



## Medical Futility and Disability Bias

Part of the Bioethics and Disability Series



National Council on Disability

November 20, 2019

National Council on Disability (NCD)  
1331 F Street NW, Suite 850  
Washington, DC 20004

***Medical Futility and Disability Bias: Part of the Bioethics and Disability Series***

National Council on Disability, November 20, 2019

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## National Council on Disability

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An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

### Letter of Transmittal

November 20, 2019

The President  
The White House  
Washington, DC 20500

Dear Mr. President:

On behalf of the National Council on Disability (NCD), I am pleased to submit *Medical Futility and Disability Bias*, part of a five-report series on the intersection of disability and bioethics. This report, and the others in the series, focuses on how the historical and continued devaluation of the lives of people with disabilities by the medical community, legislators, researchers, and even health economists, perpetuates unequal access to medical care, including life-saving care.

When a physician decides that providing or continuing health care treatment would be “medically futile” to a patient, there are a number of objective, evidence-based factors that can impact this decision. Underrecognized, however, is that a physician’s subjective judgments about whether a patient’s life would be “worth living” should they receive treatment and survive, can also play a role in decision making. This latter consideration is a frightening concept for many people with disabilities because some health care providers, most unknowingly, harbor biases and misperceptions about the quality of life and capacities of people with disabilities. These assumptions can and have impacted physicians’ willingness to provide or continue life-sustaining care to a patient that has, or will have if they survive, a disability classified as medically “severe.”

In recent years, there has been a push to regulate medical futility decisions on the state and institutional levels. State laws, which vary greatly in their content and approach, define the protections, or lack thereof, of a patient’s wishes to receive life-sustaining treatment. Hospitals have turned to process-based approaches, utilizing internal ethics committees to arbitrate medical futility disputes. Despite the increased attention, however, disability bias still finds its way into futility decision making.

The lives of people with disabilities are equally valuable to those without disabilities, and health care decisions based on devaluing the lives of people with disabilities are discriminatory. *Medical Futility and Disability Bias* provides an overview of the multiple perspectives on medical futility decisions relating to people with disabilities and analyzes how state and federal laws can be strengthened to prevent disability bias from impacting critical care decisions. It shows that additional protections are needed to ensure that a patient’s wishes are followed; their life-sustaining treatment is not removed pending transfer to another facility; and, in the absence of their competency and advance directive, a neutral, unbiased, and independent decision-making body is in place. It concludes by outlining recommendations that can remedy such discrimination.

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NCD stands ready to assist the Administration, Congress, and federal agencies to ensure that people with disabilities do not face discrimination in accessing life-saving medical care.

Respectfully,

A handwritten signature in black ink that reads "Neil Romano". The signature is written in a cursive style with a large initial "N" and a long, sweeping underline.

Neil Romano  
Chairman

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(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate and the Speaker of the U.S. House of Representatives.)

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## Acknowledgments

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# Executive Summary

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## Purpose

Over the past three decades, medical futility decisions by healthcare providers—decisions to withhold or withdraw medical care deemed “futile” or “nonbeneficial”—have increasingly become a subject of bioethical debate and faced heavy scrutiny from members of the disability community. Negative biases and inaccurate assumptions about the quality of life of a person with a disability are pervasive in US society and can result in the devaluation and disparate treatment of people with disabilities. Health care providers are not exempt from these deficit-based perspectives, and when they influence a critical care decision, the results can be a deadly form of discrimination.

This report addresses the following ethical and legal questions: Who should have ultimate decision-making authority to withdraw or withhold lifesaving or life-sustaining care to patients? What criteria should be used to define and identify when a medical treatment is “futile”? What procedures should be followed in the decision-making process? How can healthcare providers improve their understanding of the value of life with a disability? How can the medical futility decision process be reshaped to eliminate biases and ensure that the rights of all patients, regardless of disability, are equally effectuated?

## Background

The debate over the appropriate use of medical futility decisions has a long, tumultuous history. While the concept of withholding or withdrawing ineffective care dates back to at least 400 BC, the contemporary debate took off in the 1980s, following a period of prolific development of advanced medical technology, changes to the US healthcare reimbursement system, and evolving concepts of patient autonomy. Increasingly, physicians began to question whether it was appropriate to use invasive, often expensive technology on patients they believed could not benefit from it. On the opposing side of the debate, however, were disability and patient rights advocates, who grew concerned with how medical futility decisions would be made for patients with existing or newly acquired disabilities.

Disability and patient rights advocates, among others, argue that medical futility decisions often lack objectivity and procedural safeguards, leaving room for the physician’s recommendation to be impacted by biases about the quality of life of people with disabilities. It has been well-documented that healthcare providers significantly undervalue life with a disability, in part because most medical education does not include accurate information on the lived experiences of people with disabilities. As a result, healthcare providers

remain largely unaware of the high quality of life and happiness that many people with disabilities experience. This lack of awareness has impacted medical futility decision making and, in some cases, robbed people with disabilities of their chance to recover.

## Key Findings

- Healthcare providers have been criticized for allowing medical futility decisions to be impacted by subjective quality-of-life judgments, without requiring education or training in disability competency and, specifically, in the actual life experiences of people with a wide range of disabilities.
- Many healthcare providers critically undervalue life with a disability. Providers often perceive people with disabilities to have a low quality of life when, in reality, most report a high quality of life and level of happiness, especially when they have access to sufficient healthcare services and supports. This misperception has negatively influenced physicians' medical futility decisions and resulted in the withdrawal of necessary medical care from people with disabilities.
- When physicians diagnose persistent vegetative state (PVS) or "brain death," they sometimes rush to make this

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*Disability and patient rights advocates, among others, argue that medical futility decisions often lack objectivity and procedural safeguards, leaving room for the physician's recommendation to be impacted by biases about the quality of life of people with disabilities.*

determination and do not properly follow the American Academy of Neurology's (AAN) well-established and widely respected guidelines, robbing individuals of their chance to recover.

- Internal ethics committees are not an ideal forum for mediating and rendering medical futility decisions. By virtue of being a mechanism of the hospital, they are subject to financial, professional, and personal conflicts of interest. Further, their procedures typically lack due process protections and their composition rarely reflects racial, ethnic, and disability diversity.
- Hospitals are rarely transparent with their medical futility policies. Seldom do they disclose their decision-making policies to patients and even less frequently do they make futility policies available to the general public.

The lack of transparency hinders open discussion, mutual understanding, and trust among patients, their representatives, and their healthcare providers.

- All states have at least one law that relates to medical futility. Of these, 19 state laws protect a physician's futility judgment and provide no effective protection of a patient's wishes to the contrary; 18 state laws give patients a right to receive life-sustaining treatment, but there are notable problems with their provisions that reduce

their effectiveness; 2 state laws require life-sustaining measures for a limited period of time pending transfer of the patient to another facility; 11 states require the provision of life-sustaining treatment pending transfer without time limitations; and 1 state prohibits the denial of life-sustaining treatment when it is based on discriminatory factors.

- Medical futility decisions implicate numerous federal and state constitutional,

statutory, and regulatory provisions, including the Fourteenth Amendment of the US Constitution, the Emergency Medical Treatment and Active Labor Act (EMTALA), Section 504 of the Rehabilitation Act, the Americans with Disabilities Act (ADA), and Section 1557 of the Affordable Care Act (ACA). While still largely unexplored, Section 504, the ADA, and Section 1557 may be relied on to prevent or remedy medical futility discrimination.

## Key Recommendations

### Congress

- Congress should enact legislation that requires hospitals and other medical entities to have due process protections for medical futility decisions; utilize an independent due process mechanism for mediating and deciding medical futility disputes; and disclose medical futility policies to patients, their surrogates, or their family members.
- Congress should enact legislation to make federal funding for hospitals and other medical entities contingent on the provision of due process protections in medical futility decisions.

### Executive Branch

#### The US Department of Health and Human Services (HHS) Office for Civil Rights (OCR)

- OCR should issue guidance to healthcare providers clarifying that medical futility decisions that rely on subjective quality-of-life assumptions or biases about disability violate federal disability rights laws.

### **Executive Branch, *continued***

- OCR should seek compliance from hospitals and medical facilities that violate disability rights laws by making medical futility decisions that rely on subjective quality-of-life assumptions or biases about disability and withhold federal financial assistance when compliance cannot be obtained.
- HHS should encourage hospitals and medical facilities to use an independent due process mechanism for mediating and deciding medical futility disputes and disclose medical futility policies to patients, their surrogates, or their family members. OCR should issue guidance to healthcare providers clarifying that medical futility decisions that rely on subjective assumptions or biases about disability violate federal disability rights laws.

### **Medical and Health Professional Schools**

- Medical and health professional schools should include disability competence as a component of or in addition to cultural competence training.
- Medical and health professional schools should be physically and programmatically accessible for students with disabilities in order to facilitate diversity among healthcare providers.

### **Hospitals and Medical Facilities**

- Hospitals and medical facilities should utilize an independent board to mediate and, if necessary, make medical futility decisions for patients deemed incompetent. The board should be independent from the relevant facility and provider(s), offer procedural due process protections, reflect diversity, and have at least one disability rights advocate as a member. Its decisions should be appealable to a court of law.
- Hospitals and medical facilities should provide full and open disclosure of their medical futility policies to patients, their surrogates, and their family members.

## **State Legislatures**

- State legislatures should adopt or amend relevant statutes and regulations to mandate that hospitals and healthcare providers utilize an independent board to mediate and, if necessary, make medical futility decisions for incompetent patients; expressly prohibit disability discrimination in the medical futility context; and require providers to provide unlimited life-sustaining treatment to an individual pending their transfer to another facility.





## Acronym Glossary

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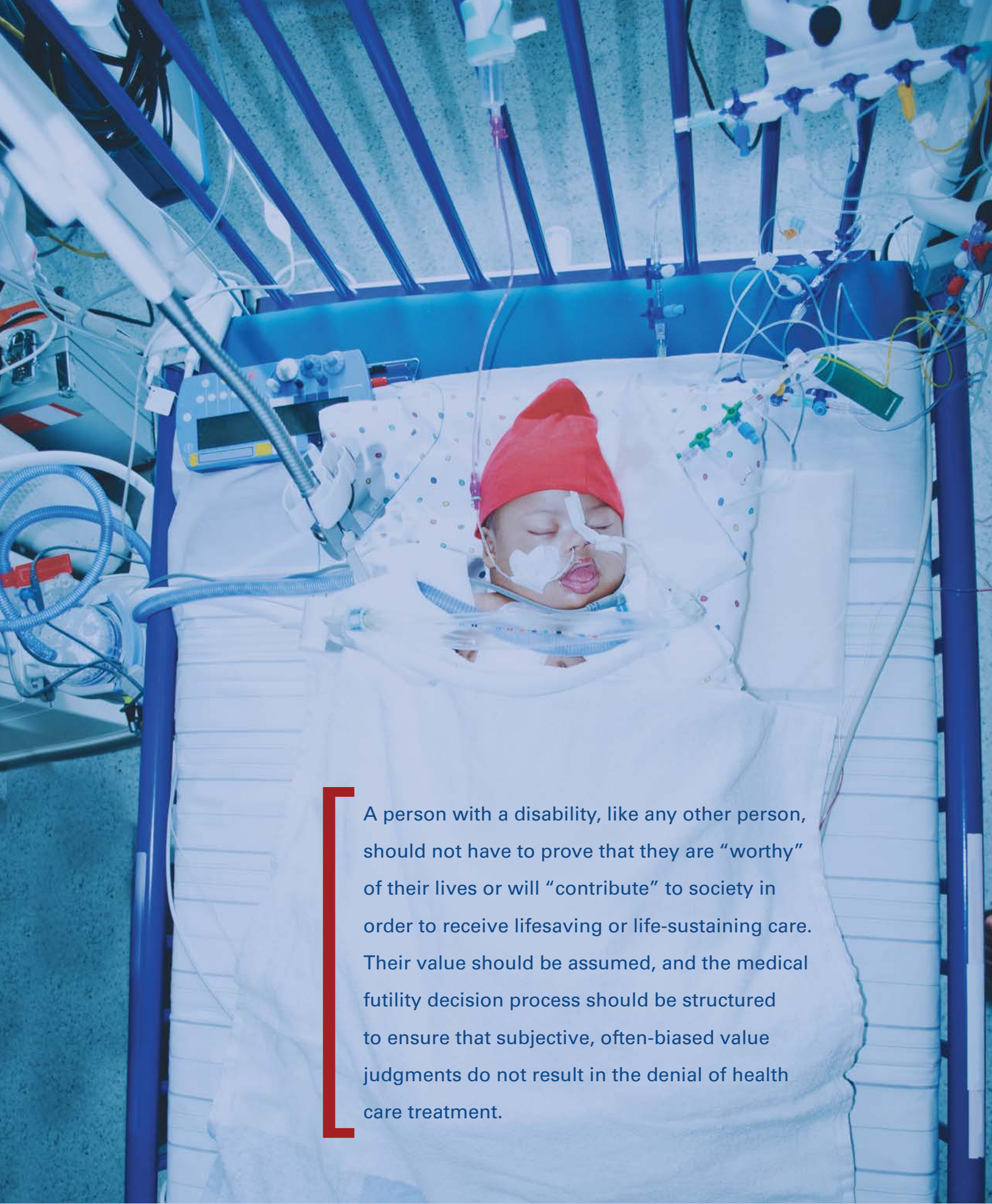
AAN	American Academy of Neurology
ACA	Active Labor Act
ADA	Americans with Disabilities Act
AMA	American Medical Association
CPR	cardiopulmonary resuscitation
DNR	do not resuscitate
DREDF	Disability Rights Education & Defense Fund
EMTALA	Emergency Medical Treatment and Active Labor Act
HHS	Health and Human Services
ICU	intensive care unit
NCD	National Council on Disability
NDRN	National Disability Rights Network
OCR	Office for Civil Rights
PVS	persistent vegetative state
SCI	spinal cord injury
SDRMOV	Supporters of Disability Rights in the Mid-Ohio Valley



## Methodology

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In order to develop the medical futility report and its recommendations, NCD conducted a cross-sectional literature review, engaged in legal research, and conducted in-depth interviews with diverse stakeholders. The informed perspectives of these individuals, particularly of those who have experienced or witnessed futility discrimination, helped shape the content of this report and its recommendations.



A person with a disability, like any other person, should not have to prove that they are “worthy” of their lives or will “contribute” to society in order to receive lifesaving or life-sustaining care. Their value should be assumed, and the medical futility decision process should be structured to ensure that subjective, often-biased value judgments do not result in the denial of health care treatment.

## Introduction

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“**T**hat night made me realize I was not a human being but a tragic figure. Out of the kindness of the physician’s heart, I was being given the chance to end my life.”<sup>1</sup>

The words of William Peace—Doctor of Anthropology, disability advocate, and survivor of medical futility discrimination—are sobering and terrifying. What set of circumstances led to his physician’s wholly inappropriate, yet frighteningly well-intentioned, offering? If Dr. Peace were not a wheelchair user, would his physician have even considered, let alone expressed, such a thought? Dr. Peace faced disability discrimination in the context of a medical futility decision, and he lived to tell his story.

