

# HAUERWAS AND DISABILITY LAW: EXPOSING THE CRACKS IN THE FOUNDATIONS OF DISABILITY LAW

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## I

### INTRODUCTION

Stanley Hauerwas argues that “[n]o group exposes the pretensions of the humanism that shapes the practices of modernity more thoroughly than the mentally handicapped.”<sup>1</sup> He describes people with intellectual disabilities<sup>2</sup> as “the crack I desperately needed to give concreteness to my critique of modernity.”<sup>3</sup> Indeed, modern practices with respect to the mentally handicapped are undeniably puzzling. On the one hand, advances in the ability to prenatally diagnose genetic conditions that cause mental retardation are

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\* Professor of Law, Thomas J. Abood Research Scholar, and Co-Director, Terrence J. Murphy Institute for Catholic Thought, Law, and Public Policy, University of St. Thomas School of Law (Minneapolis). I was introduced to Stanley Hauerwas’s work on people with disabilities while writing my master’s thesis in Catholic Studies at the University of St. Thomas. I am indebted to all my teachers in that innovative interdisciplinary program, and particularly to my thesis adviser, Paul Wojda. My appreciation for Samuel Bagenstos’s insights about the contradictions in the disability law grew over the course of a series of discussions with student groups at Boston College Law School, Georgetown Law Center, Yale Law School, and Columbia Law School. I thank the students who invited me and shared their insights. I would also like to thank the participants of the 2011 Summer Seminar at the MacLaurin Institute of the University of Minnesota and the participants of a University of St. Thomas School of Law faculty colloquium. For the opportunity to bring Hauerwas and Bagenstos together in this article, I am grateful to the editorial staff of *Law and Contemporary Problems*, and particularly the brilliant and creative Special Editor of this volume, John Inazu, who has lived his commitment to people with disabilities in many ways. And, of course, I must thank Peter, my son and my muse, for his inspiration.

1. Stanley Hauerwas, *Timeful Friends: Living with the Handicapped*, in CRITICAL REFLECTIONS ON STANLEY HAUERWAS’ THEOLOGY OF DISABILITY 11, 14 (John Swinton ed., 2004) [hereinafter Hauerwas, *Timeful Friends*].

2. The focus of this article is people with intellectual, rather than physical, disabilities. The appropriate terminology for this population can be problematic. This is graphically illustrated by the different terms Hauerwas himself has used over the past thirty years of his writings on this topic—including the quotes in this article—that track the evolving conventions of the subject. See Simi Linton, *Reassigning Meaning*, in THE DISABILITY STUDIES READER 223, 223–28 (Lennard J. Davis ed., 2010) (describing evolving usages). Although I typically use the “people first” terminology currently favored by most disability advocates, see, e.g., Kathie Snow, *People First Language*, DISABILITY IS NATURAL (May 2012), <http://www.disabilityisnatural.com/images/PDF/pfl09.pdf>—preferring, for example, “people with intellectual disabilities” over “the mentally retarded”—this article sometimes refers simply to “the disabled” in the interest of brevity. These references should be understood to refer primarily to people with intellectual, rather than physical, disabilities.

3. Hauerwas, *Timeful Friends*, *supra* note 1, at 14.

widely heralded and enthusiastically embraced, as evidenced by the declining numbers of children born with Down Syndrome worldwide, despite advancing maternal ages that should be causing those numbers to increase.<sup>4</sup> On the other hand, laws expressing a strong commitment to the equal treatment of our fellow citizens with disabilities continue to be enacted, typically with overwhelming support, since the passage of the Individuals with Disabilities Education Act in 1975<sup>5</sup> (“IDEA”), which ensured the education of children with disabilities in public schools. The Americans with Disabilities Act of 1990<sup>6</sup> (“ADA”) prohibited discrimination against people with disabilities in public accommodations and employment, and the Genetic Information Nondiscrimination Act of 2008<sup>7</sup> prohibited employers or health insurers from discriminating based on information from genetic tests.

There are, indeed, puzzling inconsistencies in contemporary society’s attitudes toward the disabled—inconsistencies that Hauerwas identifies as evidence of the flaws of modern humanism. Humanism’s emphasis on rationality and capacity for reason is the most obvious target of any critique focused on people with intellectual disabilities, whose capacity for reason is, by definition, compromised to some degree. But Hauerwas focuses his critique on two related corollaries—namely, that autonomy and the ability to freely create one’s own identity constitute equally fundamental markers of humanity.

Disability law scholar Samuel Bagenstos identifies and attempts to explain a series of contemporary contradictions in disability law, including those stemming from recent case law restricting the scope of the ADA and the debate about abortion after a prenatal diagnosis of a disability.<sup>8</sup> A careful analysis of these arguments reveals similarities between Bagenstos’s explanations for the contradictions he observes and significant aspects of Hauerwas’s critique of modern humanism. I will argue that Bagenstos’s arguments could be strengthened by incorporating more completely Hauerwas’s full critique. Appreciating the similarities between Bagenstos’s arguments and Hauerwas’s insights does more than simply clarify and strengthen Bagenstos’s arguments. It also evidences a growing and potentially powerful convergence of theological and secular reflection on the thorny conundrum posed by contemporary society’s treatment of the significantly disabled. By joining forces, proponents of both religious and secular arguments might be able to work together for the development of a less contradictory—and more inclusive—set of laws and practices for people with disabilities.

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4. See *infra* note 120 and accompanying text.

5. 20 U.S.C. §§ 1400–1482 (2006) (originally enacted as the Education for All Handicapped Children Act of 1975).

6. 42 U.S.C. §§ 12101–12213 (2006).

7. Pub. L. No. 110-233, 122 Stat. 881 (codified in scattered sections of 26, 29 and 42 U.S.C.).

8. SAMUEL R. BAGENSTOS, LAW AND THE CONTRADICTIONS OF THE DISABILITY RIGHTS MOVEMENT (2009).

## II

HAUERWAS'S CRITIQUE OF MODERN HUMANISM:  
THE PRETENSIONS EXPOSED BY PEOPLE WITH INTELLECTUAL DISABILITIES

Over the course of Hauerwas's voluminous writings about people with intellectual disabilities, he admits serious misgivings about instrumentalizing the disabled by making them a part of his intellectual agenda.<sup>9</sup> However, he is unable to resist either working with or writing about such people, because by being "drawn into the world of the mentally handicapped," he eventually came to realize that "[o]ur humanism entails we care for them once they are among us, once we are stuck with them; but the same humanism cannot help but think that, all things considered, it would be better if they did not exist."<sup>10</sup> The folksy idiom of this quote belies the complexity of its insights. Why should being "stuck with" people with intellectual disabilities give us a responsibility for care that we could otherwise evade by preventing their existence? Why should this intellectual epiphany—this recognition that the core idea underlying his substantial body of theological writing about the disabled was, in fact, a critique of modern humanism—only be possible for him after being "drawn into" the "world of the mentally handicapped"?<sup>11</sup>

The complex layers of Hauerwas's disability-based critique of modern humanism reflect the different perspectives through which he encountered the disabled, both personally and in his written work. Much of his earliest writing on the topic addressed experiences of parents of intellectually disabled children—a community he grew to know intimately while teaching at the University of Notre Dame and volunteering at a neighboring center for disabled children. Later writing reflected Hauerwas's growing friendship with Jean Vanier, the founder of L'Arche, an international federation of small, residential faith-centered communities where people with and without intellectual disabilities live together in friendship. His work based on these personal encounters drew him into more theoretical engagements with philosophers of modern humanism, such as Immanuel Kant, John Rawls, and Martha Nussbaum, whose accounts of humanity Hauerwas criticizes for their failure to account adequately for the disabled. Hauerwas invariably judges these intellectual engagements to be futile, and he concludes that the witness provided by those living with the disabled is the strongest argument for his critique of modern humanism. In this part, a brief description of the modern humanism that Hauerwas critiques will set the stage for a discussion of what each of these three perspectives contributed to his critique.

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9. Hauerwas, *Timeful Friends*, *supra* note 1, at 14.

10. *Id.*

11. *Id.*

### A. A Brief Description of “Our” Modern Humanism: Rationality and its Two Corollaries

Humanism is generally characterized as a philosophy concentrating on human values and human nature. It typically identifies the human capacity for self-realization as the source of universal human dignity, rather than any religious belief. John Swinton, the editor of the most comprehensive collection of Hauerwas’s writings on disability, offers a helpful description of how Hauerwas understands the target of his critique:

For Hauerwas, post-Enlightenment Western culture is liberal in its worldview, assumptions, and expectations. Liberalism emphasizes the importance of reason, rationality, independence, and the capacity for self-advocacy. The assumed norm for authentic human living is that a person should be able to articulate their ideas cognitively, logically, and rationally. From the perspective of liberalism, society is assumed to be an association of free and independent equals. To be a “person” means that one must be able to live one’s life, develop one’s potential and develop a purposeful life-course without any necessary reference to others. Importantly, these capacities are not only necessary for entry into the socio-political system, they are also considered necessary for a person to live in a way which can be deemed authentically human. . . . The experience of profound developmental disabilities sits uneasily with the expectations, hopes, and dreams of liberal society.<sup>12</sup>

Swinton’s description captures the complexity of the various dimensions of contemporary humanism that are particularly problematic for people with cognitive disabilities. The most obvious is the emphasis on reason and rationality. By definition, this norm assumes a capacity that is compromised to some extent for people with intellectual disabilities. But Hauerwas does not tend to focus on the capacity for reason in his critique of humanism.<sup>13</sup> Instead, he focuses on two corollaries flowing from this starting point, namely that authentic personhood is characterized, first, by a person’s autonomy, and, second, by a person’s capacity for self-definition. Though these two corollaries are not entirely independent of each other, they are distinct. Each idea illuminates different aspects of modern humanism that Hauerwas finds particularly problematic for the disabled.

### B. Corollary One: Autonomy is Fundamental to Personhood

The past few decades have witnessed no dearth of criticisms of the presumption of autonomy as a fundamental attribute of humanity. Feminist legal philosophers such as Robin L. West, Martha Albertson Fineman, and Joan Williams have offered dependency-based theories of justice focusing on the particular dependency of children on their parents that in turn results in dependency for the care-giving parent.<sup>14</sup> Others, such as the philosophers

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12. John Swinton, *Introduction: Hauerwas on Disability*, in *CRITICAL REFLECTIONS ON STANLEY HAUERWAS’ THEOLOGY OF DISABILITY*, *supra* note 1, at 1, 5.

