

October 31, 2022

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Dr. Kevin Olson, Chair, MD
Health Policy & Analytics Division
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Health Evidence Review Commission
500 Summer St. NE, E-65
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Re: Public Comment on Draft Policy Statement on HERC Use of Quality Adjusted Life Years

Dear Dr. Olson,

I am writing as a member of the public, and as the father of two Medicaid-eligible children with disabilities, to provide comment on the Draft Policy Statement on HERC Use of Quality Adjusted Life Years.

I oppose both of the two options proposed for consideration.

As the Hon. Tony Coelho – author of the Americans with Disabilities Act – testified on October 6, “the use of discriminatory metrics does not serve a purpose” – even in the approach outlined in Option 1, where QALYs are only used “to compare treatments for the same population.” The QALY metric is inherently biased, and uses perceptions from non-disabled people about the value of the life of a person with disabilities.

Further, the assertion in Option 1 that “QALYs will not inform scoring used to rank lines for the Prioritized List” won’t really be true in practice – if QALYs are used in any way to determine what services are included on a list, or guidance notes for how services on the list are to be covered, then any service that is not included (or excluded in part based on guidance notes) is automatically ranked “below the line” and is excluded from coverage.

Option 2 – where QALYs aren’t discussed openly at Commission meetings, and references to QALYs are redacted – simply hides use of QALYs from public view, if Commission reports are based on research findings derived from use of QALYs. Hiding this use of QALYs from public view by redacting them may also violate ORS 192.314, Right to inspect public records.

Instead of moving quickly to adopt one of these two options, I urge you to convene an expert panel representing the disability community at its next meeting, and then to work with stakeholders.

Ultimately, HERC should instead adopt a policy explicitly renouncing use of discriminatory measures such as QALYs, such as this:

“Prohibition on Reliance on Discriminatory Measures. The Oregon Health Evidence Review Commission shall not develop or utilize, directly or indirectly, in whole or in part, through a contracted entity or other third-party, a dollars-per- quality-adjusted life year or any similar measures or research in determining whether a particular health care treatment is cost-effective, recommended, the value of a treatment, or in determining coverage, reimbursement, appropriate payment amounts, cost-sharing, or incentive policies or programs.”

To recap the background on this issue, Oregon’s initial Medicaid waiver application was denied in 1992 on grounds that “Oregon’s plan in substantial part values the life of a person with a disability less than the life of a person without a disability. This premise is discriminatory and inconsistent with the Americans with Disabilities Act.” (I have provided a copy of this HHS denial letter to the HERC staff).

Nevertheless, Oregon has consistently used discriminatory “Quality Adjusted Life Year” (QALY) metrics as a factor in ranking services on the prioritized list. QALY is a tool that estimates the value of a treatment according to years of additional life – discounted by the level of disability. This approach places a lower value on years of life for those with disabilities – such as my children – than on years of life for people without disabilities – and is inherently discriminatory.

Over the past year, I have studied the Oregon Health Plan’s use of QALY metrics in detail, and have met with senior OHA leadership for input. Here are my initial observations:

- Oregon Health Authority records show that when the US Department of Health and Human Services directed Oregon NOT to use the QALY metric in 1992, on grounds that it violated the Americans with Disabilities Act, the HRC simply worked around this by voting to adopt essentially the same discriminatory results derived from the QALY-based formula.¹
- Despite Federal guidance to the contrary, Oregon continued to use the QALY as an explicit input in the “cost effectiveness” factor in the prioritization formula until 2017
 - Most of the condition-treatment pairs now on the list continue to be ranked using the old QALY-based factor
- HERC continues to rely upon QALY-based cost effectiveness reports from ICER, NICE, and other organizations. When staff prepare summaries of those reports for the commissioners, they frequently cite and call attention to the QALY scores, as is clearly documented in meeting materials
- Other factors in the formula, such as “Impact on Healthy Life” closely resemble the QALY concept. When HERC commissioners vote on these factors, they do so immediately after reviewing staff briefings and reports with QALY scores

¹ Bob DiPrete and Darren Coffman, “A Brief History of Health Services Prioritization in Oregon,” Oregon Health Authority, March 2007. <https://www.oregon.gov/oha/HPA/DSI-HERC/Documents/Brief-History-Health-Services-Prioritization-Oregon.pdf>

When the Oregon Health Plan ranks services on the prioritized list, using QALYs in any way, it engages in discrimination against individuals in violation of the Americans with Disabilities Act and contrary to the mission of the Oregon Health Policy Board to promote health equity.

As the U.S. Department of Health and Human Services wrote to the State of Oregon in 1992, there are many ways that Oregon can allocate medical resources without violating the ADA:

“Of course, there is a wide range of factors that Oregon may consider in allocating medical resources consistent with the ADA. These factors include, but are not limited to, the cost of medical procedures, the length of hospital stays, prevention of death, and prevention of contagious diseases. In general, Oregon may consider, consistent with the ADA, any content neutral factor that does not take disability into account or that does not have a particular exclusionary effect on persons with disabilities.”

Please work with the disability policy community to revise your processes and adopt methods that are not discriminatory, and comply with civil rights protections.

Sincerely,

/s

Paul Terdal