

November 24, 2023

Submitted via website (<https://rfi.grants.nih.gov/?s=64caaa8bb1112e46ad0a1d52>)  
and via email ([RFIMissionStatement@nih.gov](mailto:RFIMissionStatement@nih.gov))

Office of the Director  
National Institute of Health  
9000 Rockville Pike  
Bethesda, Maryland 20892

**Re: EPPC Scholars' Comment on Proposed Update to NIH Mission Statement,  
Notice Number: NOT-OD-23-163**

Dear Director Bertagnolli:

I write in response to the National Institutes of Health's ("NIH") Request for Information: Inviting Comments and Suggestions on Updating the NIH Mission Statement, NOT-OD-23-163 ("RFI"). My name is Eric Kniffin. I am a scholar at the Ethics and Public Policy Center (EPPC), where I serve as part of its HHS Accountability Project. I am also a practicing attorney and previously served in the U.S. Department of Justice's Civil Rights Division.

NIH's current mission identifies four goals it hopes to achieve: enhance health, lengthen life, reduce illness, and reduce disability. NIH denies that its proposal to drop "reduce disability" indicates a change in priorities: it says that this merely reflects its sensitivity to the perception that this wording suggests that "disabled people are flawed and need to be 'fixed.'" I accept that statement at face value. However, NIH's RFI says nothing about why it is proposing to drop "lengthen life" from its mission statement. My comment is directed at this aspect of NIH's proposal.

For the reasons set out below, I ask NIH to modify its proposed new mission statement and maintain its commitment to lengthening life. In the alternative, I ask that NIH publicly explain why it is proposing to drop this aspect of its mission and what this change would mean to the agency's goals and priorities.

## **BACKGROUND**

### **A. The NIH's current and proposed mission statements.**

NIH has requested input regarding proposed changes to its mission statement. The RFI states that NIH is seeking feedback "to ensure" that its "efforts to update its mission statement" "reflect[] the NIH mission as accurately as possible."

The current NIH mission statement and its proposed new mission statement read as follows, with new language set out in bold text:

## **CURRENT MISSION STATEMENT:**

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 and disability.

## **NIH PROPOSAL:**

To seek fundamental knowledge about the nature and behavior of living systems and to **apply** that knowledge **to optimize health and prevent or reduce illness for all people.**

**B. According to the RFI, the proposed changes to NIH’s mission statement is based only feedback the agency received from a working group on individuals with disabilities.**

The RFI lists only one impetus for the proposed mission statement: the feedback it has received from its Advisory Committee to the Director Working Group on Diversity, Subgroup in Individuals with Disabilities.<sup>1</sup> The RFI cites a report issued by this subgroup in December 2022.<sup>2</sup> The report includes a list of nine suggestions; the first is that NIH update its mission statement:<sup>3</sup>

One immediate action for the NIH to support disability inclusion is to remove the language of “reducing disability” from the NIH mission statement. The current mission statement could be interpreted as perpetuating ableist beliefs that disabled people are flawed and need to be “fixed” (Appendix B). 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.”<sup>4</sup>

The proposed NIH mission statement differs from the recommendation provided by the Working Group, which merely suggested removing the words “and disability.”

**C. The RFI offers no explanation for why it has proposed removing “lengthen life” from its mission statement.**

Nothing in the RFI or in any sources cited or referenced in the RFI explain why the NIH is proposing to abandon its current commitment to “lengthen life.”

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<sup>1</sup> NIH, Advisory Committee to the Director Working Group on Diversity, Subgroup on Individuals with Disabilities, <https://www.acd.od.nih.gov/working-groups/disabilitiessubgroup.html>.

<sup>2</sup> National Institutes of Health, Advisory Committee to the Director Working Group on Diversity, Subgroup on Individuals with Disabilities, *Report*, Dec. 1, 2022, [https://www.acd.od.nih.gov/documents/presentations/12092022\\_WGD\\_Disabilities\\_Subgroup\\_Report.pdf](https://www.acd.od.nih.gov/documents/presentations/12092022_WGD_Disabilities_Subgroup_Report.pdf).

<sup>3</sup> *Id.* at 8.

<sup>4</sup> *Id.* at 14-15.