13. *But see* Stanley Hauerwas, *The Retarded and the Criteria for the Human*, in *CRITICAL REFLECTIONS ON STANLEY HAUERWAS’ THEOLOGY OF DISABILITY*, *supra* note 1, at 127 (criticizing definitions of humanness applied in contemporary bioethical debates that focus exclusively on cognitive ability).

14. MARTHA ALBERTSON FINEMAN, *THE AUTONOMY MYTH: A THEORY OF DEPENDENCY*

Alasdair MacIntyre, Hans S. Reinders, and Eva Feder Kittay, have focused on the inherent dependency of the disabled in developing alternative moral or political philosophies based on humanity's mutual vulnerability and dependency.<sup>15</sup>

Hauerwas joins this chorus, arguing that people with intellectual disabilities present an uncomfortable challenge to the modernity-infused view of the self as autonomous by painting the more honest picture of the person as vulnerable and dependent:

As much as we fear suffering, we fear more the loneliness that accompanies it. We try to deny our neediness as much, if not more so, to ourselves as to others. We seek to be strong. We seek to be self-possessed. We seek to deny that we depend on others for our existence.

The retarded, therefore, are particularly troubling for us. Even if they do not suffer by being retarded, they are certainly people in need. Even worse, they do not try to hide their needs. They are not self-sufficient, they are not self-possessed, they are in need. Even more, they do not evidence the proper shame for being so. They simply assume that they are what they are and they need to provide no justification for being such. It is almost as if they have been given a natural grace to be free from the regret most of us feel for our neediness.<sup>16</sup>

In addition to the power of the witness provided by this "natural grace" of people with disabilities, Hauerwas observes that those who care for people with intellectual disabilities, particularly those in voluntary associations such as the L'Arche communities, offer powerful prophetic witness to the possibility of a world that is *not* structured around the autonomy fallacy. The L'Arche communities are radical living arrangements for the disabled because they are characterized by their commitment to communal life marked by genuine, mutual friendship, rather than the more conventional commitment of fostering the autonomy of the disabled while providing adequate care.<sup>17</sup> Such a genuine friendship depends on the *mutual* dependence of the friends, rather than a one-sided dependence of the disabled on the nondisabled. Vanier explains that

[o]ur focal point of fidelity at L'Arche is to live with handicapped people in the spirit of the gospel and the Beatitudes. "To live with" is different from "to do for." It doesn't simply mean eating at the same table and sleeping under the same roof. It means that we create relationships of gratuity, truth and interdependence,<sup>18</sup> that we listen to the handicapped people; that we recognize and marvel at their gifts.

Hauerwas considers this witness to lives structured around mutual

(2004); ROBIN L. WEST, *CARING FOR JUSTICE* (1997); JOAN WILLIAMS, *UNBENDING GENDER: WHY FAMILY AND WORK CONFLICT AND WHAT TO DO ABOUT IT* (2000). For a more detailed discussion of this work, see Elizabeth R. Schiltz, *West, MacIntyre and Wojtyła: Pope John Paul II's Contribution to the Development of a Dependency-Based Theory of Justice*, 45 J. CATH. L. STUD. 369 (2007).

15. EVA FEDER KITTAY, *LOVE'S LABOR* (1999); ALASDAIR C. MACINTYRE, *DEPENDENT RATIONAL ANIMALS: WHY HUMAN BEINGS NEED THE VIRTUES* 3 (1999); HANS L. REINDERS, *THE FUTURE OF THE DISABLED IN LIBERAL SOCIETY* (2000); HANS L. REINDERS, *RECEIVING THE GIFT OF FRIENDSHIP* (2008).

16. Stanley Hauerwas, *Suffering the Retarded: Should We Prevent Retardation?*, in *CRITICAL REFLECTIONS ON STANLEY HAUERWAS' THEOLOGY OF DISABILITY*, *supra* note 1, at 87, 102.

17. MICHAEL DOWNY, *A BLESSED WEAKNESS* 40 (1986).

18. JEAN VANIER, *COMMUNITY AND GROWTH* 106 (1979).

dependency rather than autonomy to be so powerful as to be “dangerous”—“too strong for most of us.”<sup>19</sup> At the same time, though, he insists that “[t]heir witness remains crucial for the rest of us [who] are not part of their community; for without such examples imaginations lack the resources to know that what we have become used to doing is not done by necessity.”<sup>20</sup>

### C. Corollary Two: Capacity for Self-Definition is Fundamental to Personhood

Hauerwas captured modern humanism’s conviction that personhood is fundamentally characterized by man’s capacity for self-definition in his writings: “[W]e live in a time when people believe they have no story except the story they chose when they thought they had no story.”<sup>21</sup> He asks readers to test the extent to which they accept this notion by reflecting on whether they think a person should be responsible for any decision made when they did not know what they were doing. Most readers do not. As Hauerwas explains, “[T]his ethos of freedom is deep in our souls. We believe we should be held responsible only for the things we freely chose when we knew what we were doing.”<sup>22</sup> Our own self-definitions—our own, freely created stories—set the parameters for how we should be judged.

Hauerwas draws this vivid insight from his work with parents of children with intellectual disabilities who are directly confronted with the fallacy that our personhood is fundamentally the product of our self-definition in two ways—one of which is direct and essentially existential, the other of which is slightly more indirect and instrumental.

#### 1. The Direct Existential Insight

Hauerwas argues that parents of children with intellectual disabilities are confronted more directly than most people with the reality that we do not, in fact, create and define ourselves from limitless blank slates of possibility, but that we are, rather, creatures of God. In an essay about how parenting disabled children teaches parents skills that ought to be used in raising *all* their children, he argues that we have to understand *all* of our children as *gifts*, rather than as the products of our choices.

For children are not beings created by our wills—we do not choose them—but rather they are called into the world as beings separate and independent from us. They are not ours for they, like each of us, have a Father who wills them as his own prior to our choice of them.

Thus, children must be seen as a gift, for they are possible exactly because we do not determine their right to exist or not to exist. Now it is important to notice that the language of gift involves an extremely interesting grammar. For gifts come to us as a given[;] they are not under our control. Moreover, they are not always what we want or expect and thus they necessarily have an independence from us.

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19. Hauerwas, *Timeful Friends*, *supra* note 1, at 23.

20. *Id.*

21. Stanley Hauerwas, *The Politics of Gentleness*, in STANLEY HAUERWAS & JEAN VANIER, *LIVING GENTLY IN A VIOLENT WORLD* 77, 82 (2008) [hereinafter Hauerwas, *Gentleness*].

22. *Id.*

Insofar as gifts are independent they do not always bring joy and surprise, but they equally may bring pain and suffering. But just such pain and suffering is the condition for their being genuine gifts, for gifts that are genuine<sup>23</sup> do not just supply needs or wants, as they would then be subject to our limitations.

The essential giftedness of human existence is more easily recognized in a child with an intellectual disability than a non-disabled child. A non-disabled child can more readily be seen as the product of a parent's choice—she is a child a parent would likely have chosen. The notion of human agency in the creation of that child—whether the agency of the parent who chose the child or the agency of the child in self-defining—is not disturbed. The disabled child, however, is less likely to have been freely chosen by the parent. Moreover, we would typically assume that the child himself would not have chosen a disability. Thus, the very concept of agency—both the parent's and the child's—is disturbed by the disability. The disability forces the parents to consider that their children are gifted to them by another—in Hauerwas's theology, by God.<sup>24</sup> And once a parent acknowledges the essential giftedness of her child, she is forced to acknowledge her own giftedness, and is thus confronted with the fallacy of the belief that our personhood is fundamentally the product of our self-definition.

Such a confrontation with the limits of self-definition is the subject of a poignant exchange between Hauerwas and Michael Bérubé, the author of a book about his experiences as the father of a son with Down Syndrome. Hauerwas singles out Bérubé's wistful description of his dreams for his son with Down Syndrome, Jamie, as an example of the limits of modernity's humanism. Bérubé writes: "I have no sweeter dream than to imagine—aesthetically and ethically and parentally—that Jamie will someday be his own advocate, his own author, his own best representative."<sup>25</sup> Hauerwas commented in response as follows:

How sad. All Bérubé can imagine for Jamie is that he be "his own author." That Bérubé can imagine no other future is not his fault. His imagination reflects the same limits that formed the conceptions of justice he found so unsatisfactory. What other possibility could there be in a world in which God does not exist?

. . . Bérubé has been gifted with Jamie, but he lacks the practices of a community that would provide the resources for narrating his own and Jamie's life.<sup>26</sup>

Bérubé responds to Hauerwas by arguing that Hauerwas has misunderstood his use of the terms "his own advocate, his own author": He was not incorporating a robust capacity for self-definition into his dreams for Jamie, but rather a more modest hope that Jamie would someday be able to make his own contributions to advocating for himself.<sup>27</sup> Bérubé's response directly engages the

23. Stanley Hauerwas, *Having and Learning to Care for Retarded Children*, in CRITICAL REFLECTIONS ON STANLEY HAUERWAS' THEOLOGY OF DISABILITY, *supra* note 1, at 149, 155–56.

24. *But see* MICHAEL SANDEL, THE CASE AGAINST PERFECTION (2007) (making a secular philosophical argument for giftedness as a fundamental attribute of personhood).

25. MICHAEL BÉRUBÉ, LIFE AS WE KNOW IT 264 (1996).

26. Hauerwas, *Timeful Friends*, *supra* note 1, at 16.

27. Michael Bérubé, *Response: Making Yourself Useful*, in CRITICAL REFLECTIONS ON STANLEY

second way in which Hauerwas argues parents of children with disabilities are confronted with the fallacy of self-definition as a fundamental marker of humanity—the more indirect and instrumental way.

## 2. The Indirect Instrumental Insight

The more indirect and instrumental confrontation with the fallacy of self-definition is not as exclusively accessible to parents, for it is an issue with which many disability rights advocates, whether parents or not, struggle. However, much of Hauerwas's writing on this point is directed at parents who, as first and primary advocates for their children, tend to struggle with this most intensely. Contemporary resources for supporting parents of children with disabilities often begin with an introduction to current "best practices" in disability advocacy, in particular the "social construction model" of disability. The decades of the 1970s and 1980s saw the emergence in the United States of the "disabilities rights movement," in which people with disabilities modeled their struggles for freedom and equal treatment on the civil rights movements of the 1960s that saw the successful assertion of freedom and equality by racial minorities and women.<sup>28</sup> This movement saw significant successes on many fronts, including the eradication of the presumption that people with disabilities should be segregated into isolated institutions rather than living and working in the community and the enactment of legislation such as the IDEA and the ADA.

