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## Hospital Medical Futility Policy & the Severely Disabled Child: Is Disability a Death Sentence?

Laura C. Hoffman  
lawreview@hamline.edu

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**HOSPITAL MEDICAL FUTILITY POLICY & THE  
SEVERELY DISABLED CHILD:  
IS DISABILITY A DEATH SENTENCE?**

*Laura C. Hoffman, Esq.\**

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“Futility policies, like all institutional policies, attempt to bridge the gap between the cultures of medicine and the law—doctors trying to say legal things, lawyers trying to say medical things.”<sup>1</sup>

**I. INTRODUCTION**

Parents of severely disabled children are often unaware of hospital medical futility policies. Because of this, several states are taking legislative

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\* Dr. Laura C. Hoffman earned her S.J.D. from Loyola University Chicago School of Law's Beazley Institute of Health Law and Policy in 2012. She earned a LL.M. in Child and Family Law from Loyola University Chicago School of Law in 2010. She holds a second LL.M. in Government and Law with a concentration in Civil and Constitutional Rights from American University Washington College of Law, '09. She became licensed to practice law in the State of Ohio in 2008. Laura earned her J.D. from Ave Maria School of Law in 2007. She holds a B.A. in Political Science, cum laude, from the University of Notre Dame, '04. She would like to thank her professional mentors, Professor Diane Geraghty, Professor John Blum, and Professor Michael Zimmer for their support and encouragement of her professional career. Finally, she leaves a special thank you to her parents, Ronald and Janet Hoffman, Rebecca L. Hoffman, and Robert L. Choromanski, Esq. for their gifts of unconditional love. She may be reached at [lhoffman@luc.edu](mailto:lhoffman@luc.edu).

<sup>1</sup> Lawrence J. Schneiderman, *Defining Medical Futility and Improving Medical Care*, 8 J. BIOETHICAL INQUIRY 123, 128–29 (2011), available at <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC3106156/>.

efforts to combat the control medical professionals exercise in making vital medical decisions involving the treatment of severely disabled children without their parents' knowledge or consent. Most recently, states have been active in pushing forward legislation to change the current state of operations in hospitals so that the concept of medical futility will no longer be foreign to parents and families of severely disabled children. In Minnesota, a 2012 proposed bill would have required hospitals to display and explain medical futility policies to parents of severely disabled newborns.<sup>2</sup> Hospitals would also have been required to register a medical futility policy with the Minnesota Department of Health.<sup>3</sup>

Research has shown that many parents make decisions to forego life-sustaining treatments and end the life of their newborns with serious medical conditions, but a number of other cases indicate that parents often do not get to make those decisions when it comes to a severely disabled newborn.<sup>4</sup> Americans were stunned to learn of the Canadian case of Baby Joseph, a severely disabled child who was denied medical treatment that doctors determined was "futile," yet similar cases of "Baby Joseph" are common in the U.S.<sup>5</sup> A 2004 law review article analyzing the legal rights of disabled infants and their caretakers in medical decision-making stated:

No perfect proxy decision-maker exists for disabled infants. No perfect treatment decision exists either, for the outcome of every available treatment option in each circumstance can never be known. But if a society desires to treat each life with the same dignity and respect as each other life, consistency must exist among end-of-life decision-making options for all.<sup>6</sup>

This article aims to examine whether or not the case of severely disabled children warrants the beginning of a state legislative trend toward making medical futility policies more accessible and transparent across the U.S. First, this article will examine the history of the use of medical futility

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<sup>2</sup> S.F. 2238, 87th Leg. (Minn. 2012); Christopher Snowbeck, *Minnesota Senate Bill Says Hospitals Must Disclose 'Futility Policies,'* PIONEER PRESS, Mar. 15, 2012, [http://www.twincities.com/politics/ci\\_20183534/hospital-futility-policies-withholding-care-would-be-disclosed?source=rss](http://www.twincities.com/politics/ci_20183534/hospital-futility-policies-withholding-care-would-be-disclosed?source=rss).

<sup>3</sup> S.F. 2238, 87th Leg. (Minn. 2012).

<sup>4</sup> *Medical Futility Trend Seen in Neonatal Deaths*, HEALTHDAY (July 5, 2011), <http://consumer.healthday.com/Article.asp?AID=654477> [hereinafter *Medical Futility Trend*].

<sup>5</sup> Sabriya Rice, *Baby Joseph Transferred to the U.S.*, CNN (Mar. 14, 2011), <http://www.cnn.com/2011/HEALTH/03/14/baby.life.support/index.html>; Mikaela Conley, *Parents Fight Canadian Hospital Over Child's Survival*, ABC NEWS (Mar. 1, 2011), <http://abcnews.go.com/Health/baby-josephs-treatment-sparks-controversy-pediatric-end-life/story?id=13032001#.T3YCy9lyWeR>.

<sup>6</sup> Jeannine Wyszowski, *The Legal Rights of Disabled Infants to Receive Life-Sustaining Medical Treatment*, 4 CONN. PUB. INT. L. J. 181, 207 (2004).

that has emerged as a hotly debated bioethical theory in medical decision-making and the challenges that have arisen in this area in making a determination of “medical futility” as well as competing views of how to define “medical futility.”<sup>7</sup> Next, this article will look at the history of hospital treatment of severely disabled newborns, issues surrounding care of these children, and medical treatment in relation to life-sustaining and/or end-of-life decision-making.<sup>8</sup> Then, this article will explore the current legislative landscape for states across the U.S. and recent developments internationally involving medical futility policies and severely disabled children.<sup>9</sup> Finally, this article will offer an opinion on the movement of states to pass legislation requiring the disclosure of medical futility policies and whether justification of these policies exists in the case of the severely disabled child.<sup>10</sup> The question becomes whether hospitals, which under current practices do not disclose medical futility policies to parents of severely disabled children, leaving critical life decisions in the hands of medical professionals, are discriminating against these children because of severe disability. Does a child’s severe disability equate to a death sentence in U.S. hospitals today?

## II. THE DIFFICULTY OF DEFINING AND DETERMINING “MEDICAL FUTILITY”

In a 1997 opinion, the American Medical Association (AMA) Code of Medical Ethics describes medical futility in terms of end-of-life decision-making.<sup>11</sup> According to this opinion, physicians have an obligation to change the course of medical care when it becomes “futile.”<sup>12</sup> Basically, “[w]hen further intervention to prolong the life of a patient becomes futile, physicians have an obligation to shift the intent of care toward comfort and closure.”<sup>13</sup> However, physicians are required under this opinion to take into account a number of considerations in making such decisions.<sup>14</sup> The AMA provides the following guidance on the decision-making process in determining whether or not care would be considered futile:

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<sup>7</sup> See *infra* Part II–III (discussing the controversy over how to define medical futility).

