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Alicia Ouellette
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Introduction

AS AN APPELLATE ATTORNEY WORKING IN THE NEW YORK State Attorney General's office, I was assigned a case that involved an adult woman with profound physical and mental disabilities. The woman was terminally ill and unable to digest any food or water. After consulting with her doctors, her family requested that she be allowed to die without being provided any further nutrition or hydration, which could be administered – if at all – through an intravenous catheter. Although the provision of nutrition and hydration would extend her life, the treatment would not change the fact that she was dying. Instead, it would increase her pain through an extended dying process. Everyone directly involved in the woman's medical case – the doctors, family, and ethics consultants – agreed the plan for palliative care and the termination of the intravenous nutrition and hydration was in the patient's best interest. In most states, the treatment plan would have been carried out and the patient allowed to die peacefully in a matter of days. Because the patient was in a New York State hospital, however, and because she had never had capacity to express her own wishes with respect to end-of-life treatment, the case ended in litigation, which prolonged her life for several excruciating months.

At the time, New York law did not permit family members or doctors to withhold nutrition or hydration from a person who never

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had the capacity to make her own decisions. The state agency charged with advocating on behalf of persons with mental disabilities sought representation by the State's attorney to enforce the law. The client agency was adamant in its demand that the law requiring the provision of nutrition and hydration be enforced. In its view, the patient's family and doctors wanted to do something that was not legal in New York, and allowing for any exception to the rule would open the door to the slippery slope of euthanasia or even a new eugenics. My role was to support the trial attorney in his representation of the agency and then to handle any appeal arising after a trial court decision. My job was to keep the patient alive.

Despite the clear New York rule requiring life-prolonging treatment, there was nothing straightforward about application of the law in this particular woman's case. The patient's family and doctors submitted evidence that although providing nutrition and hydration would extend her life, the treatment was medically inappropriate. The woman's body was no longer able to digest or metabolize caloric intake. As a result, her body bloated; her organs deteriorated; her skin stretched to the point where it fell off; and her condition made pain relief impossible. The doctors documented the patient's excruciating journey toward death in her medical chart. They argued that applying the law as written was morally wrong, even inhumane. Eventually the trial court judge was persuaded to put the law aside and issue an order allowing the doctors to stop the treatment. The woman at the center of the litigation suffered for months before finally dying, just as an appellate court was ready to hear arguments.

By the time I wrote the appellate brief and prepared my arguments for the appellate court, it was clear to me and everyone else on the legal team that New York's rigid law was having unintended – even tragic – consequences. We saw that the patient at the center of our case was in intractable pain because of the very treatment that was prolonging her life. In our brief to the appellate court, we modified our position from the one taken at the trial court, where we vigorously advocated

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application of New York's law, to one tempered by recognition that the presence of iatrogenic harm caused by the life-extending treatment might justify an exception to the rule. It was too little too late. The case was dismissed without a written decision.

After leaving the Attorney General's office to begin teaching at a law school, I wrote a law review article that put together the ideas and arguments I had been thinking about since my involvement in the case.[1] The paper criticized New York's end-of-life law for its insistence that people who had not specifically expressed a desire to forgo life-prolonging treatment be given life-prolonging treatment. My intent was to use principles from bioethics to make an argument for disability rights at the end of life. Specifically, I argued that New York's law was especially harmful to people with cognitive disabilities who could never express their wishes regarding end-of-life care because the law made them particularly vulnerable to the horrific death experienced by the patient in my case. It seemed clear to me that New York's law hurt people who never had decision-making capacity because they could never access medically appropriate comfort care without artificial nutrition and hydration. I saw the barriers to comfort care as a form of disability discrimination. In short, I thought I'd written a pro–disability rights paper.

Although it seems naïve in retrospect, I was shocked and upset when I received angry e-mails from disability rights activists following publication and even angrier responses in person after I presented my argument at conferences. The activists charged that by advocating for a change in New York's laws to allow people with disabilities to die without the use of all available life-prolonging treatments, I was promoting the myth that life with disability is not worth living. I was cast as someone complicit in a new eugenics that would kill off people with disabilities as "useless eaters."