Central to the ideology of the disability rights movement is the rejection of the "medical model" of disability in favor of a "social construction model" of disability. The medical model of disability assumes that a disability is a "deficient or flawed human condition, a bodily deviation due to a 'loss' of capacity in one way or another, which holds a person back from participation in society. Hence, disability represents an inability, abnormality, or disadvantage calling for management and correction in order to restore proper functioning."<sup>29</sup> Axiomatic to this model is that it is the nondisabled who must do this management and correction, and that the management and correction is aimed at making those with disabilities more like the nondisabled. The disability is reduced to "a problem requiring diagnosis and treatment, a broken object to be fixed, made better, or overcome."<sup>30</sup> In the process, though, "the person becomes reduced to a function of disabilities rather than vice versa."<sup>31</sup> Disability rights advocates argue that this model deprives the disabled of their own voice—that is, the nondisabled determine what is best for the disabled based on their own

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HAUERWAS' THEOLOGY OF DISABILITY, *supra* note 1, at 31, 33.

28. See HANS J. REINDERS, RECEIVING THE GIFT OF FRIENDSHIP: PROFOUND DISABILITY, THEOLOGICAL ANTHROPOLOGY, AND ETHICS 24 n.3 (2008) (citing foundational works on the disability rights movement).

29. THOMAS E. REYNOLDS, VULNERABLE COMMUNION: A THEOLOGY OF DISABILITY AND HOSPITALITY 25 (2008).

30. *Id.*

31. *Id.*



views of “the normal” and impose those views on the disabled. This complaint is captured in the slogan: “Nothing About Us Without Us,”<sup>32</sup> and it is given concrete expression by the disability rights movement’s insistence on “people first” language that emphasizes the person rather than the disability, such as “a child with Down Syndrome” rather than “a Downs child.”<sup>33</sup>

The disability rights movement advocates an alternative model that views the disability as a social construct. Under the social construction model, a disability is more a function of the physical and social standards established by society as normal than a function of some defect in the body of the individual with the disability. It is society that disables a person who uses a wheelchair by constructing buildings with stairs, rather than elevators or ramps—not the paralysis of her legs. Under this model,

[g]enuine healing is more than a matter of an individual’s bodily adjustment to fit society’s definition of normalcy. It is instead a matter of society adjusting to the presence of diverse people with a range of impairments. And with this we enter the arena of civil rights and social justice.<sup>34</sup>

Although the ideology of the disability rights movement described above has, indeed, been a powerful force for significant improvements in the civil rights and justice accorded people with disabilities, it is not immune from criticism. For one thing, it ignores the reality of physical conditions responsible for some physical and cognitive disabilities that are not the product of social construction.<sup>35</sup> More significant for Hauerwas’s critique of modern humanism, though, is the argument that the social construction model of disability is based on a concept of human nature in which self-representation and the freedom to shape one’s own identity are the paramount values. As Dutch philosopher Hans Reinders argues,

Underlying the [social construction model] is an anthropological claim about the nature of our being. As human beings, we are free to construe the nature of our own being in the act of self-identification. This freedom is shaped, and thus constrained, by numerous cultural, political, and economic contingencies, but as ontological freedom it is certain. Human beings are the kinds of beings who have their existence as a task, not a preordained destination. This anthropological claim reinforces the appearance of people with profound intellectual disability as problematic.<sup>36</sup>

Furthermore, this model “espouses an ethics of political activism” from which the intellectually disabled are also excluded.<sup>37</sup>

[T]he suggestion that acts of will are essential in overcoming ‘disability’ is indebted to a model of political rationality that presupposes a liberal notion of autonomy. . . . It suggests that ‘emancipation from repression relies on the intellectual and emotional resources of the individual.’ In this respect, it clearly does not represent people with intellectual disabilities, let alone people with profound intellectual disabilities.<sup>38</sup>

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32. JAMES I. CHARLTON, *NOTHING ABOUT US WITHOUT US* (1998).

33. See Snow, *supra* note 2.

34. REYNOLDS, *supra* note 29, at 29.

35. *Id.* at 26–27.

36. REINDERS, *supra* note 28, at 86.

37. *Id.* at 67.

38. *Id.* (quoting Tobin Siebers, *Disability Studies and the Future of Identity Politics*, in *IDENTITY*

Parents of children with intellectual disabilities are thus often confronted with the tension between the reality of a child whose capacity for articulating or constructing even a rudimentary type of self-definition is diminished, and a model of advocacy on behalf of that child that rejects that reality. As Tom Reynolds, a theologian and the parent of a son with intellectual disabilities, explains,

There is a two-sided charge that obligates parents of children with disabilities. . . . First, there is a responsibility to affirm, nurture, and empower the unique person, helping to foster his or her own peculiar way of being. Second, there is a responsibility to encourage independence and capacity to live productively with others in society. However, these two charges often run against one another.<sup>39</sup>

This quandary is troubling because it implicates a commonly accepted articulation of modern humanism's valorization of self-definition, namely Immanuel Kant's second formulation of the categorical imperative—never to treat another human as a means only. Parents of intellectually disabled children do, however, have to act on behalf of their children in many ways, without any regard to the will of the child who cannot express herself. Does that mean they are “using” their child as a means? Indeed, this is the quandary that Bérubé explains he was thinking about when he expressed the hope that his son might someday be his own “author.” Bérubé acknowledges that he is “caught in a terrible paradox—affirming autonomy and dependency at once, and for different reasons.” He explains,

It is . . . urgent . . . that persons with mental retardation be represented in the public square when they cannot represent themselves; and it is all the more urgent that persons with mental retardation who have long been presumed to be constitutively unable to represent themselves be granted the material means to represent themselves as best they can. If, as is likely, Jamie cannot be his own best representative, his own ‘author,’ in this secular sense, then he—like millions of persons with disabilities who cannot communicate any adequate and accurate sense of themselves to other people—will be all the more dependent on the intercession of others.<sup>40</sup>

Hauerwas suggests that this tension could be mitigated for Bérubé and others like him by rejecting Kant's second formulation out of hand, as a flawed consequence of modern humanism's obsession with self-definition.

Of course, we “use” the handicapped, but we are here to be of use to one another. The notion that any use we make of one another can only be justified if it is done voluntarily can now be seen as one of the peculiar sentimentalities of modernity that results in self-supervision all the more tyrannical since what we do is allegedly what we want to do. That the handicapped are subject to care for their own good—a good they may not have chosen—is not an indication that such care is misguided, but rather requires that the good that such care is serving be properly named. After all, they (like us who are not retarded) exist to serve and to be served for our mutual upbringing. As Christians we should not feel embarrassed to discover that the mentally handicapped among us help us better understand the narrative that constitutes the very purpose of our existence.<sup>41</sup>

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POLITICS RECONSIDERED 10, 15 (Linda Martin Alcoff et al., eds., 2006)).

39. REYNOLDS, *supra* note 29, at 75.

40. BÉRUBÉ, *supra* note 27, at 33.

41. Hauerwas, *Timeful Friends*, *supra* note 1, at 20.

As a non-Christian, Bérubé resists the existential insight about the giftedness of each human being on which Hauerwas depends,<sup>42</sup> but he does accept the instrumental insight in the end by accepting Hauerwas's critique of Kant's second formulation of the categorical imperative. Bérubé acknowledged that, after first resisting Hauerwas's critique, his experience with Jamie has caused him to realize that "Professor Hauerwas is right: In the course of our lives we cannot not make use of others, and how awful would it be, in ethical theory or in family gatherings, if we did not set out making ourselves *useful* to others."<sup>43</sup> The admission that "we cannot not make use of others" is an acknowledgement that no one can absolutely and entirely be the author of her own existence.

#### D. The Futility of Theoretical Engagements with the Concepts of Modern Humanism

In a 2008 book co-authored with Jean Vanier, Hauerwas expanded on his earlier observations about the power of the L'Arche communities' witness to a world structured around modernity's deficient humanism, showing that alternative structures are possible.<sup>44</sup> Hauerwas attributes the extraordinary strength of that witness to its subversive gentleness.<sup>45</sup> While acknowledging the irony of presenting a characteristically "aggressive and confrontational" piece of writing to support gentleness, he contends, "My only defense is that God has given us different tasks. My task has been to put Vanier's wisdom into conversations with philosophical and political positions that I fear are antithetical—if not outright threats—to the people we call 'intellectually disabled.'"<sup>46</sup> He admits that he will not be practicing what Vanier preaches:

I do not want to learn to be gentle. I want to be a warrior on behalf of L'Arche, doing battle against the politics that threaten to destroy these gentle communities. Jean, of course, is no less a warrior. But where I see an enemy to be defeated, he sees a wound that needs to be healed.<sup>47</sup>

With these words he puts the reader on notice that what follows will be something qualitatively different from the narrative approach in his previous writing on disability: a more abstract engagement with the theoretical basis for modern humanism. Tellingly, though, Hauerwas concludes that such abstract engagements will not accomplish anything. The more powerful impetus for changing the practices of modernity is the prophetic witness of those whose practices reflect a different understanding of humanity—in families or in communities such as L'Arche.

Hauerwas takes off the gloves in this battle by naming the enemy directly—John Rawls and his intellectual heir, Martha Nussbaum. He argues that

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42. BÉRUBÉ, *supra* note 27, at 33–34.

43. *Id.*

44. See Hauerwas, *Gentleness*, *supra* note 21.

45. *Id.*

46. *Id.* at 78–79.

47. *Id.* at 80.

Nussbaum's attempt to more adequately account for the interests of the disabled among others in the "capabilities approach" set forth in her book *Frontiers of Justice* is doomed by her unwillingness to abandon the essential presumptions of the social contract theory. Hauerwas singles out two presumptions of social contract theory as being particularly problematic for Nussbaum's attempt to account for the disabled. First is its faith in what Nussbaum calls "strong rationalism" aimed at avoiding appeals to intuitions and prejudices. Hauerwas characterizes this as liberal political theory's "attempt to avoid contingency [by providing] an argument that is true without appealing to our experience in contingent historical conditions."<sup>48</sup> Second is its conviction that the presumption that people will act in accordance with their own self-interest is a more realistic and secure basis for a just society than a presumption that people will act altruistically.