<sup>8</sup> See *infra* Part IV (describing the treatment of severely disabled newborns).

<sup>9</sup> See *infra* Part IV–V (discussing state legislative developments regarding medical futility and the international understanding of this issue).

<sup>10</sup> See *infra* Part VI (analyzing the importance of the proposed state legislation regarding medical futility).

<sup>11</sup> *Opinion 2.037—Medical Futility in End-of-Life Care*, AM. MED. ASS’N (June 1997), available at <http://www.ama-assn.org/ama/pub/physician-resources/medical-ethics/code-medical-ethics/opinion2037.page>.

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

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

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

[T]here are necessary value judgments involved in coming to the assessment of futility. These judgments must give consideration to patient or proxy assessments of worthwhile outcome. They should also take into account the physician or other provider's perception of intent in treatment, which should not be to prolong the dying process without benefit to the patient or to others with legitimate interests. They may also take into account community and institutional standards, which in turn may have used physiological or functional outcome measures.<sup>15</sup>

The AMA Code of Ethics also does not ignore the fact that there may be disagreement between those closely involved in the course of action to be taken.<sup>16</sup> Here, the AMA Code of Ethics states that "conflicts between the parties may persist in determining what is futility in the particular instance. This may interrupt satisfactory decision-making and adversely affect patient care, family satisfaction, and physician-clinical team functioning."<sup>17</sup> It seems the AMA finds it challenging to precisely define "futility," and because of this, instead offers a list of factors to consider in making that critical assessment.<sup>18</sup>

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

<sup>16</sup> *Id.*

<sup>17</sup> *Opinion 2.037, supra* note 11. The AMA offers the following guidance in its Code of Ethics:

To assist in fair and satisfactory decision-making about what constitutes futile intervention: (1) All health care institutions, whether large or small, should adopt a policy on medical futility; and (2) Policies on medical futility should follow a due process approach. The following seven steps should be included in such a due process approach to declaring futility in specific cases. (a) Earnest attempts should be made in advance to deliberate over and negotiate prior understandings between patient, proxy, and physician on what constitutes futile care for the patient, and what falls within acceptable limits for the physician, family, and possibly also the institution. (b) Joint decision-making should occur between patient or proxy and physician to the maximum extent possible. (c) Attempts should be made to negotiate disagreements if they arise, and to reach resolution within all parties' acceptable limits, with the assistance of consultants as appropriate. (d) Involvement of an institutional committee such as the ethics committee should be requested if disagreements are irresolvable. (e) If the institutional review supports the patient's position and the physician remains unpersuaded, transfer of care to another physician within the institution may be arranged. (f) If the process supports the physician's position and the patient/proxy remains unpersuaded, transfer to another institution may be sought and, if done, should be supported by the transferring and receiving institution. (g) If transfer is not possible, the intervention need not be offered.

*Id.*

<sup>18</sup> *Id.*

Specifically, the AMA provides guidance to hospitals and medical institutions on how to construct medical futility policies. Even with this guidance by the AMA, challenges continue to persist in defining medical futility and the debate has only grown in dealing with the complicated issues associated with it. A number of issues have been raised regarding why this debate has intensified, including the cost of medical care, the development of technology, and examination of the physician-patient relationship. The difficulty of defining and determining “medical futility” has challenged members of the medical profession to consider the role physicians play in these matters and the extent of their duties in this role. Additionally, it has created an even greater debate about the relationship between the medical profession and society at large.<sup>19</sup> One recent definition offered for “medical futility” is “the unacceptable likelihood of achieving an effect that the *patient* has the capacity to appreciate as a *benefit*.”<sup>20</sup> In fact, a major consideration in the medical futility debate is whether or not the patient receives a “benefit” from the treatment.<sup>21</sup> Some argue that failing to define “medical futility” can be detrimental to medicine. This argument focuses on the fact that physicians also have a duty to alleviate a patient’s suffering to the extent possible and treat the patient with dignity, especially concerning end-of-life matters.<sup>22</sup> There are still some who believe that “medical futility” can’t and shouldn’t be defined.<sup>23</sup>

There has been ample discussion about how precisely to define “medical futility” and whether or not it should actually be defined in the context of medicine. The Oxford-English dictionary defines “futile” to mean “incapable of producing any useful result; pointless.”<sup>24</sup> In general, there are two essential components to medical futility—the quantitative and the qualitative.<sup>25</sup> The quantitative component of medical futility can be traced back to the Hippocratic Corpus, which stated “[w]henver the illness is too strong for the available remedies, the physician surely must not expect that it can be overcome by medicine . . . . To attempt futile treatment is to display an

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<sup>19</sup> See Schneiderman, *supra* note 1, at 125 (exploring the current debate surrounding “medical futility”).

<sup>20</sup> *Id.*

<sup>21</sup> *Id.* at 123.

<sup>22</sup> *Id.*

<sup>23</sup> *Id.* As one commentator explains,

Although the concept of medical futility, to judge from ancient documents, is as old as medicine itself, the topic became particularly contentious over the last few decades. Some critics argued that medical futility could not be meaningfully defined, even calling for the term to be expunged from the medical lexicon.

*Id.* at 124 (citation omitted).

<sup>24</sup> *Futile*, OXFORD DICTIONARIES, <http://oxforddictionaries.com/definition/english/futile> (last visited Apr. 5, 2013).

<sup>25</sup> Schneiderman, *supra* note 1, at 124.

ignorance that is allied to madness.”<sup>26</sup> The qualitative component of medical futility can be linked to the time of Plato. For example, Plato stated that “a life with preoccupation with illness and neglect of work is not worth living.”<sup>27</sup> While some may argue it is impossible to put a number on anything compared to the value of the life of a human being, others argue that medicine actually demands quantitative evidence and that medicine would not be medicine without the numbers to back a practice—even if it means inevitably the loss of life.