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[1] Alicia Ouellette, *When Vitalism Is Dead Wrong: The Discrimination Against and Torture of Incompetent Patients by Compulsory Life-Sustaining Treatment*, 79 Ind. L. J. 1 (2004). *See infra* Chapter 7.

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The response I got paled in comparison to the disability community's attacks against Michael Schiavo, triggered by his decision to withhold artificial nutrition and hydration from his wife, Terri Schiavo, who had been kept alive in a persistent vegetative state for more than ten years.[2] In response to the Schiavo case, the disability rights community engaged in a desperate battle for the life of a woman they viewed as representative of the lives of all people with disabilities.[3] The Schiavo case pitted disability rights activists against bioethicists who emerged in defense of Michael Schiavo on a very public stage.

The activists confronted bioethicists directly in my hometown when a bus full of members of the activist disability group Not Dead Yet took over in vocal protest the plenary session of a large national conference I had helped organize with my local bioethics institute. Their message was clear: Laws that facilitate dying, whatever their form, discriminate against and hurt people with disabilities. People who advocate such laws are enemies to people with disabilities.

In the years following the publication of my first article, I immersed myself in the teachings of people who study about and advocate for people with disabilities. My feeling was that I could no longer hold myself out as an advocate for people with disabilities until I understood a perspective I had never considered. I have learned a great deal from that course of study as well as from the people I've met along the way. I now understand on a much more fundamental level the history that drives that branch of the disability rights community most vocally opposed to laws that allow for choice in dying. I also see more clearly why and how bioethics is a discipline largely vilified by many disability rights activists. But my immersion into disability studies has not shaken my belief that laws like New York's are more harmful than

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[2] The Schiavo case is discussed at length in Chapter 7.

[3] For a comprehensive overview of the disability community's response to the Schiavo case, *see* Kathy L. Cerminara, *Critical Essay: Musings on the Need to Convince Some People with Disabilities That End-of-Life Decision-Making Advocates Are Not Out to Get Them*, 37 LOY. U. CHI. L. J. 343 (2006).

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helpful to the very people they are designed to protect. Nor has my immersion into disability studies shaken my belief that application of the core principles of bioethics – autonomy, beneficence, nonmaleficience, and justice – is fundamental in a health care system that best respects individuals as human beings.

Although my analytic orientation remains rooted in bioethics, I have taken more from my immersion in disability studies than a scholarly understanding of an alternative worldview. My study of disability scholarship and activism has fundamentally altered my understanding of life with disability and has convinced me that as a field, bioethics is often indifferent to and sometimes insensitive about disability issues. Although I frequently disagree with disability rights activists about what it means to advance the interests of individuals with disability in the health care system, I have come to believe that bioethics would be richer – and more effective in promoting respect for all persons – were it deliberately conscious of disability issues.

This book is the result of my ten-year journey toward disability-consciousness. It draws on materials from bioethics, law, and disability studies to make the case that health care professionals, policy makers, and bioethicists can and should be both mindful of and knowledgeable about the issue of disability in medical cases. In other words, they need to develop an informed disability consciousness. Being disability conscious does not need to undermine patient self-determination, as feared by some bioethicists, nor does continued respect for self-determination and surrogate decision making need to result in disability discrimination, as feared by some disability rights activists. Instead, becoming disability conscious will require bioethicists, policy makers, and health care professionals to engage the work of disability scholars and participate in civil discourse with disability experts. If successful, this book will serve as a useful resource in facilitating that cross-disciplinary conversation and study.

In addition to presenting disability and bioethics perspectives on a wide range of cases, the book proposes an analytic framework for a

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disability-conscious bioethics. The framework is a starting point for a much-need conversation about how to promote respect for people of all abilities in the health care setting, but it is by no means a panacea. Even if it is successful in moving bioethics toward disability-consciousness, my proposal will not eliminate the distrust and fear expressed by many disability activists toward medicine and bioethics. Nor will it provide answers to vexing issues in health care. But moving toward a disability-conscious bioethics should allow scholars, practitioners, and activists on both sides of the divide to come together to place individuals with disabilities at the center of the decision-making process with a full and accurate awareness of the realities of life with disability, including its gifts. If nothing else, I hope this book makes room for nuanced discourse beyond the angry rhetoric that characterizes and stunts the current debate.