Somewhat ironically, Nussbaum launches her critique with three intimate, personal stories of particular parents raising children with disabilities: Sessa, a young woman with cerebral palsy and severe mental retardation, the daughter of the philosopher Eva Kittay and her husband Jeffrey; Arthur, Nussbaum's own nephew with Asperger's syndrome and Tourette's syndrome; and Bérubé's son Jamie.<sup>49</sup> Nussbaum acknowledges that people with significant disabilities have been excluded from Rawlsian accounts of justice, because they are not the "human beings possessed of no serious mental or physical impairments" who are the parties in the Original Position designing the just society.<sup>50</sup> She argues, however, that this omission could be remedied if those "by whom" the just society is structured keep in mind all of those "for whom" the society is structured.<sup>51</sup> She writes,

One might have strong reasons for seeking such a theory and separating the two questions, if one starts from the idea that many different types of lives have dignity and are worthy of respect. If one thinks that way, one would acknowledge from the start that the capacity to make a contract, and the possession of those abilities that make for mutual advantage in the resulting society, are not necessary conditions for being a citizen who has dignity and deserves to be treated with respect on a basis of equality with others.<sup>52</sup>

Nussbaum's "capabilities" approach is an attempt to expand the Rawlsian understanding of "what is dignified and worthy in the human being," and thus in the self-interest of those in the Original Position to maximize for all members of society.<sup>53</sup> Whereas Rawls considered human rationality to be the basis of dignity, and measures of productivity—like income and wealth—as the sole legitimate indices of well-being, Nussbaum argues for a broader focus. Nussbaum's capabilities approach rests on an understanding of human dignity

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48. *Id.* at 85.

49. MARTHA NUSSBAUM, *FRONTIERS OF JUSTICE*, 96–98 (2006).

50. *Id.* at 16–17.

51. *Id.* at 17.

52. *Id.*

53. *Id.* at 160.

that includes not just rationality, but also sociability and “bodily need, including the need for care.”<sup>54</sup> This broader account of dignity suggests to Nussbaum that a more appropriate measure of the social well-being to be maximized would be an expansive list of various essential capabilities that incorporate people’s different needs and abilities.<sup>55</sup> Nussbaum believes that if those in the Original Position understand their essential dignity to be enhanced by maximizing a combination of all of these capabilities, the interests of those with significant disabilities will be protected, because those interests will be included in the self-interested calculations of those in the Original Position.

Hauerwas contends that Nussbaum’s theory fails for two reasons. First, it fails logically because of her commitment to avoiding contingencies:

The very notion of capabilities depends on close analysis of practices that allow us to correlate the needs of a particular person with what will satisfy those needs. But that kind of concreteness is not available as long as Nussbaum is determined to maintain Rawls’s liberal framework. It’s the same problem all over again: when we try to imagine politics without the contingencies of human life, people with disabilities get in the way.<sup>56</sup>

Hauerwas’s second argument is a critique of the social contract theory’s presumption that self-interest can assure a just society. He argues that Nussbaum has not—and indeed cannot—demonstrate that it is really in the self-interests of the non-disabled to care for the disabled. If “justice” is defined as what society can achieve if it acts in enlightened self-interest, “justice” will never adequately provide for the disabled. A theoretical argument based on why it *should* be in one’s self-interest to care for the disabled will not convince anyone. Only the *experience* of such care will convince anyone of its value, and no one will rationally undertake such an obligation out of self-interest. Some other motivation than self-interest—such as altruism, the happenstance of giving birth to an intellectually disabled child, or Jean Vanier’s direction by his spiritual mentor to start living with two intellectually disabled men—must provide the impetus for the experience that teaches the value of the care of the disabled. In the end, Hauerwas agrees with Reinders that

[t]here is no point in arguing with a skeptical spectator that he or she should care about the disabled. Instead, . . . it is crucial for a liberal society that people exist who are willing to engage in the practice of caring for the disabled. . . . [N]o public policy or theory can resolve the problem of what appears to be the burden of the lives of the disabled unless “it can tap [cultural] resources that motivate citizens to value the commitment that it requires.” After all, significance found in sharing one’s life with another person—a significance that will usually come as a surprise—cannot be found outside the activity itself.<sup>57</sup>

This same skepticism about the efficacy of abstract argument on this point is displayed in Hauerwas’s exchange with Bérubé. Hauerwas takes a passing swipe

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54. *Id.* at 159–60.

55. *Id.* at 164–68.

56. Hauerwas, *Gentleness*, *supra* note 21, at 87.

57. *Id.* at 89 (quoting HANS REINDERS, *THE FUTURE OF THE DISABLED IN LIBERAL SOCIETY* 207 (2000)).

at engaging some of Bérubé's attempts to defend aspects of modern humanism, but he concludes that these attempts are irreconcilable with Bérubé's commitment to his son Jamie's care. The only thing that justifies that commitment is the fact that Bérubé, by virtue of his fatherhood, had the experience of caring for Jamie.

Bérubé's criticism of Rawls and Habermas rings hollow in the light of his own narrative. He either cannot or does not choose to make intelligible his admirable commitment to Jamie. For example, with great candor Bérubé tells us that he and his wife are as pro-choice after the birth of Jamie as they were prior to his birth. Indeed, he notes that they intentionally did not use amniocentesis, assuming they would "just love the baby all the more" if the baby was born with Down Syndrome. He confesses such a stance was "blithe and uninformed" and that if they had known that their child's life "would be suffering and misery for all concerned" they might have chosen to have an abortion. . . . Bérubé notes, however, that it is extremely difficult to discuss Jamie in this way. Just as it was hard to talk about him as a medicalized being when he was in the ICU, it is still harder to "talk about him in terms of our philosophical beliefs about abortion and prenatal testing. That's partly because these issues are so famously divisive and emotionally charged, but it's also because we can no longer frame any such questions about our child now that he's here."

"Now that he is here" is the nub of the matter. Bérubé does not pretend to be able to do much more than represent Jamie "now that he is here."<sup>58</sup>

And, indeed, Bérubé concedes this point in his response to Hauerwas. As noted above, though he cannot accept the theological basis of Hauerwas's critique of modern humanism, he finds the critique convincing. Without the theological basis, though, he cannot explain why it is convincing. He just knows, from his experience with Jamie, that it is correct. He writes:

As non-Christians, . . . we therefore find a place in Hauerwas's model, a place where we, too, can be of use . . . precisely to the extent that we do not feel compelled to justify the existence of the mentally handicapped. . . . I will try to eschew justification altogether, . . . quoting something Jamie said to me last month as he fell asleep on my arm while we were riding a train to New York. "Daddy," he said, groggily and with reference to nothing at all, "always be my friend." As I assured him, with all my heart, that I would always be his friend, I couldn't help wondering, *now, where in the world did that come from?* Thanks to Hauerwas and Vanier, I now know I need not bother asking. The question, like the fact of our obligations to each other, does not "come from" anywhere. It is simply here, now that Jamie is here, and the only thing that matters is that Christians and non-Christians alike respond to it with all the *caritas* they can invent or imagine.<sup>59</sup>

In summary, Hauerwas answers the questions posed by his puzzling language in the opening quote about how people with intellectual disabilities provided "the crack [he] needed to give concreteness to [his] critique of modernity" in the following way. What are the false pretensions underlying modern humanism? That man is essentially rational, autonomous, and self-defining. Why does being "stuck with" the disabled create obligations toward them, even for modern humanists and why was it necessary for Hauerwas to

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58. Hauerwas, *Timeful Friends*, supra note 1, at 15 (quoting MICHAEL BÉRUBÉ, *LIFE AS WE KNOW IT: A FATHER, A FAMILY, AND AN EXCEPTIONAL CHILD* (1996), at 47, 48).

59. BÉRUBÉ, supra note 27, at 35–36.

have been “drawn into”<sup>60</sup> the world of the disabled for him to recognize how they expose the pretensions of modern humanism? Because the grip that modern humanism has on our collective minds and imaginations is so strong that only the immediate, direct, emotional experience or witness of a relationship with a human who does not conform to the false ideal of modern humanism is sufficient to release us from that grip.

Although Bérubé’s attempt to express a rationale for his commitment to his son that is consistent with his intellectual commitment to liberal humanism fails, he does not deny the strength of the commitment to his son. Nussbaum’s attempt to reconcile her intellectual commitment to a Rawlsian social contract theory of justice with the commitments that friends of hers displayed to their children with disabilities<sup>61</sup> is similarly futile. However, it is telling that her personal encounters with people with disabilities and those who care for them suggested to her that there is some deficiency in the Rawlsian account worth struggling with intellectually. Both Bérubé and Nussbaum present examples of modern humanists whose practices—demonstrating a strong commitment to caring for people with intellectual disabilities—cannot be explained by their intellectual commitments to modern humanism’s presumptions of rationality, autonomy, and self-definition, no matter how hard they struggle to do so.

### III

#### UNCOVERING HAUERWAS’S INSIGHTS IN CONTEMPORARY DISABILITY LAW SCHOLARSHIP

*Law and the Contradictions of the Disability Rights Movement*,<sup>62</sup> by Samuel R. Bagenstos, one of the most prominent disability law scholars, represents another attempt to grapple intellectually with reconciling modern humanism’s presumptions with a commitment toward people with disabilities. In his introduction, Bagenstos explains that his interest in disability law was initially motivated by professional ambition: as a young lawyer in the Department of Justice’s Civil Rights Division, early cases brought under the ADA gave him the chance to argue and make new law.<sup>63</sup> When he transitioned to the legal academy, he found himself intellectually intrigued by the juxtaposition of the politically conservative rhetoric of the disability right’s movement’s focus on self-reliance and independence, and the politically liberal civil rights tradition on which the movement based its demands for equality. Then, when his first article on disability rights was in the editorial process, his son was born with a physical disability, and he “began to see disability rights from yet a new

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60. Hauerwas, *Timeful Friends*, *supra* note 1, at 14. Hauerwas uses this same language in a similar, more recent non-apology for “using” the L’Arche community for an intellectual critique, even though he is not willing to commit to living their lives, saying, “But I am going to make the most from being drawn into the world of L’Arche and try as best I can to say why L’Arche has so much to teach us.” Hauerwas, *Gentleness*, *supra* note 21, at 78.