The significance of defining “medical futility” in terms of including a quantitative component can be described in this manner: “How many times and to what degree do we have to fail before we agree to call a treatment futile? In medicine, as in our daily affairs, we act on the basis of empirical evidence.”<sup>28</sup> There is a danger to medicine’s validity by not requiring medical futility to embrace a quantitative component. In general, “[t]he medical community, or society at large, may prefer longer (or shorter) odds, but in the end we all will have to accept some empirical notion of medical futility or else throw all commonsense to the wind.”<sup>29</sup> The absence of a quantitative component to medical futility could run contrary to medical ethics and even constitute medical malpractice based on the principle of harm.<sup>30</sup> A physician could conceivably face charges of medical malpractice for seeking to perform a medical procedure with a significantly low, if not rare, success rate. Essentially, the slim possibility that a patient “might” benefit from the medical procedure is clearly outweighed by the potential harm and clearly disproportionate. The medical ethics involved with this decision to include a quantitative component to medical futility is articulated as follows:

If you truly want to make a case for attempting aggressive, life-sustaining, rib-cracking CPR on a patient who has a “one in a hundred chance” of working, you are claiming that it is appropriate to subject ninety-nine patients to an intervention that is painful, burdensome, and almost certainly useless in pursuit of one possible rare success. This violates medicine’s duty to avoid unnecessary harm and the ethical duty of proportionality. Any physician who knowingly prescribed a drug with such a low therapeutic ratio and such severe side effects would be (deservedly) vulnerable to the charge of medical malpractice.<sup>31</sup>

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<sup>26</sup> *Id.* (citation omitted).

<sup>27</sup> *Id.* (citation omitted).

<sup>28</sup> *Id.* at 125.

<sup>29</sup> *Id.*

<sup>30</sup> *Id.*

<sup>31</sup> Schneiderman, *supra* note 1, at 125.

Medical futility must also embrace a qualitative component.<sup>32</sup> The qualitative component of medical futility can be explained from a medical perspective as follows:

[M]edical futility is the unacceptable likelihood of achieving an effect that the *patient* has the capacity to appreciate as a *benefit*. Both emphasized terms are important. A patient is neither a collection of organs nor merely an individual with desires. Rather, a patient (from the word “to suffer”) is a person who seeks the healing (meaning “to make whole”) powers of the physician. The relationship between the two is central to the healing process and the goals of medicine. Medicine today has the capacity to achieve a multitude of effects, raising and lowering blood pressure, speeding, slowing, and even removing and replacing the heart, to name but a minuscule few. But none of these effects is a benefit unless the patient has at the very least the capacity to appreciate it, a circumstance that is impossible if the patient is permanently unconscious.<sup>33</sup>

Furthermore, some medical professionals believe that treatment that merely keeps a patient alive to the extent he or she is confined to a hospital for the remainder of life is “futile” and contrary to the purpose of medicine. For example,

[I]f the best outcome physicians can achieve to maintain survival requires keeping the patient perpetually confined to the Intensive Care Unit or the acute care hospital setting, that outcome should not be regarded as a success, but rather as a failure to achieve the goals of medicine. Such treatment . . . is also futile.<sup>34</sup>

Of course, a medical professional’s ability to provide care for a patient is not without limitations.<sup>35</sup> As a result, “[i]t is important that we make clear to society as well as to the profession that medicine has great powers, but not unlimited powers. The medical profession has important obligations, but not unlimited obligations.”<sup>36</sup> Despite this difficulty that medical professionals do not possess super powers to provide complete

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<sup>32</sup> *Id.*

<sup>33</sup> *Id.*

<sup>34</sup> *Id.* at 126.

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

<sup>36</sup> *Id.*

healing to patients, this should not be used as an obstacle for failing to provide some definition for “medical futility.”<sup>37</sup> Furthermore,

Failing to seek a precise definition of medical futility only leaves us in a state of ambiguity, which encourages the very abuses many people fear. Physicians should not be free to invoke medical futility unless they can justify it before their peers with good evidence-based data and before society with professional standards of practice. This requires that we examine the notion, not hide from it.<sup>38</sup>

There has not only been debate about whether or not to define “medical futility” but how to define it.<sup>39</sup> One such definition of medical futility has focused on what the patient wants.<sup>40</sup> This definition holds that “the patient is entitled to receive any treatment and seek any outcome he or she wishes from the physician. This view has arisen out of the patient autonomy movement in reaction to abuses that took place in the previous era of strong physician paternalism.”<sup>41</sup> But physicians have challenged this definition of medical futility because it suggests the physician should simply accommodate whatever the patient dictates, which often conflicts with the other duties of the physician.<sup>42</sup> As a result, an alternative definition of medical futility defines the concept in terms of treatment that will prolong the life of the patient.<sup>43</sup> Under this view, physicians “cannot declare a treatment futile as long as it can prolong life, even permanently unconscious life.”<sup>44</sup> However, the idea of prolonging life in medicine has actually been a recent development and history suggests that it is contrary to the concept of medical care to promote the use of life prolonging treatment.<sup>45</sup> A third

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<sup>37</sup> Schneiderman, *supra* note 1, at 126.

<sup>38</sup> *Id.*

<sup>39</sup> *Id.*

<sup>40</sup> *Id.*

<sup>41</sup> *Id.*

<sup>42</sup> *Id.*

<sup>43</sup> Schneiderman, *supra* note 1, at 126.

<sup>44</sup> *Id.* (citation omitted).

<sup>45</sup> *Id.* Regarding the history of prolonging life:

In ancient Greece and Rome, as expressed particularly through the Hippocratic writings, the physician’s duties were described as assisting nature to restore health and alleviate suffering. Life and death were viewed as natural cycles. Indeed, the Hippocratic physician shunned claims of supernatural powers in order to avoid the taint of charlatanism. It was not until many centuries later in the late Middle Ages, when religion began to play a dominant role in Western Europe, and later in the seventeenth century, when scientists began to view science as a power to be exerted *against* nature, that the goal of prolonging life was introduced. It is important to keep in mind, however, that neither theologians, nor scientists, nor for that matter anyone else prior to the modern era could

alternative to defining medical futility focuses on functionality and the ability of the treatment in question to improve the functioning of some bodily part.<sup>46</sup> Under this alternative,

the physician cannot regard a treatment as futile as long as it can maintain the function of any part of the body, such as pumping blood by means of cardiac compression, moving air by means of mechanical ventilation, or eliminating wastes via dialysis, even if the patient is permanently unconscious or in the last moments of a terminal condition. In short, the instruments of technology are the focus of attention rather than the patient. This definition, physiologic futility, has been presented as a “value-neutral” definition.<sup>47</sup>