Medical futility is an ethically, medically, and legally divisive concept concerning whether and when a healthcare provider has the authority to refuse to provide medical care that they deem “futile” or “nonbeneficial.” Medical futility elicits a host of ethical questions, including: How do we define medical futility? Who should decide whether to withdraw or withhold lifesaving or life-sustaining care to patients who are deemed critically ill? What criteria should be used to identify when a medical treatment is “futile”? What procedures should be followed in the decision-making process? The debate becomes even more

complex in the context of disability, where biases and negative assumptions about the quality of life of a person with a disability have been shown to be pervasive.<sup>2</sup> Many providers simply assume that life is “not worth living” when a person has, or if they survive will have, a disability classified as medically “severe.”<sup>3</sup> When misinformed perspectives influence a decision to withhold or withdraw life-saving or life-sustaining care, the results can be a deadly form of discrimination.

This report frames the medical futility debate from this perspective, focusing on the importance of achieving equal protection for people with disabilities in medical futility

### **What Is Medical Futility?**

Medical futility is an ethically, medically, and legally divisive concept concerning whether and when a healthcare provider has the authority to refuse to provide medical care that they deem “futile” or “nonbeneficial.” A “medical futility decision” is a decision to withhold or withdraw medical care deemed “futile” or “nonbeneficial.”

decisions. It will examine the evolution of the concept of medical futility; the ethical and disability rights perspectives on the debate; the transparency, or lack thereof, of hospital futility policies; state law approaches to medical

futility; and the lawfulness of futility decisions under federal nondiscrimination law. The report concludes with a set of recommendations on how to reduce and eliminate disability bias in medical futility decisions.

# Chapter 1: The Evolution of the Concept of Medical Futility

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Over the past three decades, whether, when, and who has the authority to withhold or withdraw medical care that is deemed “futile” has increasingly become a subject of bioethical and legal debate. The contemporary concept of medical futility emerged in medical literature in the 1980s.<sup>4</sup> Following a period of prolific development of advanced medical technology and a shift in medical reimbursement methodologies, debate arose in the healthcare community over whether it was appropriate to use invasive, often expensive technology on patients who the physician believed could not benefit from it.<sup>5</sup> The early debates focused on the definition and utility of the concept of medical futility, with some scholars proffering quantitative or qualitative definitions and others advocating for process-based approaches for resolving futility disputes.<sup>6</sup> Parallel to the substantive disagreements over the meaning of medical futility was a debate, playing out in courts across the country, over who should have the final authority to make life-saving or life-sustaining treatment decisions.<sup>7</sup> The still-evolving debates evidence shifting perspectives on the nature of the doctor–patient relationship and the role—or lack thereof—that resource rationing should have in the healthcare setting. Today, the medical futility debate continues, but it has also broadened to encompass a wider range

of therapeutic modalities, and it has deepened, as individuals, families, and disability advocates have increasingly held the medical community and surrogate decision makers<sup>8</sup> accountable for subjective decision making, misguided quality-of-life assumptions, and conflicts of interest.<sup>9</sup>

## Origins of the Medical Futility Debate

The concept of medical futility has a complex, multifaceted history. Some scholars trace its roots as far back as 400 BC, when Hippocrates suggested that physicians need not treat individuals who were “overmastered by their diseases, realizing that in such cases medicine is powerless.”<sup>10</sup> In the context of modern medicine, however, debates over the meaning and ethical implications of futility decisions did not become prominent until the late 20th century.<sup>11</sup> The emergence of the futility debate has been credited to a number of factors, including the development of advanced life-saving medical technologies,<sup>12</sup> changes in the US healthcare reimbursement system,<sup>13</sup> evolving concepts of patient autonomy,<sup>14</sup> and the rise of the right-to-die movement.<sup>15</sup> By the 1980s, these developments, among others, converged and the contemporary concept of medical futility began to take shape.

Advances in lifesaving and life-sustaining medical technologies have radically changed the provision of medical care. Beginning in



## Factors Influencing the Futility Debate

- Advanced life-saving medical technology
- Changes in healthcare reimbursement
- Evolving concepts of patient autonomy
- Rise of the right-to-die movement

the 1960s, the development of technologies such as the mechanical ventilator, intravenous nutrition, intensive care unit (ICU) treatment, and hemodialysis

have extended the lives of countless patients and changed the way physicians practice medicine.<sup>16</sup>

Accompanying these advancements, however, was a budding concern among physicians

about whether it was medically and ethically appropriate to use invasive technologies on patients who may not benefit from it.<sup>17</sup> The archetypal example is the use of cardiopulmonary resuscitation (CPR). CPR was developed in the late 1960s to treat individuals experiencing an arrest of cardiac or pulmonary function resulting from an acute trauma.<sup>18</sup> Soon, CPR became a presumptive treatment for any patient experiencing cardiopulmonary arrest in hospitals across the country.<sup>19</sup> Shortly thereafter, fueled by studies demonstrating poor long-term prognoses of individuals resuscitated with CPR, some physicians began to question whether the invasive technique should be used

on patients who did not explicitly consent to it and who, in their opinion, would receive little medical benefit.<sup>20</sup> The CPR debate reached its peak in the early 1980s, when reports revealed that some physicians were unilaterally placing do-not-resuscitate (DNR) orders (i.e., no CPR) or “slow code” orders (i.e., delayed CPR, which is likely to fail) on patients with terminal conditions, often unbeknownst to the patient, their family, or their surrogate.<sup>21</sup> In this context, the concept of medical futility emerged as a response to and purported defense for a physician to withhold potentially life-saving treatment from certain patients.

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*[R]eports revealed that some physicians were unilaterally placing do-not-resuscitate (DNR) orders . . . or “slow code” orders . . . on patients with terminal conditions, often unbeknownst to the patient, their family, or their surrogate.*

Parallel to the development of advanced medical technologies was a shift in the methodology for medical cost reimbursements.<sup>22</sup> For much of US history, the most common healthcare payment structure was

a fee-for-service model, wherein third-party payers provided cost-based reimbursements to cover the patient’s healthcare expenses.<sup>23</sup> This reimbursement model incentivized doctors and hospitals to provide healthcare services and support the use of complex, often expensive, medical technologies.<sup>24</sup> However, by the 1980s, public and private health insurance companies alike increasingly moved to prospective payment systems or managed care programs, which shifted a portion of the financial risk to doctors and hospitals.<sup>25</sup> Soon, healthcare providers were faced with the prospect of absorbing healthcare expenditures that exceeded their prospective payments.<sup>26</sup> This had a predictable impact



on the provision of care: providers were now economically *disincentivized* to treat patients, especially when the treatment was expensive and the provider perceived it to provide a marginal benefit.<sup>27</sup> At the same time, studies began to emerge analyzing the financial costs and benefits to hospitals in providing advanced medical technologies to patients covered by prospective payment plans.<sup>28</sup> For example, one study showed that hospitals lost an average of \$23,000 for each Medicare patient who required 72 hours of mechanical ventilation.<sup>29</sup> Another study showed that one hospital lost nearly 1 million dollars in 1 year from providing nutritional support to Medicare patients.<sup>30</sup>

These developments—changes in healthcare payment systems and the correlated increase in cost-benefit analyses of advanced medical technologies—fueled the medical futility debate.

Around the same time, the concept of the doctor–patient relationship was also evolving in public discourse. By the late 20th century, notions of patient autonomy, medical information transparency, and respect for patient treatment choices were increasingly replacing paternalistic practices in the healthcare setting.<sup>31</sup> This shift in principles of medical decision making was evidenced, at the time, through a movement advancing a patient’s right to die.<sup>32</sup> Starting in the 1970s and culminating in a decision by the US Supreme Court in 1990, a series of highly publicized right-to-die cases permeated the

public discourse.<sup>33</sup> Two cases, concerning the lives of Karen Ann Quinlan and Nancy Cruzan, established that an individual or their surrogate has the right to refuse life-sustaining treatment.<sup>34</sup> Principles of this movement shaped the early medical futility debate.

## The Evolving Debate on the Definition and Utility of the Concept of Medical Futility

The early medical futility debate can be characterized by attempts to substantively define “medical futility” for clinical use. By the

early 1990s, scholars and medical entities began to proffer various, purportedly objective definitions of futility.<sup>35</sup> Most commonly cited among them were quantitative futility (treatment with less than a defined probability of succeeding),<sup>36</sup> qualitative futility (treatment that would not result in an acceptable quality of

life),<sup>37</sup> and physiological futility (treatment that cannot achieve its physiological objective).<sup>38</sup>

All proposed definitions of medical futility have been criticized for relying on the value judgments of physicians.<sup>39</sup> For example, quantitative futility relies on the medical community’s assumption that no patient or their surrogate would choose to continue a treatment with, for example, a less than 1 percent chance of success (an assumption that research has clearly disputed);<sup>40</sup> qualitative futility depends on how the physician defines “quality of life” (a definition that may be laden

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*Soon, healthcare providers were faced with the prospect of absorbing healthcare expenditures that exceeded their prospective payments. This had a predictable impact on the provision of care: providers were now economically disincentivized to treat patients, especially when the treatment was expensive . . .*

with biases and assumptions); and physiological futility could rely on the physician's judgment of a favorable physiological outcome. All of these definitions depend on subjective judgments about whether an individual's life is worth living and prioritize the physician's opinions on these matters over the patient's or their surrogate's.<sup>41</sup>

Attempts to define medical futility have also been criticized for their lack of pragmatic applications.<sup>42</sup> While

the definitions give rise to lively debate among academics, medical professionals, and disability activists, none of them have been effectively adapted into an operational policy

that hospitals and physicians can utilize in a meaningful and consistent manner.<sup>43</sup> As such, many question the usefulness of the pursuit.

Concurrent to the debates over the definition and utility of the concept of medical futility were a series of novel court cases challenging physicians' legal authority to refuse to provide life-sustaining treatment.<sup>44</sup> Litigation involving the lives of Helga Wanglie,<sup>45</sup> Baby K,<sup>46</sup> and Catherine Gilgunn<sup>47</sup> gained national attention; however, it failed to produce consensus on the meaning and legality of futility decisions. For example, in *In re Wanglie*, the court sided with the family of an 87-year-old woman in a PVS following a cardiopulmonary arrest, who strongly objected to the removal of her mechanical ventilation, believing it would be contrary to Ms. Wanglie's wishes and religious beliefs.<sup>48</sup> In contrast, in *Gilgunn v. Massachusetts General Hospital*, the court sided with a hospital's judgment to unilaterally impose a DNR order on Ms. Gilgunn,

a 71-year-old woman in a comatose state following a neurological injury.<sup>49</sup> The mixed judicial guidance only further fueled the confusion and debate over the meaning and proper role of medical futility decisions.

In response to the problems with defining "medical futility" and a lack of clear, consistent judicial guidance, hospitals and medical associations began to develop their own

futility policies, which generally pivoted away from a universal futility definition and toward individualized, process-based approaches.<sup>50</sup>

Most notably, in 1999, the American Medical Association (AMA),

recognizing that the concept of medical futility could not be "meaningfully defined,"

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*All of these definitions depend on subjective judgments about whether an individual's life is worth living and prioritize the physician's opinions on these matters over the patient's or their surrogate's.*

### **AMA Procedural Guidelines for Making Futility Determinations**

1. Deliberation of values;
2. Joint decision-making using outcome-based data and values;
3. Involvement of consultant(s) for discussions between physician and patient;
4. Involvement of an ethics committee;
5. Attempt to transfer the patient within the institution;
6. Attempt to transfer the patient to another institution; and, if impossible
7. Discontinuation of treatment

published procedural guidelines for making futility determinations on a case-by-case basis.<sup>51</sup> The process included a succession of steps: (1) a deliberation of values; (2) joint decision-making using outcome-based data and values; (3) involvement of consultant(s) to facilitate discussions between the physician and patient and/or patient’s representative; (4) involvement of an ethics committee; (5) attempt to transfer the patient within the institution; (6) attempt to transfer the patient to another institution; and, if impossible, (7) discontinuation of the medical treatment.<sup>52</sup>

While the AMA Council on Ethical and Judicial Affairs describes their guidelines as a “fair process approach,”<sup>53</sup> it has been criticized by some disability rights advocates.<sup>54</sup> Not Dead Yet, a national, grassroots disability rights group that opposes legalization of assisted suicide and euthanasia, views the AMA’s guidelines as advocating a structured effort by medical professionals to persuade patients or their representatives to agree to withhold or withdraw treatment. In their view, if a provider believes a treatment is medically futile and a patient disagrees, then the AMA policy encourages the provider to move through a series of steps, involving additional and often affiliated professionals (e.g., consultants and ethics committees, both of which are often associated with the medical facility and thus may have a conflict of interest), in an attempt to influence the patient to discontinue treatment. This approach risks magnifying the existing unequal power differential in the typical provider–patient

relationship and, thereby, undermining the fairness of the process and its outcome.<sup>55</sup>

In the years following the AMA’s publication of procedural guidelines, the use of process-based approaches and the use of internal ethics committees as a mediator and/or decision maker in the futility decision process proliferated in hospitals and state laws across the country.<sup>56</sup> Moreover, the language used to describe medical futility began to change. Some medical organizations abandoned the term

“futile” altogether, in favor of language such as “nonbeneficial,” “medically inappropriate,” “medically inadvisable,” or “not medically indicated.”<sup>57</sup> Although the terminology is different,

these classifications still allow healthcare providers to rely on subjective determinations of what is beneficial, advisable, or indicated—which, in turn, can be influenced by misinformed perceptions of disability. This report utilizes the term “medical futility” because it is the original and most widely used term.

Today, mainstream opinion still favors process-based approaches to the concept of

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*[F]utility processes often employ mediation and decision-making bodies that reflect institutional biases, lack diversity, and fail to provide due process protections.*

### **Different Phrases for Medical Futility**

- “nonbeneficial”
- “medically inappropriate”
- “medically inadvisable”
- “not medically indicated”

medical futility. However, disability activists and disability rights organizations have increasingly questioned the lack of adequate protections in the standard procedures for determining medical futility. As detailed further in Chapter 2, futility processes often employ mediation and

decision-making bodies that reflect institutional biases, lack diversity, and fail to provide due process protections. As a topic that is still fiercely debated today, the concept of medical futility will surely continue to evolve in the years to come.

## Chapter 2: The Ethical, Medical, and Disability Rights Perspectives on Medical Futility Decisions Relating to People with Disabilities

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The contemporary debate over medical futility decisions is complex and nuanced. From the medical perspective, the withholding or withdrawing of lifesaving or life-sustaining care is frequently considered the ethical, well-reasoned, and compassionate course of treatment. From a disability rights perspective, such decisions are often impacted by biases and misguided quality-of-life judgments. From a legal perspective, medical futility decisions can run afoul of federal and state laws if disability stereotypes have an impact on care or if the provider fails to ensure due process protections in the decision-making process. This chapter will review these multifaceted perspectives on medical futility decisions as they relate to people with disabilities, beginning with a case study that illustrates some of these conflicting perspectives.

### **Case Study: The Unethical and Discriminatory Treatment of Terrie Lincoln**

Terrie Lincoln is a 39-year-old disability activist and proud mother who lives in Marietta, Ohio.<sup>58</sup> Terrie holds degrees in social work and public administration. When Terrie was 19, she was in an automobile accident that severed her spinal cord and caused her to become quadriplegic. When she was in the hospital just following her accident, Terrie's doctors repeatedly tried to

influence her family to "pull the plug," stating that Terrie was a "vegetable" and, even if she were to regain consciousness, would have no quality of life. "What kind of life will she have? She won't. She won't be able to dance, walk, work, have a social life, or be independent," her doctors urged. At one point, one of Terrie's physicians told her mother, who diligently remained by Terrie's side throughout her hospital stay, that "any good mother would pull the plug instead of seeing their baby suffer."