61. NUSSBAUM, *supra* note 49, at 96–103.

62. BAGENSTOS, *supra* note 8.

63. *Id.* at ix.

perspective. The stigma, stereotypes, and failure to take account of disability came home to me in an especially pointed way.”<sup>64</sup> This combination of perspectives, he explains, has caused him to focus on the tensions and contradictions within the disability rights movement and how those tensions play themselves out in our legal system.

#### A. Bagenstos’s Tensions and Their Relation to Hauerwas’s Insights

Bagenstos argues that many aspects of contemporary disability law commonly criticized by scholars and advocates in fact simply reflect different strands of thought in the disability rights movement, revealing unresolved tensions within the movement itself. Like all social movements, the disability rights movement embraces a wide spectrum of people with different concerns, life experiences, and ideological perspectives. Bagenstos’s account of its history, with the gradual development of alliances between a variety of organizations, local and national social movements, activists with disabilities, and activists caring for the disabled, stresses this wide spectrum of interests. He asserts, however, that all of these groups did eventually reach one point of consensus: the rejection of the medical model of disability in favor of the social construction model.<sup>65</sup>

This rhetorically powerful consensus, though, masks what Bagenstos identifies as three continuing, but often unacknowledged, tensions in the movement. The first is the tension between the universal and the minority group model of disability.<sup>66</sup> Under the social construct model, all people are recognized as being arrayed on a spectrum of ability; only social norms “divide[] the level of ability we call ‘normal’ from the level we call ‘disability.’”<sup>67</sup> Some in the disability rights movement in effect accept that this dividing line has been drawn by society, creating a distinct minority group of people with disabilities, and argue that the proper policy response to this is to direct resources and accommodations at that group, following an affirmative action model. Others argue that the proper response is to reject the dividing line drawn by society, and focus instead on policies that recognize that *everyone* on the spectrum is at risk for manifesting some aspect of any disability, such as “the universal design of the built environment to embrace the largest variety of potential users, as well as a general rule of flexibility to recognize that all people are different.”<sup>68</sup>

The second is the tension inherent in reliance on nondisabled professionals working with the disabled as doctors, psychiatrists, therapists, social workers, teachers, and advocates.<sup>69</sup> Bagenstos points out that

the critique of professionalism stood in tension with the actual practices of disability

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64. *Id.* at x.

65. *Id.* at 18–20; *see also supra* notes 29–33 and accompanying text.

66. BAGENSTOS, *supra* note 8, at 20–21.

67. *Id.* at 20.

68. *Id.* at 21.

69. *Id.* at 21–22.



rights movement activists, who often relied on the assistance and endorsement of professionals who shared their views. The movement relied on lawyers, often ones who had no disabilities themselves, to bring disability rights cases; it relied on the assistance of psychologists who opposed institutionalization and forced medication; it relied on the nondisabled parents of disabled children, especially in efforts to secure educational rights; and it relied on special-education teachers.<sup>70</sup>

The third tension that Bagenstos identifies is the tension underlying the movement's embrace of independence, rather than welfare, as its predominant goal.<sup>71</sup> The disability rights movement was generally uncomfortable with disability welfare programs. Some disability activists dismissed them as attempts to "buy off" activism that might result in more fundamental changes to structures of discrimination. Others were uncomfortable with the culture of dependence that welfare programs risk creating in the disability community. Others criticized the stigmatization and paternalism inherent in programs excusing the disabled from ordinary responsibilities of citizenship. In addition to these ideological arguments, Bagenstos identifies some pragmatic motives for framing the goals of the disability rights movement as aimed at achieving independence, rather than expanding entitlements. It provided an alternative to the civil rights frame that was facing increasing political resistance in the 1980s. Furthermore, it resonated with the Reagan Administration's focus on fiscal conservatism and opposition to welfare programs. It also helped unite the members of the disability community itself, historically fragmented into interest groups representing specific types of disabilities. However, despite the rhetorical utility of independence in getting favorable laws enacted, the fact remains that these laws are not devoid of elements of charity and welfare. Bagenstos notes the persistence of this inherent tension: "Movement adherents claim to seek 'independence,' 'self-reliance,' and 'self-help.' But to obtain the 'independence' they seek, they rely significantly on assistance from third parties," including some of the support traditionally associated with welfare or entitlement programs—such as physical assistance with personal care, transportation, or other practical facets of daily life.<sup>72</sup>

Bagenstos frames all three tensions as fitting comfortably under the umbrella of the social construct theory of disabilities. His uncritical embrace of that theory as a point of agreement for all disability activists, however, ignores the difficulties that this theory poses for people with profound intellectual disabilities.<sup>73</sup> Moreover, if one considers these tensions through the lens of

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70. *Id.* at 22.

71. *Id.* at 22–32.

72. *Id.* at 32.

73. *See supra* notes 35–39 and accompanying text. Bagenstos tends to focus on the physically disabled in his analysis. His discussions of paternalism do not address the hardest cases, involving intellectual impairments that significantly compromise a person's capacity for any meaningful exercise of agency. Even with respect to physical disabilities, one scholar has criticized Bagenstos's "complete rejection of the medical model of disability," noting that "when someone cannot get out of bed to go to the bathroom without assistance, it is not inaccessible social structures that cause that limitation; it is the paralysis or weakness of the legs." Nicole B. Porter, *Relieving (Most of) the Tension*, 20 CORN. J.L. & PUB. POL'Y 761, 768 (2011).

Hauerwas's critique of modern humanism, it begins to look as though Bagenstos shares many of Hauerwas's concerns, even though his allegiance to the social construct theory prevents him from characterizing his critiques in this way. The inherent tensions that Bagenstos identifies in the embrace of "independence" as the frame for disability rights are arguably criticisms of the social construct theory's elevation of self-representation and the freedom to shape one's own identity at the expense of other aspects of human need. Both this tension, and the tension concerning the role of professionals, are aspects of the instrumental quandary that so troubled Bérubé and that Hauerwas suggests could be addressed by releasing the hold of Kant's second formulation of the categorical imperative. Finally, the tension between the universal and the minority group model of disability could be placed within the debate between theories of justice based on autonomy and those based on dependency. The disability rights advocates arguing for the minority group model arguably accept the autonomous non-disabled as embodying the "norm" that the dependent disabled need accommodations to achieve. Those asserting the universal model arguably advocate a new "norm" based on our common dependency.

After identifying these underlying tensions, Bagenstos then analyzes how they are displayed in a number of areas of contemporary disability law. Two of the areas on which he focuses are, first, ADA jurisprudence and, second, beginning and end of life issues. A close look at his argument in both areas supports the suggestion that Bagenstos is, in fact, articulating a critique that is deeply compatible with that of Hauerwas, and that his argument could be strengthened by recognizing and embracing this critique more fully.

## B. ADA Jurisprudence

Bagenstos's book has been widely heralded as an innovative contribution to the analysis of ADA jurisprudence.<sup>74</sup> The more conventional explanations for the low success rates of ADA plaintiffs in the federal courts—particularly in the Supreme Court—had focused on a social backlash against, and judicial betrayal of, the principles of the disability rights movement embodied in the law.<sup>75</sup> Bagenstos, in contrast, argues that the often-criticized restrictive readings of what constitutes a "disability" under the ADA can actually be justified by the tenets of the disability rights movement, and that the discomfort some might have in seeing those tenets instantiated in the developing case law manifests the internal tensions in disability rights theory.

The ADA defines "disability" as one of three conditions affecting an individual:

- (A) a physical or mental impairment that substantially limits one or more major life activities of such individual;

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74. See *id.* at 772; Robert W. Pratt, *Whither the Disability Rights Movement*, 109 MICH. L. REV. 1103, 1105–06 (2011) (book review); Michael A. Stein et al., *Cause Lawyering for People with Disabilities*, 123 HARV. L. REV. 1658, 1659–60 (2010) (book review).

75. BAGENSTOS, *supra* note 8, at 1–2.

- (B) a record of such an impairment; or
- (C) being regarded as having such an impairment . . .<sup>76</sup>

In a series of cases interpreting this provision of the ADA, the Supreme Court has consistently narrowed the meaning of the disability definition. In *Sutton v. United Airlines, Inc.*,<sup>77</sup> *Murphy v. United Parcel Service*,<sup>78</sup> and *Albertson's, Inc. v. Kirkingburg*,<sup>79</sup> the Court rejected plaintiffs' arguments that they were entitled to the protection of the ADA in the face of denial of employment opportunities because of disabilities. In each case, the disability at issue could be mitigated by medication—in the case of hypertension—or by other means, such as eyeglasses or adaptation of the brain for cases involving vision impairments. Even though the disability at issue was the reason for each employer's denial of employment opportunities, the Court held that the plaintiffs were not entitled to invoke the ADA because they did not fall within the first prong of the ADA's disability definition—being substantially limited in a major life activity.<sup>80</sup> In *Sutton* and *Murphy*, the Court also rejected arguments that the plaintiffs fell within the third prong of the ADA's disability definition—being “regarded as” having such an impairment.<sup>81</sup> The Court held that this definition required the employers to have regarded the plaintiffs as being unfit for work generally—rather than simply unfit for this particular kind of work.<sup>82</sup> In *Toyota Motor Manufacturing v. Williams*, the Court ruled that the plaintiff's carpal tunnel syndrome did not prevent her from “doing activities that are of central importance to most people's daily lives” even though it rendered her unable to perform the tasks central to her particular job.<sup>83</sup>

Although Bagenstos does not endorse these decisions, he rejects the common argument that they represent a “betrayal” of the aims of the ADA.<sup>84</sup> Rather, he argues that they can be understood as being entirely consistent with different strands of the disability rights agenda. They are arguably in line with the independence framework that some in the disability rights community embraced in place of the welfare framework. Bagenstos argues that

[i]f the ADA is understood . . . as a means of saving society money by moving people off disability benefits rolls and into the workforce . . . [then] the statute should focus on protecting those people who would be unable to work—and thus dependent on public assistance—without antidiscrimination and accommodation protection.<sup>85</sup>

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76. 42 U.S.C. § 12102(1) (2006).

77. 527 U.S. 471 (1999).

78. 527 U.S. 516 (1999).

79. 527 U.S. 555 (1999).

80. *Sutton*, 527 U.S. at 488–89; *Murphy*, 527 U.S. at 521; *Kirkingburg*, 527 U.S. at 566.