However, some in the medical profession challenge that the physiological approach to futility does not actually promote the “value-neutral” approach its advocates suggest.<sup>48</sup>

While it is recommended that a definition of medical futility be agreed upon by the medical profession, some suggest that there can still be instances when exceptions to that definition are not only a possibility but a necessity.<sup>49</sup> For example,

If the physician has the right to withhold a futile treatment, does this mean the physician enjoys the privilege of withholding discussion about such treatment? Certainly physicians do not describe to patients all the many tests and treatments they have no intention of pursuing. In my view, however, an important distinction should be made between treatment and information. Depending on the context and the patient’s state of mind, patients may be entitled to information even though they are not entitled to treatments.<sup>50</sup>

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ever imagine life in the many forms it comes today, the many states between health and death that are the outcomes of modern medical treatments. The diagnosis of persistent vegetative state, to name just one condition, was not coined until 1972. Thus, the claim that the goal of medicine is to preserve life has ambiguous meanings and dubious roots in the historical tradition of the profession.

*Id.* (citation omitted).

<sup>46</sup> *Id.*

<sup>47</sup> *Id.* (citation omitted).

<sup>48</sup> See Schneiderman, *supra* note 1, at 127 (“To specify narrow physiological objectives as the goals of medical practice is not ‘value neutral,’ but a value choice that is about as far from the patient-centered tradition of the medical profession as it is possible to be.”).

<sup>49</sup> *Id.*

<sup>50</sup> *Id.*

Even if the physician is ultimately making a decision on medical futility, the physician should not remove the patient entirely from the discussion of treatment. On the contrary, “[m]aking a decision that a treatment is medically futile does not absolve the physician of the obligation to discuss and inform the patient/surrogate about what is going on in terms of the patient’s condition, prognosis, and treatment options.”<sup>51</sup> Additionally, a physician may need to consider special cases where compassion prevails.<sup>52</sup> Some physicians emphasize the importance of “comfort” care and the “dignity” of the patient in decisions involving futile treatment.<sup>53</sup> Unfortunately, “in the futility debate this important area has in large part been neglected, not only in treatment decisions at the bedside, but in public discussions—the physician’s obligation to alleviate suffering, enhance well-being, and support the dignity of the patient in the last few days of life.”<sup>54</sup> Other distinctions have been pointed out in the medical futility debate. For example, there is a difference between futility and rationing. As one commentator argues,

For the sake of clarity I propose that medical futility signifies that a treatment offers no therapeutic benefit to a patient. Rationing specifically acknowledges that a treatment *does* offer a benefit, and the issue becomes how to distribute beneficial but limited resources fairly. To clarify the distinction further: futility decisions are made at the bedside of a specific patient, whereas rationing decisions, involving categories of patients or treatments or circumstances, inevitably should be made at a policy level in order to assure just distribution of resources.<sup>55</sup>

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<sup>51</sup> *Id.*

<sup>52</sup> *Id.* The physician’s decision to act compassionately regarding futile treatment may be described as follows:

The physician can easily make a compassionate exception in the case of a severely burned patient or a patient with metastatic cancer whose request for treatment will result only in a brief prolongation of dying (a clear and limited goal and small exception to the physician’s ordinary duty). But in the case of permanent vegetative state, obligating the physician to accede to a request for long-term life maintenance could lead to unaccounted decades of futile treatment. In contrast to those who raise fears about the erosion in value of the patient, giving the physician the opportunity to view each patient as a unique person in unique circumstances enhances the value of the patient. It encourages the use of appropriate medical measures rather than useless, thoughtless pursuit of inappropriate measures. A treatment may be futile. A patient is never futile.

*Id.* at 127–28 (emphasis omitted).

<sup>53</sup> Schneiderman, *supra* note 1, at 128.

<sup>54</sup> *Id.* (citation omitted).

<sup>55</sup> *Id.* (emphasis in original).

There is also an argument that defining medical futility is essential because it will force the necessary development of research and testing to demonstrate the effectiveness of treatments.<sup>56</sup>

As a significant struggle still exists in the medical community about how to define “medical futility”, it should come as no surprise that attempting to incorporate this concept into law will be complicated further as discussed in the next section.

### III. WHEN LAW & FUTILITY MEET

The question becomes, how do we incorporate the concept of medical futility into law and what could this mean for particular groups, such as children with disabilities? Immediately, it appears problematic to try to delve into law when, as the previous section discussed, debate still exists over how to define “medical futility” among medical professionals. Federal law has provided some guidance on the role of physicians in making such decisions:

In the United States, at the federal level, the *Uniform Health-Care Decisions Act* states: “A health-care provider or institution may decline to comply with an individual instruction or health-care decision that requires medically ineffective health care or health care contrary to generally accepted health-care standards applicable to the health-care provider or institution” . . . . It further clarifies that “medically ineffective” health care means “treatment which would not offer the patient any significant benefit” . . . . This statute has already been adopted by more than a half dozen states. In addition, professional societies—including the American Medical Association, the Society for Critical Care Medicine, and the American Thoracic Society—have published guidelines on medical futility.<sup>57</sup>

The development of hospital medical futility policies began in the 1990s.<sup>58</sup> As one commentator explained, “[w]orking groups of professionals

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<sup>56</sup> *Id.* For example,

I believe that pursuing a clear-cut concept of medical futility will encourage a more aggressive search for precisely the kind of evidence-based information that our medical enthusiasm has caused us to overlook. I refer to the publication of clinical trials that report not only treatments that are successful, but also treatments that are unsuccessful. Both kinds of data are important to the practice of medicine; both provide guidelines for physician choice.

*Id.*

<sup>57</sup> *Id.* at 129 (citations omitted).

