

May 12, 2021

Mr. Andrés J. Gallegos  
Chairman  
National Council on Disability  
331 F Street, NW, Suite 850  
Washington, DC 20004

Dear Chairman Gallegos:

As chair of the Partnership to Improve Patient Care and the original author of the Americans with Disabilities Act (ADA), I am writing to you, your Board and the staff of the National Council on Disability (NCD) to applaud its timely work and thoughtful recommendations. From one administration to the next, the NCD has always brought to policymakers a policy perspective that uniquely represents people with disabilities. Your work has always been important, but in this moment it has proved to be more essential than ever.

When the NCD published its Bioethics Series in 2019, we did not know a pandemic was coming. Yet, those publications described how the lives of persons with disabilities continue to be devalued in medical decision-making, and the stigma and negative bias that is pervasive, causing disparate treatment with often deadly consequences. Those publications provided a well-researched call to action on issues that those of us in the disability may have known based on our experiences, but that policymakers needed to learn and understand in order not to further promote health inequities by stoking stigma and bias in policy.

During the pandemic, NCD took this knowledge and tirelessly fought to communicate the perspectives of people with disabilities to Congress and the administration. The patient and disability communities appreciate your work to educate state and federal administrators about civil rights laws and disability policy so that discriminatory Crisis Standards of Care were amended to ensure fair allocation of health resources in a shortage, as well as your efforts to ensure equitable vaccine distribution. We also appreciate your input to Congress related to the priorities of the disability community for COVID-19 legislation, particularly for home and community-based services that are essential to ensure access to critical services now, during the pandemic, and later, once the pandemic ends.

We appreciate that the NCD has continued a steady drumbeat of concern about the use of quality-adjusted life years (QALYs) in federal health programs. The NCD's report in 2019 provided a comprehensive overview of the QALY metric and the discriminatory implications of its use, as we have seen in foreign countries. Since that report, we appreciate that the NCD has consistently expressed concerns about referencing prices in foreign countries that rely on QALYs, whether in the form of an International Pricing Index, a Most Favored Nation policy, or

the recently reintroduced H.R. 3. *As part of your ongoing work, we hope that NCD will also study the use of QALYs in the development of formularies for the Veterans Health System, as well as Tricare, where QALY-based studies are used to inform formulary development.*

The case of Michael Hickson in Texas, an African American man in a wheelchair who was denied COVID-19 care, sickened all of us, as you discussed in your Health Affairs article recently. The subjective judgement that any person with a disability does not have a life worth saving should scare us all. As you may know, the National Minority Quality Forum, PIPC and sickle cell patient advocates partnered to conduct a landscape review of the literature on how traditional value assessments exacerbate health inequities.<sup>1</sup> We believe that more work needs to be done to provide a full picture and understanding of the inherent bias of discriminatory metrics used in health care decision-making, and how they promote the stigma that disabled lives, especially in communities of color, do not have a quality of life worth saving. *It is our hope that NCD will make it a priority to study and help policymakers understand the intersection of race and disability, and the heightened stigma and bias that then lead to exacerbated health inequities.*

As you begin your quarterly meeting on May 13, 2021, please know your thoughtful work to bring forward the disability perspective is very much appreciated by all of us – people with disabilities, chronic conditions, and older adults - who are protected under civil rights law and disability policy. The enforcement of those laws and policies is essential.

Thank you for your work and please reach out to me anytime I can be helpful.

Sincerely,



Tony Coelho  
Chairman, Partnership to Improve Patient Care

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<sup>1</sup> See <https://www.nmqf.org/nmqf-media/traditional-value-assessment-methods>