81. *Sutton*, 527 U.S. at 490; *Murphy*, 527 U.S. at 522.

82. *Sutton*, 527 U.S. at 493–94 (plaintiffs were airline pilots whose less than 20/20 vision caused their employer to consider them unfit to fly airplanes but not to perform other jobs); *Murphy*, 527 U.S. at 524–25 (plaintiff was considered to be unfit to drive a commercial motor vehicle but not to work as a mechanic).

83. 534 U.S. 184, 198 (2002).

84. BAGENSTOS, *supra* note 8, at 38.

85. *Id.* at 39.

People trained as pilots or mechanics would presumably *not* be relegated to the welfare rolls if they were forced to choose alternative jobs.

Moreover, Bagenstos argues that these decisions are also consistent with the minority group model, even though they might be inconsistent with the universal model. The plaintiffs in these cases had conditions that likely did *not* put them into the ambit of the “discrete, stigmatized minority group” that advocates of the minority group model suggest require the accommodations of disability law.<sup>86</sup> As support for his interpretation of the Supreme Court’s position, Bagenstos points to *Bragdon v. Abbot*,<sup>87</sup> in which the Supreme Court accepted the argument of another plaintiff that her condition—asymptomatic HIV, a highly stigmatizing condition—did fall within the ADA’s disability definition.<sup>88</sup>

But even if these decisions might be consistent with some strands of the disability rights movement, Bagenstos argues that they do not serve the disability rights movement as a whole. He criticizes both the independence framework and the minority group model as being inadequate to rectify the currently unsatisfactory situation of how we treat people with disabilities more generally, a state of affairs he calls “disability inequality.”<sup>89</sup> With respect to the independence framework, he argues,

If the goal of disability rights law is to promote equal opportunity to participate in the economic and civic life of the community, the law must strike at those limitations, even if they do not compromise individual ‘independence.’ Mere ‘independence,’ without equality, is not what disability rights activists *really* seek, and a statute constrained by a focus on independence is unduly limited.”<sup>90</sup>

The minority group model is similarly too narrow to protect all those who need the protection of the ADA, since the problem of disability inequality is not limited to “society’s identifying a discrete class of people with disabilities and discriminating against them. . . . [It] also consists in the neglect of people who differ, physically or mentally, from the norms taken as a given by those who design institutions, and by those institutions’ inflexibility in responding to difference.”<sup>91</sup> Moreover, the minority group model adherents’ attempt to identify the discrete circle of people rests on a false view that there is one single disability identity. In fact, however, “[d]isability identity is too multifarious, society’s responses to conditions identified as disabilities too diverse, for the notion of a societally created disability category to offer much traction.”<sup>92</sup>

With these sorts of arguments, Bagenstos appears to be struggling to express a critique of the ADA that illustrates what Hauerwas might recognize as the inevitable frustrations of a person whose life experience and commitments

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86. *Id.* at 41.

87. 524 U.S. 624 (1998).

88. BAGENSTOS, *supra* note 8, at 42–43.

89. *Id.* at 46.

90. *Id.*

91. *Id.* at 47.

92. *Id.* at 50.

confront him with the inadequacies of modern humanism. Bagenstos acknowledges that addressing “disability equality” demands attention to more than a person’s autonomy and capacity for self-definition. He recognizes the limits of the minority group model of disability, and its acceptance of an autonomy-based understanding of humanness, rather than a dependency-based model. Indeed, he even seems to echo Hauerwas’s critique of Nussbaum’s capabilities approach, arguing that the particular contingencies of disabled people’s lives render a theory based on the denial of contingencies ultimately unsatisfactory. But Bagenstos’s stubborn adherence to the social construct theory as the “unifying concept” for disability rights theory reveals the limits of his critique of modern humanism.

In 2008, Congress reacted to the Supreme Court’s narrow reading of the definition of disabilities in cases such as *Sutton*, *Murphy*, and *Williams* by enacting the ADA Amendments Act, explicitly rejecting the restrictive interpretations of the Supreme Court without substantively changing the definitions themselves.<sup>93</sup> Bagenstos is skeptical that these amendments will address the problems identified above. He writes, “I doubt that a mere change in language would overcome the powerful momentum of the minority-group model and the independence frame.”<sup>94</sup> However, he is equally pessimistic about the possibility of enacting a statutory definition that might reflect a more all-encompassing “universal” approach to disability rights that acknowledges the aspects of human need that might not lead to economic independence.<sup>95</sup> In the end, Bagenstos argues that disability rights activists should accept the limits of the ADA’s approach and concentrate their activism on expanding the coverage of public health insurance, which he sees as “the most significant barrier to employment and community integration for people with disabilities.”<sup>96</sup> Though he does not express it in these terms, this would seem to be an appropriate reaction to his confronting the limits of the modern humanism underlying the ADA. The social welfare system accepts vulnerability and need as a legitimate basis for social support. Without the need to fight the rhetorical battles of independence, disability rights advocates could perhaps tap common moral intuitions, rather than arguments justified by fictional constructs such as enlightened self-interest. Bagenstos writes bluntly, “the effort to avoid an association with ‘charity’ or ‘welfare’ at all costs is an effort that makes no sense.”<sup>97</sup> He cautions, though, that this does not mean that disability advocates should reject the indisputable value of the lessons learned in the earlier stages of the disability rights movement, and that “[s]ocial welfare interventions must be tailored to promote employment, integration, and community participation,

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93. Pub. L. No. 110-325, § 2, 122 Stat. 3553, 3553 (2009) (codified at 42 U.S.C. § 12101 (Supp. III 2009)).

94. BAGENSTOS, *supra* note 8, at 51.

95. *Id.* at 53.

96. *Id.* at 138.

97. *Id.* at 136.

and to avoid unnecessary paternalism and dependence.”<sup>98</sup>

But with the insights provided by Hauerwas, Bagenstos’s critique could be expanded and generalized. The ADA—even after recent amendments—instantiates an inadequate notion of the human person, a notion that leaves out those with significant cognitive disabilities who will never be moved off the disability rolls and into the work force. Loosening the constrictive grip of modern humanism might expand the scope of the values that disability rights activists fight to protect to include the interests of those with significant cognitive disabilities. If the powerful voices of disability advocates—such as Hauerwas, writing from a theological perspective, and Bagenstos, writing from a secular, legal perspective—are converging on the same sort of critique, perhaps there is common ground for working together to address the more fundamental issues at stake in resolving the contradictions between our practices and our expressed commitments to the value of the lives of people with disabilities.

### C. The Contradictions of Life, Death, and Choice

Another context in which Bagenstos notes significant internal inconsistencies of the disability rights movement is the debates about beginning and end of life issues. Bagenstos notes that disability rights groups that generally support a woman’s right to abortion have joined forces with pro-life groups on three issues, making the same kind of argument in each instance: withholding treatment, food, or water for infants born with disabilities; right-to-die cases; and selective abortions after a prenatal diagnosis of a disability. The basic argument in all three cases begins by embracing the principle of “choice.” However, societal stigmas and other social pressures, often presented by professionals without disabilities, effectively coerce people into making decisions that reflect biases against people with disabilities. Given that reality, regulation of the particular form of killing at issue is arguably not restrictive of free choice, but instead is necessary to preserve true freedom of choice.

In the early 1980s, disability rights groups joined right-to-life groups as amici curiae in support of the Reagan Administration’s ultimately futile attempt to prohibit the practice of withholding medical treatment or food and water from infants born with disabilities.<sup>99</sup> Their briefs included two arguments. The first was that “the decision to withhold treatment from an infant with a disability is often based on an erroneous, if not prejudiced, understanding of the ‘quality of

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98. *Id.*

99. *Id.* at 99 (citing Brief for the Am. Coal. Of Citizens with Disabilities et al. as Amici Curiae Supporting Petitioner, *Heckler v. Am. Hosp. Ass’n*, 476 U.S. 610 (1986) (No. 84-1529), 1985 WL 669107; Brief for the Am. Ass’n on Mental Deficiency et al. as Amici Curiae Supporting Petitioner, *Heckler*, 476 U.S. 610 (No. 84-1529), 1985 WL 669104; Brief for the Ass’n for Retarded Citizens et al. as Amici Curiae Supporting Petitioner, *Heckler*, 476 U.S. 610 (No. 34-1529), 1985 WL 669102); Brief for the Disability Rights Ed. & Defense Fund, Inc. Women’s Legal Defense Fund as Amici Curiae Supporting Petitioner, *Heckler*, 476 U.S. 610 (No. 84-1529), 1985 WL 669109).

life’ experienced by individuals with disabilities.”<sup>100</sup> The second was that “it was the physicians’ biases, and not the unconstrained exercise of parental choice, that led to the withholding of treatment from newborns with disabilities.”<sup>101</sup> They argued that the parents making these choices were in states of extreme mental and emotional vulnerability, and that the decisions typically had to be made quickly. In such a situation, parents tend to rely on the specialized knowledge and experience of their physicians. And, unfortunately, physicians tend to misinform them about the nature of the disability and the prospects for the child’s development and future, and often obfuscate their explanations with confusing medical terminology to disguise the *non*-medical grounds for their recommendations—that is, their own biases against the quality of life of people with disabilities.<sup>102</sup> Given the lack of authentic agency by parents in such situations, this decision should not be respected.

The right-to-die cases include the highly publicized cases in the 1980s and 1990s in which Dr. Jack Kevorkian assisted with suicides, and the Terry Schiavo case, involving the removal of feeding and hydration tubes from a young woman in a persistent vegetative state.<sup>103</sup> Many of Dr. Kevorkian’s assisted suicides involved people with disabilities, prompting a group of disability rights activists to form an advocacy group called Not Dead Yet, which opposes assisted suicide and euthanasia as “a deadly double standard for people with severe disabilities, including both conditions that are labeled terminal and those that are not.”<sup>104</sup> The disability activists of Not Dead Yet made the same two basic arguments in briefs filed in most of these right-to-die cases.<sup>105</sup> The first was that the practice of assisted suicide reflects a discriminatory belief that life with a disability is not worth living. They argue that, if a person without a disability decides to commit suicide, society considers that an irrational choice that should *not* be respected, and society intervenes to prevent the free exercise of that choice. However, if a person with a disability makes the same choice, it is seen as entirely rational and something that should be supported.<sup>106</sup> This reflects a fundamental bias about the quality of life with a disability, based on “inaccurate understandings about the quality of life enjoyed by people with disabilities or erroneous predictions about the future course of an individual’s medical condition.”<sup>107</sup> Second, the social stigma associated with disability as well as other significant pressures—such as advice by physicians sharing these fundamental

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100. *Id.*

101. *Id.*

102. *Id.* at 100.