In the subsequent 5 months that Terrie was in the hospital, her medical providers neglected major aspects of her care, seeming to have already made up their minds that Terrie would not or should not survive. Terrie repeatedly experienced respiratory distress in the hospital; she had pneumonia and collapsed lungs, and she frequently aspirated. At one point, she coded. While her doctors did resuscitate her, they did not offer any suggestions on how to keep her lungs inflated and help her breathe going forward. In Terrie's words, they were "killing [her] slowly."

Despite her treatment in the hospital, Terrie did eventually regain consciousness. However, upon waking, she too was inundated with pleas from her doctors: "Are you sure this is something you can live with? Do you want to spend the rest of your life on a ventilator?" she was repeatedly asked. "We could inject you with morphine

so you don't feel anything [while dying]," they offered. Despite the clear lack of support from her medical team, Terrie persisted. Then, to the hospital's surprise, Terrie's health improved and she was taken off her ventilator. Eventually, Terrie returned home.

In the following years, Terrie gained greater sensation and usage of her neck and arms. She also began to learn more about disability rights, as she was suddenly thrust into a world with inaccessible housing, transportation, and public spaces. She was appalled with this reality, but also motivated to advocate for the civil rights of people with disabilities. Several years after her accident, she accepted a position as a Systems Advocate at a regional center for independent living in Rochester, New

York. A few years after that, she gave birth to a daughter and relocated to Ohio. In 2014, Terrie founded and became

President of Supporters of Disability Rights in the Mid-Ohio Valley (SDRMOV), a nonprofit organization that protects and promotes the human and civil rights of people with disabilities through advocacy, community awareness and education, and information and referral. Terrie is currently raising her daughter and serving as President of SDRMOV, where she shares her experiences and passion for disability rights with the world.

### **Breaking Down the Divide: The Disparate Viewpoints of the Medical and Disability Communities on Medical Futility**

Terrie's story is all too common within the disability community. Healthcare providers often

harbor stereotypes and assumptions about the quality of life and capacities of people with disabilities. Many providers simply assume that an individual's life is "not worth living" when they have a medically classified "severe" disability. However, sometimes, they could not be more wrong, as Terrie's story demonstrates. Despite what many of Terrie's healthcare providers assumed, her quality of life was not decimated because of her newly acquired disability. Yes, her life was forever changed, but that did not mean that it was not worth living. To the contrary, Terrie's life with a disability has been incredibly meaningful. She has earned an education, founded and led a nonprofit organization, and created a family. The larger point, however, is

that even if Terrie had not gone on to have a successful career and foster a beautiful family, her life is still inherently valuable. A person with

a disability, like any other person, should not have to prove that they are "worthy" of their lives or will "contribute" to society in order to receive lifesaving or life-sustaining care. Their value should be assumed, and the medical futility decision process should be structured to ensure that subjective, often-biased value judgments do not result in the denial of health care treatment.

Unfortunately, however, procedural protections are fleeting in the critical care setting, and there is a lack of consensus on the appropriate role of futility decisions in the healthcare treatment of people with disabilities.<sup>59</sup> As a general matter, the medical community supports the use of medical futility decisions to withhold or withdraw life-saving or life-sustaining care to patients with serious injuries or illnesses.

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As Professor Thaddeus Pope explained, many physicians genuinely believe that maintaining, for example, a ventilator on an individual with a catastrophic injury would amount to “torture.”<sup>60</sup> In contrast, many disability activists and organizations vehemently oppose the concept of futility determinations, at least in the broad, value-laden sense with which it is often applied. From a rights perspective, such decisions are often injected with disability biases and fail to recognize the equal value of the life of a person with a disability.

Medical futility decisions are a prime concern for numerous disability rights organizations,<sup>61</sup> in large part because the majority of such determinations involve a patient with a disability. Almost by definition, nearly every individual who is the subject of a futility determination has a disability within the meaning of the ADA.

The ADA is a federal nondiscrimination statute that broadly defines “disability” to mean “a physical or mental impairment that substantially limits one or more major life activities;” “a record of such an impairment;” or “being regarded as having such an impairment.”<sup>62</sup> This definition would encompass not only people with pre-existing disabilities such as autism, Down syndrome, or cerebral palsy, but also people with newly acquired spinal cord or brain injuries or those experiencing cardiac, respiratory, or other major organ impairments as a result of an acute illness or injury. Thus, disability lies at the core of nearly every futility determination, necessitating a critical examination of how biases can fatally impact

people with disabilities in the critical care context and how to bridge the divide between competing views on medical futility.

The fundamental tension between the medical and disability communities’ views on medical futility lies in their differing understandings of the quality of life that an individual with a disability experiences. Several studies have demonstrated that health care providers’ opinions about the quality of life of a person with a disability significantly differ from the actual experiences of those people.<sup>63</sup> For example, one study found that only 17 percent of providers anticipated an average or better quality of life after a spinal cord injury (SCI) compared with 86 percent of the actual SCI comparison group.<sup>64</sup> The same study found

that only 18 percent of emergency care providers imagined that they would be glad to be alive after experiencing a spinal cord injury, in contrast to the 92 percent of actual SCI

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survivors. Providers often perceive people with disabilities to have a low quality of life when, in reality, most report a high quality of life and level of happiness, especially when they have access to the healthcare services and supports that they need to equally participate in and contribute to their communities.<sup>65</sup> In another study which surveyed healthcare providers without giving them any further information about the patient’s circumstances, 72 percent of physicians would deem mechanical ventilation “futile” for a “30-year-old quadriplegic patient with malignant melanoma who becomes unconscious.”<sup>66</sup> Yet another study found that 71 percent of pediatric residents question whether aggressive treatment should be used on children with severe disabilities.<sup>67</sup>



The medical community's inaccurate perceptions of the quality of life of a person with a disability can be traced back to their general misunderstanding of the meaning of disability and the correlated conception of how an individual's disability should be managed. The disability rights community has identified two primary models of disability: the medical model and the social model.

Most of the medical establishment still holds a deficit-oriented medical framework of disability (medical model) instead of sociopolitical models of disability where disability can be neutral, an identity, the basis for a community, or ever-evolving depending on barriers and supports in the environment (social model). Notwithstanding the names of the models, medical providers can treat patients from a sociopolitical orientation, respecting patients' lives and choices and not assuming that their disability status is an inherently negative problem. Moreover, despite the binary classification, the models are not mutually exclusive and, particularly in the context of health care, they can operate in relation to each other, with physicians' utilizing one model or another, or a combination of the models, depending on the context.

Healthcare providers can over rely on the medical model when treating patients with

disabilities.<sup>68</sup> Nachama Wilker, the Deputy Executive Director for Training and Technical Assistance at the National Disability Rights Network (NDRN), explained: "Physicians predominately view disability as connected to

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disease, and diseases are to be cured or avoided; on the whole, providers fail to see disability as a 'natural part of life's experience.'"<sup>69</sup> Whether due to the historical, purely clinical lens

through which health care has traditionally been approached (as opposed to a whole person model, which also considers social determinants of health) or the lack of education and training in disability competency,<sup>70</sup> healthcare providers largely depend on medical model thinking when treating patients, which fosters negative attitudes toward and biases about people with disabilities.

Indeed, recent studies have indicated that attitudinal biases about patients with disabilities remain pervasive among physicians, nurses, and students in the health professions.<sup>71</sup> Specifically,

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negative assumptions about the cognitive abilities, independence, interest in maintaining current function, and quality of life of people with disabilities are common and continue to impact care.<sup>72</sup>

Disability rights advocates and organizations have criticized the medical community's overuse of the medical model, arguing that it places a misguided focus on "fixing" or "normalizing" an individual, when that goal is often not helpful



or desirable for people with disabilities.<sup>73</sup> To be clear, the medical model has a role in health care—as Dr. Clarissa Kripke, the Director of the Office of Developmental Primary Care and a Clinical Professor at the University of California, San Francisco, explained: If an individual falls and breaks their leg, then we would expect the provider to “fix” the leg through appropriate medical treatment so that the individual can walk again.<sup>74</sup> The broken leg was a disability and, in this context, it was appropriate to “fix” it.<sup>75</sup> Likewise, if an individual experiences chronic pain associated with their disability and desires habilitative or rehabilitative treatment, pain medications, or other appropriate healthcare services, then the medical model could function to serve their needs and reduce their pain. Depending on the context, the medical model can be applied appropriately and with respect for the individual with a disability.

Where the medical model can break down, however, is when the physician, viewing the disability only as a medical condition, fails to properly value the individual’s life or accurately diagnose the acute reason for their medical visit. For example, people with disabilities have been—and many continue to be—institutionalized because of medical model thinking and lack of adequate community supports.<sup>76</sup> Others have been deemed “unfit to reproduce”—seen only as a negative health outcome that should be prevented in future generations—and forcibly sterilized under state eugenics laws, some of

which were not taken off the books until the late 20th century.<sup>77</sup> Even the US Supreme Court has, in a decision that is still binding precedent today, explicitly endorsed the forced sterilization of adults and children with disabilities.<sup>78</sup> In *Buck v. Bell*, the Court upheld the constitutionality of a Virginia law that authorized the sterilization of people deemed “unfit to reproduce.”<sup>79</sup> In the decision, Justice Holmes infamously wrote: “Three generations of imbeciles are enough.”<sup>80</sup>

Today, the negative impact of misplaced medical model thinking and disability bias on the provision of health care is still pervasive. Healthcare providers, predominantly viewing a

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person’s disability as an undesirable “medical condition,” often place too heavy a clinical focus on the disability, such that it “overshadows” the acute reason for their visit.<sup>81</sup> Moreover, few physicians have the expertise and training necessary to accurately

diagnose and treat people with disabilities; often, they simply do not know how to apply diagnostic standards to people who physically or mentally deviate from the statistical norm, or they fail to differentiate the conditions associated with the individual’s disability from the acute symptoms behind their medical visit.<sup>82</sup> Physical and programmatic access barriers are also widespread among healthcare providers. Providers’ offices, diagnostic equipment, weight scales, and tables are largely physically inaccessible, and communication breakdowns between providers and patients with hearing, intellectual, or developmental disabilities are

common.<sup>83</sup> These problems, among others, contribute to wide disparities in health outcomes and access to care for people with disabilities.<sup>84</sup>

In the context of medical futility decisions, disability bias and quality-of-life misconceptions

are particularly

dangerous. Dr. Kripke

explained that she

observes negative

assumptions about

disability impact

futility determinations

“all the time.”<sup>85</sup> In

her practice, she

typically treats patients

with developmental

disabilities, whose lives she observes to be

frequently undervalued by providers.<sup>86</sup> For

example, she has encountered a number of

instances where hospital or emergency room

physicians prematurely attempted to force

palliative or hospice care on patients with a

disability with treatable diseases—or they

delayed care in medical emergencies to first

determine the patient’s code status, presuming

that a primary care physician would have (or

*should have*) encouraged a DNR order for

patients with certain disabilities.<sup>87</sup> These kinds

of occurrences are disturbingly common, she

states.<sup>88</sup>

Several studies have

confirmed the role that

subjective judgments

play in futility decisions.<sup>89</sup>

For example, one study observed that “most

often when futility arguments were invoked [in

interviews of physicians], they were used to

support evaluative judgments based on quality

of life considerations, only rarely to designate

treatments that were medically inefficacious.

Indeed, throughout the transcripts, physicians

sought to frame value judgments as medical

decisions.”<sup>90</sup> Moreover, in its influential report

*Devaluing People with Disabilities: Medical*

*Procedures That Violate*

*Civil Rights*, NDRN

documented numerous

stories of people who

were subjected to futility

discrimination because

of negative assumptions

about their life with a

disability.<sup>91</sup> In one case,

a 78-year-old man with

intellectual and other

disabilities had colon cancer and needed surgery

to survive; however, his surgeon expressed that

“there was no reason to prolong [his] life due

to his significant disabilities.”<sup>92</sup> Thankfully, the

Rhode Island Disability Law Center stepped in

and was able to persuade the surgeon that the

man still had a good quality of life and the surgery

should be performed.<sup>93</sup> The man enjoyed his life

for another 2 years.<sup>94</sup> In another case, a 20-year-

old man with physical and intellectual disabilities

was denied treatment for a serious wound and

bone infection, his physicians asserting that he

was not a candidate for IV antibiotics, withholding

supplemental fluids

and nutrition, and

issuing a DNR order.<sup>95</sup>

Documentation indicated

that part of this decision

was based on his disabilities.<sup>96</sup> Despite the

gross neglect by the hospital, the young man

survived and was discharged 2 months later,

weighing only 89 pounds.<sup>97</sup> He was far from well,

though.<sup>98</sup> The young man required two additional

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hospitalizations. At the second hospital, the doctors stabilized his conditions by providing IV antibiotics and aggressive wound treatment for his ulcer and bone infection.<sup>99</sup> He was discharged back into his community shortly thereafter.<sup>100</sup>

As these examples demonstrate, devaluing the lives of people with disabilities can have life-threatening or life-ending consequences in the context of medical futility. In both of these cases, the physicians who denied treatment relied on their subjective assumptions about the individuals' quality of life—conceptualizing the patient's disability to be a negative health outcome, which, when compounded with the acute clinical reason for their hospital visits (colon cancer and a wound,

respectively), allowed the physician to assert that life-saving treatment was not medically indicated.

If, in contrast, the physicians had viewed the life of the individual with a disability as

inherently valuable and understood the patient's right to equally effective health care, unimpacted by biases and stereotypes, they may have come to a very different medical recommendation.

Another illustration is in the context of brain injury and the premature diagnosis of PVS. Consider, for example, the case involving the removal of life-sustaining treatment from 11-year-old Haleigh Poutre.<sup>101</sup> Haleigh was severely abused by family members and sustained a brain injury.<sup>102</sup> Only 8 days after she was admitted to the hospital, her physicians asserted she was "virtually brain dead," and the state, which had taken custody of Haleigh, sought to remove her life support.<sup>103</sup> A judge granted the request,

stating that Haleigh should "pass away with dignity."<sup>104</sup> The very next day, Haleigh regained consciousness.<sup>105</sup> Subsequently, she was transferred to a rehabilitation hospital and later discharged and adopted by a loving family.<sup>106</sup>

Haleigh's near-fatal experience illustrates what some disability advocates term a "rush to judgment." When physicians diagnose PVS or "brain death," sometimes they rush to make this determination and do not properly follow the AAN well-established and widely respected guidelines.<sup>107</sup> In too many cases, people who have sustained severe brain injuries are not given adequate time to heal and recover before their medical team moves to withdraw life-

sustaining treatment.

Indeed, one retrospective study found up to 43 percent of patients are misdiagnosed with PVS.<sup>108</sup> Other studies have increasingly found that late-stage recovery from disorders

of consciousness is more common than once understood in the medical community.<sup>109</sup> One physician even posited: "Reliable information about the character of an injured person's future may be especially hard to find at those times during the course of treatment when there may be a 'convenient' window of opportunity to stop interventions and allow a patient to die."<sup>110</sup> Considering the irreversible consequences of withdrawing life-sustaining treatment, such determinations should not be made in haste. People experiencing unconsciousness should be given the proper time and support that they need to recover. Only if and when the patient is properly determined to be experiencing brain

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death, as detailed in the AAN’s guidelines, should a futility judgment be contemplated. Individuals should not be robbed of their chance to recover.

