The Marianjoy community has been committed to advocacy for people with disabilities since its founding. It is from this lens that we are requesting that Northwestern Medicine take an official stance against physician assisted suicide/medical aid in dying before the Illinois state legislature reviews proposed legislation in late September or early October 2023. The reasons for this request are summarized in an attached document prepared by the National Council on Disabilities (NCD) in 2019.

The NCD, founded in 1984, is comprised of presidentially and congressionally appointed Council Members who are the federal voice for the over 61 million Americans with disabilities across the country. NCD has long opposed assisted suicide laws. In 1997, after a thorough review of the forms of discrimination against people with disabilities experienced in American society, the NCD issued a document entitled *Assisted Suicide: A Disability Perspective*, opposing legalization of assisted suicide, concluding that the evidence indicated that the interests of the few people who would benefit from assisted suicide were "heavily outweighed by the probability that any law, procedures, and standards that can be imposed to regulate physician-assisted suicide will be misapplied to unnecessarily end the lives of people with disabilities". In 2019 an updated full report was prepared which confirmed the prior study's conclusions.

On the basis of all of this evidence, Instead of legalizing assisted suicide, the Marianjoy community joins the NCD in calling for a comprehensive, fully-funded, system of assistive living services for people with disabilities.

A copy of the full 2019 report is attached, but in summary, the NCD's recent research reveals extensive significant and dangerous policy and procedural flaws in existing and proposed laws which have become ever-more apparent over the almost 30 years since Oregon legalized assisted suicide in 1994.

Dr. Lisa Lezzoni, with Harvard Medical School and her colleagues, published a study in *Health Affairs* in February 2021, which found that over 82% physicians nationwide view people with significant disabilities as having a low quality of life. An October 2022 follow-up study conducted by Dr. Lezzoni and her colleagues, also published in *Health Affairs* documented conversations with physicians under the cloak of anonymity wherein they revealed their preference not to treat people with disabilities; admitting sending them to cattle processing plants, supermarkets, zoos and grain elevator facilities to get weighed; and telling people with disabilities that their practices are closed and not accepting new patients, when in fact they are open and accepting new patients, *but not those with disabilities.*

Diane Coleman, president and founder of Not Dead Yet, a grassroots disability organization opposed to legalizing assisted suicide, noted that the public image of severe disability as a fate worse than death . . . become[s] grounds for carving out a deadly exception to longstanding laws and public policies about suicide [prevention] services.

Legalizing assisted suicide means that some people who say they want to die will receive suicide intervention, while others will receive suicide assistance. The difference between these two groups of people will be their health or disability status, leading to a two-tiered system that results in death to the socially devalued group.

In addition, studies show an increased rate of general suicide in states where assisted suicide is legal. In Oregon, government reports show a statistical correlation between assisted suicide under the Oregon law and an increase in other suicides. Before Oregon legalized assisted suicide, its suicide rate was similar to the national average. Yet by 2010, Oregon's suicide rate was 41 percent above the national average, and 16 in states overall, assisted suicide laws are associated, on average, with a 6 percent increase in a state's total suicide rate.

The NCD also examined information from 20 years of annual reports from Oregon's experience with their law and found many disturbing trends. Of note, the top five reasons doctors give for their patients' assisted suicide requests are not pain or fear of future pain—that alone is noteworthy—but psychological issues that are all-too-familiar to the disability community: "loss of autonomy" (95.5 percent), "less able to engage in activities" (94.6 percent), "loss of dignity" (87.4 percent), "losing control of bodily functions" (56.5 percent), and "burden on others" (51.9 percent).

These "reasons" are not directly gathered from the individuals themselves, but are gathered from proxies (their doctors) after assisted suicides have already occurred, which means there is no way of validating the reports, which could be a source of error. The mere fact that the reporting forms include these particular check boxes as options to express one's reasons means that they were viewed as acceptable from the beginning of the laws' implementation, and yet they are all uninformed expressions of common disability-related experiences. By rendering them acceptable explanations for requesting assistance in one's suicide, these laws are communicating dangerous, *discrimination-filled messages to people with disabilities and the public* that common disability experiences, like requiring assistance with personal care activities, are understandable and acceptable grounds for ending one's life. There is a clear double standard in suicide prevention efforts where people with disabilities are not referred for mental health treatment when seeking assisted suicide, while people without disabilities receive such referrals.

The recent NCD report further points out: *Assisted suicide laws contain provisions intended to safeguard patients from problems or abuse. However, research for this report showed that these provisions are ineffective, and often fail to protect patients in a variety of ways, including*:

- Insurers have denied expensive, life-sustaining medical treatment but offered to subsidize lethal drugs, potentially leading patients toward hastening their own deaths.
- Misdiagnoses of terminal disease can cause frightened patients to hasten their deaths.
- People with the disability of depression are subject to harm where assisted suicide is legal.
- Demoralization in people with disabilities is often based on internalized oppression, such as being conditioned to regard help as undignified and burdensome, or to regard

disability as an inherent impediment to quality of life. Demoralization can also result from the lack of options that people depend on. These problems can lead patients toward hastening their deaths—and doctors who conflate disability with terminal illness or poor quality of life are ready to help them. Moreover, most health professionals lack training and experience in working with people with disabilities, so they don't know how to recognize and intervene in this type of demoralization.

- Financial and emotional pressures can distort patient choice.
- Assisted suicide laws apply the lowest culpability standard possible to doctors, medical staff, and all other involved parties, that of a good-faith belief that the law is being followed, which creates the potential for abuse.
- There is a substantial lack of data about assisted suicide, due not to lack of research, but to unnecessarily strict privacy and confidentiality provisions in assisted suicide laws.
- Where assisted suicide is legal, states have no means of investigating mistakes and abuse, nor even a complaint mechanism for the public to report suspected problems.
- Assisted suicide laws require no evidence of consent when the lethal drugs are administered.
- Trends show that the minimal amount of data collection that was mandated by earlier state laws is decreasing over time as some newer states adopt less restrictive assisted suicide laws.

Although the slippery slope has been described as a fallacious argument, the history of such laws here in the United States and around the world actually prove that it is true.

Conclusion

Instead of legalizing assisted suicide, the Marianjoy community joins the National Council on Disabilities in calling for a comprehensive, fully funded system of assistive living services for people with disabilities, that medical providers inform patients seeking assisted suicide of these supports; and that medical providers receive training in disability competency and disability-risk factors for suicide.

Northwestern Medicine Marianjoy Rehabilitation Hospital
Ethics Committee

NCD_Assisted_Suicide_Report_508.pdf