Before I begin, some disclosures and caveats are in order. First, I am an American lawyer by training and profession. Like many people who write or think about bioethical issues, I am not credentialed in bioethics. Nor am I a philosopher, historian, social worker, clinician, or theologian. This disclosure is important in several respects. As a "naked JD," my formal training and practical experience are limited, as is my analytical approach to bioethical disputes. My training in legal analysis (and lack of training in other disciplines) shows throughout the book. Like any good lawyer, I start with some factual background, move into rules, and then apply those rules to the specific facts of individual cases. And like most lawyers and legal academics, I am a firm believer in the case-study method for nuanced understanding of legal doctrine and policy. For that reason, most of this book focuses on case studies rather than abstract theory or debate.

Also, I have a U.S. bias. My primary focus as a practitioner and academic has been and remains American law and its relationship to the provision of health care. Although I consider international perspectives in analyzing issues (specifically I draw from the United Nations Convention on the Rights of Persons with Disabilities in addressing

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what a disability-conscious bioethics might look like), and I have included international perspectives about some of the cases that make up this work, the book relies heavily on U.S. cases and U.S. law. In some respects, the U.S. bias in the book might be explained as reflective of the field's origins. Although bioethics has spread to countries around the globe where it has taken on decidedly local dimensions, the recent histories of the field recognize bioethics as a discipline with American origins,[4] and the U.S. legal system as a major player in its development.[5] Moreover, many of the case studies I've included are seminal cases that are indispensible to any study of the tension between bioethics and disability. I have no doubt, however, that the main reason I rely so heavily on American cases is that I am familiar with them.

Next, I have no visible disabilities. I have a neurological condition that is completely disabling when it strikes, chronic struggles with blood sugar, a damaged shoulder, and an arthritic hip. But I am physically and genetically lucky. In other words, I have no condition so immediately apparent as to give me the presumed authority to talk about life with disability that sometimes comes with a visible disability. I provide this bit of information to answer the question that has inevitably arisen whenever people are considering whether to invite me to participate in a panel or debate about disability. I've learned that to many people, my lack of visible disability is a disqualifier as real as the lack of any other professional credential. Although I would like to think that I have something to offer in discussions of disability despite my relative physical and genetic luck, I know my approach to problems is shaped by my experience in the body I inhabit. I understand and respect the people who have been forthright about their belief that

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[4] Even Spanish medical historian Diego Gracia, who takes issue with those who claim bioethics is essentially American, acknowledges that "bioethics had its first development in the US." Diego Gracia, *History of Medical Ethics, in* BIOETHICS IN A EUROPEAN PERSPECTIVE, at 44–45 (2001).

[5] Renee C. Fox and Judith P. Swazey provide an excellent summary of the various theories offered to explain the origins of the field in *Observing Bioethics* (2008).

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only those who have had the lived experience of visible disability have standing in disability-related discussions. For that reason, I acknowledge at the outset my limitation in experience and my position as an interested outsider.

Finally, I have excluded from this book some of the most contentious issues in bioethics and disability studies. By starting my study of the human life span at the moment of birth rather than the moment of conception, I avoid discussion of prenatal screening, abortion, and genetic manipulation of embryos. Those omissions are obviously not trivial. The treatment of embryos with disabilities ranks with the treatment of seriously disabled newborns and end-of-life decision making as among the most disputed in the conflict between disability rights advocates and bioethicists. I decided to exclude cases raising questions about the treatment of embryos with disabilities for practical and substantive reasons. As a practical matter, addressing life before birth would require a thorough analysis of unresolved questions about the moral and legal status of the embryo and the role of abortion politics in the debate – discussions so complicated that they could easily overwhelm the book.[6] As a matter of substance, the debate about embryos with disabilities is, in my view, conceptually distinct from the others I address because of the interdependent nature of the maternal-fetal relationship. Excluding discussions about life before birth, therefore, seemed a reasonable way to keep the book focused, as intended, on documenting and reconciling the views of disability and bioethics experts in a manner that will be useful both inside and outside the United States. In any event, if it is successful, the model of disability-conscious bioethics I propose here should be applicable to issues that arise during human gestation, but my explanation of how the model applies before birth will have to wait for another day.