As these cases demonstrate, understanding the value of every individual’s life, not rushing to futility judgments, and eliminating explicit and implicit biases about disability is essential to ensuring equity in medical treatment decisions. Moreover, at a time when stereotypes and assumptions regarding disability remain pervasive in the medical community, it is essential that medical futility is only defined and applied narrowly, that there are procedural protections in the decision-making process, and that there are affordable and accessible means of legal appeal.

### **Defining Medical Futility and Its Criteria to Avoid Disability Bias**

For decades, medical professionals and scholars have attempted

to craft a workable clinical definition and criteria by which to evaluate medical futility. Numerous conceptions have been proffered, ranging from the treatment *will not* produce the desired benefit, to the treatment is *unlikely* to produce the desired benefit, to the treatment will not result in a desired *quality of life*.<sup>111</sup> Each formulation has its own set of criticisms, some being more fraught with the danger of injecting disability bias than others.

In its purest sense, medical futility means that a treatment will not produce the desired medical benefit. In other words, there is *no chance* that the treatment will achieve the goals for which it was intended.<sup>112</sup> For example, a treatment of

antibiotics would be considered futile under this approach if the patient had a viral infection.<sup>113</sup> Because it has been widely established that antibiotics do not have an effect on viruses, it is virtually certain that this treatment will not achieve the desired benefit of curing or reducing the patient’s viral infection.<sup>114</sup> Proponents of this approach, which is sometimes referred to as “absolute futility”<sup>115</sup> or “physiologically impossible futility,”<sup>116</sup> argue that it is the concept of medical futility that comes the closest to an objective exercise of medical judgment.<sup>117</sup> Only when the concept is limited to medically certain circumstances can we truly ensure that it is free of the physician’s subjective value judgments.<sup>118</sup> However, critics of absolute futility argue that

it is too narrow to be useful. Rarely does any treatment offer *no* benefit and there needs to be a mechanism to refuse care when the treatment would offer some short-term benefit, but would

ultimately not change the patient’s prognosis, critics argue.<sup>119</sup>

Broader, more value-laden definitions of medical futility have also been suggested. One of the most widely cited of the proposals was that of bioethics academics Lawrence Schneiderman and Nancy Jecker, who framed the concept of medical futility as having two components: quantitative and qualitative.<sup>120</sup> Quantitative futility attempts to evaluate the chance of success of the treatment, considering how likely it is to produce the desired benefit.<sup>121</sup> Of course, this concept then begs the questions: How likely does success need to be? And how will this probability be determined?<sup>122</sup> Schneiderman and

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Jecker draw a seemingly arbitrary line, asking: In the past 100 cases, was the treatment useless for people with similar clinical indications?<sup>123</sup> Others, building off this proposal, have suggested alternative quantifications, suggesting that a treatment is futile if it has, for example, less than a 1, 2, or 5 percent chance of success.<sup>124</sup> Critics of quantitative futility—or any concept of futility that requires less than near medical certainty, for that matter—argue that quantitative futility leaves too much room for subjectivity and variability in application.<sup>125</sup> Necessarily, the healthcare provider must determine the probability that the treatment will succeed for a given patient and this evaluation leaves room for providers to rely on subjective factors.<sup>126</sup> It also assumes that the patient would not want to pursue a treatment that has a low probability of succeeding—an assumption that may align with the physician’s values and opinions on appropriate medical decision making, but may *not* align with the patient’s values and what they would chose for themselves. As Professor Pope explained, this broad conception of futility allows the clinician, given their own individual training, to decide whether the chance that the treatment is going to work is so low that it is simply “not worth trying.”<sup>127</sup> When a clinician starts considering what is “worthwhile,” it allows them to “smuggle in all sort of biases,” he explained.<sup>128</sup> Moreover, “what one clinician thinks is not worthwhile is not necessarily the same as another,” resulting in great variability in decision making.<sup>129</sup>

A qualitative approach to medical futility focuses not only on whether a treatment will provide a specific benefit, but also on whether

it will result in a desired quality of life.<sup>130</sup> Under this conception of futility, there is an explicit evaluation of whether the patient could meaningfully appreciate the benefit of the treatment.<sup>131</sup> Schneiderman and Jecker provided an example of a woman with advanced dementia, who they assert that, because of her dementia, cannot achieve a qualitative benefit from the insertion of a G-tube.<sup>132</sup> This example, however, demonstrates the clear danger of relying on a qualitative definition of futility: by design, it incorporates judgments about quality of life and allows for bigotry. In this example, the physicians are imposing their own subjective opinion that a life is not worth living—or, at least, is not worth expending medical resources on—if an

individual has dementia. This conception of medical futility is thus ripe for abuse. Negative assumptions and biases about the quality of life

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and inherent value of people with disabilities can easily make their way into futility decisions under this model. If a provider believes that an individual’s physical or mental disability decreases their quality of life, then this judgment, by definition, will be taken into account in the futility decision. Considering how pervasive disability biases are within the medical profession,<sup>133</sup> it is easy to see how a deadly form of disability discrimination can result under this model.

Because of these dangers, medical futility should only be defined in its limited, absolute sense. This narrow conception of futility is the closest to achieving objective, value-free decision making.<sup>134</sup> All other definitions of futility almost invariably incorporate the value judgments of physicians.<sup>135</sup> For example,

under quantitative and qualitative approaches to futility, the provider is always having to make some judgment—assessing whether the treatment is “worth it,” when either considering the chance of success or the resulting overall quality of life, respectively—and that flexibility permits inappropriate and discriminatory considerations. It allows providers or hospitals to apply their own opinions on whether a life is “worth living” to medical decision making, and this is wholly unacceptable. As a matter of principle, only the patient’s value judgments regarding quality of life should matter in futility decisions. Thus, to prevent the possibility that a provider’s potential biases will guide decisions, a narrow definition of futility that only considers whether, as a matter of scientific certainty, a treatment will not produce the desired benefit, is necessary.

However, even a narrow definition of medical futility can leave some space for subjectivity, which is why adequate safeguards are also essential. For example, the level of generality through which the desired benefit of treatment is defined can impact the outcome. In other words, one could ask *what* is there “no chance” of achieving through the treatment: the immediate, short-term objective? Long-term survival? Quality of life? The broader the level of generality of the desired outcome, the greater the potential that subjective quality-of-life judgments could be relied on. To protect against this, the default level of generality should be the immediate, short-term objective, and it should only be broadened if and when the patient or their duly acting

surrogate decides to do so; it should not be left up to the healthcare provider or the hospital to unilaterally decide that the desired benefit of a treatment is long-term survival or their conception of a “high quality of life.”

Moreover, there is also a danger that providers, in practice, will rely on subjective criteria in determining that a treatment has “no chance” of succeeding.<sup>136</sup> In other words, a standard of futility that requires 0 percent chance of success would be deemed virtually meaningless if there were not also standards defining the types of criteria that can be relied on in making this determination. A provider cannot, for example, only rely on their own intuition or experiences with their own past patients

to deem a treatment futile. Instead, they should rely on objective, evidence-based criteria, such as peer-reviewed medical literature. Additionally, as is

discussed in Chapter 3, there should be policies and procedures in place to ensure that the procedural rights of patients are effectuated in the decision-making process and that a medically justified and bias-free decision is reached.

### **Who Decides and How? Shaping Medical Futility Protocols to Effectuate the Procedural Rights of Patients with Disabilities**

While the substantive limits of the conception of medical futility is a key definitional question, the heart of the futility debate really lies in *who* should make a futility determination and *how*, in coming to this decision, the procedural rights of patients are effectuated. The “proper decision maker”

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question, like the definition of medical futility, has been extensively examined and debated among bioethical and medical scholars. Several “decision makers” have been suggested: the provider(s), the patient, the patient’s surrogate or family, an ethics committee, an independent board, or a court of law. However, while much of the focus has been on the “who,” equally important is the “how.” A decision-making body should be diverse and unconflicted, and the decision process should be structured with adequate safeguards.

### **Physicians**

Traditionally, physicians have been the primary decision makers regarding a patient’s healthcare treatment. Before the late 20th century, few patients and families questioned the medical orders of physicians, even at the end of life.<sup>137</sup> Physicians were widely regarded as the parties with the best perspective on medical decisions, by virtue of their intelligence, knowledge, and extensive training.<sup>138</sup> However, with the emergence of advanced technologies and a broader societal movement toward patient autonomy, the assumption that physicians should always dictate an individual’s course of treatment began to wane.<sup>139</sup> Today, the view that physicians should solely make medical futility decisions is still held by many bioethical scholars and medical community members.<sup>140</sup> However, others question the appropriateness of allowing a physician to unilaterally make a futility decision, asserting that it is a paternalistic viewpoint that allows consideration and reliance on the physician’s value judgments and biases.<sup>141</sup>

With a study finding that 14 percent of physicians nationwide have withheld or withdrawn health care they deemed futile without informing patient’s families, and 80 percent have withdrawn care over the family’s objections,<sup>142</sup> the cause for alarm over providers unilaterally determining medical futility is salient.

From a disability perspective, there are three primary problems with allowing a physician to be a sole futility decision maker. First, as previously discussed, healthcare providers often harbor stereotypes and misguided quality-of-life judgments about patients with disabilities. These biases and assumptions can and do make their way into medical decisions and, when

those decisions involve medical futility, they can have fatal results for people with disabilities. Second, physicians and hospitals have financial conflicts of interest. The US healthcare system is dominated by

prospective payment systems and managed care programs, which economically incentivize the underutilization of health care, especially when the treatment is expensive (as most advanced life-sustaining care is) and the provider perceives the treatment as providing a marginal benefit to the patient (a perception that may rely on biases).<sup>143</sup> This healthcare structure, put simply, encourages the rationing of health care, and people with disabilities are often the first to be subjected to cuts in healthcare expenditures. Finally, as a matter of principle, the *patient’s* values, beliefs, and preferences are the only ones that should matter in healthcare treatment. By allowing a physician to unilaterally decide that a

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*By allowing a physician to unilaterally decide that a treatment is medically futile, it is the physician’s subjective beliefs that are injected into that decision. That is ethically unacceptable.*

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### ***Patients, Surrogates, and Family Members***

In an ideal world, the patient—free of outside influence and with an accurate perception of life with a disability and access to sufficient healthcare services and supports—should have the right to control their own medical treatment, including a determination to withhold or withdraw life-saving or life-sustaining care on the grounds of medical futility. However, as is frequently a reality in these cases, the patient may be incapacitated or lack the mental capacity to make critical healthcare decisions

without assistance. Thus, an alternative decision-making mechanism should also be in place to represent the patient's perspective or best interests.

In the absence of an advance medical directive, an adult patient's surrogate or family members have been proposed as medical futility decision makers.<sup>144</sup> Surrogates are representatives identified, or appointed by a court, to make medical decisions for or with the individual.<sup>145</sup> This surrogate can be an individual previously identified by the patient through a legal instrument, designated by statute (usually their next of kin), or a representative assigned by a court.<sup>146</sup> Unfortunately, while in theory, surrogates should accurately represent the patient's values and act in their best interest, this is not always the reality. As an example, consider the case of a 51-year-old woman with a physical disability

in Illinois who was bleeding internally and needed treatment to survive.<sup>147</sup> Her surrogate, who had not seen the woman in years, called the nursing home where the woman resided and instructed the caregivers not to follow the doctor's treatment recommendation, wanting to allow the woman to die.<sup>148</sup> Equip for Equality, the state's federally mandated protection and advocacy organization, stepped in and assisted the nursing home with appointing an alternative surrogate, allowing the woman to receive the life-saving care she needed.<sup>149</sup> While the motive behind this surrogate's actions were unclear, surrogates can have conflicting interests with the patient. For example, the surrogate or deciding family member may have financial interests in

the futility decision or a desire to avoid the time and expense associated with caregiving. They may also have their own biases about disability, acting on the same quality-of-

life assumptions that some physicians hold. Because of the potential for conflicting interests, before critical healthcare decisions are made on behalf of an incapacitated patient, there should be careful scrutiny of the surrogate's potential conflicts to ensure that they are acting in a manner consistent with the patient's wishes and best interests.<sup>150</sup>

### ***Ethics Committees***

Increasingly, providers and hospitals have relied on ethics committees to render medical futility decisions.<sup>151</sup> Ethics committees are forums, typically composed of medical professionals, social workers, and other hospital staff, that serve

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***[T]here should be careful scrutiny of the surrogate's potential conflicts to ensure that they are acting in a manner consistent with the patient's wishes and best interests.***



as mediators and sometimes decision makers of bioethical disputes, including those involving medical futility.<sup>152</sup> Hospital ethics services are incredibly common; by one measure, 81 percent of general hospitals and 100 percent of hospitals with 400 or more beds had some form of ethics consultation services.<sup>153</sup> In some states, such as Texas, ethics committees actually have legal authority to render a binding decision on a disagreement between the patient's provider and surrogate.<sup>154</sup> Such a decision then gives the provider civil and criminal immunity, shielding them from any potential future litigation regarding the matter.<sup>155</sup> While ethics committees are largely favored by the medical community and bioethical scholars, they are rife with conflicting interests and disability biases.

Ethics committees are not neutral decision-making bodies; they are typically internal hospital forums composed of professionals who are employed or contracted by the hospital.<sup>156</sup> This mechanism is a far cry from an unbiased, independent decision-making body. Conflicts abound: the committee members have both professional and financial incentives to side with the hospital's position, by virtue of their working relationship; the members, largely being health providers themselves, may give added weight, even unconsciously, to the opinions of the treating provider over the patient's surrogate; the members may have pre-existing relationships with the treating provider, causing overreliance on their opinion; or the members may fear retaliation from the hospital or treating provider should they disagree.<sup>157</sup>

Additionally, ethics committees, by virtue of being an internal mechanism of and funded by the hospital, are financially incentivized to minimize hospital expenditures, especially

those that are very costly, such as advanced life-sustaining technologies. The case of Brianne Rideout, a 3-year-old girl with a brain tumor, illustrates the influence that prospective costs can have on an ethics committee's futility decision.<sup>158</sup> Brianne had a brain stem glioblastoma and relied on a ventilator for respiratory function.<sup>159</sup> One day, Brianne's health insurer informed the hospital that her coverage would soon be exhausted, meaning that the hospital would have to absorb any further healthcare expenditures.<sup>160</sup> The very next day, her physician appealed to the hospital's ethics committee for a medical futility determination and imposition of a DNR order.<sup>161</sup> Despite her parents' vocal opposition to the withdrawal of life-sustaining care, the committee ordered the removal of her ventilator and Brianne's provider quickly executed that order, removing her life support while her mother temporarily left the room to speak with her lawyer.<sup>162</sup> As Brianne's case demonstrates, the financial conflict created by the nature of the healthcare reimbursement system makes it ethically inappropriate for ethics committees to be operated and staffed by employees of the hospital.

