benefit analysis. This has the potential for reducing medical decisions and interventions to a simple, but primary, matter of cost where the cost overshadows all other considerations. The disability community is well aware of the many dehumanizing aspects of healthcare and cold actuarial assessments of cost vs. benefit, which have historically worked against their wellbeing and identity. The rule change will make clear that a better balance must be struck between the medical needs of people with disabilities and issues of cost.

Overarching Issues

Two overarching issues are worth noting:

1. The proposed rule changes relating to the five bioethical components outlined above are most timely not only because they are long overdue, but also because they will help to ease the minds of people living with disabilities regarding their medical care. It is perhaps in this potential scenario that the rule changes discussed above will have their most significant impact.

Many people with disabilities and the wider disability community are acutely aware they often need, as a matter of living productive and secure lives, expensive and comprehensive medical treatment, interventions and on-going care. Many are also aware from their lived experience that they are routinely denied medical care, and in many cases they spend inordinate amounts of time, energy and resources fighting for what is rightfully theirs. As part of that fight they also know that medical bias routinely sees them as having a poor quality of life that, in some circumstances, means they are viewed as less than whole and therefore susceptible to medical and health professionals' tendency to discount their medical needs.

The disability community is further aware that they are often seen as a burden, both in terms of their disability and their cost to society, costs that many think are inappropriate and wasted on people perceived as different. This is especially concerning to people with disabilities when confronted by the increasing dominance of futile care arguments, cost-benefit analyses and the growing acceptance and legalization of assisted suicide (12). There are many anecdotal reports of people with disabilities being subtly or not so subtly pressured to consider assisted suicide not only in states where this is legal, but in states where assisted suicide is not legal.

Further, the disability community in the US is cognizant that assisted suicide laws, as has happened in Europe (13) and Canada (14), will eventually expand to include disability as a category qualifying for assisted suicide

2. Perhaps the most encouraging aspect of the rule changes, across the board, is that aside from obvious updating and harmonizing with other legislation, the rule changes much more fully support the rights of people with disabilities and add legal and policy heft for the disability community to be more fully heard, and to more fully recognize and enshrine what is rightfully theirs as full citizens of the United States. The rule changes also mean that in several important areas, where once difficulties and frustration reigned, there is now greater clarity and detail about how society must accommodate, support, and acknowledge people with disabilities.

As many commenters have noted, these changes are long overdue and necessary, but there is still more work to do. While the rule changes will require enhanced accommodation of people with disabilities, there is still much more to do. While legislation supporting the disability community has made significant progress, there are still too many places where those with disabilities are devalued and perceived as second-class citizens (or worse).

Able Americans appreciates the opportunity to provide this input on selected aspects of the rule changes and congratulates HHS on this important step forward.

Sincerely,

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