103. *Schiavo ex rel. Schindler v. Schiavo*, 403 F.3d 1223 (11th Cir. 2005).

104. *About Not Dead Yet*, NOT DEAD YET, <http://notdeadyetnewscommentary.blogspot.com> (last visited Apr. 4, 2012).

105. See BAGENSTOS, *supra* note 8, at 100 (citing Brief of Amici Curiae Not Dead Yet et al. In Support of Appellant and Requesting Reversal, *Bush v. Schiavo*, 885 So. 2d 321 (Fla. 2004) (No. SC04-925), 2004 WL 1713757).

106. *Id.* at 101.

107. *Id.*

biases, financial issues, or the desire not to be a burden to loved ones—together compromise the authentic “freedom” of the “choice” of a person with disabilities to end her own life. Given that there is no possibility for truly free choices in this situation, these disability rights activists argue that the practice should be banned, a position upheld as constitutionally permissible by the Supreme Court.<sup>108</sup>

In recent years, the astronomical increase in the number of genetic conditions that can be identified through prenatal testing has been the subject of increasing concern to a number of disability rights activists. Although some of these tests have a therapeutic purpose—to identify conditions that can be treated *in utero*—the vast majority of them are used to identify disabilities for the purpose of abortion. In response, some disability rights advocates have begun to develop a critique of the practice of prenatal testing for the purpose of selective abortion similar to the critiques of withdrawing treatment and assisted suicide.<sup>109</sup> They argue that decisions to abort based on prenatal testing are generally misinformed, and often effectively coerced. Recent studies tend to show that “many members of the health professions view childhood disability as predominantly negative for children and their families, in contrast to what research on the life satisfaction of people with disabilities and their families has actually shown.”<sup>110</sup> There have been many studies demonstrating that genetic counseling offered to parents after prenatal diagnosis tends to be influenced by these same sorts of negative prejudices and misinformation about the prospects of people with disabilities.<sup>111</sup> The parents faced with the decision of whether to abort a child after a prenatal diagnosis are in states of extreme mental and emotional vulnerability, are typically pressured to make the decision to have an abortion quickly, and are thus extremely susceptible to the unfairly biased pressure of the “professionals” surrounding them.

Bagenstos points out, though, that in contrast to the withholding treatment and assisted suicide debates, disability rights activists tend *not* to argue that the appropriate form of intervention in this choice is a restriction of the legal right to abortion. Rather, they typically argue that parents undergoing prenatal

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108. See *Washington v. Glucksberg*, 521 U.S. 702, 735 (1997) (upholding Washington’s ban on physician-assisted suicide); *Vacco v. Quill*, 521 U.S. 793, 808–09 (1997) (upholding New York’s ban on physician-assisted suicide).

109. See Samuel R. Bagenstos, *Disability, Life, Death, and Choice*, 29 HARV. J.L. & GENDER 452, 435 (2006) (citing NAT’L COUNCIL ON DISABILITY, ASSISTED SUICIDE: A DISABILITY PERSPECTIVE 22–28 (1997)); Carol J. Gill, *Health Professionals, Disabilities, and Assisted Suicide: An Examination of Relevant Empirical Evidence and Reply to Batavia*, 6 PSYCHOL. PUB. POL’Y & L. 526 (2000).

110. BAGENSTOS, *supra* note 8, at 104 (citing Erik Parens & Adrienne Asch, *Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, in PRENATAL TESTING AND DISABILITY RIGHTS 3, 20 (Erik Parens & Adrienne Asch eds., 2000)); see also Marsha Saxton, *Opposition to Prenatal Diagnosis and Selective Abortion*, in PRENATAL TESTING AND DISABILITY RIGHTS, *supra*, at 147, 155.

111. See DEFIANT BIRTH (Melinda Tankard Riest ed., 2006); Brian G. Skotko, *Prenatally Diagnosed Down Syndrome: Mothers Who Continued their Pregnancies Evaluate their Health Care Providers*, 192 AM. J. OBSTETRICS & GYNECOLOGY 670 (2005); Parens & Asch, *supra* note 110, at 6–7.



testing ought to be presented with fuller and more accurate information about disabilities and the positive aspects of parenting children with disabilities, while endorsing a decision to abort in light of this fuller information. Bagenstos identifies this as another significant internal inconsistency in the disability rights movement. In the first two contexts, the disability rights movement argues that powerful social biases effectively constrain the freedom to make a choice of life or death. Thus, a complete prohibition of such a choice—that is, the choice not to treat the disabled infant or the choice to assist in a suicide—actually best serves autonomy.<sup>112</sup> In the abortion context, however, the disability rights movement backs away from this conclusion. Bagenstos argues that the Supreme Court’s recent abortion jurisprudence would probably support this type of an argument.

[I]t is apparent that the [Court’s] rationale for upholding the informed consent requirement had exactly the same structure as the disability rights critique discussed above. . . . Both the disability rights critics and the [Court] . . . point . . . to social pressures and the lack of information as significant obstacles to free choice. Although governmental regulation may in some ways restrict choice, it does so in an effort to remove even greater obstacles to free choice.”<sup>113</sup>

Despite this, however, Bagenstos notes that disability rights groups have not joined pro-life groups in arguing for a restriction of a woman’s right to elect abortion after a prenatal diagnosis of a disability.

Bagenstos concludes his analysis of this contradiction with a rather weak argument for consistency on the part of the disability rights community. He describes one group of disability rights activists that has avoided the inconsistency noted above by supporting the right to assisted suicide, stating that the group “probably constitutes a minority of disability rights activists but a majority of people with disability.”<sup>114</sup> Though this group concedes that the decision process should be regulated to some extent to ensure unbiased decisionmaking, they argue that the *right* to make the choice of assisted suicide ought to be preserved. Bagenstos argues that this position is “appealing, because it seems to avoid the internal inconsistencies of the disability rights approach.”<sup>115</sup>

In an earlier law review article on which this chapter in his book is based, however, Bagenstos delves a bit deeper into the implications of this internal inconsistency, revealing something more about the premises underlying the inconsistency. He searches for some way to both “endorse the disability rights

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112. BAGENSTOS, *supra* note 8, at 110.

113. *Id.* at 109.

114. *Id.* at 112. Bagenstos cites the amicus curiae brief submitted to the Supreme Court in *Glucksberg* and *Quill* by the Gay Men’s Health Crisis and Lambda Legal Defense and Education Fund and “Five Prominent Americans with Disabilities” who are affiliated with the group Autonomy, Inc., an organization of people with disabilities who oppose the position of Not Dead Yet. Brief for the Amici Curiae, *Washington v. Glucksberg*, 521 U.S. 702 (1997) (No. 96-110), 1996 WL 711205 (1996). This Brief includes results of a 1995 Gallup poll finding that 66% of people with disabilities support the right to assisted suicide. *Id.* at \*4.

115. *Id.*

critique while at the same time adhering to support for broad abortion rights.”<sup>116</sup> He argues that “gender equality” could serve as a brake on the “kinds of (publicly or privately imposed) constraints that we are going to treat as rendering a choice unfree.”<sup>117</sup> One could accept the theory that “many abortions that result from prenatal testing are effectively coerced by social stigmas filtered through powerful professional cultures,” but also believe that

any prohibition of a particular class of abortion will be abused to harass women who seek abortions more generally. Such a prohibition might also chill doctors from performing abortions, particularly if its terms are vague. If those risks outweigh the risk that disability-selective abortions will occur and harm disability equality—or if nonregulatory means such as public education can effectively address the harms caused by such abortions—then abortion should not be regulated, even if one accepts the critique.<sup>118</sup>

Examining the premises underlying this argument reveals how fundamentally it is undergirded by the assumptions of modern humanism. The starting premise is that the right to an abortion is essential to women’s equality, since any restriction of this right necessarily compromises a woman’s autonomy and capacity to define herself.<sup>119</sup> The fact that Bagenstos provides no argument in support of his starting premise is symptomatic of the hold that modern humanism has on the terms of the abortion debate in our country. This premise is asserted as the only argument he gives for his conclusion. The argument is that one could weigh the risk that some people with disabilities will be aborted because of social stigma against the risk that some women and doctors might be dissuaded from obtaining or providing abortions, and determine that the latter risk is greater than the former. And, because women’s equality must depend on unhindered access to abortions, one must therefore conclude that gender equality trumps disabled people’s right to exist.

The contradiction that Bagenstos thus exposes in this area of disability rights jurisprudence makes an extremely powerful statement about the current social consensus that supports Hauerwas’s observation that “[o]ur humanism entails we care for [the disabled] once they are among us, once we are stuck with them; but the same humanism cannot help but think that, all things considered, it would be better if they did not exist.” The ADA’s abstract commitment to the equal worth of every person, regardless of ability or disability, has limits. It guarantees people with disabilities—at least within the ADA’s narrow definition—access to workplaces, schools, public spaces, and transportation. But that access does not extend to our homes or to our families.

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116. BAGENSTOS, *supra* note 109, at 457.

117. *Id.* at 451–52.

118. *Id.* This earlier article by Bagenstos provides a sensitive and nuanced effort to grapple fairly with many of the difficulties raised by asserting gender equality as the justification for permitting disability-selective abortions, including the argument that gender equality could be asserted as an argument for restricting sex-selective abortions. *Id.* at 455. Bagestenos’s book, however, seems to embrace the gender equality argument described above.

119. For a comprehensive critique of this assumption, see Erika Bachiochi, *Embodied Equality: Debunking Equal Protection Arguments for Abortion Rights*, 34 HARV. J.L. & PUB. POL’Y 889 (2011).

When modern humanism's commitment to the autonomy of women is weighed against its commitment to the continued existence of the disabled, the autonomy of women trumps.