Further, the typical composition of an ethics committee is void of diversity and fails to represent the rights of patients with disabilities. It is exceedingly rare for a disability advocate, or even a person with a disability, to be on the committee.<sup>163</sup> The one known committee to have a disability representative is that of Seattle Children's Hospital and Regional Medical Center, after it was mandated to do so following the infamous Ashley X growth attenuation case.<sup>164</sup> However, such representation is rare.<sup>165</sup> As goes an adage of the disability rights movement: "Nothing About Us Without Us."<sup>166</sup>

Ethics committees should be representative of the communities within which they lie and the groups that they disparately affect. The presence of disability is common among patients subject to futility decisions and, considering the pervasiveness of medical model thinking and the high stakes, it is essential that there be a disability advocate at the table.

Finally, ethics committees, as currently structured, have insufficient procedural protections of the patient's rights. As Nachama Wilker explained, hospital ethics committees rarely have a system of due process in place to ensure proper consideration of the patient's perspective and weeding out of any potential biases.<sup>167</sup> Instead,

hospitals are generally able to set their own rules for their committees (unless a state law dictates otherwise) and such rules are highly variable from hospital to hospital. This lack of continuity and potential for low procedural standards is simply unacceptable when considering the magnitude of decision making these committees are charged with.

### **Courts**

As the paradigm of neutrality, independence, and due process in the United States, disagreements about medical futility may also go to a court of law for the rendering of a decision. The clear advantage of a court is that it is a neutral decision maker, with both sides having the opportunity to present their case and an independent judge making a binding (yet appealable) decision. Further, a court offers greater procedural

protections of the patient's interests and is not fraught with the same conflicts of interest that pervade ethics committees. In many ways, a court of law sounds like the optimal forum for futility disputes; however, there are practical drawbacks that prevent it from functioning as an ideal frontline futility arbitrator.

Put simply, courts are expensive. Access to a court is rarely free of cost; there is no constitutional right to a civil attorney and, while a plaintiff could theoretically proceed *pro se* and obtain indigent fee waivers, this approach is not to their advantage. Any *pro se* litigant would be against a team of the hospital's experienced attorneys, placing them

at a clear disadvantage in navigating and succeeding in the legal proceeding. Moreover, the patients or surrogates who would be opposing a medical futility decision rarely have the

funds available to hire an attorney. Many have a disability, are low-income, and reliant on public healthcare programs. Thus, in most cases, the only real option for plaintiffs is to obtain *pro bono* legal representation from a law firm, public interest organization, or their state's federally mandated protection and advocacy organization. However, firms rarely choose to take on these cases, as there is little potential for economic damages,<sup>168</sup> and nonprofit legal organizations lack the resources and capacity to take on every case. Due to these barriers to the US legal system, which inhibit justice in many contexts, a court is not a viable option for many medical futility cases.

Moreover, even if a medical futility dispute were to make it to court, legal proceedings

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*[H]ospital ethics committees rarely have a system of due process in place to ensure proper consideration of the patient's perspective and weeding out of any potential biases.*

take an exceedingly long time—time that many patients simply do not have. Plaintiffs could face years of litigation before the case is resolved. This makes a court of law a less than optimal forum for futility decision making.

### ***A Better Process: Independent Mediation and Decision-Making Boards, with Judicial Appeal Available***

To address all of these issues, independent boards should be established to mediate disputes on medical futility involving an incompetent person and, if necessary, render a decision that would be appealable to a court of law. Currently, in states such as New York and Iowa, there are state-run substitute medical decision-making boards, which make medical decisions for patients who are incompetent and do not have a surrogate.<sup>169</sup> The scope of these boards, however, is often specific to state facilities or do not address decisions involving the withholding or withdrawal of life-sustaining treatment.<sup>170</sup> These models should be expanded to medical futility decisions, provided they are also accompanied by a diversifying of the board members and due process protections.

An independent mediation and decision-making board would serve to avoid potential conflicts of interest in ethics committees, while also circumventing the cost and time that prove to be barriers to the judicial system.<sup>171</sup> However, the composition and procedures of such boards would need to be carefully considered. Board members should include medical professionals

who are not affiliated in any way with the health providers and facilities involved in the futility dispute; social workers; disability advocates; and members with a diversity of characteristics (such as gender, race, ethnicity, disability, religion, etc.) in relation to the local community. Members could be appointed by the state agency that has oversight of medical providers and hospitals, in consultation with community-based organizations. Disability advocates may come from or be identified by the state's protection and advocacy organization or nonprofit disability rights legal organizations.

Independent boards would need sufficient procedural protections in place to ensure

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***An independent mediation and decision-making board would serve to avoid potential conflicts of interest in ethics committees, while also circumventing the cost and time that prove to be barriers to the judicial system.***

that the patient's due process rights are effectuated. For example, the board's procedures could be structured as follows: The board would provide notice, in an accessible format, to the patient and/or their

authorized representative. Then, after at least 72 hours and on a mutually agreeable date and time, the board would conduct a mediation among parties, discerning whether a mutually agreeable solution can be reached. During these discussions, the board would ensure that no party is inappropriately influenced or misled with inaccurate statements about disability or prospective quality of life. If the disagreement is intractable, then the board would conduct an evidentiary hearing. At the hearing, both parties to the dispute would have the opportunity to fully present their case and any relevant evidence. Evidence would not

include stereotypical quality-of-life judgments, and testimony from healthcare providers would be limited to technical medical information and analysis. If the decision is in favor of a futility determination, then the patient or their duly acting legal representative, surrogate, or family member would be notified of their right

to appeal the decision to a court of law and provided with contact information for the state's federally mandated protection and advocacy organization. Through procedures such as these, the rights of all patients, including those with disabilities, could be better effectuated in the medical futility decision process.

## Chapter 3: The Disclosure of Hospital Futility Policies

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Hospitals are rarely transparent with their medical futility policies. For decades, guidelines regarding end-of-life decision making and the withholding or withdrawing of lifesaving or life-sustaining medical treatment have largely been kept from the public. The secrecy surrounding medical futility policies and decision making has bred skepticism and fear among many members of the disability community, who rightly want to examine, evaluate, and engage in discussion on how to improve futility procedures to protect the rights of all patients.

Seldom do hospitals make futility policies available to the general public. At least 22 hospitals have published their futility policies in the public domain.<sup>172</sup> However, disclosure is not widespread.<sup>173</sup> At first consideration, this lack of public disclosure may seem suspect. However, as Professor Pope explained, there are less nefarious explanations for this lack of public transparency. It is common industry practice to keep all internal hospital policies private; it is not a practice specific to futility guidelines.<sup>174</sup> Futility policies are designed to be used within the hospital and thus, it is not generally expected that such internal policies be disclosed outside the walls of

the hospital. However, public disclosure would be beneficial to external policy analysts and advocates; it would enable a closer and more well-informed examination of futility policies and the decisions made pursuant to them. Perhaps, however, this is precisely the reason for withholding such policies.

While public disclosure would be ideal, the more pressing question from a patient's rights perspective is: How prevalent is it for hospitals to disclose medical futility policies to patients, their surrogates, or their family members? Unfortunately, the answer is similarly problematic:

disclosure is rare. Despite the American Medical Association<sup>175</sup> and some state-level medical associations, such as in Texas,<sup>176</sup> recommending full and

open disclosure to patients, surrogates, and families, most hospitals remain secretive with their policies. This truth is evident from the fact that many state laws are beginning to mandate disclosure, recognizing the clear ethical violation of withholding these policies from affected parties.<sup>177</sup> Over the past several years, at least six states have attempted to enact laws that would mandate medical futility policy disclosure to patients, their surrogates, and their families.<sup>178</sup> The legislative history behind these bills reveals

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that disclosure has been limited and hospitals have largely prioritized physician autonomy over patient choice. For illustration, consider the testimony of Mary Kellett, a mother of a child with a disability, who testified to Minnesota legislators about a state bill that mandates the disclosure of medical futility policies applying to children:

At 33 weeks pregnant, I had an emergency C-Section. Peter weighed 3 lbs and 2 oz. Peter was given excellent care until day 2 of his life when a test revealed he [had] Trisomy 18. At that time, it was recommended to us that we stop all treatment, wrap him up in a blanket, and let him die. We were told he would lead a life of terrible pain and suffering and would never know us or respond to us. My daughter went on the Internet and found many children living with this, some in their twenties and thirties. When I asked the doctor why he had lied to me, he said, "Well, how these children do largely depends on the choices their parents make for them." I responded, "How can parents make decisions when they don't receive accurate information?" He then said, "Well, we have to think about resources and, you know, Peter will never be able to contribute to society and will be a horrible burden to your family." I started to cry, because I knew resources meant money, and it hurt so badly to have a doctor tell me my son wasn't worthy of the needed treatment to help him live. . . .

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***Over the past several years, at least six states have attempted to enact laws that would mandate medical futility policy disclosure to patients, their surrogates, and their families.***

We were pressured over and over to sign a DNR. We were even told we could not receive home care visits from a nurse unless we signed a DNR. I called the Director of the Home Care Nursing Program and asked her if this was true. She was flabbergasted and told us this was not their policy, nor had it ever been their policy. When I confronted the doctor about that she said, "Well, they must have changed their policy," to which I responded no, "it has never been their policy."<sup>179</sup>

As Peter and his mother's story demonstrates, the disclosure of medical futility policies is essential to providing patients, their surrogates,

and their families with the information they need to protect their rights and ensure accountability. Contrary to what the physicians in Peter's case assumed, he lived a joyous life for

over 6 years.<sup>180</sup> As Peter's mother explained, the disclosure of futility policies "provides a level of consumer protection in health care choice. Parents shouldn't carry the burden of fear and stress over the policies of the hospital, especially during a medical crisis. They have a right to know before they bring their child, [whether they have a disability] or not, to that hospital."<sup>181</sup>

The reasons behind hospitals' lack of historical disclosure of medical futility policies is twofold: hospitals largely support the concept and execution of physician autonomy and they want to protect against patient scrutiny and potential litigation. If a hospital were to disclose its policy to, for example, the family member

of an individual who is reliant on a mechanical ventilator, then this disclosure opens up room for that family member to challenge the application of that policy. For decades, the concept of physician autonomy in decision making has dominated the medical profession. By disclosing the inner workings of their decisions, they allow room for patient questioning, and the potential for litigation is dramatically increased. It is no secret that, in the United States, hospitals are largely private operations and often operate for-profit; their goal is to maximize revenue and decrease expenditures.<sup>182</sup> Litigation, especially if it is lost, is expensive. By withholding information that potentially provides fuel for disagreeing patients, surrogates, or family members, hospitals are protecting their bottom line. It is far safer, from an economics perspective, to make futility decisions

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*It is far safer, from an economics perspective, to make futility decisions behind the scenes rather than out in the open, where they could be subject to questioning and eventual litigation.*

behind the scenes rather than out in the open, where they could be subject to questioning and eventual litigation. This is a stark characterization, but it is also the reality in a country filled with for-profit hospitals.

To protect against inappropriate medical futility policies and the improper application of futility

policies, disclosure to patients, surrogates, and family members is key. It enables accountability, discussion, and mutual understanding among all parties; it fosters trust among the providers and the patients; and it has

the potential to weed out biases and assumptions about the quality of life of a person with a disability. For these reasons, full and open disclosure of medical futility policies to patients, their surrogates, and their family members, in a format that is accessible to people with disabilities and/or limited English proficiency, should be required.





## Chapter 4: State Laws on Medical Futility

All states have at least one statute that relates to medical futility—whether it be by immunizing a healthcare provider’s decision to deny life-sustaining care, protecting the patient’s right to receive life-sustaining care, or something in between.<sup>183</sup> In June 2017, the Robert Powell Center for Medical Ethics at the National Right to Life Committee published a revised report analyzing the degree of protection, or lack thereof, that state laws provide to patients who face medical futility determinations in the context of life-saving or life-sustaining treatment.<sup>184</sup> The comprehensive publication, which surveys statutory codes in all 50 states plus Guam and the US Virgin Islands, groups the state laws in accordance with how protective they are of the patient’s wishes for life-sustaining measures.<sup>185</sup>

### State Laws Without Patient Protections

Nineteen states, plus Guam and the US Virgin Islands, have laws that allow healthcare providers to deny life-saving or life-sustaining treatment and provide no effective protection of a patient’s wishes to the contrary.<sup>186</sup> These states are Arkansas, Connecticut, Illinois, Iowa, Kentucky, Louisiana, Montana, Nebraska, Nevada, New Jersey, North Carolina, North Dakota, Oregon, Pennsylvania, South Carolina, Tennessee,

Washington, West Virginia, and Wisconsin.<sup>187</sup> The impetus behind these state laws is clear: they protect healthcare providers from medical futility liability, with many explicitly codifying the physician’s civil and criminal immunity.<sup>188</sup>

In all of these states and territories, the healthcare provider may, on various “medical” or “moral” grounds, refuse to comply with the patient’s, their surrogate’s, or their family member’s life-sustaining treatment decision or the patient’s advance directive.<sup>189</sup> For example,

#### State Laws Without Patient Protections

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|----------------|--------------------|
| 1. Arkansas    | 11. North Carolina |
| 2. Connecticut | 12. North Dakota   |
| 3. Illinois    | 13. Oregon         |
| 4. Iowa        | 14. Pennsylvania   |
| 5. Kentucky    | 15. South Carolina |
| 6. Louisiana   | 16. Tennessee      |
| 7. Montana     | 17. Washington     |
| 8. Nebraska    | 18. West Virginia  |
| 9. Nevada      | 19. Wisconsin      |
| 10. New Jersey |                    |

in Connecticut, a provider may base their denial of care on their “best medical judgment . . . in accordance with the usual and customary standards of medical practice.”<sup>190</sup> In Nebraska, they may base their decision on “a formally adopted policy of the health care provider organization that is expressly based on religious beliefs or sincerely held ethical or moral convictions central to the operating principles of the [organization].”<sup>191</sup> In West Virginia, it may be based on “the individual provider’s sincerely held religious beliefs or sincerely held moral convictions.”<sup>192</sup> In Tennessee and North Carolina, it may be based on the provider’s “conscience.”<sup>193</sup>

If a provider does deny care contrary to the patient’s wishes, then the patient has the right to transfer to another provider under these laws.<sup>194</sup> In 12 of these states and territories, the provider must take “all reasonable steps” to arrange the transfer of the patient to another facility that would provide the desired life-sustaining care.<sup>195</sup> But in other states, a provider need only use some “efforts”<sup>196</sup> or a “good faith attempt”<sup>197</sup> to effectuate the transfer. In yet other states, the law puts the impetus on the patient or their surrogate to find a new provider,<sup>198</sup> with some imposing a mere duty to “not impede”<sup>199</sup> or to “cooperate”<sup>200</sup> with the transfer.

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*Nineteen states, plus Guam and the US Virgin Islands, have laws that allow healthcare providers to deny life-saving or life-sustaining treatment and provide no effective protection of a patient’s wishes to the contrary.*

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*From a rights perspective, these laws are wholly inadequate; they endorse a dangerous level of subjectivity and expressly permit providers to make decisions based on their personal quality-of-life judgments.*

From a disability perspective, there are a number of problems with these 21 “unprotective” state laws. First, the standards, or lack thereof, by which a provider can base a denial of life-

sustaining treatment under these laws are subjective. Grounds such as “best medical judgment,” “ethical or moral convictions,” and one’s “conscience” leave extensive room for the injection of the physician’s own value judgments

and biases. In fact, the latter two are, on their face, wholly reliant on the physician’s personal beliefs. This subjectivity creates a potential for the physician’s treatment decision to be impacted by disability bias. What if, for example, the physician has a preconceived notion of what life with paraplegia is like, and then, citing grounds of “moral conviction,” chooses to deny life-sustaining treatment to that individual when they develop an acute infection? With malleable standards such as “ethics” and “morals,” this result would be

permitted. From a rights perspective, these laws are wholly inadequate; they endorse a dangerous level of subjectivity and expressly permit providers to make decisions based on their personal quality-of-life judgments.