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[6] For a thorough discussion of these issues, *see* Hasting Center Studies in Ethics, PRENATAL TESTING AND DISABILITY RIGHTS (Erik Parens & Adrienne Asch eds., Georgetown University Press 2000).

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Even though this book does not address prebirth issues, it does address issues that arise throughout the rest of the human life cycle: in infancy, childhood, the reproductive years, the adults years, and at the end of life. It is a book about perspectives, debate, and respect. And, as a book written to follow the advice I constantly give students – "show, don't tell" – it is a book of stories. Chapter 1 shows how the conflicting perspectives and conflicts between the bioethics and disability rights communities have developed, as a result of various social, legal, and cultural events that have influenced the thinking and advocacy in bioethics and the disability rights communities.

Chapter 2 serves two purposes. First it tests the depth of conflict between disability studies and bioethics by comparing, at an introductory level, the methodology and teachings of both fields. To illustrate the contrasting perspectives and illuminate practical points of tension, the chapter contrasts the perspectives of each group on the case of Elizabeth Bouvia, a young healthy woman with disabilities who sought and ultimately received court authority to refuse artificial nutrition and hydration. The Bouvia case is heralded within bioethics as a triumph for autonomy and by the disability rights community as a key example of disability discrimination in action. It is as clear an example as any of a case subject to different interpretation depending on one's perspective. Having identified the points of tension central to the conflict, the chapter makes the case for and proposes a methodology of reconciliation.

The next five chapters do the major work of the book. Focusing on different stages of the human life cycle, they use case studies – stories from people's lives – as a platform for looking beyond the rhetoric, and building a more nuanced understanding of the interests, concepts, biases, and fears that inform discussion within the disability and bioethics communities. Each chapter begins with two or three case studies. In first describing the cases, I try to report objective facts. I then compare the reactions and analysis to the cases from a disability rights perspective with analysis and reaction from a bioethics perspective.

Where possible, I rely on the words of members of the bioethics or disability rights community to highlight the different approaches. In some cases, I offer my own analysis from one or the other perspective. At the end of each of these chapters, I include a section entitled "Observations." The Observations sections are intended to highlight the features of the debate emerging from the case studies that inform the development of a disability-conscious bioethics in Chapter 8. The chapters are organized to take the reader through the human life span from birth to death.

I found two things especially challenging as I wrote each of the chapters containing case studies. First, choosing the cases was difficult. I ultimately decided to include cases about which there have been significant and public disagreements between members of the disability rights movement and bioethicists, in order to best illustrate conflicting perspectives and leave room for finding common ground. Of course, that decision affected the story the book tells. Most of the case studies involve a decision that had the effect of hastening a person's death. Although such cases are in the eye of the stormy dispute between disability rights activists and bioethicists, they do not represent the everyday challenges faced by people with and without disabilities in the health care system. They are extraordinary cases. The focus on the extraordinary cases that cause extraordinary disputes tends to exaggerate the divide between the bioethics and the disability rights communities. Indeed, there is much common ground between the camps, which brings me to my second area of difficulty.

As I emphasize repeatedly throughout the book, there is neither a single bioethics nor a single disability rights perspective. Even knowing that, I present "views from bioethics" and "views from the disability community" for each case study. In choosing the representative "views," I sorted through the internal debates among bioethicists and the internal debates among disability rights advocates and scholars to ferret out what can be fairly characterized as mainstream or representative views from each camp. If there was no apparent mainstream