Bagenstos's discussion of the inherent contradictions of the disability rights movement in the beginning and end of life context is subject to the same Hauerwasian critique as his analysis of the ADA jurisprudence on the definition of a disability. Again, Bagenstos seems unable to recognize that the "contradictions" he exposes are in fact related to the inadequacies of modern humanism. He identifies the inconsistency in the disability rights movement's position in the right-to-die cases and the right-to-life cases, but, without any reasoned argument, asserts that this inconsistency should be resolved by favoring "autonomy"—of either the disabled person contemplating suicide or the woman whose freedom to create her own identity might be cramped by an unwanted pregnancy—over the life of the person with a disability. Indeed, his adherence to the contestable premises of modern humanism as absolutely determinative in the abortion context seems to blind him to the need to provide any argument for his positions, and prevents him from considering how the insights he has drawn from his experiences with people with disabilities might raise questions about his proposal for resolving this inconsistency.

This sort of a position is perhaps the most disheartening example of the dangers of the practices of modernity resulting from the false pretensions of modern humanism. The evidence is irrefutable that prenatal testing for disabilities is resulting in a decreased number of children with those disabilities being born.<sup>120</sup> This can be seen most clearly by examining the declining

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120. Barron H. Lerner, *When Diseases Disappear—The Case of Familial Dysautonomia*, 361 N. ENG. J. MED. 1622 (2009) (noting precipitous decline in incidence of familial dysautonomia, a severe neurologic condition); Babak Khoshnood et al., *A Population-Based Evaluation of the Impact of Antenatal Screening for Down's Syndrome in France, 1981–2000*, 111 BJOG 485 (2004) (noting "a major impact on live birth prevalence of Down's syndrome as a result of the increases in prenatal detection"); Allyson J. Peller et al., *Trends in Congenital Malformations, 1974–1999: Effect of Prenatal Diagnosis and Elective Termination*, 104 OBSTETRICS & GYNECOLOGY 957 (2004) (noting correlations between increases in rates of prenatal screening for various conditions and elective terminations of pregnancies); F. M. Lai et al., *Birth Prevalence of Down Syndrome in Singapore from 1993 to 1998*, 43 SINGAPORE MED. J. 70 (2002), available at <http://www.sma.org.sg/smj/4302/4302a3.pdf> (noting increased numbers of live births of children with Down Syndrome "due to antenatal diagnosis and selective termination"); Lynn Gillam, *Prenatal Diagnosis and Discrimination Against the Disabled*, 25 J. MED. ETHICS 163, 164 (1999), available at <http://jme.bmj.com/content/25/2/163.full.pdf> (summarizing "the very clear evidence that in response to moderate to severe fetal abnormality, the vast majority of women choose to terminate their pregnancy" to support "the claim that prenatal diagnosis will cause a reduction in the number of people living with disabilities"); C. Mansfield, S. Hopfer & T. M. Marteau, *Termination Rates After Prenatal Diagnosis of Down Syndrome, Spina Bifida, Anencephaly, and Turner and Klinefelter Syndromes: A Systematic Literature Review*, 19 PRENATAL DIAGNOSIS 808 (1999) (meta-analysis of twenty international studies suggesting correlation between prenatal diagnosis of various conditions and pregnancy terminations). *But see* Jaime L. Natoli & Deborah L. Ackerman, *Prenatal Diagnosis of Down Syndrome: A Systematic Review of Termination Rates (1995–2011)*, 32 PRENATAL DIAGNOSIS 142 (2012) (arguing that termination rates after prenatal diagnosis for Down Syndrome in the United States have decreased in recent years); G. de Graaf et al., *Changes in Yearly Birth Prevalence Rates of Children With Down Syndrome in the Period 1986–2007*, 55 J. INTELL. DISABILITY RES. 462 (2011) (noting that, despite increased prenatal testing in the

worldwide population of the “poster child” for prenatal testing for conditions that cannot be treated prenatally—Down Syndrome. This condition is simple to identify prenatally, and there are no therapeutic treatments for the condition once it is identified. The only way to prevent the birth of a child with Down Syndrome is to abort it. A 1999 meta-analysis of data from studies worldwide concluded that about 92% of women who receive a definitive diagnosis of Down Syndrome choose to abort their children.<sup>121</sup> The absolute number of babies born with Down Syndrome in the world is decreasing as testing becomes more widespread, even though women are tending to have children at older ages and the risk of having a child with Down Syndrome increases as women age.<sup>122</sup> This dramatic reduction in the total number of people with Down Syndrome clearly expresses to those living with Down Syndrome that society is not unified in its belief that they are just as valuable, and valued, as people without Down Syndrome. And if Hauerwas is correct, dwindling numbers of people with cognitive disabilities in the world will render their crucial witness to the inadequacy of the presumptions of modern humanism ever fainter.

It is not realistic to think that focusing on the convergences of Hauerwas’s and Bagenstos’s critiques will resolve the contentious issue of the morality of abortion after a prenatal diagnosis of a disability. But perhaps an appreciation for the common ground between the general critiques of each of these disability rights advocates could give both sides a clearer understanding of the presumptions underlying the arguments being made. Underlying Hauerwas’s position is a radical critique of autonomy and self-determination as crucial to human flourishing. That critique is shared by many feminists and philosophers, and to a great extent by Bagenstos himself. However, Bagenstos does not apply that critique to his commitment to a woman’s right to abortion. Some disability rights activists, such as Adrienne Asch, while expressing a commitment to “reproductive choice for all women,” have articulated arguments that selective abortions after prenatal diagnosis are morally problematic in a way that other abortions are not, because of the attitudes they express.<sup>123</sup> Asch argues that “[w]hat differentiates abortion after prenatal diagnosis (and abortions for sex selection) from all other abortions is that the abortion is a response to characteristics of the fetus and would-be child and not to the situation of the woman.” Selective abortion, she argues, “expresses negative or discriminatory attitudes not merely about a disabling trait, but about those who carry it.”<sup>124</sup>

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Netherlands, “Down syndrome live birth prevalence has risen in the last two decades as a result of rising maternal age”).

121. Brian G. Skotko, *With New Prenatal Testing, Will Babies with Down Syndrome Slowly Disappear?*, 94 ARCHIVES DISEASE CHILDHOOD 823 (2009).

122. Trends in the United States are consistent with this global trend. Studies conducted in 2004 and 2005 in the United States show a 15% decrease between 1989 and 2005 in the number of babies born with Down Syndrome, even though an analysis of maternal age trends indicates there should have been a 34% increase. *Id.*

123. Adrienne Asch, *Reproductive Technology and Disability*, in REPRODUCTIVE LAWS FOR THE 1990s 70 (Sherrill Cohen & Nadine Taub eds., 1989); Saxton, *supra* note 110, at 158–62.

124. Asch, *supra* note 123, at 70. This argument might be termed an “expressivist” argument against

While Bagenstos cites Asch extensively in his article, he does not directly engage her argument. The major collections of writings on the morality of prenatal testing similarly and quite consciously make clear that a woman's right to abortion is off limits for engagement.<sup>125</sup> Perhaps appreciating the common ground that many on opposing sides of the abortion debate share in their critiques of the presumptions of autonomy and self-determination might open the door for a more careful consideration of the emerging expressivist arguments against abortion after a prenatal diagnosis of a disability.

#### IV

#### CONCLUSION

Bagenstos and Hauerwas represent two equally eloquent and powerful advocates for people with significant disabilities. Both have expended considerable intellectual energy confronting and trying to explain inconsistencies in our practices—including the practices embodied in the laws we enact—and our commitments to the disabled. Their personal commitments to this vulnerable population have led both to many of the same conclusions about the inadequacies of modern humanism's presumptions that rationality, autonomy, and self-determination are the paramount values to be protected in our laws and our practices. Hauerwas reaches these conclusions as a theologian, from a conviction that the existence of God best explains these contradictions. Bagenstos reaches these conclusions as a legal scholar, from a conviction that a clearer understanding of the values served by the political forces shaping our laws best explains these contradictions. That these two scholars who have radically different starting points reach many of the same conclusions should both comfort and validate those sharing either of these divergent starting points.

With respect to the areas of disagreement, a focus on the common commitments of each side at least helps clarify the unacknowledged premises in the arguments, which might enable more conversation, and perhaps more cooperation, despite remaining disagreements. In his essay, *Intractable Moral Disagreements*, Alasdair MacIntyre asks “what rationality requires of us in situations in which we confront others who are in radical moral disagreement with us.”<sup>126</sup> Sometimes, even free, open, unthreatening, and noncoercive deliberations will not result in agreement on certain intractable moral issues—such as the morality of abortion after a prenatal diagnosis of a disability.<sup>127</sup> MacIntyre asks, “When we have reached this point, how should we proceed further? The urgent practical question will have become that of how we may

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selective abortion, as Asch criticizes what the discriminatory attitudes that the act expresses.

125. See *QUALITY OF LIFE AND HUMAN DIFFERENCE: GENETIC TESTING, HEALTH CARE, AND DISABILITY 13* (David Wasserman et al. eds., 2005); Parens & Asch, *supra* note 110, at 12.

126. Alasdair MacIntyre, *Intractable Moral Disagreements*, in *INTRACTABLE DISPUTES ABOUT THE NATURAL LAW: ALASDAIR MACINTYRE AND CRITICS 1, 3* (Lawrence E. Cunningham ed., 2009).

127. *Id.* at 18–24.

most effectively find common ground with at least some of those with whom we are in continuing and irremediable disagreement.”<sup>128</sup> MacIntyre concludes that, in such situations, the most effective way to defend what he considers to be the precepts of natural law

is not an attempt to demonstrate the falsity of the conclusions of [our interlocutors] . . . . What is needed instead is attention to the premises from which they argue and an attempt to undermine belief in those premises by demonstrating the flaws and confusions that inform those premises . . . . The best defense of natural law will consist in radical philosophical, moral, and cultural critiques of rival standpoints.<sup>129</sup>

This sort of debating posture, however, will necessarily look very different from failed rational deliberation that preceded it. Quoting John Henry Newman, MacIntyre warns,

“Controversy, at least in this age,” said Newman, “does not lie between the hosts of heaven, Michael and his Angels on the one side, and the powers of evil on the other; but it is a sort of night battle, where each fights for himself, and friend and foe stand together.” What Newman said of his age remains true of ours.<sup>130</sup>

Although Hauerwas, Bagenstos, and those who share their commitments and presumptions, might be foes in some particular aspects of this debate, perhaps they might “stand together” in the fight for a more satisfactory combination of practices and laws affecting people with significant cognitive disabilities, drawing on, in Bérubé’s words, “all the *caritas* they can invent or imagine.”<sup>131</sup>

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128. *Id.* at 4.

129. *Id.* at 52.

130. *Id.* at 328.

131. BÉRUBÉ, *supra* note 27, at 36.