## RESPONSE TO RFI

### A. Feedback on whether the proposed new mission statement reflects the goals and objectives as outlined in the NIH-Wide Strategic Plan for Fiscal Years 2021-2025<sup>5</sup>

The proposed mission statement is out of sync with the NIH-Wide Strategic Plan because the Plan states that the NIH is committed to lengthening life,<sup>6</sup> while the proposed mission statement does not repeat this commitment. The Strategic Plan in many places touts the NIH's role in developing advancements that have or promise to prevent premature deaths. Some notable examples include the following (with bold text added for emphasis):

- NIH claims that the findings from its Systolic Blood Pressure Intervention Trial have “helped change the national guidelines for treating hypertension, which . . . [i]f successfully adopted into clinical practice across the U.S., [] are expected to **prevent about 107,500 deaths** per year. . . .”<sup>7</sup>
- The Plan also touts NIH-supported suicide prevention research, noting that “suicide remains one of the top-10 leading causes of death in the U.S., **claiming the lives of more than 48,000** people each year.”<sup>8</sup> It notes that “NIH-supported researchers are testing brief interventions and follow-up care to prevent recurring self-harm and related comorbidities, such as substance use disorder.”<sup>9</sup>
- The Plan notes NIH's involvement in the development of a new cystic fibrosis treatment: “Now, **instead of being a fatal disease**, there is promise that cystic fibrosis in many individuals could soon be a chronic condition that **can be managed over a lifetime**.”<sup>10</sup>
- NIH has launched the “Helping to End Addiction Long-term (HEAL) Initiative, an aggressive, NIH-wide effort” to address “opioid misuse and addiction,” “a rapidly evolving U.S. public health crisis.”<sup>11</sup> The Plan notes that “**more than 46,000 Americans died of opioid overdose**” in 2018 alone, “making it one of the most common causes of **non-disease-related deaths** for adolescents and young adults.”<sup>12</sup>
- Finally, the Plan touts that NIH is “transforming treatment of sickle cell disease”<sup>13</sup> with work that could offer “a cure to the approximately **100,000 people in the U.S.**”

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<sup>5</sup> National Institutes of Health, NIH-Wide Strategic Plan: Fiscal Years 2021-2025, <https://www.nih.gov/sites/default/files/about-nih/strategic-plan-fy2021-2025-508.pdf>.

<sup>6</sup> *Id.* at vii, 1.

<sup>7</sup> *Id.* at 9.

<sup>8</sup> *Id.* at 9.

<sup>9</sup> *Id.*

<sup>10</sup> *Id.* at 12.

<sup>11</sup> *Id.* at 14.

<sup>12</sup> *Id.*

<sup>13</sup> *Id.* at 15.

**and 20 million globally** who suffer severe pain and **premature death** from this condition.”<sup>14</sup>

As I have noted, NIH has not explained why it wants to abandon its present commitment to “seek fundamental knowledge about the nature and behavior of living systems and the application of that knowledge to . . . lengthen life.” As such, it is difficult to reach any certain conclusions about how NIH’s proposal to abandon this mission would change its commitment to the aspects of the Strategic Plan highlighted above.

When NIH’s current mission was fixed, the agency set its sights on four separate goals: it would seek out knowledge that would “enhance health,” “reduce illness,” “reduce . . . disability,” *and* “lengthen life.” Now NIH proposes to keep the first two but drop the others.

If enhancing health and reducing illness encompasses lengthening life, why has NIH listed it as a separate goal until now? If NIH is proposing to drop “lengthen[ing] life” as a goal, what does that indicate about its new priorities? Would this new mission statement affect NIH’s commitment to lowering “premature deaths”? Would this affect any of the specific goals or projects from the Strategic Plan identified above?

Unfortunately, NIH offers nothing to assuage concerns its proposed mission statement raises. Without any explanation or reassurance from NIH, the public may reasonably conclude that the proposed new mission statement would signal that NIH is no longer seeking to prolong life with the same zeal and focus.

**B. Suggestions for specific language that could be added to the proposed mission statement and why.**

The easiest way for the NIH to address the problem identified above would be to maintain its current commitment to “lengthen life.” This would affirm that NIH still believes that human life is an objective good that is worth preserving. It would also advance NIH’s stated goal of rebutting the belief “disabled people are flawed” and their lives are worth less than non-disabled people.

As I noted in a recent public comment to HHS, one of the ways that disabled persons are discriminated against is in the assisted suicide context.<sup>15</sup> Assisted suicide is now legal in ten states and the District of Columbia, almost all of which are under Democratic control.<sup>16</sup> It would be most unfortunate if NIH were changing its mission statement in order to support, or to avoid conflict with, political allies that have legalized assisted suicide.

Though proponents of assisted suicide promise that “strict procedures” ensure that assisted suicide is only available to a small subset of the population, that is not what has happened in practice. Last year in Canada the number of assisted deaths jumped more than thirty percent, accounting for 4.1% of all deaths.<sup>17</sup>

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<sup>14</sup> *Id.* at 35.