Second, after the provider denies treatment, it may be exceedingly difficult, as a practical matter, for a patient to find an alternative provider to whom they may transfer. Because none of these laws actually

require the treating physician *to effectuate* a transfer (but only, at its strongest, to use “reasonable efforts”), the burden is on the patient or their surrogate to find an alternative provider. This may prove to be a challenging task. Moreover, even if they do find an alternative provider, there is a glaringly obvious omission from these laws: They do not impose a duty to provide life-sustaining treatment while a transfer is organized or pending.<sup>201</sup> As the Robert Powell Center succinctly explained: “It does the patient little good to be transferred already dead.”<sup>202</sup> If a provider determines life-sustaining treatment is medically futile, especially when considering their own “morals” or “ethics,” it cannot be assumed that they will provide sufficient care in the interim period.<sup>203</sup> There should be state law protections in place to ensure, at a minimum, that care is provided while a patient or their surrogate searches for an alternative facility.

### State Laws with Weak Patient Protections

Eighteen states, plus the District of Columbia, have laws that arguably provide a right to receive life-sustaining measures, but there are notable problems with their language that reduce their protectiveness of patients with disabilities.<sup>204</sup> These states are Alaska, Arizona, California, Colorado, Delaware, Georgia, Hawaii, Idaho, Indiana, Maine, Michigan, Mississippi, Missouri, New Mexico, Rhode Island, South Dakota, Utah, and Vermont.<sup>205</sup>

The laws of all states and territories within this category permit healthcare providers to deny life-sustaining treatment; however, each offers

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*[T]here is a glaringly obvious omission from these laws: They do not impose a duty to provide life-sustaining treatment while a transfer is organized or pending.*

### State Laws with Weak Patient Protections

- |                         |                  |
|-------------------------|------------------|
| 1. Alaska               | 10. Indiana      |
| 2. Arizona              | 11. Maine        |
| 3. California           | 12. Michigan     |
| 4. Colorado             | 13. Mississippi  |
| 5. Delaware             | 14. Missouri     |
| 6. District of Columbia | 15. New Mexico   |
| 7. Georgia              | 16. Rhode Island |
| 8. Hawaii               | 17. South Dakota |
| 9. Idaho                | 18. Utah         |
|                         | 19. Vermont      |

some (albeit weak) form of patient protections after this decision is made.<sup>206</sup> Five states require the treating provider to transfer the disagreeing patient to another provider.<sup>207</sup> These laws are a clear improvement from those previously discussed, as they appropriately place the burden on the physician to find an alternative provider.

However, they still allow providers to deny treatment on value-laden grounds such as one’s “conscience” or “moral convictions,” and they are silent on the provision of

life-sustaining care during the interim transfer period.<sup>208</sup> For these reasons, while perhaps intended to effectuate the medical preferences and decisions of the patient,<sup>209</sup> these laws remain problematic from a rights perspective.

Closer to the goal of protecting the rights of patients with disabilities are the laws of eight states in this category, which require healthcare providers to either give “continuing care” or “care and comfort” pending the patient’s transfer.<sup>210</sup> The problems with these laws, as the Robert Powell Center aptly identifies, is that the “care” required pending transfer is not defined.<sup>211</sup> These laws do not say that “life-saving” or “life-sustaining” care must be provided—they only say some “care,” which could be interpreted to mean “palliative care, pain medication, and the like.”<sup>212</sup>

Three states in this category correct this ambiguity, either by requiring life-sustaining continuing care or requiring the provider to follow the patient advocate’s instructions.<sup>213</sup> However, each of these states also immunizes providers from violating this provision if they were acting pursuant to the medical standard of care, thus wholly undermining the protection provided by these laws.<sup>214</sup>

In Missouri, state law permits healthcare providers to deny life-sustaining treatment on grounds of “sincerely held moral convictions”; however, it contains one important exception: if the provider has received the patient’s durable power of attorney for health care beforehand.<sup>215</sup> While a step in the right direction, the Missouri law is clearly underinclusive of patients who wish to receive life-sustaining care, yet have not executed an advance directive. As is especially common among low-income individuals, they may simply have lacked the funds to draft these legal instruments, or lacked awareness that this was a necessary option. Regardless of the reasons, Missouri’s law, like the others in this category, fails to adequately protect the rights of patients with disabilities who are facing medical futility judgments.

Finally, Idaho law prohibits the denial of life-sustaining treatment if such care is directed by a competent patient or their surrogate decision maker, unless such care would be “futile.”<sup>216</sup> The law narrowly defines “futile” as care that, in “reasonable medical judgment” would not prevent “imminent death” or the denial of which would “not result in or hasten” death.<sup>217</sup> In other words, Idaho utilizes a physiological definition of futility that limits its application only to cases in which the treatment would not work medically. It does not, on its face, seem to permit quality-of-life considerations. However, Idaho’s law contains one very notable exception: it “does not require provision of treatment to a patient if it would require denial of the same or similar treatment to another patient.”<sup>218</sup> Under this broad, unqualified exception, if a hospital experienced a shortage of ICU beds, ventilators, or any other life-sustaining services or devices, then it could use this resource shortage to justify denying treatment to a patient with a disability. This result is ethically unacceptable and a glaring hole in Idaho’s approach.

## State Laws with Time-Limited Patient Protections

Two states, Virginia and Texas, have laws that require an unwilling provider to give life-sustaining treatment for a limited period of

### State Laws with Time-Limited Patient Protections

1. Texas
2. Virginia

time to patients pending a transfer to another facility.<sup>219</sup> In Virginia, the physician has the right to deny any health care that they determine to be “medically or ethically inappropriate.”<sup>220</sup> If the patient, their surrogate, or their family member disagrees, then the physician must make a “reasonable effort” to transfer the patient to a willing provider.<sup>221</sup> During the interim period, the physician must provide life-sustaining care that is “reasonably available” to them; however, such care is limited to 14 days.<sup>222</sup>

Texas law also establishes time-limited protections; however, only after a highly controversial and binding extrajudicial process for the rendering of medical

futility determinations.<sup>223</sup>

In Texas, if a physician believes that a healthcare treatment is futile, then the physician must inform the patient or their surrogate of this decision and, after at least 48 hours, an ethics

committee will hold a hearing to review this decision.<sup>224</sup> If the ethics committee agrees with the physician, then the provider will discontinue life-sustaining care after 10 days (with an option for extension via court order).<sup>225</sup> If, after 10 days, no willing provider is found, then treatment may be discontinued and the physician is immunized from liability.<sup>226</sup>

The problems with the laws in Virginia and Texas are rampant. First, it is highly likely that a person who requires life-sustaining care will need more than 10 or 14 days of treatment. While providing *some* care in the interim transfer period is a step in the right direction, these time-limited laws are wholly insufficient to protect against

value-laden futility judgments. Second, Texas’s law in particular creates a binding decision-making body, but fails to offer due process protections for patients and blocks them from any future challenges in a court of law. The lack of detail in Texas’s law gives hospitals a dangerous level of discretion to create and manage their own ethics committees and determine their own standards for a finding of medical futility. There is no continuity in these committees throughout the state, no diversity among its members, and little oversight of their operations. Even more concerning, however, is that the decisions they render are virtually unappealable. By granting

physicians immunity through using the state’s futility law, a disagreeing patient is left with few legal options. They have 10 days to find a new, willing provider—or their life-sustaining treatment will be discontinued.

With the stakes so high, the lack of procedural protections in Texas’s law is unacceptable.

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***By granting physicians immunity through using [Texas’s] futility law, a disagreeing patient is left with few legal options. They have 10 days to find a new, willing provider—or their life-sustaining treatment will be discontinued.***

## **State Laws with Strong Patient Protections**

Finally, the remaining 11 states—Alabama, Florida, Kansas, Maryland, Massachusetts, Minnesota, New Hampshire, New York, Ohio, Wyoming, and Oklahoma—each have laws that can be characterized as protective of the rights of patients with disabilities to receive life-sustaining care, even in the face of a disagreeing provider.<sup>227</sup>

Ten of these states—Alabama, Florida, Kansas, Maryland, Massachusetts, Minnesota, New Hampshire, New York, Ohio, and

## State Laws with Strong Patient Protections

- |                  |                  |
|------------------|------------------|
| 1. Alabama       | 7. New Hampshire |
| 2. Florida       | 8. New York      |
| 3. Kansas        | 9. Ohio          |
| 4. Maryland      | 10. Oklahoma     |
| 5. Massachusetts | 11. Wyoming      |
| 6. Minnesota     |                  |

Wyoming—have laws that protect the right of an individual to receive life-sustaining treatment pending a transfer to another facility, without time limit.<sup>228</sup> These laws are a significant improvement from those in Virginia and Texas, enabling a disagreeing patient to actually survive the interim period through which they search for an alternative provider. The laws provide concrete, understandable, and unlimited protection for patients who wish to receive life-sustaining treatment.

In Oklahoma, state law prevents the denial of life-sustaining treatment when it is based on potentially discriminatory factors.<sup>229</sup> The law provides:

A health care provider shall not deny to a patient a life-preserving health care service the provider provides to other patients, the provision of which is directed by the patient or a person authorized to make health care decisions for the patient:

1. On the basis of a view that treats extending the life of an elderly, disabled, or terminally ill individual as of lower value than extending the life of an individual who is younger, nondisabled, or not terminally ill; or
2. On the basis of disagreement with how the patient or person authorized to make health care decisions for the patient values the trade-off between extending the length of the patient's life and the risk of disability.<sup>230</sup>

Oklahoma's law provides strong protections for patients with disabilities by expressly prohibiting reliance on quality-of-life misconceptions. It notably covers *any* situation where inappropriate disability biases are injected into a futility decision, and not just a situation where the patient or their surrogate expresses their objection (as in Idaho). This places less of a burden on the patient or surrogate to identify and communicate their disagreement; instead, the burden is on the healthcare provider to critically examine their own potential biases and ensure that the criteria through which they are relying is purely objective, outcome-based medicine and is not impacted by their own values. Other states should adopt or amend their laws to incorporate either nondiscrimination protections in the medical futility context (such as Oklahoma) or mandated life-sustaining treatment pending transfer, without time limits (such as Alabama, Florida, Kansas, Maryland, Massachusetts, Minnesota, New Hampshire, New York, Ohio, and Wyoming)—or, ideally, both.

## Chapter 5: The Lawfulness of Medical Futility Decisions

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Medical futility disputes rarely make it to a court of law.<sup>231</sup> For reasons previously discussed, it is often financially prohibitive or impracticable for patients or their surrogates to appeal to a court for injunctive relief from futility decisions and the treatment actions made pursuant to them. Despite this reality, medical futility decisions, especially in the context of advanced illness, implicate numerous federal and state constitutional and statutory provisions, and there are competing perspectives on whether and how the withholding or withdrawing of life-sustaining care, when based on assumptions or biases about the quality of life or capacities of people with disabilities, violates such laws. Disability nondiscrimination laws, including the ADA and Section 504 of the Rehabilitation Act, provide a viable, yet largely unexplored vehicle for enforcing the rights of people with disabilities in the medical futility context.

### Surveying the Field: Legal Implications at the Intersection of Medical Futility and Disability

The concept of medical futility first emerged within legal discourse in the early 1990s, when

cases such as *In re Helga Wanglie* gained national attention. Ms. Wanglie was a 87-year-old woman who was in a PVS following a cardiopulmonary arrest.<sup>232</sup> Her physicians believed she would never regain consciousness and recommended that her mechanical ventilation be removed.<sup>233</sup> Ms. Wanglie's family strongly objected, believing that the withdrawal of life support would be contrary to her wishes and religious beliefs.<sup>234</sup>

When her family refused to consent, the medical center filed suit under the state's surrogacy law, seeking to appoint an agreeing conservator for her.<sup>235</sup> The court ultimately sided with Ms. Wanglie's family, allowing her husband to continue to make her medical decisions.<sup>236</sup> A few days later, while still connected to her respirator, Ms. Wanglie passed away.<sup>237</sup>

Since *In re Helga Wanglie*, there have been at least 40 appellate-level cases involving a medical futility dispute between a patient or surrogate who wishes to receive or continue life-sustaining treatment and a healthcare provider that seeks to withdraw or withhold it.<sup>238</sup> These cases have been litigated under many different causes of action, including the Fourteenth Amendment to the US Constitution, the Emergency Medical

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Treatment and Active Labor Act (EMTALA), Section 504 of the Rehabilitation Act, the ADA, and state-level constitutions, statutes, and common law doctrine.<sup>239</sup> The outcomes of these challenges have varied.

Fourteenth Amendment challenges have been historically unsuccessful at effectuating the rights of people with disabilities in the medical context. The Fourteenth Amendment provides that no state shall “deprive any person of life, liberty, or property, without due process of law; nor deny to any person within its jurisdiction the equal protection of the laws.”

Because the Fourteenth

Amendment only

reaches state action,

its application to the medical futility context is

limited. However, were there to be a finding of

state action, a wrongful futility determination or a state law that endorses such a result may violate an individual’s substantive due process right to life. It probably would not constitute a violation of equal protection.

The Fourteenth Amendment’s Due Process Clause protects against the arbitrary deprivation of fundamental liberty interests. In a doctrine known in the legal community as substantive due process, fundamental privacy interests such as the right to parental decision making,<sup>240</sup> the right to choose an abortion,<sup>241</sup> the right to use contraception,<sup>242</sup> and the right to marry<sup>243</sup> have been well established. In the context of healthcare decision making, there have been two highly controversial decisions by the US Supreme Court, neither of which directly address the issue of medical futility discrimination. In *Cruzan v. Director, Missouri Department of Health*, the

Supreme Court upheld a state law that required clear and convincing evidence of the patient’s wishes if and when their surrogate wished to withdraw life-sustaining treatment.<sup>244</sup> Citing the state’s interest in protecting and preserving human life, the Court held that the law did not unconstitutionally infringe on an individual’s right to refuse unwanted medical treatment.<sup>245</sup> It explained: “a State may properly decline to make judgments about the ‘quality’ of life that a particular individual may enjoy, and simply assert an unqualified interest in the preservation of human life.”<sup>246</sup> In *Washington v. Glucksberg*,

a group of physicians

tested the limits of the

*Cruzan* holding, arguing

that a state statute

prohibiting physician-

assisted suicide ran afoul

of an individual’s right

to medical self-determination.<sup>247</sup> The Supreme Court disagreed.<sup>248</sup> In holding that there is no constitutional right to commit physician-assisted suicide, the Court announced the outer limits of due process at the end of life.<sup>249</sup> However, it left open the question of whether, in the opposite, an individual has a fundamental right *to live* and thus *receive* life-sustaining treatment in the face of a disagreeing provider.