<sup>58</sup> Schneiderman, *supra* note 1, at 129.

and laypersons throughout the country have started to develop consensus-based futility hospital policies.”<sup>59</sup> Those within the medical profession and those within the legal profession tend to have different concerns and perspectives about how to define “medical futility.”<sup>60</sup> One individual involved in the process of developing a medical futility policy observed the following:

During the proceedings I observed that physicians tended to seek specific and descriptive *definitions* of futile, inappropriate, or burdensome treatments. By contrast, lawyers and judges were more concerned about putting in place detailed *procedures* that protect vulnerable patients. I concluded that policies on futility should provide both specific definitions and a well described dispute resolution process that will bear scrutiny by outside, impartial observers.<sup>61</sup>

However, there is concern that the legal profession is somewhat disconnected from situations involving medical futility compared to those in the medical profession that may result in legal standards that do not adequately address complex medical situations. For example,

Hospitals are likely to find the legal system willing (even eager) to defer to well defined and procedurally scrupulous processes for internal resolutions of futility disputes. Although courts are capable of providing due process protections, judges are largely unfamiliar with the complexity of medical treatment and are neither expected nor even able to follow up medical outcomes once they have entered judgment; it is the physicians seeking to cease futile treatment—and not the judges who are called upon to rule on the case—who have to live with the decision. For example, a judge who assigns a guardian and orders that a severely disabled child be kept alive rarely sees firsthand the long-term consequences of that decision, which remain a continuing vivid experience for the health professionals who must provide care for the child.<sup>62</sup>

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<sup>59</sup> *Id.* (citations omitted).

<sup>60</sup> *Id.*

<sup>61</sup> *Id.* (emphasis in original).

<sup>62</sup> *Id.*

Medical professionals, thus, play a significant role in the shaping of medical futility policies.<sup>63</sup> Arguably, their role can minimize the need for the involvement of legal professionals:

If the decision to forgo treatment has been reached by a process that is careful both in medical and procedural terms, including full discussion (where possible) with the patient or family, ethics committee review, and adequate aid to the patient and family in seeking care elsewhere, health care providers should not seek prior permission from the courts to carry out their professional duties. Indeed, there is substantial legal history in the United States to show that courts are more likely to support physicians who refrain from providing non-beneficial treatment and then defend their decisions as consistent with professional standards than when they seek advance permission to withhold such treatment. Judges do not want to make “medical decisions.” In fact, they will rightly point out that they are being asked to agree to end life-sustaining treatment some time in the future when the patient’s condition may have changed. If the rightness of that action is questioned after the fact, judges will want to know the answer to the third question, “How does the medical profession behave?” Thus, health care professionals need not only to develop policies but also to act in accordance with their policies. They also need to justify, through discussion and publication, their conduct in dealing with situations that have presented the issue of the limits of professional obligations when treatment does not yield results that would be regarded as beneficial by most patients and consistent with the goals of medicine.<sup>64</sup>

Thus, defining “medical futility” is not an easy task and becomes even trickier when it must be shaped into legal policy. There is an ongoing debate as to how to define “medical futility.” This task becomes even more complicated because medical futility must also involve the law and deal with the dynamics that exist between medical professionals and legal professionals. Both professions look at the concept from often differing perspectives that must somehow meet to preserve the proper role of the physician while also protecting the legal rights of the patient. While it is hoped we can rely on medical professionals to do the right thing for their patients, medical futility cases thus far have suggested that there needs to be

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<sup>63</sup> *Id.*

<sup>64</sup> Schneiderman, *supra* note 1, at 130 (citation omitted).

some legal protections or processes that ensure that families and loved ones not be left behind to only find out about such critical decisions after the fact.

#### IV. MEDICAL FUTILITY & CHILDREN WITH DISABILITIES IN THE U.S.

The issues surrounding medical futility and children with disabilities were brought to the forefront when news of the case of Baby Joseph emerged and, along with it, the idea that not only may physicians and families differ on the inevitable treatment of children but that a child with a disability may, in fact, never be favored for treatment by physicians because the child has no chance of recovery.<sup>65</sup> The case of “Baby Joseph” involved a Canadian baby, Joseph Maraachli, who was known to have a serious disability—a progressive neurological disorder—that would eventually result in his death.<sup>66</sup> A battle ensued between the Canadian hospital treating Baby Joseph and his parents over the course of treatment as the hospital sought to remove Baby Joseph’s breathing tube.<sup>67</sup> Baby Joseph’s parents asked the hospital to perform a tracheotomy to allow Baby Joseph to return home and die there with his parents rather than simply remove him from the breathing tube that would have resulted in his imminent death.<sup>68</sup> The hospital refused to perform this surgery claiming that this was life-sustaining treatment only meant to prolong Baby Joseph’s life and inevitable death.<sup>69</sup> Some argued that the treatment Baby Joseph’s parents sought actually should not have been considered “futile.”<sup>70</sup> Because physicians often disagree over what constitutes “futile,” the procedure at issue in the case of Baby Joseph is no different. As one perspective offers:

[T]he request for a tracheotomy raises different ethical issues than requesting that life support be maintained in hospital. In my view, refusing the tracheotomy surgery is not a futile care imposition, since the surgery is not primarily intended to maintain the baby’s life, but rather is an elective procedure, to allow the parents to bring him home to die. That is a completely understandable, nay, laudable, desire on their part, but it presents a different wrinkle to the situation than the usual futile care dispute. And let me emphasize: It

<sup>65</sup> *Medical Futility Trend*, *supra* note 4.

<sup>66</sup> Maggie Schneider and Sabriya Rice, “Baby Joseph” Focus of Treatment Dispute, *Dies in Sleep*, CNN (Sept. 29, 2011), <http://www.cnn.com/2011/09/28/health/baby-joseph/index.html>.

<sup>67</sup> *Id.*

<sup>68</sup> *Id.*

<sup>69</sup> *Id.*

<sup>70</sup> Wesley J. Smith, *Baby Joseph Futile Care Case Has Emotional Non Futile Care Wrinkle*, CTR FOR BIOETHICS & CULTURE, <http://www.cbc-network.org/2011/02/baby-joseph-futile-care-case-has-emotional-non-futile-care-wrinkle/> (last visited Apr. 18, 2013).

wouldn't be an issue if the hospital weren't trying to force the baby off life support.<sup>71</sup>

Physicians have ethical duties that include the duty to prevent harm to the patient. The case of Baby Joseph may not have actually been one of futility; the primary consideration was or should have been the ethical duty to prevent harm. Of course,

[T]he medical team has a point too. A tracheotomy is surgery. It requires anesthesia and can cause suffering. Once the ventilator was hooked up, if it wasn't maintained properly, it could cause a very difficult time for the baby. So the question becomes whether the hospital/doctors, by refusing to perform the requested surgery, are fulfilling their ethical duty to do no harm to their patient. I am not a medical expert, and so don't know the answer from that perspective. But it is a legitimate argument and a question for real concern.<sup>72</sup>