<sup>15</sup> EPPC, *EPPC Scholar and Others Comment on HHS Proposed Rule on Disability Rights*, Nov. 14, 2023, <https://eppc.org/news/eppc-scholar-and-others-comment-on-hhs-proposed-rule-on-disability-rights/>.

<sup>16</sup> See Compassion and Choice, *States where Medical Aid in Dying is Authorized*, <https://www.compassionandchoices.org/resource/states-or-territories-where-medical-aid-in-dying-is-authorized>.

<sup>17</sup> Benjamin Lopez Steven, *Number of assisted deaths jumped more than 30 per cent in 2022, report says*, CBC News, Oct. 27, 2023, <https://www.cbc.ca/news/politics/maid-canada-report-2022-1.7009704>.

There is reason to believe that medical providers are especially likely to relax their assisted suicide protocols when patient is disabled. This concern is highlighted by a pending lawsuit in California, filed last April. A website put together by people associated with the lawsuit states the following:

**In [states that have legalized assisted suicide], there is a two-tiered system of law and medicine, where a medical professional would be subject to civil and professional liability if they did not provide non-disabled people or people with non-life-threatening disabilities suicide prevention, according to the standard of care, if those people expressed a desire to harm or kill themselves in a medical setting. If those same professionals actually helped the person kill themselves by providing the means, i.e., a prescription for a lethal dose of drugs, that medical professional would also be criminally liable under manslaughter statutes for helping another person die by suicide.**

People with life-threatening disabilities, however, are not afforded the same criminal, civil, and professional liability protections as everyone else where assisted suicide is on the books. **When they get suicide assistance on the basis of their disability, namely the condition that is given a 6-month or less prognosis, this is treating members of a protected class in a different way than everyone else, thereby violating the anti-discrimination law that protects the civil rights and inherent equal human dignity of people with disabilities.**<sup>18</sup>

Additionally, last May researchers published the largest study yet of how physician-assisted suicide is carried out in people with intellectual disabilities and/or autism spectrum disorders. The study of 39 Dutch case reports over a decade yielded the following chilling results:

**Factors directly associated with intellectual disability and/or ASD were the sole cause of suffering described in 21% of cases and a major contributing factor in a further 42% of cases.** Reasons for the EAS request included social isolation and loneliness (77%), lack of resilience or coping strategies (56%), lack of flexibility (rigid thinking or difficulty adapting to change) (44%) and oversensitivity to stimuli (26%). In one-third of cases, physicians noted there was 'no prospect of improvement' as ASD and intellectual disability are not treatable.<sup>19</sup>

As these sources show, individuals with disabilities are often pressured and coerced into preemptively ending their lives to avoid the alleged “burden” (financial or otherwise) they pose on their family or society. Assisted suicide laws may also give insurance companies perverse financial incentives to push assisted suicide as a cheaper alternative to the ongoing, expensive medical care that is often required to maintain disabled persons’ quality of life. When physicians help a person commit suicide, they violate their oath to “do no harm” and corrupt the medical profession. Moreover, if NIH abandons its commitment to lengthening the lives of disabled persons, it is likely that NIH and the medical establishment more generally will stop committing resources that will help improve disabled persons’ quality of life.

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<sup>18</sup> End Assisted Suicide, <https://endassistedsuicide.org/> (emphases added).

<sup>19</sup> Irene Tuffrey-Wijne, et al, *Euthanasia and physician-assisted suicide in people with intellectual disabilities and/or autism spectrum disorders: investigation of 39 Dutch case reports (2012-2021)*. *BJPsych Open*. 2023 May 23;9(3):e87, [doi: 10.1192/bjo.2023.69](https://doi.org/10.1192/bjo.2023.69) (emphasis added).

By retaining the goal of lengthening life, the NIH would help push back against the dangerous and incorrect belief that some people—and persons with disabilities in particular—are better off dead.

**C. Feedback on any specific language that could be removed from the proposed mission statement and why.**

I do not have any specific concerns with any of the goals currently stated in the NIH proposed mission statement. The concerns identified above would be best addressed by adding language to the proposed mission statement, not by removing any more language from it.

**CONCLUSION**

For the reasons stated, I urge NIH to maintain its current commitment to lengthening human life. This is an important goal that protects human dignity for all Americans, but most especially those with disabilities. At the very least, before NIH finalizes the proposed mission statement, it ought to state publicly why it has proposed to drop the goal of lengthening life and explain why this change in mission is in the public interest.

Sincerely,

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