There is a colorable legal argument that an individual with a disability has a right to life that is protected by substantive due process. While this legal theory remains largely untested in the federal courts, dicta from both *Cruzan* and *Glucksberg* support substantive due process protections in the context of medical futility. Namely, by engaging in analysis that balances the state’s interest in preservation of life and the individual’s right to medical self-determination,

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the Court implies that a competent individual has some sort of fundamental liberty interest in dictating their own course of medical treatment.<sup>250</sup> In *Cruzan* and *Glucksberg*, that individual interest was framed as a negative right—that is, an individual may have a right to *refuse* unwanted medical treatment in certain circumstances; however, there are compelling arguments for extending the liberty interest to a positive right, one that provides an individual with a right to *receive* wanted medical treatment, especially in the face of a biased decision maker. Indeed, in many ways, an individual’s right to life is far more rooted in “our Nation’s history, legal traditions, and practices”<sup>251</sup> than a right to death. Principles of the inherent value of life, nondiscrimination in health care, and equality are, at least in theory, central to the evolving traditions of US society.<sup>252</sup> It is not a far stretch to assert a fundamental right to receive life-sustaining medical treatment and be free from quality-of-life judgments that cause discrimination in medical futility decisions.

However, medical futility laws or the decisions made pursuant to them that discriminate on the basis of disability would likely not violate the Fourteenth Amendment’s Equal Protection Clause. Equal protection does reach classification on the basis of disability, however, in *Cleburne v. Cleburne Living Center*, the US Supreme Court held that such classifications are only subjected to a rational basis test (“a rational

relation to a legitimate state interest”).<sup>253</sup> As presently articulated, this low bar would make it exceedingly difficult to challenge discriminatory futility decisions through equal protection.

EMTALA offers a viable, yet substantively limited, cause of action for patients with disabilities facing a futility judgment. EMTALA is a federal statute that imposes a duty on hospitals to stabilize all patients who come to the hospital and have an emergency medical condition.<sup>254</sup> EMTALA was originally designed to address “patient dumping,” a practice where hospitals would turn away or transfer patients

for nonmedical reasons (such as lack of health insurance).<sup>255</sup> The hospital’s duty under EMTALA is limited only to medical stabilization—after the patient is stable, they may transfer them to another facility.<sup>256</sup> The US Court of Appeals for the Fourth Circuit has expressly recognized that a hospital must provide

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*The US Court of Appeals for the Fourth Circuit has expressly recognized that a hospital must provide life-saving treatment to a patient with a disability experiencing an emergent medical condition under EMTALA, even if the hospital deems that treatment “medically futile” in the long term.*

life-saving treatment to a patient with a disability experiencing an emergent medical condition under EMTALA, even if the hospital deems that treatment “medically futile” in the long term.<sup>257</sup> In *In re Baby K*, a hospital sought judicial approval to withhold life-saving respiratory treatment from an infant with anencephaly, asserting that it was medically “futile” to provide the care because of the baby’s anencephalic condition.<sup>258</sup> Baby K’s mother vehemently opposed the measure, expressing her wishes that her daughter receive all treatment necessary to save her life.<sup>259</sup> The court, citing EMTALA, refused the hospital’s

request and required the facility to continue to provide life-saving treatment to Baby K when she presented at the emergency department as needed.<sup>260</sup> The plain language of EMTALA required medical stabilization and the hospital could not avoid this duty by hiding behind an assertion that life-sustaining care would ultimately prove “futile” in saving Baby K’s life.<sup>261</sup>

While the *In re Baby K* holding was groundbreaking, it only offers a limited solution in the face of a provider who is relying on quality-of-life assumptions to gauge medical futility. EMTALA’s reach is limited to medical stabilization; while a provider, under common law principles, could not just abandon a patient, they could certainly attempt to transfer them to another facility. Moreover, in some jurisdictions, the hospital could simply admit the patient, immunizing it from liability under EMTALA’s provisions, which apply emergency department protocols.<sup>262</sup> EMTALA thus offers an incomplete solution.

Section 504 of the Rehabilitation Act and the ADA offer a promising, yet largely unexplored, option for litigants with disabilities facing a wrongful futility decision.<sup>263</sup> Section 504 and the ADA both prohibit discrimination on the basis of disability. Section 504 covers programs and activities that accept federal financial assistance;<sup>264</sup> while the ADA covers programs operated by state and local governments and places of public accommodation (including private medical facilities).<sup>265</sup> Section 504 and the ADA are largely coextensive and, as detailed in the following section, provide a

broad and hopeful litigation solution for patients with disabilities.

Likewise, Section 1557 of the ACA offers a novel cause of action for an individual with a disability who has been discriminated against in futility decision making.<sup>266</sup> In relevant part, Section 1557 prohibits disability discrimination by any health program or activity, any part of which is receiving federal financial assistance, and any publicly administered health program or activity.<sup>267</sup> Litigation under Section 1557 is just emerging, with no known futility cases. However, given its similarity to Section 504 and the ADA, it offers a promising legal mechanism for prospective litigants.

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Finally, many state constitutions, statutes, and common law principles offer potential causes of action to enforce the rights of people with disabilities and seek redress against wrongful

medical decisions; however, these laws vary considerably from state to state. For example, in *Rideout v. Hershey Medical Center*, the parents of Brianne Rideout sued the medical center, which had withdrawn mechanical ventilation against their objections and subsequently allowed their daughter to die, under Pennsylvania law theories of negligent and intentional infliction of emotional distress, lack of informed consent, and privacy-based parental rights.<sup>268</sup> In *Gilgunn v. Massachusetts General Hospital*, the family of Catherine Gilgunn sued the hospital, which had withdrawn life support and issued a DNR against their objections, under the Massachusetts common law doctrine of negligence.<sup>269</sup> And in

*Betancourt v. Trinitas Regional Medical Hospital*, the family of Ruben Betancourt sued for injunctive relief and guardianship under New Jersey law to restrain the hospital from discontinuing or suspending life-sustaining treatment.<sup>270</sup> The outcomes of cases like *Rideout*, *Gilgunn*, and *Betancourt* have been mixed and are largely fact-specific. In *Rideout*, the dispute settled before the court reached the full merits of the state law claims; in *Gilgunn*, a jury found in favor of the hospital, agreeing that further treatment would have been futile; and in *Betancourt*, the court granted the family's guardianship petition and restrained the hospital from removing Mr. Betancourt's life support.<sup>271</sup> Because of the wide variability, individuals, their legal representatives, and state-level advocates should carefully explore the potential causes of action under their state's constitution and doctrines of informed consent, surrogate, and tort liability.

## Disability Nondiscrimination Law and Medical Futility

The ADA is the most significant and comprehensive legislation ever enacted to prohibit discrimination against and provide accommodations for people with disabilities. Enacted in 1990—just following the emergence of the medical futility debate—it affords broad protections to people with disabilities in employment, state and local governments, and places of public accommodation.<sup>272</sup> All healthcare provider offices and hospitals are covered under the ADA, with public facilities operated by a state or local government subject to Title II and private medical offices and hospitals subject to Title III.<sup>273</sup> Additionally, all medical providers and facilities that accept federal financial assistance (including Medicare and Medicaid reimbursements) are covered under Section 504 of the Rehabilitation

Act. While it is clear that the disability nondiscrimination law is binding on providers, it remains unclear whether and under what circumstances futility decisions could constitute unlawful discrimination. This section will analyze that question, specifically examining whether a provider's conscious or implicit considerations of disability-related quality of life in futility decisions can give rise to a successful claim of discrimination under the ADA.

The breadth and purposes of disability nondiscrimination law reveal congressional intent to eliminate the widespread exclusion and marginalization of people with disabilities. For example, the ADA affords broad protections to people with disabilities in employment;<sup>274</sup> public services that state and local governments, departments, and agencies provide;<sup>275</sup> public accommodations, including certain private entities that operate public services;<sup>276</sup> and telecommunications.<sup>277</sup> The statute's express purpose is to provide "a clear and comprehensive national mandate for the elimination of discrimination against [people] with disabilities."<sup>278</sup> In its findings, Congress noted: "historically, society has tended to isolate and segregate individuals with disabilities, and, despite some improvements, such forms of discrimination against individuals with disabilities continue to be a serious and pervasive social problem."<sup>279</sup> In particular, Congress emphasized the importance of eliminating discrimination in certain "critical areas," including "health services."<sup>280</sup> Moreover, during the ADA's passage, legislative history shows that Congress explicitly recognized the pervasiveness of discrimination in the provision of medical treatment.<sup>281</sup>

Pursuant to these expansive purposes, Title II of the ADA and Section 504 of the Rehabilitation

Act provide that “no qualified individual with a disability shall, by reason of her or his disability, be excluded from participation in, be denied the benefits of, or be subjected to discrimination” by a public entity (under Title II) or any program or activity receiving federal financial assistance (under Section 504).<sup>282</sup> Similarly, Title III of the ADA provides that “[n]o individual shall be discriminated against on the basis of disability in the full and equal enjoyment of the goods, services, facilities, privileges, advantages, or accommodations of any place of public accommodation by any person who owns, leases (or leases to), or operates a place of public accommodation.”<sup>283</sup>

In order to succeed in an ADA or Section 504 claim, a plaintiff must generally prove: (1) she is an individual with a disability; (2) she was discriminated against by a covered entity; and (3) discrimination was on the basis of disability.<sup>284</sup> The ADA and Section 504 broadly define disability as “a physical or mental impairment that substantially limits one or more major life activities of such individual,” “a record of such impairment,” or “being regarded as having such an impairment.”<sup>285</sup> Covered entities under Title II and Title III are, respectively, public entities and private entities that operate a place of public accommodation.<sup>286</sup> A “public entity” includes “any State or local government” or “instrumentality of a State . . . or local government;”<sup>287</sup> and a “place of public accommodation” is a facility whose operations fall into an enumerated category, including a “professional office of a health care provider, hospital, or other service establishment.”<sup>288</sup> Covered entities under Section 504 are programs or activities that receive federal funding, including Medicaid or Medicare reimbursements, which

are accepted by virtually every hospital and most healthcare providers.<sup>289</sup>

The second and third prongs of an ADA or Section 504 claim examine whether a person with a disability experiences discrimination and whether that discrimination was “by reason of” or “on the basis of” her disability.<sup>290</sup> Unlawful discrimination under the ADA or Section 504 can be proven through one of two primary legal theories—disparate treatment or disparate impact. Disparate treatment considers whether a covered entity treats an individual with a disability differently because of their disability; while disparate impact considers whether a facially neutral policy or practice disproportionately impacts people with disabilities. Notably, Congress intended disability nondiscrimination protections to reach not only discrimination that is the result of “invidious animus,” but also of “thoughtlessness,” “indifference,” and “benign neglect.”<sup>291</sup>

In the context of medical futility decisions, people with disabilities and their families have had some success in using the ADA and Section 504 to block the withholding or withdrawal of life-sustaining care. The most pertinent case is *In re Baby K*. In *Baby K*, a hospital sought a declaratory judgment permitting the withdrawal and refusal of life-sustaining care to a baby with anencephaly who was struggling to breathe.<sup>292</sup> The hospital argued that providing ventilator care to Baby K was medically futile, given the baby’s low chance of living for more than a few days.<sup>293</sup> Baby K’s mother strongly objected, asserting her belief that “all human life has value, including her anencephalic daughter’s life.”<sup>294</sup> The US District Court for the Eastern District of Virginia, considering both parties’ positions, held that the refusal of life-sustaining

care to Baby K would constitute disability discrimination within the meaning of the ADA.<sup>295</sup> The court explained:

[T]he plain language of the ADA does not permit the denial of ventilator services that would keep alive an anencephalic baby when those life-saving services would otherwise be provided to a baby without disabilities at the parent's request. The Hospital's reasoning would lead to the denial of medical services to anencephalic babies as a class of disabled individuals. Such discrimination against a vulnerable population class is exactly what the American with Disabilities Act was enacted to prohibit.<sup>296</sup>

In sum, the court held that, because the treatment *would* be provided to an infant *without* a disability at the parent's request, the hospital could not escape ADA liability by asserting that the treatment was "futile."<sup>297</sup> The hospital appealed the decision, and the US Court of Appeals for the Fourth Circuit affirmed—but only on grounds of the EMTALA violation.<sup>298</sup> The court stated that it was unnecessary to review the lower court's ADA decision because the denial of care would constitute a clear violation of EMTALA.<sup>299</sup>

Disability advocates have also seen success in using the ADA and Section 504 to prevent medical futility discrimination outside of the judicial context. In the mid-1990s, the state of

Oregon proposed a revision to their Medicaid demonstration that would have expanded Medicaid to all individuals below the federal poverty line; however, to pay for it, they proposed a system of healthcare rationing.<sup>300</sup> Under the plan, Oregon would have developed a healthcare prioritization system that relied on three criteria: the probability of death, the probability of returning to an asymptomatic state, and the cost of avoiding death.<sup>301</sup> From a disability perspective, there were clear concerns over the disparate impact this plan would have had on the rights of patients with disabilities in need of life-sustaining treatment. The US Department

of Health and Human Services, listening to the well-voiced concerns of disability advocates, rejected Oregon's proposal on grounds that it would violate the ADA and Section 504.<sup>302</sup>

Some federal courts, however, have been resistant to applying disability

nondiscrimination law to the context of withdrawal of life-sustaining treatment.<sup>303</sup>

Professor Pope explained the general reasoning: "when an individual's disability is relevant to the patient's capacity to benefit from the medical treatment at issue, then it may not be a violation of the ADA or Section 504."<sup>304</sup> The primary case cited for this position is *Schiavo v. Schiavo*, a case involving a woman diagnosed with PVS whose family members (*not* a family member and provider) disagreed over whether her life-sustaining care should be withdrawn.<sup>305</sup> In *Schiavo*, the US Court of Appeals for the

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***"The Hospital's reasoning would lead to the denial of medical services to anencephalic babies as a class of disabled individuals. Such discrimination against a vulnerable population class is exactly what the American with Disabilities Act was enacted to prohibit."***

Eleventh Circuit considered whether the removal of nutrition and hydration from Ms. Schiavo on the basis of her PVS condition constituted discrimination on the basis of disability.<sup>306</sup> The court rejected the discrimination claim on narrow grounds, holding that the surrogate-defendant was not a public entity or accommodation subject to the ADA and that the Hospice-defendant, following a court order, did not act “on the basis of [Ms. Schiavo’s] disability.”<sup>307</sup> The Eleventh Circuit also asserted in dicta that “[t]he ADA was never intended to provide an avenue for challenging court orders in termination of care cases.”<sup>308</sup> *Schiavo*’s precedent can be distinguished, both factually and legally, from medical futility disputes. While the disagreement in *Schiavo* was among family members, medical futility decisions are

primarily characterized by a dispute between a provider and an individual or their family. Further,

*Schiavo*’s holding is limited, only reaching the threshold issues of the ADA’s applicability and the challenged action’s nexus to disability. Its precedential value to medical futility disputes is therefore questionable.

Upon review of the limited caselaw, it is clear that people with disabilities may have a viable basis for enforcing their ADA and Section 504 rights in the context of medical futility decisions.<sup>309</sup> HHS and at least one US District Court have expressly recognized the rights of people with disabilities to receive life-saving or life-sustaining care. While there are dicta from other federal courts suggesting limitations to the ADA and Section 504’s protections, these cases, such as *Schiavo v. Schiavo*, can largely be distinguished and are arguably not binding on a

medical futility case. Indeed, an examination of the elements of a disability discrimination claim, especially when considered in the context of the statute’s broad purposes and the gravity of futility decisions, indicates that a medical futility determination that relies on disability-related quality of life assumptions likely would violate the statute.