In examining the perspective of futile care in this instance, it was observed that in futile care theory, "the treatment isn't being removed because it won't work, but because it is working, e.g., maintaining life. In such cases, it is actually the life that is seen as futile, not the treatment."<sup>73</sup> In the end, Baby Joseph's parents were able to leave the Canadian hospital and have the tracheotomy performed at a U.S. hospital.<sup>74</sup> Baby Joseph later died peacefully at home with his parents.<sup>75</sup>

Immediately, this raises questions about what we know about disability and how we define "disability." The Oxford-English dictionary defines disability as "a physical or mental condition that limits a person's movements, senses, or activities."<sup>76</sup> There is no indication in this definition that such limitations make an individual's life invaluable or that someone is less of a human being because of these limitations. The concept of disability embraces a wide range of limitations and includes those that may affect a person's hearing, vision, movement, thinking, remembering, and learning, according to the Centers for Disease Control and Prevention.<sup>77</sup> One of the categories under the umbrella of disability includes neurological disorders

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<sup>71</sup> *Id.* (emphasis omitted).

<sup>72</sup> *Id.*

<sup>73</sup> *Id.*

<sup>74</sup> Schneider and Rice, *supra* note 66.

<sup>75</sup> *Id.*

<sup>76</sup> *Disability*, OXFORD DICTIONARIES, <http://oxforddictionaries.com/definition/english/disability> (last visited Apr. 5, 2013).

<sup>77</sup> *Types of Disabilities*, CTRS. FOR DISEASE CONTROL & PREVENTION, <http://www.cdc.gov/ncbddd/disabilityandhealth/types.html> (last updated July 21, 2010).

such as Leigh's disease, the disorder that Baby Joseph had.<sup>78</sup> If we truly accept what we know about "disability" and how it is defined, it would seem that greater care would be taken to ensure that children with disabilities are not subject to purposeful disability discrimination when it comes to medical decision-making.

Such efforts have been advanced since the 1980s to ensure that medical professionals do not discriminate against those with disabilities, including children, in decision-making regarding medical futility.<sup>79</sup> The federal government was even instrumental in providing a very public demonstration of commitment to these principles:

The Principles of Treatment of Disabled Infants . . . has been signed by the American Academy of Pediatrics, the National Association of Children's Hospitals and Related Institutions, the Spina Bifida Association of America, the American Association on Mental Deficiency, the Association for the Severely Handicapped, the American Coalition of Citizens with Disabilities, the Down's Syndrome Congress, and the Association for Retarded Citizens. These groups were convened by the Department of Education for a public ceremony signaling their commitment to resolve the controversies surrounding medical treatment for severely disabled infants. The group pledged support to appropriate medical care, the need for more information by medical professionals, parents, and the public, and government and community support for disabled children.<sup>80</sup>

The very first principle spelled out by the Principles of Treatment of Disabled Infants articulates that individuals should not be discriminated against simply due to their classification as disabled.<sup>81</sup> It states, "[d]iscrimination of any type against any individual with a disability/disabilities, regardless of the nature or severity of the disability, is morally and legally indefensible."<sup>82</sup> Among the principles articulated, the Principles of Treatment of Disabled Infants advocates for the use of "beneficial" treatment.<sup>83</sup> The Principles of Treatment of Disabled Infants states:

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<sup>78</sup> See *List of Neurological Disorders*, DISABLED WORLD (Oct. 22, 2008), <http://www.disabled-world.com/artman/publish/neurological-disorders-list.shtml> (providing a list of neurological disorders, including Leigh's Disease).

<sup>79</sup> *Medical Treatment of Disabled Infants*, 4 FUTURE REFLECTIONS (Jan/Feb/March 1985), available at <https://nfb.org/images/nfb/publications/fr/fr04/issue1/f040106.html>.

<sup>80</sup> *Id.*

<sup>81</sup> *Id.*

<sup>82</sup> *Id.*

<sup>83</sup> *Id.*

When medical care is clearly beneficial, it should always be provided. When appropriate medical care is not available, arrangements should be made to transfer the infant to an appropriate medical facility. Consideration such as anticipated or actual limited potential of an individual and present or future lack of available community resources are irrelevant and must not determine the decisions concerning medical care. The individual's medical condition should be the sole focus of the decision. These are very strict standards.<sup>84</sup>

Obviously, opinions may differ substantially as to what constitutes “clearly beneficial.” The principles go on to indicate that certain treatments should not be utilized when such treatments would be “futile.”<sup>85</sup> However, the principles do provide guidance as to futile treatment and advocate that futile treatment should not be confused with intentionally discriminating against the disabled infant.<sup>86</sup> Here the principles offer the following:

In cases where it is uncertain whether medical treatment will be beneficial, a person's disability must not be the basis for a decision to withhold treatment. At all times during the process when decisions are being made about the benefit or futility of medical treatment, the person should be cared for in the medically most appropriate ways. When doubt exists at any time about whether to treat, a presumption always should be in favor of treatment.<sup>87</sup>

The principles describe these restrictions on treatment as follows:

It is ethically and legally justified to withhold medical or surgical procedures which are clearly futile and will only prolong the act of dying. However, supportive care should be provided, including sustenance as medically indicated and relief of pain and suffering. The needs of the dying person should be respected. The family also should be supported in its grieving.<sup>88</sup>

The principles also emphasize the role of the government in protecting the disabled:

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<sup>84</sup> *Id.*

<sup>85</sup> *Medical Treatment of Disabled Infants, supra* note 79.

<sup>86</sup> *Id.*

<sup>87</sup> *Id.*

<sup>88</sup> *Id.*

The Federal Government has an historic and legitimate role in protecting the rights of its citizens. Among these rights is the enforcement of all applicable federal statutes established to prevent and remedy discrimination against individuals with disabilities, including those afforded by Section 504 of the Rehabilitation Act. States also have legitimate roles in protecting the rights of their citizens and an obligation to enforce all applicable state laws.<sup>89</sup>

Another portion of the principles emphasizes the significance of continually dispensing information to not only those closely tied to the disabled child but also to society as a whole to allow for a more informed decision-making process.<sup>90</sup> The significance of providing information is detailed as follows:

There is a need for professional education and dissemination of updated information which will improve decision-making about disabled individuals, especially newborns. To this end, it is imperative to educate all persons involved in the decision-making process. Parents should be given information on available resources to assist in the care of their disabled infant. Society should be informed about the value and worth of disabled persons. Professional organizations, advocacy groups, the government and individual care givers should educate and inform the general public on the care, need, value and worth of disabled infants.<sup>91</sup>

When a disabled child was denied food and hydration in the U.S. in 1984, even at the decision of the child's parents, the U.S. passed a law that would prevent future disabled children from dying in this manner.<sup>92</sup>

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<sup>89</sup> *Id.*

<sup>90</sup> *Id.*

<sup>91</sup> *Medical Treatment of Disabled Infants*, *supra* note 79.

