



Discrimination on the Basis of Disability...What the Experts are Saying

Recently, the Department of Health and Human Services (HHS) proposed to strengthen prohibitions against discrimination on the basis of disability in health care. Disability advocates banded together to comment on the proposed rulemaking and to call upon HHS to take additional action in banning discriminatory metrics. Let's hear what the experts are saying...

"Discriminatory denials of drugs or other medical interventions are still possible under the evLYG metric, even if that given intervention would provide a clinical benefit and lead to life extension. In addition, as part of its metrics used to assess changes in quality of life, evLYG continues to rely on health utilities that do not properly account for the variety of unique patient preferences and experiences and discriminate against people with disabilities whose perceived ceiling for quality-of-life improvements is limited by the health utility weights. Because the current proposed rule's prohibition focuses solely on the use of those assessment tools that discount the value of life extension on the basis of disability, we have concerns that the rule would not prohibit discrimination occurring under the evLYG metric when being used alone for the purposes of making treatment or coverage decisions." [Consortium for Constituents with Disabilities, Caring Across Nations, and National Disability Rights Network](#)

"No one serious about studying how a treatment improves quality of life would use a generic questionnaire, like those used as an input to the QALY, to rate quality of life over a disease specific tool because the questionnaires use very broad categories to describe quality of life. In fact, the QALY's bias emanates from the reality that people with disabilities are living with different conditions which have different impacts on their quality of life. The QALY metric, by effectively rating treatments by the degree to which they cause a person with a disability's health and physicality to resemble that of a person without a disability, inherently favors people with some kinds of disabilities over people with other kinds of disabilities and treats life lived without a disability as 'ideal.' Additionally, people with disabilities, including those with serious and/or chronic illnesses, do not assign the same values to health gains as people without disabilities." The Center called for "continuous review mechanisms" to assess "other types of disability discrimination" including categorial exclusion, implicit bias, limited representation, economic factors over health, quality of life assumptions, generic application of tools, lack of regular updates, inadequate data, overemphasis of independence, and lack of transparency. [The National Center for Disability, Equity, and Intersectionality](#)

"It is important to differentiate between the use of general population surveys or surveys of doctors from those of patients' own reported symptom improvements. It is also worth pointing out that the questions themselves in such a survey can be biased against people with disabilities." [Disability Rights Oregon](#)

"The final rule should also reflect that any form of cost effective standards that results in discriminatory denials of drugs or other medical interventions for people with disabilities is a form of discrimination and therefore prohibited (for example the evLYG metric)." [ITEM Coalition](#)

“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.” [Autistic Self Advocacy Network](#)

“The evLYG represents a major issue in curbing the use of discriminatory metrics: when key stakeholders become persuaded that a particular metric has adverse effects on healthcare access for a specific patient group, it creates an opportunity for the introduction of a new metric with comparable issues, essentially restarting the entire process.” [Alliance for Aging Research + 45 signatories](#)

“Utility weights used in value assessments, such as the EQ-5D, have also come under scrutiny. These measures often fall short in capturing the nuanced experiences of patients, particularly those with disabilities. The EQ-5D, for instance, might devalue the quality of life for nonambulatory individuals by using standards that equate walking with a higher quality of life”. [HealthHIV and the National Coalition for LGBTQ Health](#)

“Consider a treatment for migraines that greatly improves quality of life, but has no effect on life extension. An assessment tool centered on life extension would show such a treatment to be relatively less cost effective. If such an approach were used for treatment decisions, it could lead to skewed outcomes that systematically discriminate against certain types of disabilities.” [National Health Law Program](#)

“Traditional value assessment frameworks might not adequately capture the full benefits of treatments that lead to functional improvements, especially for individuals with chronic or disabling conditions. These systems might prioritize certain outcomes that may not necessarily reflect the priorities of individuals with disabilities. For instance, an emphasis on complete cure as an ultimate positive outcome might undervalue treatments that provide significant functional improvements but stop short of a complete cure.” [National Health Council](#)

“In addition, as part of its metrics used to assess changes in quality of life, evLYG continues to rely on health utilities that do not properly account for the variety of unique patient preferences and experiences and discriminate against people with disabilities whose perceived ceiling for quality-of-life improvements is limited by the health utility weights. Because the current proposed rule’s prohibition focuses solely on the use of those assessment tools that discount the value of life extension on the basis of disability, we have concerns that the rule would not prohibit discrimination occurring under the evLYG metric when being used alone for the purposes of making treatment or coverage decisions.” [National Disability Rights Network](#)

“...HHS should advance a final rule that uses language consistent with Section 1182(e) of the Affordable Care Act. Doing so would: Be consistent with current developments and laws and discourage confusion; Allow for consideration of how value assessments may discriminate by classifying people with disabilities as inferior whether in measures of life extension or in quality-of-life improvement; Be consistent with NIH efforts to address ableist assumptions about quality of life that may also drive value assessments; Spur meaningful innovation in the development and use of measures of quality of life and improvement that do not discriminate based on the assumed ‘worth’ of patients with disabilities to treat.” [Partnership to Improve Patient Care and 100 signatories](#)