As previously detailed, a successful ADA or Section 504 plaintiff must prove she has a qualifying disability; the provider is a covered entity; and she was subjected to discrimination on the basis of disability by that provider.<sup>310</sup> The first element will be relatively easy to prove in the medical futility context: any substantial impairment to respiratory, cardiac, or other major body functions would qualify, and thus

most individuals facing a futility judgment would likely have a “disability” within the meaning the ADA and Section 504.

Likewise, nearly every provider is within the purview of the ADA and/or Section 504—if the medical entity is funded by the state or local government, it would be within the purview of Title II; if it is private, it would be covered under Title III, by virtue of all hospitals and provider offices being places of public accommodation; and if it accepts federal funding (including public healthcare program reimbursements), it would be covered under Section 504.<sup>311</sup>

The heart of the legal issue lies in whether the plaintiff, by virtue of being subjected to a decision that relies on biases and stereotypes about current or prospective disability, was “subject to discrimination on the basis of disability” by the provider. Admittedly, this element is heavily dependent on the facts of

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**[*Schiavo v. Schiavo*’s] precedential value to medical futility disputes is therefore questionable.**

the case at issue; however, under the holding of *Baby K*, discrimination could generally be proven by showing that a medical futility policy, or a provider acting pursuant to it, denied life-sustaining treatment to a person with a disability, and that treatment would otherwise have been provided to a person without a disability. From an evidentiary perspective, this could be demonstrated through a similarly situated comparator; through medical records that either explicitly reference the individual's disability or a low quality of life in relation to the treatment at issue; through a written policy of the medical facility that references consideration of the individual's disability or a low quality of life; or through statistical evidence that a futility policy is disproportionately utilized on patients with disabilities unrelated to the reason for their office visit or hospital admission. The possibilities are potentially endless.

Counterarguments asserting that a provider is immunized from ADA and Section 504 liability when an individual's disability is pertinent to

the diagnosis miss the point and are indicative of medical model thinking. If an individual's "disability" were truly relevant to a treatment outcome, so as to make that treatment physiologically futile (i.e., no chance of achieving the desired benefit), then such a determination would *not* run afoul of the ADA and Section 504. Put differently, discrimination in medical futility occurs when a decision relies on assumptions about the value of life with a disability. If a treatment simply will not work, the provider would not be making a decision "on the basis of" that person's disability; they are making the decision based on objective medical facts. Therefore, there is no "slippery slope" to requiring any and all medical treatments, no matter how objectively futile, as opponents will have one believe. There is a clearly defined limit and that limit is treating a person with a disability's life as having less value than that of a person without a disability. For these reasons, the ADA and Section 504 protect the rights of people with disabilities in the medical futility context and should be utilized as such.





## Conclusion

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**M**edical futility and disability intersect in complex and nuanced ways. A solution to the discrimination in medical futility decisions that people with disabilities experience requires a multifaceted approach, including action by medical and health professional schools;

hospitals, medical facilities, and health provider offices; professional hospital accreditation bodies; healthcare insurers; state legislatures; the US Department of Health and Human Services; and Congress.



## Recommendations

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### **Congress**

- Congress should enact legislation that requires hospitals and other medical entities to have due process protections for medical futility decisions; utilize an independent due process mechanism for mediating and deciding medical futility disputes; and disclose medical futility policies to patients, their surrogates, or their family members.
- Congress should enact legislation to make federal funding for hospitals and other medical entities contingent on the provision of due process protections in medical futility decisions.

### **Executive Branch**

#### **The US Department of Health and Human Services (HHS) Office for Civil Rights (OCR)**

- OCR should issue guidance to healthcare providers clarifying that medical futility decisions that rely on subjective quality-of-life assumptions or biases about disability violate federal disability rights laws.
- OCR should seek compliance from hospitals and medical facilities that violate disability rights laws by making medical futility decisions that rely on subjective quality-of-life assumptions or biases about disability and withhold federal financial assistance when compliance cannot be obtained.
- HHS should encourage hospitals and medical facilities to use an independent due process mechanism for mediating and deciding medical futility disputes and disclose medical futility policies to patients, their surrogates, or their family members.

## **Medical and Health Professional Schools**

- Healthcare provider education and training should include disability competence as a component of or in addition to cultural competence training. Such education, at a minimum, should include topics such as disability bias and stereotypes, physical and programmatic accessibility required by law, and clinical expertise.
- Healthcare provider education must be physically and programmatically accessible for students and prospective students with disabilities, so as to facilitate and encourage greater diversity in the health professions. By fostering this diversity, more providers will experience and/or learn from their peers an accurate understanding of life with a disability, thus reducing bias in medical futility decisions.

## **Hospitals and Medical Facilities**

- Hospitals, medical facilities, and provider offices should utilize an independent board to mediate and, if necessary, make medical futility decisions for incompetent patients. The board should be independent from the relevant facility and provider(s), offer procedural due process protections, reflect diversity, and have at least one disability rights advocate as a member. Its decisions should be appealable to a court of law.
- Hospitals, medical facilities, and provider offices should provide full and open disclosure of their medical futility policies to patients, their surrogates, and their family members. Such policies should be provided in an accessible format and in advance of the provider(s) making a futility recommendation.

## **Professional Accreditation Bodies**

- Professional accreditation bodies should identify and decertify any hospitals, medical facilities, or health provider offices that fail to follow pertinent state laws protecting patient's rights in medical futility decision making; that fail to make their facilities and programs physically and programmatically accessible for patients and prospective patients; or that fail to disclose medical futility policies to patients, their surrogates, or their family members, when required by law.

## Healthcare Insurers

- Healthcare insurers should improve coverage of lifesaving and life-sustaining treatment, including the removal of arbitrary exclusions, limitations, and excessive cost sharing, to reduce healthcare disparities and improve meaningful choice in critical care decisions.
- Healthcare insurers should improve coverage of long-term services and supports.

## State Legislatures

- State legislatures should enact or amend statutes and regulations to mandate that hospitals and health providers utilize an independent board to mediate and, if necessary, make medical futility decisions for incompetent patients. The boards should offer procedural due process protections, reflect diversity, and have at least one disability rights advocate as a member. Its decisions should be appealable to a court of law.
- State legislatures should adopt or amend statutes and regulations to expressly prohibit the involuntary withdrawal of life-sustaining treatment, unless the treatment is objectively physiologically futile and such a determination is not based on a view that the life of a person with a disability is of lower value or of lower quality than that of a person without a disability, whether the person's disability is pre-existing or newly acquired.
- State legislatures should adopt or amend statutes and regulations to require health care providers to provide life-sustaining treatment to an individual pending their transfer to another facility, without time limits.



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- 160 Bassel, 513–14.
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injunction to prevent the withholding or withdrawal of care, and those where the patient has already died because of a futility judgment, and thus their family is bringing a wrongful death or other tort action. The former is more likely to find *pro bono* representation than the latter.

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- 183 Robert Powell Center, 7–11.
- 184 Robert Powell Center, 1–12.
- 185 Robert Powell Center, 1–12.
- 186 Robert Powell Center, 7–8.
- 187 Robert Powell Center, Appendix 1–7.
- 188 Conn. Gen. Stat. § 19a-571(a); N.D. Cent. Code § 23-06.5-12(3); Wis. Stat. Ann. § 154.07(1)(a).
- 189 Robert Powell Center, Appendix 1–7.
- 190 Conn. Gen. Stat. § 19a-571(a).
- 191 Neb. Rev. Stat. § 30-34-28(1).
- 192 W. Va. Code § 16-30-12(a).
- 193 N.C. Gen. Stat. § 90-321(k); Tenn. Code Ann. § 32-11-108(a).
- 194 Robert Powell Center, Appendix 1–7.

- 195 Robert Powell Center, Appendix 1–7 (“All reasonable steps” to effectuate the patient’s transfer is required in Arkansas, Connecticut, Iowa, Louisiana, Nevada, New Jersey, Oregon, Pennsylvania, South Carolina, Tennessee, Guam, and the US Virgin Islands).
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- 204 Robert Powell Center, 8–9.
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- 206 Robert Powell Center, Appendix 7–12.
- 207 Robert Powell Center, 8, Appendix 7–12 (this mandate is found in the laws of Arizona, Indiana, Rhode Island, Utah, and the District of Columbia).
- 208 Robert Powell Center, 8.
- 209 Robert Powell Center, 8.
- 210 Robert Powell Center, 9 (state laws that require continuing care include those of Alaska, California, Colorado, Georgia, Hawaii, Maine, Mississippi, New Mexico, and Vermont).
- 211 Robert Powell Center, 9.
- 212 Robert Powell Center, 9.
- 213 Robert Powell Center, 9 (the state laws that require life-sustaining continuing care are Delaware and South Dakota; the state law that requires the provider to follow the patient advocate’s instructions is Michigan).
- 214 Robert Powell Center, 9.
- 215 Robert Powell Center, 9; Mo. Rev. Stat. § 404.830.
- 216 Idaho Code § 39-4514(3).
- 217 Idaho Code § 39-4514(6).
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- 219 Robert Powell Center, 10; Va. Code Ann. § 54.1-2990; Tex. Health & Safety Code Ann. §§ 166.001–166.166.
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- 221 Va. Code Ann. § 54.1-2990.
- 222 Va. Code Ann. § 54.1-2990; Robert Powell Center, 10.
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- 268 *Rideout v. Hershey Medical Center*, 30 Pa. D. & C. 4th (Pa. Com. Pl. 1995).
- 269 *Gilgunn v. Mass. Gen. Hosp.*, No. 92-4820 (Mass. Super. Ct. Apr. 21, 1995).
- 270 *Betancourt v. Trinitas Reg’l Med. Hosp.*, No. C-12-09 (N.J. Super. Ct. Mar. 4, 2009), available at [http://thaddeuspope.com/images/Betancourt\\_v\\_trinitas\\_3-4\\_2\\_.pdf](http://thaddeuspope.com/images/Betancourt_v_trinitas_3-4_2_.pdf).
- 271 *Rideout v. Hershey Medical Center*, 30 Pa. D. & C. 4th (Pa. Com. Pl. 1995); *Gilgunn v. Mass. Gen. Hosp.*, No. 92-4820 (Mass. Super. Ct. Apr. 21, 1995); *Betancourt v. Trinitas Reg’l Med. Hosp.*, No. C-12-09 (N.J. Super. Ct. Mar. 4, 2009).
- 272 42 U.S.C. §§ 12101–12213 (2010).
- 273 42 U.S.C. §§ 12131, 12181(7), 12182; 28 C.F.R. 36.104 (2017) (establishing that public accommodations include the “professional office of a health care provider, hospital, or other service establishment”).
- 274 Title I, 42 U.S.C. §§ 12111–12117.
- 275 Title II, 42 U.S.C. §§ 12131–12165.

276 Title III, 42 U.S.C. §§ 12181–12189.

277 Title IV, 47 U.S.C. § 225.

278 42 U.S.C. § 12101(b).

279 42 U.S.C. § 12101(a)(2).

280 42 U.S.C. § 12101(a)(3).

281 National Disability Rights Network, 49; see H.R. Rep. No. 101-485, at 31, *as reprinted in* 1990 U.S.C.C.A.N. 303, 312 (quoting U.S. Commission On Civil Rights, *Accommodating the Spectrum of Individual Abilities*, p. 159). Testimony Before Senate Subcommittee on the Handicapped, S. Hrng. 101–156, May 10, 1989, p. 100 (Robert Burgdorf, Jr., Professor of Law at the District of Columbia School of Law, testifying that “it makes no sense to bar discrimination against people with disabilities in theaters, restaurants, or places of entertainment but not in regard to such important things as doctor’s offices. It makes no sense for a law to say that people with disabilities cannot be discriminated against if they want to buy a pastrami sandwich at the local deli but that they can be discriminated against next door at the pharmacy where they need to fill a prescription. There is no sense to that distinction.”).

282 42 U.S.C. § 12132; 29 U.S.C. § 794.

283 42 U.S.C. § 12182(a).

284 See 42 U.S.C. §§ 12132, 12182(a).

285 42 U.S.C. § 12102(1). Title II of the ADA also requires the individual with a disability to be “qualified,” which means that, with or without reasonable modifications, she is otherwise qualified to participate in or receive the benefit of the services of a public entity. 42 U.S.C. § 12131(2).

286 42 U.S.C. §§ 12132, 12182(a).

287 42 U.S.C. § 12131(1)(B).

288 42 U.S.C. § 12181(7)(F).

289 See 29 U.S.C. § 794.

290 42 U.S.C. §§ 12132, 12182(a).

291 See *Alexander v. Choate*, 469 U.S. 287, 295–96 (1985).

292 832 F. Supp. at 1024–26.

293 832 F. Supp. at 1024–26.

294 832 F. Supp. at 1024–26.

295 *Baby K*, 832 F. Supp. at 1028–29.

296 *Baby K*, 832 F. Supp. at 1028–29.

297 *Baby K*, 832 F. Supp. at 1028–29.

298 *In re Baby K*, 16 F.3d 590, 592 n.2 (4th Cir. 1998).

299 *Baby K*, 16 F.3d at 592 n.2.

300 See Timothy B. Flanagan, “ADA Analyses of the Oregon Health Care Plan,” *Issues of Law & Medicine* 9 (1994): 397–412; “The Oregon Health Care Proposal and the Americans with Disabilities Act,” *Harvard Law Review* 106, no. 6 (April 1993): 1296–1313.

301 Flanagan, 409–12; “The Oregon Health Care Proposal and the Americans with Disabilities Act,” 1296–1313.

302 Flanagan, 409–12; “The Oregon Health Care Proposal and the Americans with Disabilities Act,” 1296–1313.

303 Thaddeus Mason Pope, “Is the ADA an Obstacle to Appropriate EOL Care,” *Medical Futility Blog*, May 31, 2008, <http://medicalfutility.blogspot.com/2008/05/is-ada-obstacle-to-appropriate-eol-care.html> (citing, generally, *Schiavo v. Schiavo*, 403 F.3d 1289, 1294 [11th Cir. 2005] noting that “[t]he Rehabilitation Act, like the ADA, was never intended to apply to decisions involving the termination of life support or medical treatment.”); *Grzan v. Charter Hosp.*, 104 F.3d 116, 120–21 (7th Cir. 1997) (reviewing cases and legislative history); *Rideout v. Hershey Med. Ctr.*, 30 Pa. D. & C.4th at ¶ 95 (1995) (quoting *Anderson v. Univ. of Wis.*, 841 F.2d 737, 740 [7th Cir. 1988] that “the Rehabilitation Act forbids discrimination based upon stereotypes about a handicap, but it does not forbid decisions based on the actual attributes of the handicap.”); *Johnson v. Thompson*, 971 F.2d 1487, 1492–94 (10th Cir. 1992).



304 Thaddeus Pope, interview with author, February 21, 2019.  
305 403 F.3d at 1292–94.  
306 403 F.3d at 1292–94.  
307 403 F.3d at 1292–94.  
308 403 F.3d at 1292–94.  
309 Peters, 798–864.  
310 42 U.S.C. §§ 12132, 12182(a).  
311 42 U.S.C. §§ 12132, 12182(a); 29 U.S.C. § 794.



**National Council on Disability**  
**1331 F Street, NW, Suite 850**  
**Washington, DC 20004**