<sup>92</sup> Jacqueline Harvey, *Sick and Disabled Infants Starved and Dehydrated in the U.K.*, LIFENEWS.COM (Dec. 14, 2012), <http://www.lifenews.com/2012/12/14/sick-and-disabled-infants-starved-and-dehydrated-in-the-uk/>.

For Americans, this account of starving and dehydrating infants with disabilities echoes back to the infamous Baby Doe cases in the early 1980s. The most famous Baby Doe was born on April 9, 1982 in Bloomington, Indiana. The child had with trisomy 21 (otherwise known as Down syndrome) and a tracheoesophageal fistula and esophageal atresia, a common congenital abnormality where the esophagus does not connect to the stomach. While this would have been easily correctable with surgery and would have allowed the child to eat normally, the baby's parents refused treatment because they did not want an intellectually-disabled child. In spite of numerous offers from others to adopt him, the

However, the development of medical futility policies has eroded this response and has instead promoted this treatment of disabled children. This history of law in the U.S. is described below:

The U.S. responded to such cases by amending the Child Abuse Prevention and Treatment Act in 1984, to deny federal funds to hospitals that failed to enforce a new set of rules to protect disabled infants. Nonetheless, disabled children are still denied life-saving treatment, including food and water under the guise of “medical futility.” While medical care would save or sustain the life of a disabled child, proponents of denying care argue that life-saving treatment is futile not because it will not work and prevent death, but because it *will* work- and death is preferable to life with a disability. Medical futility statutes, such as the Texas Advance Directives Act of 1999 are routinely employed to deny care to disabled and chronically-ill infants and are argued to be compatible with Baby Doe regulations.<sup>93</sup>

Attention has increased again for issues surrounding disabled infants and medical futility, which returned to the spotlight when the battle over Baby Joseph erupted in Canada. Since then, several U.S. states have gotten involved in the debate over hospital medical futility policies.

Two states are the most recent to delve into this heated debate: Minnesota and Michigan. In March 2012, the Minnesota Senate considered legislation requiring the disclosure of hospital medical futility policies, with a similar bill considered in the House.<sup>94</sup> The Senate bill’s author, Sen. Sean Nienow, R-Cambridge, “said he wants to create the disclosure requirement so hospitals tell parents about the policies when they are caring for terminally ill children.”<sup>95</sup> This legislation was designed to target hospitals that have been using and making medical futility decisions on the basis of financial incentives. It “specifically targets policies that call on medical professionals to ‘discontinue treatment for a patient on the grounds of medical futility when withholding or discontinuing treatment would result in

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courts agreed to deny the baby both life-saving surgery and IV food and fluids. The baby died six days later and the physician that supported the parents stated matter-of-factly, “I believe there are things that are worse than having [such] a child die. And one of them is that it might live.”

*Id.*

<sup>93</sup> *Id.* (emphasis in original).

<sup>94</sup> Snowbeck, *supra* note 2.

<sup>95</sup> *Id.*

a financial benefit to the hospital.”<sup>96</sup> Senate File 2288 provides the following measures regarding medical futility policies:

Senate File 2238 requires hospitals to report any policy they establish regarding medical futility to the parents of minor patients and to the commissioner of the Department of Health. A “futility policy” is the practice of withholding or encouraging to withhold the medical treatment on the grounds that such treatment is a waste of medical resources. Many hospitals have established futility policies that pre-determine care for patients with life-threatening injuries or illnesses.<sup>97</sup>

The bill successfully moved through Minnesota’s Senate Committee on Health and Human Services<sup>98</sup> but was not voted on by the full Senate. A similar medical futility bill has also been debated in the state of Michigan.<sup>99</sup> In October 2012, Michigan representatives introduced SB 1343, the Medical Good-Faith Provisions Act.<sup>100</sup> The Michigan bill, like the Minnesota bill, aimed to ensure that parents of children facing serious medical decisions have the ability to access a hospital’s medical futility policy. It states:

A health facility or agency that maintains a medical futility policy that applies to the treatment of a patient from birth to 18 years of age shall, upon request, provide a copy of that medical futility policy to the patient, prospective patient, or parent or legal guardian of the patient or prospective patient.<sup>101</sup>

With Minnesota and Michigan breaking ground on the issue of disclosure of hospital medical futility policies, there is hope that there is some movement in the U.S. to at least allow parents or guardians to have the

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<sup>96</sup> *Id.*

<sup>97</sup> Press Release, Senator Sean R. Nienow, Nienow Bill Requiring Hospitals to Report Medical Futility Policies Passes Unanimously from Committee (Mar. 16, 2012), available at [http://www.senate.leg.state.mn.us/members/member\\_pr\\_display.php?ls=&id=4395](http://www.senate.leg.state.mn.us/members/member_pr_display.php?ls=&id=4395).

<sup>98</sup> *Id.* (“The Senate Committee on Health and Human Services took up Senate File 2238, a bill requiring hospitals to disclose their futility policies to the guardians of patients under the age of eighteen. After hearing testimony and discussing the bill, members of the committee passed the bill unanimously.”)

<sup>99</sup> Thaddeus Mason Pope, *Michigan Legislation to Require Disclosure of Medical Futility Policies*, MEDPEDIA (Oct. 21, 2012, 2:26 PM), [http://www.medpedia.com/news\\_analysis/203-Medical-Futility/entries/128132-Michigan-Legislation-to-Require-Disclosure-of-Medical-Futility-Policies](http://www.medpedia.com/news_analysis/203-Medical-Futility/entries/128132-Michigan-Legislation-to-Require-Disclosure-of-Medical-Futility-Policies).

<sup>100</sup> *Id.*

<sup>101</sup> S.B. 1343, 96th Gen. Assemb., 2nd Reg. Sess. (Mich. 2012).

ability to weigh in on the treatment plan of their children who are likely in life or death situations.

