



THE NATIONAL CATHOLIC BIOETHICS CENTER

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SUGGESTIONS FOR SPECIFIC LANGUAGE THAT COULD BE ADDED TO THE PROPOSED REVISIONS TO THE NIH MISSION STATEMENT, WITH RATIONALE

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November 24, 2023

On behalf of the National Catholic Partnership on Disability (NCPD), the National Association of Catholic Nurses, USA (NACN-USA), The Catholic Medical Association (CMA), and The National Catholic Bioethics Center (NCBC), we welcome this opportunity to impact a revision of the NIH Mission Statement. We share concerns for threats to the innate dignity of every human being, especially those with disabilities as well as marginalized persons. Such populations are very vulnerable to the growing trend at the state level to legalize physician assisted death. Thus, we recommend restoring the express goal to “lengthen life” into the NIH mission statement. The proposed deletion of these words may risk giving the public the incorrect impression that NIH works to preserve the “quality of life” but not also life itself, a situation in which the lives of some individuals would “count” more than those of others, based on the determination of some authority. Other federal policies have provided protection from coercion to embrace such policies, e.g., the *Affordable Care Act*. [Section 1553] NIH should also. Such a deletion is especially problematic considering the proposed new mission statement’s deletion of “disability” as well. We understand that the deletion of “disability” itself was proposed upon the recommendation of the Advisory Committee’s Subgroup on Individuals with Disability as a means of increasing inclusivity. The report of that same subgroup that made that recommendation, however, also proposed language that retained the words “lengthen life.” See Report of the Subgroup on Individuals with Disabilities, Advisory Committee to the Director Working Group on Diversity, NIH, Dec. 1, 2022, p. 15 (stating “The NIH should revise the mission statement to be, ‘To seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to enhance health, lengthen life, and reduce illness.’”).

The deletion of the words “lengthen life,” itself problematic and seemingly unexplained in the notice and request for information, risks significantly altering the meaning of the deletion of “disability,” compounding the problematic nature of the deletion of “lengthen life.” In other words, we are deeply concerned that the proposed deletion of “lengthen life,” especially considering the proposed deletion of “disability,” risks promoting a value system in which the lives of individuals with disabilities are discounted on account of perceived, problematic notions of “quality of life.” This would, in fact, directly contradict the “Discrimination on the Basis of Disability” regulations recently proposed by HHS under Section 504 of the Rehabilitation Act. Such a proposal, among other things, condemns and seeks to

remedy real and prevalent biases in the health care system that undervalue the quality of life of persons with disabilities and thereby discriminate against such persons even in matters of access to health care, and life and death. See 88 Fed. Reg. 63392, et seq.

In order to protect the equal valuation of lives of human beings from discrimination in the health care system, and to not contradict HHS's own proposed regulations, NIH's proposed mission statement amendments should restore "lengthen life" as an express goal. Additionally, since the number of persons with a disability will only increase, with the number of "Baby Boomers" aging, the threat of the potential for biases and discrimination impacting access to care is real. It cannot be ignored in public policy. While perhaps the existing terminology in the Mission Statement "to ... reduce ... disability," does seem inartful to what should be a goal, we would offer a potential alternative, such as "alleviate the impact of disability." This is a more realistic and clearly needed goal. Also, other federal policies have provided protection from coercion to embrace physician assisted death policies, e.g., the Affordable Care Act. [Section 1553]. NIH should also. Thank you for your time and consideration.

Sincerely yours,




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