## V. THE INTERNATIONAL MEDICAL TREATMENT OF DISABLED CHILDREN

While the case of Baby Joseph ignited debate over general end-of-life treatment for severely disabled children, decisions over the dehydration and starvation of disabled children have drawn particular attention and controversy internationally.<sup>102</sup> For example, “[e]ven 30 years after Baby Doe, this ‘better dead than disabled’ ideology is pervasive not simply in the U.S. but accordingly to the BMJ article, in the U.K. as well.”<sup>103</sup> These incidents are occurring internationally despite the existence of a decent body of international treaties that advocate for the protection of the rights of children and the disabled, including for the benefit of their health care. In 1990, the UN passed the UN Convention on the Rights of the Child.<sup>104</sup> Article 6 recognizes a right to life for children: “States Parties recognize that every child has the inherent right to life.”<sup>105</sup> Under this same Article, the UN describes the responsibilities of all States who adhere to this treaty in promoting the child’s right to life: “States Parties shall ensure to the maximum extent possible the survival and development of the child.”<sup>106</sup> Furthermore, the treaty specifically addresses protecting disabled children in Article 23, which states, “States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.”<sup>107</sup> This Article begins by advocating for the protection of the human dignity of the disabled child. Paragraph 2 of Article 23 emphasizes the willingness to ensure that children with disabilities are provided with appropriate health care:

Recognizing the special needs of a disabled child, assistance extended in accordance with paragraph 2 of the present article shall be provided free of charge, whenever possible, taking into account the financial resources of the parents or others caring for the child, and shall be designed to ensure that the disabled child has effective access to and receives education, training, health care services, rehabilitation services, preparation for employment and recreation

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<sup>102</sup> See Harvey, *supra* note 92.

<sup>103</sup> *Id.*

<sup>104</sup> *Id.*

<sup>105</sup> United Nations Convention on the Rights of the Child, Sept. 2, 1990, at art. 6, available at [http://www.unesco.org/education/pdf/CHILD\\_E.PDF](http://www.unesco.org/education/pdf/CHILD_E.PDF).

<sup>106</sup> *Id.*

<sup>107</sup> *Id.* at art. 23.

opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development.<sup>108</sup>

Article 24 deals with health and children generally, and acknowledges that children deserve to have access to health care services.<sup>109</sup> Paragraph one states:

States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.<sup>110</sup>

The UN Convention on the Rights of the Child marked a pivotal moment internationally in addressing the legal rights of children. The special attention given to children with disabilities cannot be overlooked. This was not the final international document to focus on the legal rights and protections of the disabled as the UN Convention on the Rights of Persons with Disabilities would follow.

In 2006, the UN passed a landmark international treaty particular to the disabled known as the UN Convention on the Rights of Persons with Disabilities.<sup>111</sup> Article 7 on Children with Disabilities states under provision one: "States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children."<sup>112</sup> Further, the second provision under Article 7 states: "In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration."<sup>113</sup> Article 25 also addresses health specifically concerning individuals with disabilities.<sup>114</sup> The opening of this article emphasizes the prevention of discriminating against individuals with disabilities based on disability in health care:

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<sup>108</sup> *Id.*

<sup>109</sup> *Id.* at art. 24.

<sup>110</sup> *Id.*

<sup>111</sup> United Nations Convention on the Rights of Persons with Disabilities, Dec. 6, 2006, available at <http://www.un.org/disabilities/default.asp?id=259>.

<sup>112</sup> United Nations Convention on the Rights of Persons with Disabilities, Dec. 6, 2006, at art. 7, available at <http://www.un.org/disabilities/default.asp?id=267>.

<sup>113</sup> *Id.*

<sup>114</sup> United Nations Convention on the Rights of Persons with Disabilities, Dec. 6, 2006, at art. 25, available at <http://www.un.org/disabilities/default.asp?id=285>.

States Parties recognize that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation.<sup>115</sup>

Article 25 continues with numerous provisions related to the health care of people with disabilities and specifies that the disabled are not to be discriminated against based on disability in the quality of their care. Article 25(d) proclaims:

Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care.<sup>116</sup>

A final relevant and interesting provision of the treaty for consideration under Article 27 is a provision describing the care of the disabled involving food and hydration: “Prevent discriminatory denial of health care or health services or food and fluids on the basis of disability.”<sup>117</sup>

It seems illogical that practices like starvation and dehydration could not only be occurring but be proclaimed as acceptable treatment plans in the face of these international treaties. This opens the questions of what value is there in international treaties if they are not enforced, and will such practices continue to be tolerated even without the backing of the international human rights protections that have been promised to the disabled.

## VI. CONCLUSION

The concept of “medical futility” and its application to the case of the severely disabled child is a complicated one, as demonstrated by the case of Baby Joseph Maraachli. As some U.S. states move towards requiring more transparent hospital medical futility policies that provide greater involvement for the child’s parents and family, the international trend seems to be taking a dangerous path towards simply deciding a disabled child’s life is valueless even contrary to, and in spite of, international treaties that promote quite the opposite for the protection of the disabled child.

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<sup>115</sup> *Id.*

<sup>116</sup> *Id.*

<sup>117</sup> *Id.*

We often observe that the U.S. lags behind other countries in promoting human rights protections. However, while the U.S. may not yet be the model for addressing issues of medical futility involving severely disabled children, the example of Baby Joseph and the movement of states towards providing a more balanced approach suggests that maybe this time the U.S. is on the better path. For the U.S. to continually defend its support of disability rights and the need to prevent discrimination on the basis of disability, it needs to step up its advocacy on the issue of medical futility and disabled children.

The notion that a disabled child's life is somehow less valuable and cannot offer anything worthy to this world could be considered archaic and goes back to the very foundation of why the disability rights movement evolved in the U.S. There may well always be disagreement about when and under what circumstances medical treatment is futile, especially when parents and families of children can and will become so emotionally invested that they overlook practical reality. However, the U.S. is a country that prides itself on respecting the rights of individuals, which includes the disabled child and the child's parents or guardians. It would seem the least that could be done would be to open the gates of transparency and allow those voices to be at the table with the physicians. If disability is a death sentence, then should we just exterminate all people with disabilities? As a vulnerable population, the disabled deserve better than that, including in childhood. The disabled child and all children deserve a chance at life. The legislative efforts promoted by the legislatures in Minnesota and Michigan represent at least a glimmer of hope for that chance.